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ETHNA THERESE PARKER

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## Ethna Therese Parker

Dementia is a disease, not a person: exploring the experiences of people with dementia, carers and mental health practitioners on dementia and dementia services via a qualitative evaluation of a community-based memory service.

## Abstract

This thesis presents a case-based qualitative evaluation of a community-based memory service for people with dementia and carers, informed by an advisory group including people with dementia and carers. Drawing on theoretical frameworks of critical and narrative gerontology, interviews with service users, carers and community mental health team staff generated rich accounts of experiences of using and delivering the memory service. Data from people with dementia and carers were analysed thematically and built on work by Willis *et al.* (2009) to generate quality indicators for dementia care. Analysis of data from CMHT staff drew on a framework of collective leadership devised for use in the NHS by the Center for Creative Leadership and The King's Fund (2014a). Findings reveal rich insights into: i) the everyday challenges faced by people with dementia and carers, ii) the positive contributions they can bring to the evaluation and development of services for people with dementia and carers and iii) the important role of collective leadership in the provision of high quality services for people with dementia. The thesis extends the current knowledge base relating to people with dementia and carers by developing particular understandings of how they can contribute to the evaluation and development of memory services.

# Dementia is a disease, not a person: exploring the experiences of people with dementia, carers and mental health practitioners on dementia and dementia services via a qualitative evaluation of a community-based memory service.

Ethna Therese Parker

A thesis submitted in fulfilment of the requirements for the degree of

**Doctor of Philosophy**

School of Applied Social Sciences

Durham University

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# Table of Contents

**Declaration** ..... **xvi**

**Copyright** ..... **xvii**

**Confidentiality statement** ..... **xviii**

**Acknowledgements** ..... **xix**

**Dedication** ..... **xxi**

**Chapter one: The research background** ..... **1**

**1.1. Introduction** ..... **1**

**1.2. What is dementia?** ..... **4**

**1.3. Dementia – a disease associated with fear** ..... **6**

**1.4. Involving people with dementia and carers in decisions about their lives – a moral, political and philosophical imperative** ..... **7**

**1.5. The starting point for the research** ..... **10**

**1.6. The philosophical foundations of this study** ..... **14**

**1.7. The theoretical foundations of the study** ..... **15**

**1.8. Research aims ..... 16**

**1.9. Terminology ..... 18**

**1.10. Outline of thesis structure ..... 20**

**Chapter Two: The literature review ..... 22**

**2.1. Introduction and background to the review ..... 22**

**2.2. The policy landscape of dementia ..... 25**

**2.3. The policy landscape of involvement ..... 29**

2.3.1. Service user involvement in health care ..... 30

2.3.2. Service user involvement in social care ..... 33

**2.4. Why is involvement a 'good thing'? ..... 38**

**2.5. Why involve people with dementia and carers in research and service development? ..... 39**

**2.6. The problematic nature of involvement ..... 41**

**2.7. The role of democracy in involvement ..... 47**

2.7.1. Consumerist and democratic approaches to involvement ..... 53

**2.8. Collective leadership: a democratic approach to leadership? ... 56**

**2.9. Barriers to involvement ..... 60**

**2.10. Facilitators of involvement ..... 65**

**2.11. Power and service user involvement ..... 68**

2.11.1. Lukes' three dimensions of power ..... 69

2.11.2. Interests in involvement ..... 74

**2.12. Chapter summary and research questions ..... 78**

**Chapter Three: Methodology ..... 81**

**3.1. Introduction ..... 81**

**3.2. Research design ..... 81**

3.2.1. Why use a qualitative methodology? ..... 82

3.2.2. What is case-based qualitative research? ..... 83

3.2.3. The case in this case-based qualitative study ..... 85

**3.3. The theoretical framework underpinning the research methods 90**

3.3.1. The role of critical gerontology in the study ..... 90

3.3.2. The role of narrative gerontology in the study ..... 92

**3.4. Involving people with dementia and carers: the research advisory group ..... 93**

3.4.1. The role of the advisory group in developing the dissemination strategy ..... 100

**3.5. Reflection and reflexivity as research tools ..... 101**

**3.6. The process of gaining ethical approval in the NHS ..... 102**

3.6.1. Selection of the research site ..... 102

3.6.2. Negotiating access ..... 103

3.6.3. Submitting to NHS ethics ..... 105

**3.7. Sampling strategy ..... 105**

3.7.1. Research population ..... 109

3.7.2. Sampling selection ..... 110

3.7.3. Inclusion and exclusion criteria ..... 110

3.7.4. Sample ..... 112

**3.8. Data collection ..... 115**

3.8.1. Strategies for reducing the researcher-researched divide ..... 116

3.8.2. Setting for the interviews ..... 117

3.8.3. Interviewing people with dementia and carers ..... 118

3.8.4. Interviewing CMHT staff..... 119

3.8.5. Recording the interview..... 120

3.8.6. Transcribing the interviews ..... 120

3.8.7. Participant observation..... 121

3.8.8. Research diaries ..... 122

3.8.9. An audit trail via field notes, reflective notes and memos..... 122

**3.9. Ethical issues..... 125**

3.9.1. Consent and capacity to consent ..... 126

3.9.2. Managing issues of confidentiality ..... 132

**3.10. Data analysis..... 132**

**3.11. Narrative adequacy: assessing the quality of narrative data . 133**

3.11.1. What is a good story? ..... 135

3.11.2. Who is a good storyteller?..... 137

3.11.3. Generating themes and data coding ..... 140

3.11.4. Triangulation of the data ..... 143

3.11.5. NVivo as an aid in data analysis ..... 144

3.11.6. Member checks..... 144

**3.12. Chapter summary ..... 146**

**Chapter Four: The initial experience of dementia ..... 148**

**4.1. Introduction..... 148**

4.1.1. Early signs and symptoms of dementia ..... 150

4.1.2. Support after the diagnosis ..... 156

4.1.3. The experience of having dementia ..... 160

4.1.4. When does ‘forgetting’ become dementia? ..... 166

4.1.5. On becoming a carer ..... 167

4.1.6. Caring responsibilities ..... 169

4.1.7. Carers’ strategies for managing stress ..... 172

4.1.8. Top tips on living well with dementia from people with dementia ..... 174

4.1.9. Top tips on living well with dementia from carers..... 179

**4.2. Chapter summary ..... 183**

**Chapter Five: Reflections by people with dementia and carers on the dementia service and associated services ..... 185**

**5.1. Introduction ..... 185**

5.1.1. Service experience ..... 187

5.1.2. Helpful interventions ..... 205

5.1.3. Normalising the catastrophic ..... 210

5.1.4. Communication ..... 229

5.1.5. Gaps in service ..... 233

**5.2. Chapter summary ..... 239**

**Chapter Six: Reflections by CMHT staff on their work as practitioners and as a dementia service provider ..... 241**

**6.1. Introduction ..... 241**

6.1.1. Drivers for change: MHSOP ..... 244

6.1.2. Challenges to the new system ..... 247

6.1.3. Drivers for change: CMHT ..... 250

6.1.4. Standardising care via standardised assessments ..... 253

6.1.5. Support for carers ..... 255

6.1.6. Transitioning from day hospital services to targeted care ..... 257

6.1.7. Embracing change as a strategy for meeting targets ..... 262

6.1.8. Building service user and carer involvement into the system ... 264

6.1.9. The importance of dementia champions ..... 271

6.1.10. Creative problem-solving ..... 272

6.1.11. Possible futures for the service ..... 274

6.1.12. Creating a no-blame culture ..... 276

**6.2. Chapter summary ..... 278**

**Chapter Seven: Discussion of the research findings ..... 279**

**7.1. Introduction ..... 279**

**7.2. RQ1: To what extent can knowledges produced by people with dementia and carers challenge negative stereotypes of dementia while extending our knowledge on how to involve them in research about dementia and in service development? ..... 281**

**7.3. Initial experiences of dementia ..... 281**

7.3.1. The ‘un-dementia-like’ symptoms of dementia ..... 281

7.3.2. Support from family and friends after the diagnosis ..... 284

7.3.3. Dementia: perceived as fearful and unknowable ..... 286

7.3.4. Challenging stereotypes of dementia ..... 288

7.3.5. Dementia: carers' journeys ..... 290

7.3.6. The problem of medically driven accounts in protecting and caring for people with dementia ..... 291

7.3.7. Dementia: the need for a personal response ..... 293

7.3.8. Challenging the system: the work of a lifetime ..... 295

7.3.9. Knowledge production: it's a learning curve ..... 296

**7.4. Gender, shifting identities and relationships ..... 297**

7.4.1. The gendered context of care ..... 301

**7.5. RQ2: What criteria do people with dementia and carers use to evaluate dementia services? ..... 316**

**7.6. Service experience ..... 317**

7.6.1. Overall satisfaction ..... 318

7.6.2. Cognitive assessments offered by the memory service ..... 320

7.6.3. Activities of living assessments offered by OTs ..... 320

**7.7. Helpful interventions ..... 321**

**7.8. Normalising the catastrophic ..... 325**

**7.9. Communication ..... 328**

**7.10. Gaps in service ..... 331**

7.10.1. Communication between services ..... 331

7.10.2. Targeted therapy groups ..... 332

7.10.3. Counselling support for people with dementia and carers ..... 334

**7.11. An interpretative account of the evaluative criteria discussed by people with dementia and carers ..... 335**

7.11.1. They were listened to ..... 336

7.11.2. They were believed ..... 338

7.11.3. They saw a person not a diagnosis ..... 340

7.11.4. They went the extra mile ..... 341

**7.12. RQ3: What values, attitudes and practices among mental health practitioners and service-level managers facilitate the development of high-quality services and the effective involvement of people with dementia and carers? ..... 342**

7.12.1. Developing a ‘no-blame’ culture ..... 346

7.12.2. Developing a culture of support for staff ..... 348

7.12.3. Getting back to putting patients and carers first ..... 349

7.12.4. From inspiring followers to developing leaders ..... 356

**7.13. Issues of reflection and reflexivity ..... 360**

**7.14. The role of critical gerontology in the study ..... 363**

**7.15. Chapter summary ..... 370**

**Chapter Eight: Conclusions and reflections ..... 372**

**8.1. Introduction ..... 372**

**8.2. Summary of the research findings ..... 372**

**8.3. Original contributions to knowledge ..... 374**

**8.4. Reflections on the research: limitations and possibilities ..... 375**

8.4.1. Generalisability ..... 375

8.4.2. The sample ..... 376

8.4.3. Interviews and interviewing ..... 376

8.4.4. Ownership of data: reciprocity and validity ..... 378

8.4.5. Presentation of data ..... 379

8.4.6. Reflections on the role of the advisory group ..... 380

8.4.7. The use of research diaries..... 383

**8.5. Recommendations ..... 383**

8.5.1. Recommendations for memory services ..... 384

8.5.2. Recommendations for the memory service in this study ..... 385

8.5.3. Recommendations for practice ..... 386

8.5.4. Recommendations for future research ..... 386

**8.6. Concluding comments ..... 389**

**List of appendices..... 394**

**Appendix 1: Autobiographical accounts of dementia ..... 395**

**Appendix 2: Participant information: advisory group members .. 397**

**Appendix 3: Independent review of research protocol ..... 402**

**Appendix 4: Ethical approval from NHS LREC ..... 405**

**Appendix 5: Ethical approval from the Trust ..... 410**

**Appendix 6: Invitation to take part in the research: CMHT staff ..... 412**

**Appendix 7: Consent form – CMHT staff ..... 414**

**Appendix 8: Participant information – CMHT staff ..... 416**

**Appendix 9: Interview topic guide: people with dementia ..... 420**

**Appendix 10: Interview topic guide: carers ..... 421**

**Appendix 11: Interview schedule: CMHT staff ..... 422**

**Appendix 12: Sophie's interview transcript ..... 424**

**Appendix 13: Example of memo made in NVivo: Sophie ..... 457**

**Appendix 14: Invitation to take part in the research: people with dementia and carers ..... 461**

**Appendix 15: Consent form for people with dementia, carers and advisory group members ..... 464**

**Appendix 16: Participant information: people with dementia and carers ..... 467**

**Appendix 17: Evaluation criteria: the Croydon memory service ..... 471**

**Appendix 18: Evaluation of the advisory group by group members ..... 472**

**Reference List ..... 475**

# List of tables

Table 2-1: Overview of PPI in health services ..... 32

Table 2-2: Interests in participation ..... 76

Table 3-1: A typology of purposive sampling strategies ..... 107

Table 3-2: Type/number of interviews: people with dementia and carers . 112

Table 3-3: Diagnosis of participants with dementia ..... 113

Table 3-4: Characteristics of carers ..... 113

Table 3-5: A breakdown of CMHT interviews ..... 114

Table 3-6: Stages of data analysis undertaken in this study ..... 142

Table 4-1: Summary of findings answering RQ1 ..... 149

Table 5-1: Summary of findings answering RQ2 ..... 186

Table 6-1: Summary of findings answering RQ3 ..... 243

# List of diagrams

Diagram 3-1: Organisational chart for The NHS Foundation Trust ..... 88

Diagram 3-2: Organisational chart for the CMHT and memory service..... 89

Diagram 3-3: Recruitment strategy for the advisory group..... 95

Diagram 3-4: Research activities of advisory group members ..... 96

Diagram 3-5: Dissemination strategies devised by advisory group..... 97

Diagram 7-1: A collective leadership organisational flowchart ..... 344

## Declaration

I declare that this is my own work and has not been submitted for the award of a higher degree anywhere else.

## Copyright

The copyright of this thesis rests with the author. No quotation from it should be published without prior written consent and information derived from it should be acknowledged.

## Confidentiality statement

Pseudonyms have been used throughout the thesis to protect the confidentiality of research participants and the NHS Foundation Trust that hosted the study.

## Acknowledgements

I would like to take this opportunity to thank my research participants, whose identities I am duty-bound to conceal, but without whose unconditional support this research would not have happened. I am indebted also to the NHS Foundation Trust in general and the CMHT for older people in particular, for hosting the study and for whole-heartedly supporting my research endeavours. At various points in my PhD journey I have been supervised by Di Bailey, Gerald Wistow, Ian Greener and Helen Charnley. Each supervisor brought unique insight and skills to bear on the thesis. Thank you for helping me to successfully complete my studies and for believing in me.

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Without doubt, my biggest supporters are my husband Chris and our two children, James and Kim. Their support began way back in 1992 when I began registered nurse training and the children started primary school and has continued unabated for over twenty years. We have studied together over the years, alternatively administering and receiving much needed doses of TLC. There have been times when I wondered about the wisdom of locking myself away on sunny days, times when I would have preferred to lose myself in a Brontë novel, rather than Bourdieu's invitation to reflexive

sociology. Times, no doubt, when I should have used the oven instead of the microwave. But, one thing has never been in doubt, how proud my three best friends are of me and how proud I am of them. Our great adventure continues.

My final thanks belong to my Heavenly Father, who, at a time I expected it least, but needed it most, stretched out His hand and rescued me. My life has never been the same. Your love covers me. Your grace sustains me. Your mercy redeems me.

## Dedication

This thesis is dedicated to the memory of my father and my two older brothers, who died suddenly and unexpectedly before I was ready to let them go. Your lives were cut cruelly short, your stories not yet fully worked out. I promise that while I live your lives and your stories will not be forgotten. I miss you.

We sat, Bella and I, on a wooden garden bench enjoying the heat of the hot September sun on our backs. I felt a gentle tap on my shoulder and in a melodic Belfast accent forty years of living in England had not diminished Bella informed me that the type of clouds drifting lazily across the clear blue sky above us, heralded rain tomorrow. ‘Surely not,’ I protested, ‘it’s much too lovely at the moment.’ But, the following afternoon at 15.58 precisely, the heavens suddenly opened and then, just as suddenly, they closed. I couldn’t help but smile, remembering. But even as I smiled, my heart ached at the knowledge that Bella would not remember. Suddenly, I wanted to weep for all the beautiful moments she will never again remember. I hate dementia.

Ethna Parker, Sunday 9th September 2012. Reflective note taken from research journal.

# Chapter one: The research background

> *We believe that everyone, everywhere, can and must do their bit to help people with dementia live well throughout the dementia journey. There is enormous power and possibility in families, friends, carers, healthcare professionals, commissioners or purchasers of care, providers, society and governments working together to improve long-term care in their country (Alzheimer's Disease International, 2013, p1).*

## 1.1. Introduction

It is rare to pick up a newspaper without coming across a story about dementia. Most often the story is a tale of tragedy and/or unexpected loss or, less frequently, it may herald the news of a wonder drug that is tantalisingly close to release. Alzheimer's Disease International (2011) argue that dementia has become one of the most urgent health and social care challenges of the 21st century and its potential effect on economies around the world is attracting global policy attention. According to Milne (2010a), dementia is the foremost cause of disability in older people posing serious challenges to health and social care systems home and abroad. In 2010 it was estimated that 36 million people were living with dementia worldwide, of whom eight million live in Europe. These numbers are predicted to increase to over 115 million worldwide, and 20 million in Europe by 2050 (Alzheimer's Disease International, 2010). In the UK, an estimated 820,000 people have dementia (Department of Health, 2012a).

In addition to the emotional costs of living with dementia, both for those with the condition and carers (Aminzadeh *et al.*, 2007; De Boer *et al.*, 2007; Papastavrou *et al.*, 2007; Rosness *et al.*, 2009), the Alzheimer's Research Trust (2010) estimated that dementia costs the UK economy £23 billion a year, which is more than the cost of cancer, heart disease and stroke combined. In terms of the financial burden of dementia worldwide, Alzheimer's Disease International (2010, p38) estimated the cost of dementia at US$604 billion in 2010, which is more than 1% of global GDP, prompting them to remark, "…if dementia care were a country, it would be the world's 18th largest economy." Despite the emotional and financial burden of dementia, research into the condition remains desperately underfunded (Alzheimer's Research Trust, 2010).

There are arguments that early diagnosis of dementia can: i) open up access to treatment (although there are few effective treatments available at the moment), ii) save money by delaying admission to hospital and to care homes (Banerjee and Wittenberg, 2009), iii) prevent crisis (Woods *et al.*, 2003), iv) reduce the stigma of dementia (House of Commons All-Party Parliamentary Group on Dementia, 2012) and v) enable people with dementia to decide in advance how they would like to be supported. There is a push for advanced care directives to become embedded in discussions of end of life care for people with dementia (The National Council for Palliative Care, 2013); although it is acknowledged that advanced care directives are not unproblematic and are poorly understood in terms of what they would mean for people with dementia

and carers (Widdershoven and Berghmans, 2001; De Boer *et al.*, 2010; Dening *et al.*, 2011; Dickinson *et al.*, 2013). Ironically, given the potential benefits of receiving an early diagnosis, one of the greatest challenges of dementia is related to low rates of diagnosis. Notwithstanding substantial variations in rates of diagnosis across the UK, on average two-thirds of those living with dementia will not receive a formal diagnosis (Department of Health, 2012a).

Arguments that an early diagnosis is best are not universally accepted. Armstrong (1995) for example voiced concerns about the intrusion that would result from the increased medical surveillance necessary to identify early stage dementia. Iliffe and Manthorpe (2004) express concern about the implications of misdiagnosis in the early stages since symptoms of dementia share many of the same characteristics as depression and other serious, but treatable, illnesses. And Pickard (2009, p73) writing about 'governing old age', has expressed concern about the growing reliance on health professionals and the, "possibility of reducing the older person's autonomy."

A benefit of early diagnosis is that people in the early stages of the disease could get involved with advocating for themselves. There is a small but growing number of authors publishing first-person accounts of living with dementia (Appendix 1). Many of these authors are current or past members of Dementia Advocacy and Support Network International. In the British context in 2011/12 the Joseph Rowntree Trust commissioned a review of dementia advocacy groups and/or networks in

the UK. The review found that people with dementia were at an early stage in terms of the development of a ‘user movement’ and that because many were still coming to terms with their diagnosis their involvement was, “still very tentative” (Williamson, 2012, p5). As early diagnosis rates increase, however, dementia advocacy should also grow in strength.

## 1.2. What is dementia?

There are multiple definitions of dementia. I include here the one published in the National Dementia Strategy for England (Department of Health, 2009, p10):

> *The term ‘dementia’ is used to describe a syndrome which may be caused by a number of illnesses in which there is progressive decline in multiple areas of function, including decline in memory, reasoning, communication skills and the ability to carry out daily activities. Alongside this decline, individuals may develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering, which cause problems in themselves, which complicate care, and which can occur at any stage of the illness.*

Much of what we know about dementia, biologically speaking, can be attributed to the discoveries of Alois Alzheimer, a German psychiatrist and neuropathologist who in 1906, documented the case of Auguste Deter, a woman in her fifties, who experienced severe cognitive difficulties with memory, language and social interaction. After her death, Alzheimer performed a brain autopsy and identified unusual growths, which he labelled neurofibrillary plaques and tangles. Alzheimer hypothesised that these growths might be the cause or effect (or possibly a combination of the two), of early onset dementia (Small and Cappai,

2006). Alzheimer also noted the presence of, "…significant microvascular injury" in the brains of those he autopsied (Mielke *et al.*, 2012, p69). In other words, brain injury caused by vascular disease was present as well as an excess of amyloid protein. Alzheimer's type dementia accounts for just over two thirds of all cases of dementia diagnosed in the UK (Department of Health, 2009).

Vascular dementia and mixed dementia account for approximately 27% of all cases of dementia reported in the UK (Alzheimer's Society, 2007). Mixed dementia is diagnosed when people show signs of having both the plaques and tangles of Alzheimer's disease and signs of brain damage due to stroke. There are several sub-types of vascular dementia, e.g. single infarct dementia (one haemorrhage damaging a large area of the brain), multi-infarct dementia (multiple small haemorrhages) and small vessel disease dementia. Frontotemporal dementia covers a range of conditions, including Pick's disease, which is a rare (and difficult to diagnose) type of dementia similar to Alzheimer's disease (Takeda *et al.*, 2012). Frontotemporal dementia is caused by damage to the parts of the brain that help control emotional responses and behaviour. Many of the initial symptoms of frontotemporal dementia involve changes in emotion, personality and behaviour (Kertesz and Munoz, 1998). Dementia with Lewy bodies is the result of the development of abnormal structures similar to the plaques (but not tangles) of Alzheimer's disease in the brain. Lewy bodies dementia usually develops gradually becoming more severe over the course of many years (McKeith, 2002).

## 1.3. Dementia – a disease associated with fear

According to the British government, “Among the over-55s, dementia is feared more than any other illness” (Department of Health, 2012a, p4). This assertion is supported by a YouGov (2012) survey that found fear of dementia had overtaken fear of cancer, which now, thanks to advances in cancer treatment regimens, “…is just a word, not a sentence” (Buckman, 2006, p11). In the 1990s, dementia pioneer Tom Kitwood (1997, p14) noted that images of dementia stirred up mixed feelings and in his seminal book *Reconsidering Dementia* suggested that, “…in being close to a person with dementia we may be seeing some terrifying anticipation of how we might become.” Part of the fear surrounding dementia may be allied to the fact that science offers no cure. Despite the development of anti-dementia drugs these, at best, offer brief reductions in the severity of symptoms.

According to Jacobs and Butcher (1986), no single unifying explanatory theory of the aetiology of dementia exists. Put simply, no one is sure why dementia develops and, once cognitive impairment begins, there is little that can be done to arrest its decline (Wilson *et al.*, 2011). In these circumstances there are two imperatives that create strong foundations for involving people with dementia in health and social care research: i) the slow progress of pharmacological research to identify effective treatments and ii) contemporary drives to include service users in a range of public services in research, planning and implementation following successful campaigns by service user movements.

## 1.4. Involving people with dementia and carers in decisions about their lives – a moral, political and philosophical imperative

There is growing political and professional consensus on the value of involving people with dementia and carers in decisions that directly affect their lives (Cantley *et al.*, 2005; CSIP Older People's Mental Health Programme, 2007; Bartlett and O'Connor, 2010; Williamson, 2012). Despite a steady increase in the number of qualitative studies involving people with dementia in research (Bunn *et al.*, 2012) the Department of Health (2012a, p16) argues that, "Compared with other conditions such as cancer, the level of public engagement in research, by donation or by direct participation in studies, is low." In relation to memory services, a comprehensive search of the literature by Willis *et al.* (2009, p27) found, "…that no study has used rigorous qualitative methods to obtain information from both people with dementia and their family carers with respect to service satisfaction." A later search of the literature identified a small number of qualitative or mixed-methods studies evaluating individual elements of memory services by Morgan *et al.* (2009),[1] Hean

[1] The research team did not publish details of the methodology used to involve people with dementia and carers. Personal correspondence with the author, however, revealed that people with dementia and carers expressed high levels of satisfaction with the service.

and Warr (2010),[2] Innes and McCabe (2012)[3] and Dixon *et al.* (2012).[4] The literature search also identified an evaluation of a dementia pathway (Beckett *et al.*, 2013)[5] and an evaluation of an Admiral Nurse service (Woods and Algar, 2009).[6] Given the proliferation of memory services and/or memory clinics since the publication of the national dementia strategy (Department of Health, 2009), more evaluations may have been completed, but not published.

The Department of Health (2012a, p12) argues, "…we must make sure…" that people with dementia and carers have the same opportunity to engage in citizenry as people without a diagnosis of dementia. The reality, however, is that service providers and family carers struggle to provide safe care (Cooper *et al.*, 2009; Royal College of Psychiatrists, 2011; Kishimoto *et al.*; Royal College of Psychiatrists, 2013). According to the Department of Health (2012a, p12) people with dementia face ageist attitudes due to the:

---

[2] The study asked for feedback via short, focused questionnaires. Feedback tended to be brief, one or two sentence answers.

[3] The research was an evaluation of tele-psychiatry, which is one element of a memory service for people with dementia living in Grampian and the Shetland Islands.

[4] Findings from the evaluation were published as a two-page summary. So, it is difficult to critique the study or compare findings.

[5] http://pathways.nice.org.uk/pathways/dementia

[6] A specialist service that supports carers of people with dementia during times of high stress.

> *…fear, misunderstanding and helplessness people feel in the face of dementia… [because people]…do not understand enough about dementia to support someone to live well with the disease.*

De Boer *et al.* (2007) argue that first-person accounts from people with dementia, carers and staff could play an important role in humanising the imagery of dementia by changing people's reaction to those diagnosed with the disease. Within the field of narrative gerontology, Zeilig (2011, p8) argues that stories of ageing, "…have become increasingly recognised as lending important insights to gerontological knowledge." Identifying ways to include the experiences of people with dementia, carers and staff in research and service development could, therefore, fill the speculative space that surrounds dementia with authentic accounts and images whilst also contributing important insights into the experience of ageing and dementia in Britain in the 21st century.

In relation to service development, Cantley *et al.* (2005, p3) pointed out that it is 'unacceptable' that the involvement of people with dementia and carers lags far behind that of other groups of devalued people, positing that, "The challenge of involving people with dementia is in essence the challenge of addressing their social exclusion." In trying to understand why the experiences of people with dementia and carers are not more influential, the Department of Health (2012a, p16) pointed to the presence of an 'involvement impasse':

> *…people with dementia and carers are not routinely offered the opportunity to participate in high-quality research and there is no nationally consistent system to enable them to do so, should they wish.*

This disjuncture between the policy and practice of involvement by people with dementia and carers is at the heart of the research problem that will be investigated in this thesis. It is an important problem to investigate for as long as representations of people with dementia are associated with fear and uncertainty, those closest to them - carers, families and friends - will struggle to understand how best to offer support. And while the views of people with dementia and carers about the services they use remain largely unsolicited, people with dementia will continue to be exposed to care of such poor-quality that they run the risk of premature death, largely from neglect (House of Commons All-Party Parliamentary Group on Dementia, 2011; Royal College of Psychiatrists, 2013).

## 1.5. The starting point for the research

The story of this research began in 2004 when I read Smith & Cantley's (1985) book *Assessing Health Care*. I enjoyed learning about the value of qualitative contributions to mental health service evaluation and learned much from their literature review on the important role of evaluation in health care. In their study exploring indicators of service success in a day hospital for older people with mental illness, Smith and Cantley (1985) recruited a diverse range of professionals and carers. They decided not to recruit the older people who used the service considering their involvement too difficult and too time-consuming.

Following Smith and Cantley's (1985) work on qualitative service evaluation, a steady trickle of research was published privileging the

voices of people with dementia, alongside the voices of carers (Naughtin and Laidler, 1991; Phinney, 1998; Husband, 1999; Proctor, 2001; Reid *et al.*, 2001; Aggarwal *et al.*, 2003; Bowes and Wilkinson, 2003; Hubbard *et al.*, 2003; Cantley *et al.*, 2005). In 2007, Banerjee *et al.* (2007) published an evaluation of the newly created Croydon Memory service. Prompted by a literature search that found no published 'rigorous' qualitative service evaluations including the views of people with dementia and carers, Banerjee *et al.* (2007) developed an analytical framework for the evaluation of community-based dementia services. An account of how they involved people with dementia and carers in the service evaluation was published by Willis *et al.* (2009). Although I did not locate the papers related to the Croydon memory service until after I had completed data collection for my study, all of the studies identified were helpful in shaping how I developed and wrote up my research.

In my own professional career as a nurse, I had been working in the community supporting people with learning disabilities, older people and people with dementia, carers and families for almost ten years and, like the authors above, had come to realise that despite the limitations imposed by cognitive decline, i) people with dementia retained insight into their condition for much longer than people without dementia realised, ii) they invested a lot of time and energy developing strategies to stay orientated and clear-minded and iii) they were able to highlight service level deficiencies and make suggestions to overcome them. Because of this, I was certain that first-person accounts from people with dementia,

carers and mental health practitioners could play a vital role in deepening our understanding of the experience of dementia and that the knowledge gained from that deeper understanding could be useful in sensitising service providers to the support needs of people with dementia and carers. Although people with dementia experience fluctuating levels of insight into their condition (Zanetti *et al.*, 1999), I believed that, if given the opportunity to do so, they would be able to articulate the strategies they use to cope with their cognitive decline and provide unique, insider perspectives on the services they use. As such, I hoped these first-person accounts of dementia would contribute to a growing body of literature challenging contemporary perceptions of dementia as fearful and unknowable, providing more nuanced accounts of ordinary people, doing ordinary things. Alongside my growing experience of working with people with dementia and carers as a nurse, my own world was turned upside down when my mother was diagnosed with dementia just as I embarked on this research journey. As the full time carer of my older brother for almost fifty years, a diagnosis of dementia meant much more than being diagnosed with an unfamiliar disease. Although worried about the impact of her forgetfulness on her day-to-day life, my mother was much more concerned about what would become of her profoundly disabled son if she could not take care of him or if she died before him. Suddenly, my perspective of dementia was intensely and uncompromisingly personal. My mother's diagnosis contributed to a shift in the focus of my research from a relatively straightforward evaluation of a memory service by people with dementia, carers and CMHT staff, to

include an exploration of how the knowledge and expertise of people with dementia and carers produced during the evaluation could be integrated into future research and service development. There is little doubt that my professional and personal experience of dementia affected the way I worked with those who participated in my study or that the stories we crafted together were, in part, helping me to understand my role in my family, my mother's changing capacities, my brother's future care and my family's capacity to support them both. The shifting focus of the research (in terms of its emphasis and my reaction to the stories shared) is as much a part of the research story as the data collected in interviews.

Gubrium and Holstein (2009) maintain that understanding the socio-cultural milieu in which narratives are created is as important analytically as what people say. Moreover, in a paper reflecting on the important role of place in equalising unequal partnerships in research, Bartlett *et al.* (2013) found that privileging place created the possibility for a more person-centred approach when doing research with people with dementia. In making clear the situated nature of research, our understanding of how knowledge is produced is sharpened, developed and, importantly, shared. This research tells the story of how I worked with people with dementia, carers and CMHT staff to produce and share knowledge on dementia and dementia services.

## 1.6. The philosophical foundations of this study

The philosophical foundations of this study are derived from the idea that there is a moral and ethical imperative to involve people with dementia and carers in decisions that directly affect their lives (Nuffield Council on Bioethics, 2009; Department of Health, 2012a). Central to the ideas expressed in this thesis is the notion that while dementia is a disease of the brain, it is the reactions of those without a diagnosis that ultimately determine how well people with dementia and carers can live with the disease (Kitwood, 1997). In other words, how we view the lives of people with dementia and carers will influence the way they are treated. It is important to acknowledge the powerful position of those without dementia in relation to those diagnosed with the disease. As Baars *et al.* (2006) articulated, “The experience of old age is dependent in large part upon how others react to the aged; that is, social context and cultural meanings are important.” Grenier and Phillipson (2013) argue that since agency is largely shaped by cultural and social norms as they relate to competency, a consideration of the ways in which people with dementia (and to a large extent their carers) are affected by other people’s perceptions of them is important. Philosophical perspectives that are deeply rooted in moral philosophy, such as Kitwood’s malignant social psychology (Kitwood, 1997), alert us to the moral and as well as the practical arguments that inform the treatment and support of people with dementia. This suggests that if we want to improve the ways in which people with dementia and carers are treated, we need to challenge and ultimately change the ways

in which their lives are viewed. One way this change can take place is via the presentation of stories from people with dementia, carers and those closest to them (Bartlett and O'Connor, 2010). However, according to Carr (2012), the involvement of vulnerable groups in research remains a challenge as the knowledge and skills to involve them in activities in which they can share their knowledge and expertise are under-developed.

## 1.7. The theoretical foundations of the study

This research falls within the theoretical claims of critical gerontology, to which narrative gerontology makes an important contribution. Critical gerontology has been described by Biggs (2008, p115) as having:

> *…taken as its starting point the discovery of the hidden, be these structural inequalities that present themselves as reasonable and natural, age prejudices that appear to be facts, or personal desires that cannot be fulfilled and may not even be raised in consciousness.*

If critical gerontology is about identifying the social structures and cultural processes that produce ageism, then narrative gerontology can be viewed as a mechanism to illustrate how structural and cultural inequalities are experienced by older people in everyday life. Narratives of people with dementia, as well as carers and professional practitioners can highlight the important role first-person accounts can play in social reform. This, argues Biggs (2008), is of central importance as contemporary research has a strong focus on making things better, rather than identifying and tackling the underlying structural influences that

render and keep people marginalised and disempowered. Critical gerontology, in common with the disabled people's movement in the UK, draws upon ideas from neo-Marxism (particularly in relation to structural poverty and structural violence) from the civil rights movement and from political feminism which strongly contests the artificial divide between the personal and the political (Biggs, 2008).

## 1.8. Research aims

This research takes as its starting point the claim made by Carr (2012) that little is known about effective processes of involving marginalised, vulnerable groups (such as people with dementia and carers) in research and service development. The Department of Health (2012a, p16) reinforces this claim, accepting that people with dementia and carers are not yet 'routinely' involved in research and, even if they wanted to be involved, there is no systematic way for this to happen. The Department of Health (2012a) suggests that the lack of involvement of people with dementia and carers has contributed to the development of a dementia narrative that is frightening for the public and isolating for people with dementia and carers. Moreover, according to the World Health Organisation and International Network for the Prevention of Elder Abuse (2002, p19), in order to challenge and change the levels of abuse that older people currently face, "People need to be educated to perceive older adults more favourably as positive contributors to society."

It is the aim of this research to make a contribution to the body of knowledge on living with dementia and dementia care through:

1. A critical analysis of the broad processes of involvement for the purpose of learning and understanding how people with dementia and carers can become engaged in research about dementia and in service development.
2. Developing and testing methodological approaches that enable people with dementia and carers to be active participants in research about dementia.
3. The production of research narratives that illuminate:
    a. The experiences of people with dementia on living with a diagnosis of dementia;
    b. The experiences of caring for a person with a diagnosis of dementia;
    c. The experiences of people with dementia and carers using community-based specialist dementia services.
4. Developing current understandings of the ways in which community mental health practitioners and service-level managers work together to develop service systems that support the development of high-quality services for people with dementia and carers.

## 1.9. Terminology

Throughout the thesis I use the phrase ‘people affected by dementia’ as shorthand for ‘people with a diagnosis of dementia and their family, carers and friends.’ When referring specifically to people with a diagnosis of dementia I write ‘people with dementia’ or ‘people diagnosed with dementia’. When writing about the broader aspects of involvement, I occasionally use the terms ‘service user’ and ‘carer’. I am aware of the ambiguous nature of these terms, but in this study I use the term ‘service user’ to denote someone who has experience of using health or social care services. I use the term ‘carer’ when referring to people who have a role in providing care for someone (not necessarily a family member) but who do not receive a payment for doing so.

The terms mild, moderate and severe dementia are highly contested, yet they continue to be used by the British Government, academics and healthcare professionals to determine (amongst other things) available treatment options. For the sake of clarity I have used the same terms.[7]

There are a number of terms commonly used in the involvement literature, e.g. involvement, participation and engagement. INVOLVE

[7] I am uncomfortable using these terms as they are reductionist and therefore depersonalising for people with dementia. However, I did not want to introduce new terms and risk confusion. My inward struggle reminded me of a line from an anti-violence poem by American poet Adrienne Rich: *“This is the oppressor’s language yet I need it to talk to you.”* Rich, A. (1971, p17) *The will to change: Poems*. New York: W.W. Norton & Co., Inc.

point out that, in relation to research these particular words point to different levels and types of involvement activities. For the sake of clarity when I discuss research-related involvement activities I follow INVOLVE's (2012, p7) definitions:

- Involvement: Where members of the public are actively involved in research projects and in research organisations, i.e. as joint grant holders or as advisory group members;
- Participation: Where people take part in a research study as interviewees.
- Engagement: Where information and knowledge about research is provided and disseminated at public events to which the public are invited.

The literatures on health services and community development use those terms in a slightly different way. For example, the involvement of NHS patients and the public is frequently referred to as patient and public involvement (PPI). Patient and public involvement are, though, two separate (albeit inter-related) spheres of activity. Florin and Dixon (2004) provide a useful separation suggesting that patient involvement is related to individuals (together with healthcare practitioners) being involved in making decisions about their own care whilst public involvement is related to groups of individuals being involved with service level changes. These definitions are not unproblematic as it is quite likely (as in this research for example) that individual patients and carers can be involved in contributing to service level changes. The language used in community

development initiatives revolves around terms such as citizens, participation, involvement, democracy, empowerment and agency (of individuals). When discussing the literature in relation to these areas, I use the same terms.

## 1.10. Outline of thesis structure

Following this introduction, chapter two addresses the first aim of the study by providing a critical analysis of the literature on service user and carer involvement. From this exploration of theoretical understandings and current empirical knowledge, three research questions are specified to guide the study of the involvement of people with dementia and carers in research about dementia and in service development. Chapter three focuses on the second aim of the study. It provides a detailed explanation of the research methodology including: i) the development of the research strategy, ii) methods of data collection, iii) issues related to access, consent, study boundaries and research setting, iv) methods of data analysis v) and strategies for dissemination. Particular attention is paid to my own research journey as a means of promoting transparency, authenticity, researcher integrity and replicability. Chapters four, five and six are the findings chapters. Relating to the third aim of the study, chapters four and five present findings in the form of narratives. Chapter four focuses on the initial experience of dementia, chapter five presents reflections by people with dementia and carers on the dementia service and associated services and chapter six presents the views and experiences of CMHT staff. Together, these chapters highlight the

challenges of meeting the differing and sometimes conflicting needs of people with dementia and carers and of staff who work in an organisational context of upward accountability to management rather than to service users and carers. Chapter seven discusses the research findings in the light of evidence from the literature review and other relevant literature and focuses in turn on issues related to each of the research questions. It also provides a reflective account of my own role in the research and the role of critical gerontology. Chapter eight summarises the main findings of the study and identifies its original contribution to knowledge. It also considers limitations of the research, reflections on the research methodology, and recommendations for policy makers, dementia services, and dementia care practitioners. The chapter, and the thesis, closes with a concluding statement.

# Chapter Two: The literature review

## 2.1. Introduction and background to the review

In this review I provide a critical analysis of the broad processes of involvement for the purpose of understanding how people with dementia and carers can become 'routinely' engaged in research (Department of Health, 2012a, p16) and in service development (CSIP Older People's Mental Health Programme, 2007). Understanding some of the mechanisms by which devalued older people, such as people with dementia and carers, are currently excluded is the everyday work of critical gerontology (Biggs, 2008; Baars *et al.*, 2013). The purpose of engaging with the literature in this way is to attempt to make visible some of the invisible structures that may be influencing the involvement (or non-involvement) of people with dementia and carers in research on dementia and in service development.

The possible reach of the involvement literature is vast, yet, as Forster and Gabe (2008, p334) observe, "The academic literature contains few attempts to bring conceptual clarity to the bewildering diversity of definitions in this field." Aware of the frustration experienced by those before me in trying to pin down just what involvement is, and is not, this review steers clear of the definitional mire, exploring instead those aspects of involvement believed to be salient to the involvement of people with dementia and carers in research and service development. It is important to do this because as long as the experiences of people with

dementia are excluded from research about dementia and from service development, their lives will continue to be cast as frightening, shadowy and other-worldly. It is my belief that finding ways to involve people with dementia and carers in dementia research and service development is a priority for those who believe their views are critical to the development of a just and inclusive society.

The British government has made it clear that involving patients and members of the public in the planning, development and evaluation of national and local services is not an optional add-on, but, "…a central element in public policy-making" (INVOLVE and Shared Practice, 2007, p1). Despite the political rhetoric supporting involvement, an independent inquiry into the state of democracy in Britain revealed thousands of people felt "quietly angry or depressed" at what they perceived to be, "…political lying and politicians' self-interest" feeling as though they have no say over decisions that affect their lives (The Power Inquiry, 2006, p9). The Power Inquiry also identified that people wanted to be involved, but found no easy ways to do so. This state of affairs, according to Cornwall (2008, p7), has given rise to a 'curious paradox' in which, "…only one in five Britons are satisfied with the opportunities they have to engage in local decision making, and in practice, probably fewer than 1 per cent actually do." Conversely, it has been acknowledged that when involvement initiatives work they, "…can give people a sense of belonging, a sense of control over their lives and can even be a source of happiness" (Cornwall, 2008, p11). Moreover, according to Barnes *et al.*

(2007, p4), public involvement can do more than simply give motivated citizens a say in running local communities. It can, by its 'transformatory potential' change the face of politics. In order to understand, and contribute to, the involvement debate, this review draws upon literatures from health, social care and community development for the purpose of better understanding how people with dementia and carers can be involved in research about dementia and in service development.

The review begins in section 2.2 by tracing the development of dementia-related policy in the UK. Key messages from the policy documents reviewed highlight the need to make dementia a national health priority. This need was formally addressed with the publication of the National Dementia Strategy for England (Department of Health, 2009). Key policy messages from the strategy identify the important role service user involvement could play in i) driving up the quality of dementia services, ii) challenging negative stereotypes of dementia and iii) containing spiralling costs. In light of this, section 2.3 traces the rise of service user involvement in health and social care, situating service user involvement within the context of the NHS and the disabled people's movement. This is followed by a review of arguments positioning service user involvement as 'a good thing' in general (2.4) and for people with dementia and carers specifically (2.5). Some of the inherent tensions in service user involvement are reviewed in section 2.6. The close relationship between democracy and involvement is explored in section 2.7, including a discussion of two common models of involvement, the consumerist and

the democratic. This is followed in section 2.8 by a discussion of the emergence of collective leadership in the NHS which has been developed as a response to the deficiencies in NHS leadership identified by the inquiry into Mid Staffordshire NHS Foundation Trust (House of Commons, 2013a). This section of the review is brought to a close with a discussion of possible barriers to involvement 2.9 and possible facilitators of involvement 2.10.

The review then turns to a critical analysis of the role of power in service user involvement (2.11). Drawing on the work of Steven Lukes (1974/2005), I identify some of the visible and invisible social structures and cultural processes that may be preventing people with dementia and carers from being routinely involved in research and service development. The review continues this exploration by positioning involvement as a process subject to a range of vested interests, only some of which lead to authentic involvement. Key messages from the literature review are summarised in section 2.12 which also identifies the gaps in knowledge addressed by this research and ends by specifying the research questions that underpin the thesis.

## 2.2. The policy landscape of dementia

Despite the fact that dementia has been a growing concern for many years, it has only recently been recognised that public policy needs to adopt a proactive approach. The slow move from the shadows began with a report by the Audit Commission (2000) on the state of the nation's

mental health services for older people. This report, *Forget Me Not*, published 79 key findings, of which the following provide a flavour of the lack of preparedness to engage with people with a diagnosis of dementia or to address their dementia-related needs:

- Only one half of GPs believed it important to look actively for signs of dementia and to make an early diagnosis;
- Less than one half of GPs felt that they had received sufficient training to identify early signs and symptoms;
- There was a lack of clear information, counselling, advocacy and support for people with dementia and their family carers;
- There was an insufficient supply of specialist home care;
- The quality of assessments was poor and treatment options reflected little joint health and social care planning and working.

The research on which this report was based was rolled out to a wider sample two years later and yielded similar findings National Audit Office (2002). *Forget Me Not* was a forerunner to the *National Service Framework for Older People* (NSF) (Department of Health, 2001a). The framework contained eight standards, the seventh of which was dedicated to the mental health needs of older people. This was the first time their needs had been identified as a public health priority. The goal was to improve the quality of mental health services for older people by tackling the service inequities flagged up in *Forget me not*.

In 2005 the Department of Health (DH) and the Care Services Improvement Partnership (CSIP) published *Everybody's Business - Integrated Mental Health Services for Older Adults: A Service Development Guide* (Department of Health and CSIP, 2005). The guide set out the detail of how mental health services should work across all areas of mental health. Importantly, it also included a plan for the development of memory services, including how they could operate separately or as part of an existing community mental health team for older people. Shortly after this, the National Institute for Health and Clinical Excellence (NICE) in association with the Social Care Institute for Excellence (SCIE) published clinical guidelines on the management of dementia (National Institute for Health and Clinical Excellence, 2006).

Despite findings from previous reports identifying the poor state of mental health services for older people, and the subsequent implementation of the NSF to rectify these findings, a report by the Alzheimer's Society (2007) found there was still an urgent need to review the quality of services for people with dementia and they pointed again to the necessity of making dementia an explicit health and social care priority. The National Audit Office (NAO) (2007) also undertook a review of dementia services. Consistent with the findings of previous reports, the NAO review identified variations in the size and availability of CMHTs (this point is made again in the National Dementia Strategy in 2009). Furthermore, GPs expressed less confidence in managing the care of their patients with dementia than in the *Forget Me Not* report seven years earlier. The

review concluded that many services were providing poor-quality care and were not providing value for money (National Audit Office, 2007). The NAO review was submitted for consideration to the House of Commons Public Accounts Committee (PAC) that subsequently published its own report on dementia services. Its comments and recommendations[8] were consistent with those of the NAO and with earlier reports. The Government accepted virtually all the conclusions and recommendations of the Committee report which informed the development of the national dementia strategy published in March 2009. The strategy identified 17 objectives to improve the quality of services to people with dementia and their carers across England. The strategy promised to address the service failures flagged up in *Forget Me Not* and subsequent reports and to do what the NSF did not, i.e. address the issue of early diagnosis and intervention, improve the availability and quality of services and improve services to carers. Implementation of the strategy was to be achieved largely through efficiency savings via a reduction of unnecessary bed use in acute care. There was a phased release of £150M to the 152 primary care trusts (PCTs) to support implementation of the strategy. However, the devolved NHS management model practised by PCTs meant that the additional funding was not ring-fenced. As a result, it is unclear how much of the £150M was used in the implementation of the strategy (National Audit Office, 2010). The issue of where the money went and issues

[8]www.publications.parliament.uk/pa/cm200708/cmselect/cmpubacc/228/22802.htm

around the escalating costs of dementia care troubled many, including the House of Commons All-Party Parliamentary Group on Dementia (2011) who launched an inquiry into the quality and cost of services for people with dementia. The inquiry concluded that many of the services on offer to people with dementia were of poor quality. This increased awareness of the unmet needs of people with dementia occurred alongside a growing awareness that involving service users in making decisions about their care, and involving them in the development and evaluation of the services they use, may lead to better quality services and to better use of financial resources (House of Commons Health Committee, 2007). It is to these issues that the review now turns.

## 2.3. The policy landscape of involvement

Despite being one of the best loved institutions in the UK (Hutton, 2000), there is an acknowledgement that the NHS has struggled with issues of transparency, parity and accountability since its inception (Klein, 1979). Despite its egalitarian ideals, it has been unable to completely level the playing field it inherited from the municipalities in the wake of World War II. Klein (1979, p70) argued that the NHS was probably one of the most wide-reaching exercises in democratic control. Yet, despite its obvious successes, he observed:

> *…it is far easier to create the organizational framework for a national health care system than to solve the problem of making it socially accountable and responsive.*

### 2.3.1. *Service user involvement in health care*

Finding ways to hold public services to account is not the preserve of modern day heroes. Gorsky (2008, p751) reminds us that members of the public were involved at various levels of governance before the NHS was created:

> *Prior to the inception of the NHS in 1948, the hospital contributory scheme movement provided ordinary members of the public with the opportunity to sit on hospital management boards.*

The strategic employment of service user involvement in health services is commonly attributed to the creation of Community Health Councils (CHCs), established via the NHS (Reorganisation) Act 1973. But, as Greener et al. (2006) have noted, although CHCs comprised appointed officials who lobbied on behalf of patients and the public, they were not a route to public involvement *per se*. There has long been considerable confusion surrounding the idea of service user involvement. The House of Commons Health Committee (2007), for example, argued there was, "…a lack of clarity about scope and purpose. Should patient and public involvement be about more accountability, better services or health promotion?" Section 11 of the Health and Social Care Act 2001 charged NHS bodies with involving patients and the public in planning and developing services, stating that they must consult with them on decisions to change services and on issues related to treatment. NHS bodies set up to oversee the implementation and development of patient and public involvement in the NHS have been subject to a number of incarnations. CHCs were abolished in 2003 following the enactment of

The Health and Social Care Act 2001, which introduced Patient and Public Involvement Forums (PPIfs). These were managed by the Commission for Patient and Public Involvement in Health (CPPIH), but could also be referred to local government Overview and Scrutiny Committees (OSC). NHS Foundation Trusts were established in 2004 and paved the way for local people to become involved in local decision-making on health issues. Local Involvement Networks (LINks) superseded OSCs in 2008 and were themselves rendered redundant with the provisions set out in the Health and Social Care Act 2012 for Local HealthWatch and HealthWatch England, which came into force in April 2013. It is too soon to tell whether the current network of Local HealthWatch will be more successful than its predecessors. Any assessment of success must be considered against the argument of the House of Commons Health Committee (2007, p7) that the bar was not set very high:

> *In practice the recent structures, currently Public and Patient Involvement forums (PPIfs), and before 2003 Community Health Councils (CHCs), have sometimes been effective, but sadly frequently ineffective.*

A brief historical overview of formal arrangements for patient and public involvement in health services is provided in table 2-1.

**Table 2-1: Overview of PPI in health services**

| | |
|---|---|
| 1973 | Provision for the establishment of CHCs under section 9 of the NHS (Reorganisation) Act 1973. |
| 1990 | Service user involvement in service planning is established via section 46 of the NHS and Community Care Act 1990. |
| 2000 | OSCs established following Local Government Act 2000. |
| 2001/2002 | Health and Social Care Act 2001 abolishes CHCs and establishes PPIfs while extending OSCs' remit to healthcare.<br><br>Section 11 of the Act charges Strategic Health Authorities, PCTs, Health Authorities and NHS Trusts with involving service users and potential service users in planning, developing and evaluating health services and in decisions affecting treatments. |
| 2003 | CPPIH established to oversee a new system of PPI. CHCs cease and PPIfs begin operating at the end of the year. |
| April 2004 | First Foundation Trusts established with Boards of Governors. |
| 2006 | PPI Forums replaced by LINks. |
| 2008 | CPPIH replaced by LINks. |
| 2008 | LINks replaced OSCs. |
| 2012 | LINks replaced by Local HealthWatch and HealthWatch England. |

### 2.3.2. *Service user involvement in social care*

Alongside the integration of involvement ideals in health services (driven primarily by legislation), there was a parallel rise in involvement initiatives in social care, driven largely by the development of the social model of disability and the work of disability activists. Shakespeare (1993, p250), in an early paper examining the ways in which disabled people came together to form a coherent political force in the UK, argued that the British version of the disabled people's movement was characterised by, "…political autonomy and democratic participation." The social model of disability grew out of rising discontent with the medical model which located disability within the individual and placed the onus on disabled people to adapt to the world around them (Yuill *et al.*, 2010). Critics of the medical model of disability point out that it is biologically reductionist in that it reduces people to their bodily symptoms (Silvers, 2002). Humanity, frailty and suffering are reduced to symptoms that in turn become synonymous with what Ghaemi (2010, p200) called a 'totalistic' approach to health in which people are said to 'be bipolar' or 'demented' instead of having a diagnosis of bipolar disorder or dementia. Moreover, because diagnoses are based on a structural or mechanical failure framework, it follows that the focus of the medical model will also be about 'fixing' the individual. This means that the medical model works well in a closed system such as surgery or in emergency care where few would doubt that, "…a patient who suddenly experiences heart failure needs a cardiac specialist, not an acupuncturist" (Cohen, 1998, p2). But, when individuals

are thought about in terms of a collection of symptoms, rather than as persons with a collection of symptoms affecting one aspect of their health, it is easy to forget that not every part of their life is affected by the illness/disease and that they still have parts of their body or mind that are unaffected (O'Sullivan *et al.*, 2014). The significance of this for people with dementia should not be underestimated.

In contrast to the medical model, the social model of disability placed the onus for change squarely on society, identifying, "…the economic, environmental and cultural barriers encountered by people with impairments" (Miller *et al.*, 2006, p6). Disability rights activists argue that people are not disabled by their physical, sensory or mental impairments, but by society's, "…failure to accommodate their individual and collective needs within the mainstream of economics and cultural life" (Barnes, 2003).

Mike Oliver is credited with developing the social model of disability as it is recognised today. In his influential book *The politics of disablement,* Oliver (1990) noted that, unlike other areas of social science where theory and empiricism go hand-in-hand, disability studies suffered from a distinct lack of theorising. Noting the lack of grand theorising in disability studies, Oliver nevertheless argued that all studies of disability were (implicitly at least) underpinned by a grand theory that could be characterised as the personal tragedy theory of disability. Oliver argued that it fell to disabled people to both critique the prevailing medically orientated theory and come up with a viable alternative, which he termed

social oppression theory (Oliver, 1990). Social oppression theory is concerned (among other things) with definitions of disability and the important role they play in securing the rights of disabled people. Definitions, Oliver noted, were often produced by the non-disabled and as a result they did not accurately represent the experiences of disabled people. In light of this, the disabled people's movement produced its own definition which, for the first time, clearly separated impairment from disability:

> *IMPAIRMENT lacking part of or all of a limb, or having a defective limb, organism or mechanism of the body.*
>
> *DISABILITY the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities. (UPIAS/Disability Alliance, 1976, pp3-4)*

This was a radical shift in thinking because for the first time impairment was viewed as something distinct from disability. People had impairments, but it was society that disabled them. Although the separation of impairment from disability played an important role in challenging physical, cultural and political norms that excluded people with disabilities from the mainstream of life, Shakespeare and Watson (2001, p11) argued the social model of disability, "…became a sacred cow, an ideology which could not easily be challenged." Arguments for a social model of disability that acknowledged the reality of physical impairment were raised by disabled people themselves, including Shakespeare and Watson (2001, p12) who argued that the social model of disability negated the embodied nature of disability, ignoring the

everyday frustration of living with, "…aches, pains and urinary tract infections." In their paper arguing for an expanded version of the social model of disability, one capable of incorporating impairment and disability, Hughes and Paterson (1997, p329) argued:

> *…impairment is more than a medical issue. It is both an experience and a discursive construction. It has phenomenological parameters, and it can be analysed as an effect of discourse and language.*

The social model of disability has also been criticised for failing to address the needs of disabled people who experience more than one form of oppression. Morris (1991), for example argued that the distinctive needs of disabled women, lesbians and older women had largely been ignored. Vernon (1999, p396), however, argued that rather than criticising the social model of disability for failing to address the needs of specific groups of disabled people, disabled people should not lose sight of the role of societal structures in generating and sustaining multiple forms of oppression against disabled people:

> *The politics of eradicating disability, must, therefore, take account of the whole oppressive structure of our society and be careful to challenge all forms of oppression wherever it is found.*

Despite the ever-evolving nature of the social model of disability and the progress that has been made in many areas, in the second edition of *The Politics of Disability* Oliver and Barnes (2012) noted that the personal tragedy model of disability continues to be the dominant experience of disabled people in the UK.

Much of what has been learned in the field of disability studies is useful when thinking about the involvement of people with dementia and carers. Baldwin (2005), for example, argued that historical perceptions of dementia have, in many ways, mirrored those of disability in terms of a shift away from an over reliance on the medical model as argued by the work of Tom Kitwood and the Bradford Dementia Group, towards an account of dementia that is mediated (in theory at least) by social and cultural processes and barriers. Similarly, Sabat (2001, pviii) has argued that accounts of dementia are mediated, "…by the behaviour of those in the social world in which he or she lives as well as the sufferer's own reactions to the disease." Insights drawn from the social model of disability, together with insights from the field of critical gerontology provide evidence of an invisible backcloth of ageist, disablist and marginalising attitudes and practices that pervade the everyday lives of people with dementia and, to a large extent their carers. An exploration of these processes deepens our understanding of the ways in which 'excess disabilities' defined by Brody *et al.* (1971, p124) as, "…the discrepancy which exists when the person's functional incapacity is greater than that warranted by the actual impairment," contributes to the exclusion of people with dementia and carers from acts of citizenry.

## 2.4. Why is involvement a 'good thing'?

Service user involvement is frequently cited as 'a good thing' (Becker *et al.*, 2010, p356). Yet, according to Schehrer and Sexton (2010, p5):

> *…if you ask people to go beyond this to detail what it looks like, what its purpose is and how structures and models will enable it to become a reality, the picture gets far less clear.*

Despite difficulties with operationalisation, there is an argument that if services are financed through the public purse, the public has a right to oversee and be involved with decisions affecting how services will be delivered and developed. There is, moreover, an increased appreciation of the fact that professionals do not know everything and that end users of services also have skills, knowledge and expertise to bring to the table (Department of Health, 2001b; Tattersall, 2002). A loss of faith in the power of medical and allied health professions to provide all the answers, has led to a steady growth in non-medical services across the board (Debas *et al.*, 2006). Linked to this loss of confidence in medically orientated practices, Becker *et al.* (2010, p355) also point to the inequitable distribution of power, "…between the providers of services and their users; and between the medical and social establishments and the individuals they 'serve.'" There is, therefore, a sense that service user involvement may lead to research and service developments that are more relevant to those who use services now and keep them relevant for those who may use them in the future (House of Commons Health Committee, 2007). Oliver *et al.* (2004) noted that public involvement may

produce findings that are accessible to a wider audience, more widely disseminated and help produce services that are both value for money and valued by local communities. Fobé and Brans (2013) additionally noted the critical nature of stakeholder support to the societal acceptance of policy. As this thesis is concerned with why people with dementia and carers are less involved than other groups of service users in research and service development, the following section reviews the arguments for their inclusion.

## 2.5. Why involve people with dementia and carers in research and service development?

One important reason to involve people with dementia and carers in research and service development is because to do so is a duty under section 11 of the Health and Social Care Act 2001. Healthwatch England and Local Healthwatch organisations have been charged with collecting, "…the views of people who use health or social care services and of other members of the public on their needs for and experiences of health and social care services" (Health and Social Care Act, 2012, Part 5, Chapter 1, S181, SS5a). Furthermore, the National Institute for Health and Clinical Excellence (2006) states that unless they lack the capacity to consent, people with dementia should be actively supported to be involved in all decisions related to their care.

There are a number of tangible benefits associated with involving people with dementia in research and service development. The CSIP Older People's Mental Health Programme (2007) argues that involving people

with dementia in the planning and delivery of their care can: i) provide positive examples of living with dementia, ii) provide unique perspectives on living with dementia, iii) contribute to the removal of stigma from dementia specifically and mental illness generally, iv) provide evidence for service development and v) provide a rationale for service optimisation, vi) help to generate new ideas on how care should be delivered, vii) empower those taking part in the process (including practitioners), viii) promote trust in services and ix) help to guard against abuse. McKillop and Wilkinson (2004)[9] also note the role of involving people with dementia in extending knowledge and understanding of 'how to' issues in research, for example in the conduct of interviews. This point was reiterated by Tanner (2012) who, in her research investigating the experiences of older people with dementia as they moved between care services, found that everyone who participated in the research benefitted from doing so. Drawing on the experiences of mental health service user researchers involved in the SURESearch network, Townend and Braithwaite (2002) also argued that the inclusion of service users' perspectives ensures that research methodologies reflect the concerns of those using mental health services, adds depth to research accounts and develops the skills of those who take part.

[9] This paper was co-written by a person with dementia who engages regularly in research and evaluation activities.

Perhaps the most pressing reason to involve people with dementia and carers in research and service development is that, according to O'Sullivan *et al.* (2014, p484), "The pervasive tendency to focus on the negative outcomes of dementia has effectively reinforced the stigma associated with the condition." According to the Alzheimer's Society (2010), there is compelling evidence that positioning people with dementia as active citizens reduces the stigma of dementia, a position also taken by Bartlett and O'Connor (2010, p3) who further argue that the views of people with dementia have, "…the power to influence and to bring about social change." Therefore, involving people with dementia, and those closest to them, in research and service development, may be the most effective way to challenge negative, stereotypical images of dementia, reduce the risk of abuse and develop the services they need. Given the political push for involvement and the willingness of people with dementia and carers to be engaged (CSIP Older People's Mental Health Programme, 2007), it seems paradoxical that they are still not routinely involved in research and service development. In an attempt to better understand why this is, the next section of the review explores the problematic nature of involvement.

## 2.6. The problematic nature of involvement

Involvement is still a relatively new concept in health and social care research and service development and although it has been around longer in policy initiatives, Beresford (2005, p6) concedes, "Generally speaking, we have little systematic knowledge about what the gains and

achievements of participation may actually be." Nolan *et al.* (2007, p1) noted that in relation to involvement, there are, "…many practical, ethical, moral, methodological and philosophical questions unanswered." Add to this concerns that the word involvement has become a byword for quality, and it becomes clear that while involvement *per se* is not under attack, its construction in policy documents and application in practice is problematic:

> *…the rhetoric of the 'consumer movement' within healthcare is unrelenting, politically expedient, and morally impervious. As such, the principle of consumer involvement in health research is resistant to criticism… (Hodgson and Canvin, 2005, p48).*

In coming to this conclusion, Hodgson and Canvin (2005) point to the power differential between professional researchers and lay researchers, particularly in the construction of knowledge and taken-for-granted discourses, practices and terminologies that professional researchers are exposed to over their academic careers and which are unknown, or at least unfamiliar, to lay researchers. Hodgson and Canvin (2005) also contend that the positivistic foundations of health research are problematic, as the type of knowledge thought to be of value does not generally include the voices of end users. Indeed, according to Nolan *et al.* (2007), the idea of what counts as knowledge and whose knowledge counts is at the heart of all involvement related issues. Wallerstein and Duran (2006) point out that the goals of participatory research are to close the gap between researchers and the researched and tackle the difficult issues of knowledge generation and how knowledge is defined and subsequently used. According to Nolan *et al.* (2007), at its most basic

level, authentic participatory inquiry is about tackling health disparities where they exist and preventing them from occurring where they do not.

According to Fobé and Brans (2013, p477) there is, "…insufficient translation of scientific insights into policy-relevant information." This is not a new concern. Thirty-five years ago, amid worries about the relevance of social research and development, the National Academy of Science asked: What are we learning? Who is making effective use of what we learn? (Lynn, 1978, p1). Contributors to the report noted an array of concerns including, "…the prevailing expectations for use of social science knowledge and research are much higher than reported use" (Weiss, 1978, p27). More recently, Newman *et al.* (2013, p1) reported that not only was there a shortage of evidence on the capacity of policy makers to use research, there was even less evidence illustrating how the capacity gap could be bridged. And, of further concern, is the presence of overwhelming evidence on, "…the insidious effect of corruption on the use of evidence in policy making processes." Evidence of probable corruption was reported by Crawford *et al.* (2002, p2) whose research participants, "…found evidence that involving patients was used to legitimise decisions that would have been made whether or not patients supported them." Greener *et al.* (2006, p15) in their textual analysis of policy documents concerned with the organisation of NHS services in the UK, also noted that people were attributed agency when it suited the needs of policymakers:

> *It often appears as if policymakers, by positioning patients as consumers, are hoping to achieve a legitimacy for reforms by speaking for the 'people' that cannot be achieved in the implementation of those policies.*

On a number of levels, the issues raised sit uncomfortably alongside the public rhetoric on involvement, not least because involvement is supposed to challenge the status quo, shift the balance of power, and level the uneven playing field. But, for involvement to do this, the voices of those being involved have to reach the ears of those who govern. If this is not happening, it is not unreasonable to wonder what difference the process of involvement will make.

There is little doubt that the number of opportunities available for people to get involved locally and nationally has increased in the past twenty years, but as Cornwall (2008, p13) argues, "…having a seat at the table is a necessary but not sufficient condition for exercising voice." Moreover, according to Barnes (2002, p324) the conditions necessary to support equal opportunity once a seat at the table has been secured are not available to all:

> *People do not have equal opportunity to attend and participate in decision-making forums. Nor does everyone meet the standards of cognitive and lingual competence set within forums dominated by professional/ bureaucratic norms of debate.*

There is, moreover, an ever-growing number of processes, techniques and instruments (mechanisms) aimed at turning the ideology of involvement into reality. Rowe and Frewer (2005, p252) note that although welcome, the increase in involvement mechanisms serves only

to cement the reputation of involvement as something that is difficult, intangible or uncertain:

> *The very existence of a variety of mechanisms implies uncertainty (at least, at the level of those promoting and developing the different mechanisms) as to how one should best enact involvement.*

Despite the undoubted challenges of implementation, involvement is not just an adjunct to mainstream service development; it is, rather, the mechanism by which public services (such as the NHS and Social Care) can not only be held to account, but also provide the conditions necessary for them to thrive (House of Commons Health Committee, 2007). Deepening our understanding of the role of involvement in public services can help us to understand the undemocratic forces at work which quietly and covertly work against involvement initiatives. It is important to understand how these covert forces play out, so that we can learn the 'rules of the game', or at least, learn how to mitigate their effects.

Writing in the context of organisational behaviour, Hirschman (1970) argued that strategies that minimise opportunities for involvement are counter-productive as they reduce the likelihood of feedback. This is a critical point as organisations need feedback in order to improve and develop. Feedback, even if it is unfavourable, is necessary for an organisation's survival and continued growth (Finkelstein and Fishbach, 2012; National Economic & Social Council, 2012). To ignore feedback is to risk failure. Involvement on the other hand provides not only feedback

but guidance, supporting service development on a number of important fronts including (and possibly most importantly for some) financially (House of Commons Health Committee, 2007).

In the UK, for example, despite billions of pounds being ploughed into dementia services annually, the National Audit Office (2007, p12) criticised services to people with dementia for providing poor-quality care and, "…not currently delivering value for money to taxpayers or people with dementia and their families." Baroness Greengross worded the failure to protect and care for people with dementia more strongly:

> *Dementia is a colossal challenge that costs our economy billions of pounds every year. But even with the huge sums of money spent, we know a lot is wasted on poor-quality care and many people with dementia continue to be let down by the current system (House of Commons All-Party Parliamentary Group on Dementia, 2011, pv).*

Despite assertions by the British government that the National Dementia Strategy will improve the quality of services to people with dementia, the National Audit Office has expressed serious concerns over its ability to do so:

> *Overall we conclude that improving services and support for people with dementia lacks the urgency and priority that the Committee had been led to expect, and there is a strong risk that value for money will not be significantly improved within the Strategy's five-year implementation timetable (National Audit Office, 2010, p10, para 22).*

Putting the National Audit Office's pessimism to one side, if the promised benefits of the national dementia strategy were coupled with the direct experiences of people with dementia and carers, it might be possible to

influence the development of more effective services for people with dementia and carers. Personal experience can tether formal procedures to the reality of what is needed in a way that little else can. Personal experience can, moreover, be powerfully persuasive and according to Atkinson (1998), the knowledge imparted from it is respected and accepted in many academic circles. Over time, knowledge generated from people's direct experiences of dementia should help sensitise policymakers and service providers to the real needs of people with dementia and carers. This should help to create services that meet their needs and ensure scarce financial resources are used effectively. However, given the current state of service user involvement generally, summed up here by Beresford and Andrews (2012, p55), it seems unlikely these aspirations will be realised for people with dementia and carers in the near future:

> *It is interesting that after 20 years of provisions for user involvement in social care, starting with the 1990 NHS and Community Care Act, there still seems to be a widely held view among service users that this is not working well enough.*

## 2.7. The role of democracy in involvement

The role of service user involvement in research and service development is not only to bring about safe, high-quality services but also the re-distribution of power via the democratisation of local services (House of Commons Health Committee, 2007). Like involvement, democracy can be a double-edged sword in relation to how it is viewed, and what impact it has upon the lives of people with dementia and carers.

For example, democracy is sometimes viewed via an exploration of what makes a ‘good citizen’ (Westheimer and Kahne, 2004, p241/242). To position someone as a good citizen is about devolving responsibility for the development of safe, nurturing, creative communities to individuals who live and work within the community’s borders. Positioning people as good citizens is problematic, however, because in defining what is good, there is an implicit construction of what is bad. This raises the question of who decides the criteria for a good (or bad) citizen locally.

The act of social positioning is, according to Townsend (1981), problematic for older people and because of the combined stigma associated with old age and cognitive decline, it is particularly problematic for people with dementia and carers (Milne, 2010b; Alzheimer's Disease International, 2012). In the early 1980s Townsend (1981) argued that older people were at risk from being socially positioned according to the state of the public purse. Townsend’s identification of the relationship between fiscal resources and the treatment of older people is pertinent in the light of observations made by the National Audit Office (2010) that the National Dementia Strategy for England would be funded on the back of cost-cutting measures in other parts of the system. But, despite the fact that funding for dementia research was recently doubled to approximately £66M per year (Department of Health, 2012a), the Alzheimer's Research Trust (2010) point out that in 2007/08 research into cancer care attracted £590 million. Ironically, this point was recently re-made by British Prime Minister David Cameron in a speech promoting the need for more

research into dementia.[10] The problem of social positioning is compounded by a democratic deficit in the NHS (House of Commons Health Committee, 2007). This means that people with dementia and carers may be made rendered invisible via covert or overt political and social structuring. Involvement initiatives may be one way to bridge the democratic deficit as they may help to increase the number of people with dementia who are involved and extend the types of decisions they are able to participate in. Furthermore, in relation to the involvement of service users with mental health problems, Townend and Braithwaite (2002, p117) noted that involvement could additionally serve:

> *…as a panacea for some of the negative consequences of their experiences of mental health service usage and may go some way to restoring individuals' own self-belief […] and belief in the motives of researchers.*

For people with dementia and carers who are less involved in research and service development than other devalued groups, authentic involvement could provide them with opportunities to share their experience of dementia in a way that enables them to develop their own dementia narrative (as opposed to outsiders doing it for them) and in the process correct the frightening and isolating dementia narratives prevalent in society. This is important as not only would the production of new dementia narratives contribute towards social reform (by changing

[10] http://www.bbc.co.uk/news/health-27912473

the way people with dementia and carers are viewed) but it could help people with dementia and carers find meaning in their experience of dementia, “If human experience is viewed as narrative, our stories become ourselves; narratives structure who we are as meaningful beings in the world” Gubrium and Holstein (2009, p8).

Public discourses on involvement presume a level of intellectual boldness and prowess. Public speaking, even in small gatherings, requires a significant level of confidence, particularly when sharing personal experiences. But, given the advantages that engaging in acts of democracy bring to the table, practitioners can fulfil a useful role in identifying and encouraging authentic forms of involvement for people with dementia and carers. Barnes (2002, p324) suggests:

> *We need a practice of deliberation which explicitly recognises and encompasses inequalities of power and diversity of experience and expression, rather than assuming that such inequality and diversity will be accommodated within processes governed by universalist notions of fairness and competence.*

Within Barnes’ ‘practice of deliberation’ involvement is not defined by how well you can speak or act but by what you have to say on issues that affect you, your family and your friends and may well affect us all. Finding spaces for this kind of communication to occur may hold the key to unlocking the problem of involvement for within a practice of deliberation, lay perspectives would be assigned similar levels of relevance and significance as other more ‘scientific’ methods.

Extending the borders of democracy is about exposing important issues to the democratising gaze of the public in an effort to bring them under the control of the people. It is about identifying the borders and hinterlands of citizen participation for the purpose of testing out where borders can be safely crossed. It is about finding ways to get past the trivial and banal, to allow people, such as those with dementia and carers, to wrestle with issues of importance and for their experiences and suggestions to be acknowledged and implemented (Cornwall and Coelho, 2006). Extending the scope of democracy helps to address 'black box' issues[11] (Cornwall, 2008), being clear about what involvement is and is not and about identifying how and where involvement will happen so that there is no ambiguity. Authentic democracy is about moving into the realm of involvement where governments and organisations devolve decisions of consequence to the people. It is about power-sharing not power-conserving and according to Cornwall (2008, p14) it:

> *…demands processes and structures through which citizens can claim voice, and gain the means to exercise democratic citizenship, including acquiring the skills to participate effectively.*

Cornwall and Coelho (2006) argue that the first step in the journey towards authentic democracy could very well be about helping people find ways to get involved with influencing the everyday issues that bother

[11] In the context of community participation this relates to issues that the public are not allowed to debate. They are issues that are never brought to the table for deliberation.

them personally. To find out what those everyday issues are means entering spaces we (as researchers, educators, advocates and advisors) may not have entered before. As Cornwall (2008, p8) posits, “We need to find the everyday places of democracy that remain hidden from official outreach or consultation.” Discovering what those hidden spaces look like will mean making every effort to approach those not normally approached (such as people with dementia and carers) creating space for them to talk about the issues that concern them, while finding ways for them to contribute to a plan to see the problem resolved. This is not about circumventing the knowledge, expertise and wisdom of the usual suspects (Beresford, 2013), it is more about turning the few usual suspects into an army. Cornwall (2008) believes that this kind of involvement has the potential to genuinely invigorate the public realm. Carr (2012, p39) warns, however, that attracting diverse or hidden populations will mean paying more attention to issues of diversity in terms of, “…race, sexual orientation, culture and even disability.” It also means paying attention to issues of fragility, age, gender, social status and to the needs of people defined by difference, such as people with dementia. This, according to Carr (2012) will be no easy task given the lack of knowledge on how to involve marginalised people in research and service development. Given the potential role of involvement in creating democratic communities, the review now turns to a discussion of the two main approaches to involvement.

### 2.7.1. *Consumerist and democratic approaches to involvement*

The involvement literature identifies two overarching approaches to involvement: the consumerist and the democratic (Carter and Beresford, 2000).The consumerist approach is linked to the development of, "…more market-led approaches to public policy and provision and its devaluing of state intervention and provision" (Beresford, 2002, p96). The market-led health economy has developed alongside a diverse range of non-professional groups who have lobbied fiercely for the right of ordinary citizens to have their say in matters affecting their lives. Though both approaches advocate service user involvement, according to Beresford (2002) it would be a mistake to assume both types of involvement share the same philosophical basis. Consumerist approaches view members of the public as consumers of services, where choice and access to information take centre stage. Here, involvement takes the form of consultation and collection of information through polls and surveys to provide evidence that supports managerial ends. Unsurprisingly, consumerist approaches have given rise to a raft of measures designed to gauge satisfaction with existing services and do not promote the involvement of people as co-creators or co-producers of knowledge. Consumerism is intimately linked with the notion of choice that, although seen as a critical component of high-quality health care (Department of Health, 2013a), is not unproblematic. Arrow (2006, p54) suggested that the philosophy underpinning choice is related to the idea, "…that an individual is freer if he or she can choose from an expanded set and is

therefore ‘better off’ in some sense even if the choice actually made is the same.” This makes the notion of choice seem commendable. However, as Greener *et al.* (2010) found, people often do not have enough information to make informed choices, sometimes choices are made based on whether prospective patients are likely to get a car parking space, or if the hospital is on a main bus route, or they have heard ‘good things’ about the staff from a friend or family member. Moreover, Lewis *et al.* (2009, p44) argue that choices are rarely made on the basis of sound judgement as the public have limited access to information resulting in, “…significant information asymmetries between patient and provider.” And, as Tait and Lester (2005, p168) remind us, poverty may yet be the best indicator of choice:

> *It is possible that those who have access to information systems and to transport and travel may be more easily able to exercise their right to choose than more socially excluded, hard-to-reach sectors of society, such as people with mental health problems.*

Despite their initial attractiveness choice initiatives may not always lead to authentic involvement or even real choice. Even if involvement via increased choice-making were a real possibility, Greener *et al.* (2006, p14) identify a lack of clarity about, “…how these choices are meant to be made.” However, alluding to the complex and multi-faceted tensions underpinning choice, Arrow (2006) argues that during the process of making choices (or expressing preferences) hitherto hidden information about choice is revealed. Like the process of involvement, the process of making choices can be transformational to the extent that otherwise

marginalised people can access opportunities for increased knowledge and/or personal growth. But, the act of choice-making *per se*, should not be mistaken for an act of emancipation or empowerment for, as Arrow (2006, p55) provocatively submits, “Freedom to starve or be tortured is not significant freedom.”

Another difference between consumerist and democratic approaches is in who instigates the research or service development. Consumerist approaches are inherently linked to managerialism and they tend to be instigated from above. Democratic approaches on the other hand tend to emerge from the lobbying efforts of well-organised groups, community activists, advocates and service-level practitioners. Consumerism tends to be linked with quantitative methodologies, i.e. surveys, questionnaires, polls etc. while democratic approaches tend to be linked with qualitative methodologies that privilege ‘slow research’ i.e. storied conversations and co-production of knowledge. The consumerist approach is about improving the performance of management while the democratic approach is about improving the life chances of ordinary citizens. I do not argue that one approach is inherently bad and the other good. Both approaches have their merits (Beresford, 2002) and both are imbued with challenges of power and control that need to be recognised if vulnerable groups, such as people with dementia and carers, are to be meaningfully engaged in citizenry.

The next section of the review explores a form of democrative leadership that has emerged in response to a perceived crisis of confidence in the

NHS. It is of interest to this study because of its claim to respect the primacy of patients and carers and the critical role they play in the development of high-quality services.

## 2.8. Collective leadership: a democratic approach to leadership?

Public confidence in the NHS has been shaken by a number of high-profile scandals including the neglect of people with learning disabilities receiving acute NHS care (Local Government Ombudsman and Parliamentary and Health Service Ombudsman, 2009; Department of Health, 2013b), the abuse of people with learning disabilities at Winterbourne View hospital, an NHS assessment unit (Department of Health, 2012b), the poor level of care experienced by older people when undergoing medical procedures (National Confidential Enquiry into Patient Outcome and Death, 2010), the neglect of older people in hospital generally (Parliamentary and Health Service Ombudsman, 2011), the poor-quality care experienced by people with dementia (House of Commons All-Party Parliamentary Group on Dementia, 2011) and the widespread neglect of patients uncovered at Mid-Staffordshire NHS Foundation Trust (House of Commons, 2013a). The system failures that led to tens of thousands of vulnerable people being neglected and abused cannot be understood simply in terms of ‘bad staff’ or ‘poor practice.’ A system-wide failure to protect and care for vulnerable people, such as was demonstrated in the public inquiries noted above, requires a system-wide response. While imprisoning cruel staff for committing criminal acts is important, it does not solve the problem of poor-quality

care as poor-quality care is not about 'bad staff', it is about poor systems (National Advisory Group on the Safety of Patients in England, 2013)[12]. The inquiry into Mid-Staffordshire NHS Foundation Trust[13] highlighted that system failures at the Trust could be tracked to an:

> *…unhealthy and dangerous culture [that] pervaded not only the Trust, as described in the first inquiry report, but the system of oversight and regulation as a whole and at every level (House of Commons, 2013b, para: 20.13, p1360).*

Chair of the inquiry, Sir Robert Francis, argued that the culture of poor care that permeated Mid-Staffordshire NHS Foundation Trust is to be found across the NHS. A point poignantly made in a report by the Parliamentary and Health Service Ombudsman (2011, p8) in which an investigation into the neglect of ten older NHS patients reported that even the most basic standards of care had not been met, and that in the preceding 12 months the Ombudsman's office had, "…accepted 226 cases for investigation, more than twice as many as for all other age groups put together."

A particular problem identified by the Francis Inquiry was the lack of partnership working with non-NHS organisations and with patients and their families. Challenging and changing these cultures of neglect and poor-quality care at every level in the NHS was identified as playing a

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[12] Hereafter referred to as the Berwick Report

[13] Hereafter referred to as the Francis Inquiry

critical role in the creation of cultures that value the provision of high-quality, compassionate, inclusive care. Findings from the Francis Inquiry linked the creation of new healthier cultures with effective leadership that put partnership with patients and their families at the heart of service delivery and development. This idea, that effective and innovative leadership should form the beating heart of a reimagined NHS, was taken forward by The King's Fund and The Center for Creative Leadership who argue that the only way to develop a culture of caring in the NHS is to develop a leadership that cares not only for patients but also for staff (Center for Creative Leadership and The King's Fund, 2014a, 2014b). The critical impulse driving this new kind of leadership, called collective leadership, is a vision of an NHS capable of infusing every member of staff with the imagination and vision of leadership, diffusing, yet simultaneously strengthening, the functions of responsibility and accountability across the NHS. This new breed of leader would be reflective, challenge failure and build learning into the everyday work of the organisation. Collective leadership is the opposite of 'command-and-control' leadership cultures that:

> *…invite the displacement of responsibility and accountability onto single individuals, leading to scapegoating and creating a climate of fear of failure rather than an appetite for innovation (Center for Creative Leadership and The King's Fund, 2014a, p14).*

Collective leadership is characterised by a strong desire to create healthy teams, who want not only the best for the patients they serve, but the best for other teams and services as well. Collective leadership

recognises the value in every part of the organisation doing well, not just their part. Allied to this is a strong desire to build patient and family partnerships into the day-to-day work of the team and the wider service. Professional practices that do not place patients and families at the heart of service delivery and development are cut away to make room for those that do.

The benefits of collective leadership could be far-reaching as it, "…creates the culture in which high-quality, compassionate care can be delivered" (Center for Creative Leadership and The King's Fund, 2014a, p7). In their Strategic Intent Document, Health Education England (2013, p2) argues that compassionate care needs to be at the heart of decision-making in the NHS:

> *…the NHS could employ hundreds of thousands of staff with the right technological skills, but without the compassion to care, then we will have failed to meet the needs of patients.*

In their strategy setting out the shared purpose of nurses, midwives and care staff, the Department of Health (2012c, p13) identified the key role of culture, leadership and staff training in the production of compassionate care, which they argue is characterised by acts of 'intelligent kindness.' Putting compassionate care at the heart of the NHS is, according to the Center for Creative Leadership and The King's Fund (2014a), the core function of collective leadership. The democratising effect of collective leadership with its emphasis on shared leadership and patient and family

partnerships might just provide a powerful corrective to the culture of neglect and poor-quality care uncovered by the Francis Inquiry.

The next two sections of the review provide an overview of barriers to and facilitators of involvement. I argue that these need to be understood in the context of the exercise of power which visibly and invisibly shapes not only the choices of people with dementia and carers (in this case access to involvement), but the choices they did not know they have (Lukes, 1974/2005; Biggs, 2001).

## 2.9. Barriers to involvement

The complex relationship between barriers to and facilitators of involvement makes it difficult to talk about them as separate and distinct entities. Indeed, what is viewed as a barrier by one person or group may be viewed as an opportunity for involvement by another. Issues related to barriers and facilitators associated with involvement, moreover, straddle every strata of research and service development cutting across professional boundaries, types of services and personal experiences. The lives of older people in general and the lives of people with dementia and carers in particular, are frequently shaped by barriers that are ageist in nature and as a result are even more complex to unravel. It may be impossible, therefore, to understand why involvement does or does not happen for older people, without first acknowledging the covert role that structured dependency plays in shaping their lives:

> *The inexorable process by which the status of older people has been lowered, or rather, defined at a lowly level in the course of the development of the industrial societies, has been largely ignored. The evolution of the economy, the state and social inequality has been taken for granted, and the implications of the trends for people as they become older neglected. Rather than ask how and why is society restricting life chances and opportunities at older ages, most scientists have directed their attention to the problems of elucidating adjustment so as to soften the impact of that adjustment but, indirectly, legitimate its operation (Townsend, 1981, p6).*

The effects of structured dependency can be seen in every type and level of involvement but unless we recognise the tendency of systems to reproduce the negative effects of dependency, authentic involvement will remain aspirational. For example, structured dependency is at work when people with dementia and carers are given insufficient information, preventing them from making informed decisions about their care. It is at work when insufficient thought is put into how people with dementia and carers can be involved in service development, for example, through reimbursement for their time and knowledge. It is at work when there is a lack of understanding and/or willingness to involve people with dementia and carers in the resolution of local community issues. While not wishing to see the effects of structured dependency behind every proverbial door, it is possible to see traces of it in the rise of professionalism that boasts of field-specific languages so complex that even professionals need to set time aside to learn each others' language (Bracken and Oughton, 2006). It is also possible to catch glimpses of it in the complex power hierarchies that separate service users, administrators and professionals (Sullivan and Scattolon, 1995).

As the literature on structured dependency suggests, there are multiple barriers preventing people with dementia and carers from being involved in research and service development. In their literature review on the involvement of older people in research, Fudge *et al.* (2007) identified, "…ill health, multiple medical conditions, hospital appointments, physical frailty and death" as among the reasons older people were unable to complete research activities. For people with dementia, who have a shortened life expectancy (Xie *et al.*, 2008), these issues may present an even greater challenge. Other identified barriers to involvement include a lack of confidence or familiarity with the research process, including the language (jargon) of research (Fudge *et al.*, 2007) and the over-protection (excessive gatekeeping) of older people (Alzheimer's Europe, 2011). Other significant barriers to involvement include a lack of time to involve older people properly (Warren *et al.*, 2003) and an overestimation of people's capacity to be involved (Reed *et al.*, 2002). It may also be important to consider how people perceive their role in involvement as, according to Fudge *et al.* (2007), if people believe their involvement in a project will not change anything, they are less likely to become involved in the first place.

In their discussion paper appraising a process consent framework, McKeown *et al.* (2010) found that people with dementia were excluded from research due to the perception that they were unable to contribute to debates about their condition. This links with what we know about the involvement of people with dementia in the evaluation of dementia

services with at least two studies, i.e. Blackeby and Quarmby (2005) and Wolfs *et al.* (2008) reporting they did not involve people with dementia because of the nature of their illness. Further arguments against the involvement of mental health service users include the ability of a small group of people to represent the views of a wider population (Tait and Lester, 2005), although both Beresford (1994) and Lindow (1999) argue that the same argument is rarely made of researchers, professionals and policy makers. Writing in the context of adult mental health, Tait and Lester (2005), suggested that barriers to involvement may be linked to the changeable nature of mental illness, which can prevent mental health service users from contributing to a project over the longer term. This issue is of particular importance to people with dementia, who may lose their capacity to consent during the life of a research project reaching beyond single points of data collection.

In their survey of social policy researchers' views on service user involvement, Becker *et al.* (2010) reported that researchers who were identified as adversaries of involvement claimed that it would be unfair to involve service users as they would not have the skills to understand the nuances of research methodology. This line of thinking disregards the contribution to research that service users can make in terms of developing lines of inquiry that may more closely match the needs of the people who are the 'subjects' of research and in doing so, produce research that may make a difference to people's everyday lives. It also assumes that service users are both 'other' and less able than

researchers and conveniently bypasses much needed discussion of the need to provide the necessary training. Other arguments of 'involvement adversaries' include that service user researchers may bring their own agenda to the research. Yes, they may, but as Becker *et al.* (2010) point out, so too do researchers. Why should service users be expected to act differently? Such views that serve to exclude service users from research reveal a lack of reflexivity in professional researchers and a poor understanding of the role of research in alleviating social problems and challenging inequalities.

In their research into the development of mental health clinical guidelines in the Netherlands Ham *et al.* (2013, p8) reported that although many service users and professionals thought, "…input from service user representatives was valued, evidence from literature holds a more prominent position in the guideline process and final guideline text." Not only did such beliefs constitute a barrier to service user involvement, they appeared to be used as an excuse by practitioners not to treat service user contributions seriously, fearing that guidelines produced in cooperation with service users would not be recognised by other professionals. Even those who were in favour of service user involvement were worried about what 'others' would think and that their work would, in some way, be downgraded if they were upfront about the extent of service user involvement. Professional protectionism such as this subtly but powerfully devalues the role of service user involvement and reminds us of Arnstein's (1969) poignant comment that it is disingenuous to

vigorously applaud involvement in public whilst politely clapping behind closed doors[14].

Ham *et al.* (2013) have noted that when the scientific evidence base is small, more weight is assigned to the contributions of service users and professionals. When little is known about a phenomenon, professional researchers are happy for ordinary people to contribute their ideas, skills and knowledge, but once evidence starts to accumulate, access to that knowledge easily becomes hidden behind institutional and professional 'firewalls'. This results in the up-skilling of professional researchers and the de-skilling of ordinary people that is evident in the attitudes of 'involvement adversaries' identified by Becker *et al.* (2010).

## 2.10. Facilitators of involvement

Awareness of different processes and mechanisms that serve to inhibit service user involvement in research and service development is vital in developing our understanding of how involvement can be facilitated. Finding effective ways to involve people in improving the quality of services they use is important for everyone and, according to CSIP Older People's Mental Health Programme (2007), it is particularly important for people with dementia and carers. Alzheimer's Europe (2011) argue that research protocols that do not take into consideration the unique needs of

[14] This alludes to the practice of someone saying they agree with service user involvement in public, while disagreeing and/or undermining it in private.

older people (with or without dementia) are guilty of practising ageism and structural discrimination and of reproducing systems that disrespect and exclude older people. Despite the challenging nature of involvement, Alzheimer's Europe (2011, p29) argues that, “With the necessary time, effort and perhaps financial investment, such factors could often be overcome.” Strategies to promote the involvement of people with dementia and carers in research and service development could include assigning a competent and unbiased research facilitator to research/service development projects, holding regular meetings throughout the life of a project and the allocation of, “…adequate financial resources to support the group process during the potentially long learning and decision-making process” (Irvin and Stansbury, 2004, p61). Staniszewska *et al.* (2007) identify the importance of involving people as early in the development of a project as possible, while Fudge *et al.* (2007) argue for effective and on-going strategies for communication between all those involved in research through, for example social events, agenda flexibility and suitable venues. A significant facilitator of the involvement of older people with high support needs (such as people with dementia), is the recognition that older people face significant and on-going ageist and (for older women) sexist attitudes that curtail their ability to advocate for themselves about issues that affect their lives (Rodeheaver and Datan, 1988; Proctor, 2001; Blood, 2013). In terms of process and methodological clarity Coulter and Ellins (2006, p21), in their review of evidence for patient-focused interventions argue that, “Health literacy is fundamental to patient engagement” pointing out that the

capacity of service users, carers and families to obtain, process and understand basic information is critical to the success of all involvement activities. This could be an issue of particular relevance for people with dementia who, due to their cognitive decline, may lose the ability to understand the research project and their role in it. Finding ways to confirm that people with dementia are still able to give informed consent to taking part is, therefore, of critical importance (Dewing, 2002, 2007; Warner and Nomani, 2008; Meulenbroek *et al.*, 2010).

Reciprocity is an important concept in facilitating service user involvement in research and service development. It is widely recognised that reciprocity is important in qualitative research in terms of the production of 'good enough' data (Gubrium and Holstein, 2009). Fudge *et al.* (2007) point out that reciprocity is also important in terms of what the researcher will give back to the communities they work in, arguing that if the benefits of involvement are clear and on-going, issues of recruitment and retention may be less challenging. In research exploring service users' experiences of involvement in the production of NICE treatment guidelines in mental health, Harding *et al.* (2010) identified the following facilitators of service user involvement: i) an understanding of and appreciation for how service user perspectives can situate abstract concepts within the context of everyday lives ii) an appreciation of the ways in which service user perspectives can help to challenge 'taken-for-granted-knowledge' particularly in relation to producing meaningful treatment goals, iii) an understanding/explanation of the 'unwritten rules' surrounding

involvement in research and service development and iv) the importance of group members not judging themselves in relation to other members of the group since comparisons affected people's confidence and their ability to contribute.

This review of factors that inhibit and factors that facilitate service user involvement has hinted at inequalities in power held by policy makers, professionals, service users and carers. In the following section I critically examine the role of power in influencing service user and carer involvement in research and service development.

## 2.11. Power and service user involvement

Here I build on the idea that the social oppression experienced by older people generally and people with dementia and their carers specifically can be understood within the context of structural power inequalities and culturally patterned discrimination. It is the core belief of critical gerontology that the lives of older people are shaped and determined by unseen (but not unknowable) forces (Baars, 1991). Critical gerontologists argue that these forces are the result of complex power plays that contribute to the marginalisation of devalued people (Baars *et al.*, 2013).

Much of what we understand about power is heavily influenced by the work of several key theorists including Arendt (1970), Foucault (1977/1995), Dahl (1974/2005), Bachrach and Baratz (1962) and Lukes (1974/2005). Lukes' work advances the work of Dahl (1974/2005) and Bachrach and Baratz (1962) and offers convincing arguments for how

political systems and their players distribute and re-distribute power. An understanding of Lukes' (1974/2005) analyses of power is important in terms of learning 'the rules of the game' and for understanding our own role in the distribution and re-distribution of power:

> *How much power you see in the social world and how you locate it depends on how you conceive of it, and these disagreements are in part moral and political, and inescapably so (Lukes, 1974/2005, p12).*

I draw upon Lukes' theory of power to aid understanding of involvement as something that is politically and socially constituted, an understanding that can help us appreciate more clearly the visible and invisible tentacles of power and how they help or hinder service user and carer involvement. The section begins with an overview of Lukes' (1974/2005) model of power: the three dimensions of power and the implications arising from it in relation to the involvement of people with dementia and their carers in research and service development.

### 2.11.1. *Lukes' three dimensions of power*

Lukes' (1974/2005) three-dimensional view of power resulted from critiques of Dahl's (1974/2005) and Bachrach and Baratz's (1962) theories of power which he refers to as one-dimensional (Dahl) and two-dimensional (Bachrach and Baratz). Lukes criticised Dahl's theory of power for being methodologically muddled, too narrow in focus - because it focused on observable behaviour, operational definitions and turning up evidence and because power was seen as being operationalised through

concrete decision-making. Bachrach and Baratz (1962) agreed with Dahl's view that power was embodied and fully reflected in decision-making but they pointed to the need to include a second 'face of power' the power that resides in the ability of groups or persons to create or reinforce barriers to prevent issues from being raised in the first place. In other words, politically sensitive issues are 'black boxed' (grievances are effectively shelved) before they come to the attention of a wider audience. In Bachrach and Baratz's (1962) view of power, decision-making and non-decision-making held equal sway in the distribution of power.

Lukes' critique of Bachrach and Baratz's (1962) theory was based on an argument that their view of power retained too much of a behavioural bias and was not sufficiently nuanced to identify all the ways in which choices unintentionally affect systems. Lukes (1974/2005, p26) argued that bias in systems (of power distribution) is not sustained solely by individual acts of choice but also by:

> *…the socially structured and culturally patterned behaviour of groups, and practices of institutions, which may indeed be manifested by individuals' inaction.*

While Lukes' conceded that power can be exercised when grievances (framed as issues) are black boxed, he argued that the true extent of power can be most clearly seen in the way the desires, expectations and concerns of individuals are shaped (socially and culturally patterned) so that individuals are not even consciously aware of injustices being done to them.

Lukes' (1974/2005) central argument is that given its contested nature, any discussion of power will not only be necessarily incomplete but understandings of it will be imbued with moral and political perspectives that may or may not be acknowledged. This has much in common with my earlier discussion of the social model of disability (2.3.2), in which a person's experience of power is shaped by multiple social and cultural processes and norms that are influenced by their gender, race, age, social position, wealth, health and impairment (Vernon, 1999). Lukes (1974/2005, p1) viewed these invisible processes as playing a critical role in the distribution and re-distribution of power, arguing, "…we need to attend to those aspects of power that are least accessible to observation: that, indeed, power is at its most effective when least observable."

The first step, therefore, in understanding why people with dementia and their carers are not routinely involved in research and service development, is for researchers to confront their own issues of power and powerlessness so as to avoid re-producing actions that further devalue people with dementia and their carers. Kitwood (1997) wrote about this process of self-examination in detail as he believed it played a critical role in the re-valuing of devalued people. Yet, he also owned the complexity of the task, as the motivation behind actions that advance or block involvement initiatives are rarely straightforward arguing that few possess the necessary skills to discern (and challenge) their own malign attitudes and intentions. Nevertheless, Brosnan (2012, p45) stated that, "…power dynamics emerge as one of the primary obstacles to equitable

involvement." And, writing in the context of social work practice, Braye and Preston-Shoot (2003, p114) acknowledge the importance of practitioners recognising their role in reproducing discriminatory practices, "…if practitioners are not part of the solution, they must be part of the problem."

Bachrach and Baratz (1962) linked growing self-awareness with the ability to intuitively grasp the predominant values, beliefs and rituals inherent in every interaction, otherwise known as 'the rules of the game'. In terms of service user involvement, this is important not just for researchers' ability to facilitate the best possible experience for people with dementia and their carers, but also for people with dementia and carers to have the confidence to take the research in the direction they value. Equalising power differentials by sharing the rules of the games helps to ensure the authenticity of the processes of involvement and the validity of the data produced. But, researcher self-awareness cannot be limited to a deeper understanding of their role in the involvement process, it must also stretch to a deeper appreciation of the processes by which issues arrive on the table, and of the capacity of an organisation or people to limit decision-making to relatively unimportant areas (Bachrach and Baratz, 1962). Lukes (1974/2005, p27) argues that one of the roles of leaders is to influence, shape and determine what people want, thereby effectively controlling what kind of issues arrive on the table for deliberation. This is achieved largely by controlling the flow of information

and through processes of socialisation which Lukes (1974/2005, p28) considers to be the most insidious form of control:

> *Is it not the most supreme and insidious exercise of power to prevent people, to whatever degree, from having grievances by shaping their perceptions, cognitions and preferences in such a way that they accept their role in the existing order of things, either because they can see or imagine no alternative to it, or because they see it as natural or unchangeable, or because they value it as divinely ordained and beneficial.*

In the context of critical gerontology, Biggs (2001) has argued that the existence of such structural and cultural barriers effectively prevent older people from dreaming about how things could be different. Lukes (1974/2005) argued that the creation of such barriers is a way of suffocating demands for change before they were even voiced. But not all instances of power are those of commission, there are also instances of omission; not acting on information received or simply not asking in the first place. As noted by Schattschneider (1960, p71), “Some issues are organized into politics while others are organized out.” I argue that the knowledges of people with dementia and their carers have not, so far, been successfully ‘organised into’ politics. Lukes (1974/2005) would contend that this is due to the web of social and cultural processes and norms that effectively organise them out. Foucault (1988), on whom Lukes drew, argues that the knowledges of devalued people are subjugated in a myriad of visible and invisible ways. Researchers have a role to play in desubjugating the knowledge of devalued people such as people with dementia and their carers.

The following section of the review provides an exploration of some of the underlying tensions identified by Lukes (1974/2005) in relation to whose interests are served by involvement. In doing so, it attempts to deepen our understanding of the mechanisms by which people with dementia and carers are frequently offered nominal forms of involvement, if any at all. The section begins by reviewing Arnstein's (1969) ladder of citizen participation and INVOLVE's (2012) model of involvement in research before moving on to discuss White's (1996) analysis of whose interests are served by involvement.

### 2.11.2. *Interests in involvement*

Arnstein's (1969) ladder of citizen participation is probably the most widely known model of participation. Although more nuanced frameworks have been developed taking into account the role of citizens as active agents of change in an ever-changing political landscape (Beresford, 2012), Arnstein's ladder remains useful and highly relevant particularly when it comes to the involvement of excluded groups such as people with dementia and carers. Frameworks like Arnstein's ladder of citizen participation in community development make explicit the many graduations of involvement from non-involvement through manipulated involvement to full citizen control, a knowledge of which is useful in 'cutting through the hyperbole' (Arnstein, 1969, p217) of involvement and getting to the heart of the question of how to involve those not normally involved. INVOLVE's model usefully separates out and defines involvement, participation and engagement in research and is useful for

identifying points in the research and service development cycle at which people with dementia and carers can get involved. If understood in the light of consumerist and democratic approaches to involvement, both models are useful for aiding theoretical understanding of involvement, particularly in relation to involving people with dementia and carers. Yet, to understand what makes some involvement initiatives successful and why others ultimately fail requires a deeper understanding of whose interests are served by these initiatives.

Writing nearly two decades ago in the context of international development, White (1996, pp142-143) argued that: hardly a project was without a participatory element. And while this was, at first sight, good news for supporters of ‘people-centred development policies’, it did not necessarily lead to sharing power. The danger, White argued, is that some strategies for involvement, designed to satisfy demands for participation, can take the form of control through incorporation, no less exclusionary than directly preventing participation. To develop a clearer understanding of who benefits from participation, and how, White created a matrix depicting i) four types of participation: nominal, instrumental, representative and transformative, ii) the interests of top down (designers and implementers of development programmes) and bottom up players in each form of participation, and iii) the function of each type of participation. This matrix is reproduced here as table 2-2.

**Table 2-2: Interests in participation**

| Form | Top-Down | Bottom-up | Function |
|---|---|---|---|
| Nominal | Legitimation | Inclusion | Display |
| Instrumental | Efficiency | Cost | Means |
| Representative | Sustainability | Leverage | Voice |
| Transformative | Empowerment | Empowerment | Means/End |

*White, (1996, p7) Depoliticising development: The uses and abuses of participation*.

The matrix is helpful in articulating the different uses of different forms of 'participation' by different players. Nominal participation, where a group of end users/beneficiaries is formed and consulted, serves top down interests by legitimising participation and offers intended beneficiaries a sense of being included. But this form of participation, argues White, is largely for display purposes, to provide some 'evidence' of participation. The voices of participants make no discernible difference to how the organisation or project is managed. Instrumental participation refers to participation that serves the interests of top down players by involving end users as resources to improve the cost effectiveness of achieving specific ends. But although coming at some cost to beneficiaries, they are prepared to participate since they desire the same ends. White uses the example of a community school building project with the funder covering the costs of materials but relying on the free labour of local participants who cannot spend that time and energy on other valuable daily tasks. The function of participation here is a means to an end rather than genuine power-sharing. White's third form, representative participation, is

characterised by explicit attempts to involve beneficiaries in the development of particular initiatives. For top down players this increases the chances of sustainability, while for potential beneficiaries it can be effective as a means of communicating their own interests. The function of representative participation is to ensure that the voices of bottom up participants are effectively heard. But it is only the fourth form, transformative participation, where the interests of top down and bottom up players coalesce around goals (ends) and processes (means) of empowerment to develop consciousness of injustice and confidence to take action, individually or collectively, to address that injustice. This process of involvement becomes, "…a continuing dynamic which transforms people's reality and their sense of it" (White, 1996, p9). Arguments such as these suggest that the problem of involvement is not related to methodology, therefore changing the way we do involvement will not necessarily help to resolve the issue. Cooke and Kothari (2001, p4) also argue that the problem of involvement is systemic and it is only by acknowledging the reach of the problem that we can begin to formulate a response and that to treat involvement as a methodological issue rather than a systemic one, "…embodies the potential for an unjustified exercise of power."

An understanding of power-related issues is vital if people with dementia and carers are to be authentically involved in research and service development. Much will depend on the willingness of researchers to think deeply about their own motivations for engaging people with dementia

and carers in research and about the value they place on the knowledges produced by their collaborations.

## 2.12. Chapter summary and research questions

In this chapter I have provided a critical analysis of the broad processes of involvement for the purpose of learning and understanding how people with dementia and their carers could become ‘routinely’ engaged in research (Department of Health, 2012a, p16) and service development (CSIP Older People's Mental Health Programme, 2007). This has addressed the first aim of the study which was to provide a critical analysis of those processes. In section 2.2, I provided a historical overview of the development of dementia policy in the UK. This was followed in 2.3 by a review of the rise of service user involvement in health and in social care. In section 2.4, I discussed the idea that service user involvement is seen to be ‘a good thing’ generally and for people with dementia and their carers specifically (2.5). Service user involvement is not, though, unproblematic and in section 2.6, I provided a critical analysis of the underlying tensions inherent in involvement initiatives. In section 2.7 I discussed the role of democracy in involvement, before moving on to identify two models of involvement: the consumerist and the democratic. I then discussed an emerging model of democratic leadership in the NHS: collective leadership (2.8). The section is brought to a close with a critical analysis of the barriers to involvement (2.9) and facilitators of involvement (2.10). The second section on power began by couching the relationship between power and involvement in terms of

structural power inequalities and culturally patterned discrimination (2.11) before moving on to explore Stephen Lukes' analyses of power. This critical analysis of the broad processes of involvement was closed with an analysis of whose interests are served by involvement.

The involvement literature is characterised by a conspicuous absence of any significant discussion of the potential for involving people with dementia and their carers in research on dementia and service evaluation. Manthorpe *et al.* (2013, Epub, p70), for example, commented on the, "…dearth of research about the experiences of individuals with dementia" reported by the National Institute for Health and Clinical Excellence (2006) in the lead up to the development of NICE guidelines on supporting people with dementia and carers. The Department of Health (2012a), meanwhile, identified that people with dementia and carers are not routinely involved in high-quality research and even if they wanted to be, there is currently no system in place for this to happen. A dearth of research, however, does not mean no research and, as highlighted earlier, there have been a number of studies exploring different aspects of dementia service evaluation involving people with dementia and carers including by Hean and Warr (2010), Morgan *et al.* (2011) and Innes and McCabe (2012). Moreover, people with dementia and carers have participated in qualitative research investigating their experiences of healthcare (Prorok *et al.*, 2013). To date, however, there has been only one study involving people with dementia and carers in a comprehensive evaluation of a memory service: the evaluation of the

Croydon memory service conducted by Banerjee *et al.* (2007). A comprehensive account of how the team involved people with dementia and carers was published by Willis *et al.* (2009). In order to address this gap, I have specified the following research questions which form the focus of the empirical research study that follows.

RQ1: To what extent can knowledges produced by people with dementia and carers challenge negative stereotypes of dementia while extending our knowledge on how to involve them in research about dementia and in service development?

RQ2: What criteria do people with dementia and carers use to evaluate dementia services?

RQ3: What values, attitudes and practices among mental health practitioners and service-level managers facilitate the development of high-quality services and the effective involvement of people with dementia and carers?

# Chapter Three: Methodology

## 3.1. Introduction

In this chapter I outline the methodological approach adopted to address the research questions outlined in the previous chapter. I begin by identifying the research design (3.2). Following this I identify the theoretical framework underpinning the research methods (3.3), the role of the research advisory group in supporting the study (3.4) and the role played by reflection and reflexivity in the study (3.5). This is followed by a detailed account of the process for gaining ethical approval for conducting the study in the NHS (3.6). Following this, I present details of the sampling strategy (3.7) and a detailed description of and rationale for the data collection tools (3.8). Given the seriousness of issues of capacity in relation to consent, I present a detailed account of decisions about capacity in section 3.9. In section 3.10, I describe the steps taken to analyse the data. I begin by providing a description of narrative adequacy, including an analysis of what is a good story and who is a good storyteller. I then provide an overview of the process used to generate themes, code and triangulate the data. This includes a description of the use of NVivo in the study.

## 3.2. Research design

In this section I describe the steps taken to select the research framework, produce and analyse the data, including my rationale for framing the study as case-based qualitative research.

### 3.2.1. *Why use a qualitative methodology?*

Each methodology has its strengths and weaknesses and is able to address one or more parts of the research puzzle. In my study, I wanted to talk to people with dementia and carers about their experiences of using a memory service, so I opted to use a narrative approach to data collection and analysis. Other researchers have used surveys to gather evaluation data. In one such evaluation of a memory service, Hean and Warr (2010) involved people with dementia and carers by asking them to complete a short survey. Surveys are useful for providing brief answers to simple questions but they do not facilitate understanding of context which can contribute valuable information to the data collected. Although it can be an imposition to ask people to take part in a research interview, I felt it was the best way to get the rich, nuanced data I was interested in. I used narrative interviews with CMHT staff for many of the same reasons I used them with people with dementia and carers. I knew from conversations with the CMHT leader that team members worked under immense pressure and would likely struggle to provide more than brief responses to a paper-based survey. Moreover, survey responses rates are typically low (Lepkowski *et al.*, 2008). Not only was I interested in eliciting views from a broad range of staff, I was interested in getting behind the brief responses surveys could provide, to the heart of the experience of providing a memory service for people with dementia and carers within the context of a CMHT.

Qualitative research has many strengths, one of which is that it is personalistic or, to use the language of health and social care, person-centred. Person-centred in terms of its ability to nurture differing points of view and in its preference for an emic rather than an etic perspective (Stake, 2010). Lyons *et al.* (2013) argue that qualitative research is ideal for conducting research with culturally diverse populations. And, if conducted sensitively, creatively and reflexively they further argue that qualitative research has the potential to promote ethically sound and socially just research.

### 3.2.2. *What is case-based qualitative research?*

In the study I adopted a case-based qualitative approach to collect and analyse the research data. Although not reduced to the following features, a piece of qualitative research can be thought of as being case-based when it explores what is going on in a particular situation at a given time, with a specific group of people (Stake, 1995). Characteristic of case-based qualitative research is its ability to 'make real' subjective experience - in this case the issues and concerns of people with dementia, carers and CMHT staff. Moreover, the person-centredness of case-based qualitative research means it is ideal for answering, 'What are the issues here?' type questions, as reality is described and shared meanings are constructed, thus ensuring an accurate description of the phenomenon under investigation (Stake, 2006). The person-centred approach, so vital in case-based qualitative research, also works well with emergent ideas on the concept of personhood. For example, ideas such

as the, “…centrality of relationship, the uniqueness of persons” that underpin the work of Kitwood (1997, p7) echo the core values of case-based qualitative research. This approach works best when applied to particular situations, “…certain contexts, at certain times, and with certain people” (Stake, 2010, p14). In other words it is closely focused on the particular rather than the general. Often it is possible to generalise beyond the particular, but the primary goal is to describe the possibilities existing within the case (Stake, 1995). Qualitative research is interpretive. It supports the use of non-scientific notions such as intuition, expertise, judgement, worldview and personal and professional experience to shape the whole of the research process (Silverman, 2013).

According to Eisenhardt (1989), case-based research is not genre biased and can include data grounded in positivistic (numerical) and naturalistic (talk and text) accounts of the social world. Within either tradition, case-based research usually draws upon multiple sources of data, carefully matching data collection approaches with the philosophical and practical requirements of the study (Yin, 2013). Case-based qualitative research can investigate multiple or single cases. However, Yin (2013, p57) points out the advantages and disadvantages of multiple and single case studies and comes to the conclusion, “…the conduct of a multiple-case study can require extensive resources and time beyond the means of a single student or independent research investigator.” My investigation can be classed as a i) single (focused on one mental health service for older people), ii) embedded (following multiple lines of enquiry), iii) descriptive

(because it will not make predictions or point to cause and effect issues), case-based qualitative study. Within this single case there are three nested data streams reflecting the views and experiences of people with dementia, carers and staff:

1. People with dementia and carers on their initial experience of dementia and the day-to-day challenges of living with a diagnosis of dementia.
2. People with dementia and carers in relation to the memory service they received from an integrated community mental health team (CMHT).
3. CMHT staff on the transition of the CMHT from a buildings-based service to a specialised dementia service offering targeted mental health care for people with dementia and carers.

Each data stream presents data answering each of the research questions.

### 3.2.3. *The case in this case-based qualitative study*

The case in this case-based study is a memory service provided within a CMHT for older people. The CMHT is a multi-disciplinary team comprising: CPNs, medical staff, occupational therapists, physiotherapists, psychologists, social workers and support workers. CMHT staff can draw upon the advice of other professionals, including for example dieticians and pharmacists. The CMHT sits within the wider

community mental health service for older people (MHSOP) provided by an NHS Foundation Trust which offers a range of mental health, learning disability and substance misuse services. The Trust works in partnership with local authorities and primary care trusts, a wide range of voluntary organisations, service users, carers and the public. In the Trust's first Annual Health Check by the Healthcare Commission, their services were confirmed as being among the best in the country. The CMHT office space is provided in a unit adjacent to the Trust's in-patient facility which provides mental health services for older people with functional and organic mental illness.

The memory service sits within the CMHT and provides specialist cognitive assessments for people who are worried about having a memory problem. Memory nurses are community psychiatric nurses (CPNs). In most instances in this memory service, memory nurses complete the initial memory assessment. If there is a complex presentation of dementia, the referral is passed to the consultant psychiatrist. A memory nurse will continue to be involved after diagnosis, for example to monitor memory drugs if they have been prescribed and to offer information, advice and support to the person with memory problems and their family. They can also refer patients to other members of the CMHT. Healthcare support workers work alongside memory nurses to deliver agreed packages of support. The young onset dementia service comprises a memory nurse and an occupational therapist. Like the memory service for late onset dementia, the young onset dementia

service works within the framework of the CMHT. Diagrams depicting the relationship between the memory service and other components of the MHSOP are provided in diagrams 3-1 and 3-2.

**Diagram 3-1: Organisational chart for The NHS Foundation Trust**

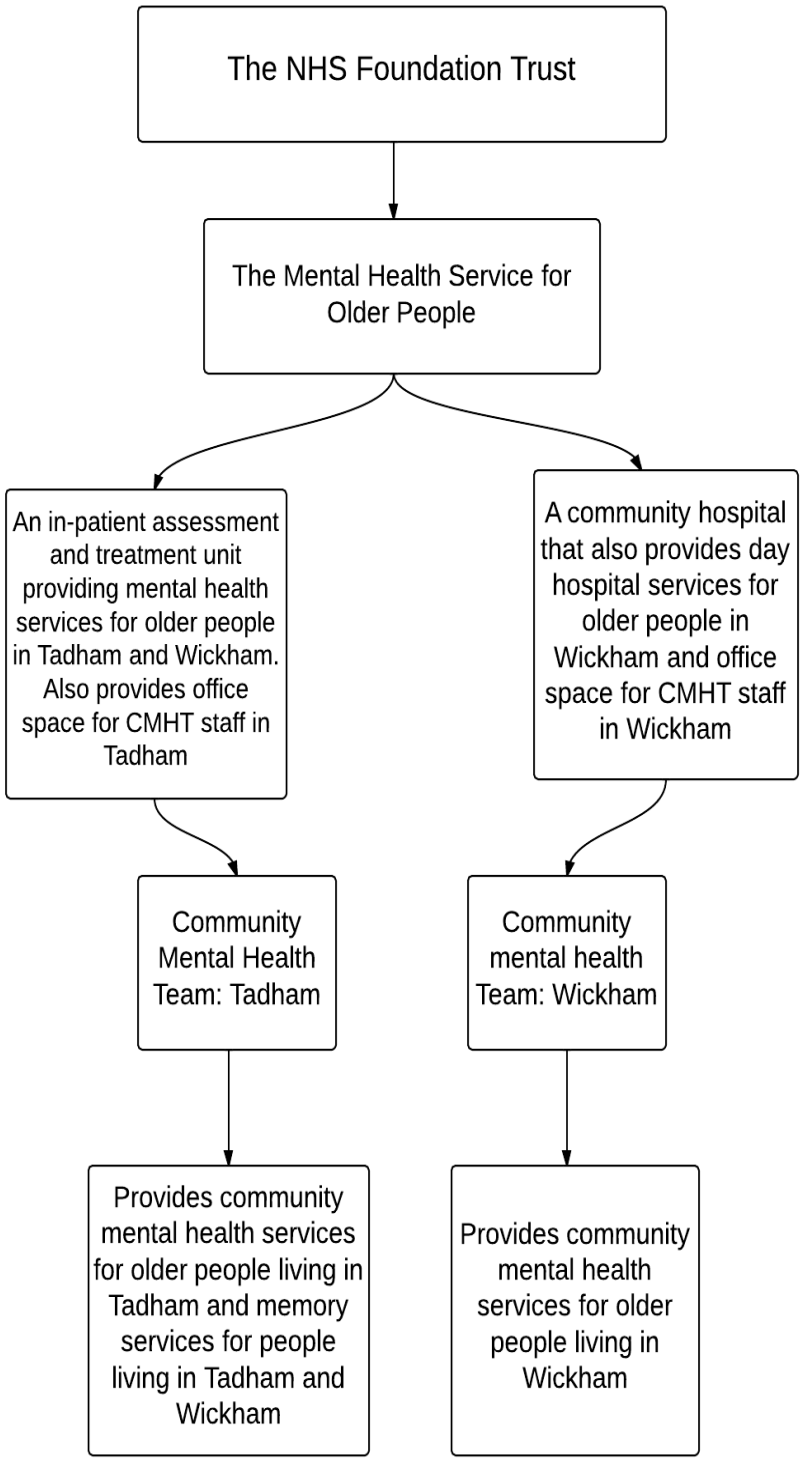
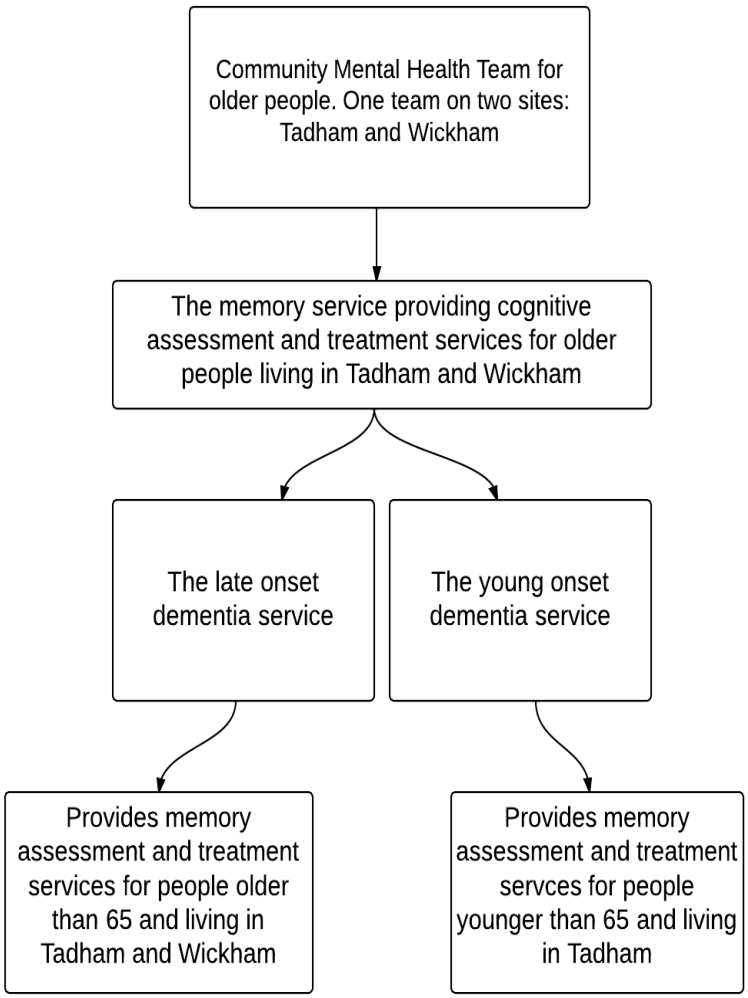


**Diagram 3-2: Organisational chart for the CMHT and memory service**



## 3.3. The theoretical framework underpinning the research methods

In this section I provide an overview of the theoretical framework underpinning the methodological approach to the study. Critical gerontology focuses on the identification of structural barriers and cultural processes that produce ageism and shares much in common with the social model of disability which focuses on how structural barriers and cultural processes produce disability. Both models strongly reject the medical model as an incomplete explanation for how people experience illness and disability.

### 3.3.1. *The role of critical gerontology in the study*

Townsend (1981) has argued that the field of gerontology is a relatively new field of inquiry with, until recently, a somewhat narrow focus on biological senescence. Critical gerontology developed during the 1980s and 1990s as a response to conventional approaches to gerontology and ageing that failed to take into account social constitution. Indeed, Baars (1991, p219) has argued that social constitution was the principal theoretical threat to conventional gerontology declaring that, "…social constitution can no longer be avoided in theoretical reflection on gerontology." Townsend's (1981) analysis of structured dependency, for example, identified the role of government in lowering the status of older people via unjust policies, a process he argued went largely unnoticed by researchers because their, "…bias was towards individualistic instead of societal forms of explanation." Baars (1991, p220) wrote that the strength

of critical gerontology lies in its ability to identify these underlying social processes for the purpose of determining what can be changed and for understanding how quality of life can be improved for older people, arguing that, “Its quality can be changed and improved if it is clear how specific forms of aging are constituted by specific social processes that can be changed.”

Baars (2012, p146) identified three types of discourses on ageing, i) discourses that are chronometric, classifying people according to their age or birth cohort (baby boomers, gen X, etc.), ii) discourses that focus on biological processes that happen to everyone if they live long enough and the health issues that flow from that and iii) discourses that frame ageing, “…as a social-existential process of persons who continue to lead their lives after they have been labelled by their societies as ‘aged’ or ‘old’”. Baars (2012) argues that in contrast to the first two, the third discourse is the least well developed, despite the role it could play in sensitising researchers to the issues that affect people’s everyday lives. In this study, I have used critical gerontology as a theoretical framework for understanding the socially constituted nature of the experiences of people with dementia and carers. I have used it specifically as a way of ‘getting behind’ the words people spoke to reveal the various ways in which their knowledges are accepted or rejected by families, friends, professionals and the communities in which they live.

### 3.3.2. *The role of narrative gerontology in the study*

If critical gerontology is the critical impulse that makes visible structural and societal discrimination then narrative gerontology can be viewed as a means of providing, "…a lens though which to see the storied nature of aging" (Kenyon *et al.*, 2001, pxi). Extending the arguments of Townsend, Kenyon and Randall (2001, p4) contend that, "…human beings are not just biological entities or sociological constructions. They are biographical beings" who constantly create and re-create themselves via the stories they tell. Baars (2012) argues that storytelling is universal and although the medium for storytelling may have changed, the need to tell someone our story has not. Zeilig (2011) argues that stories produced via narrative gerontology add important insights to what we know about ageing, particularly in relation to the construction of ageing in policy and the taken-for-granted nature of the culture that surrounds social constructions of ageing.

Kenyon and Randall (2001) argue that narrative gerontology is premised upon five theoretical assumptions: i) storytelling is a core aspect of being human, ii) lives as stories are composed of facts and possibilities, iii) stories and their meanings are temporal, iv) storied lives are made up of our own personal stories and the stories of the world in which we live and v) paradoxically, our personal stories are worked out within the bigger story being created by the world in which we live.

Narrative gerontology is concerned with both content and context. It treats narratives as data and as metaphors that add nuance and meaning

via an exploration of storylines, plot and themes. Baars (2012, p147) argues that the act of transforming oral stories into written narratives extends the power and reach of stories to a wider audience who can layer the stories with their own interpretation. In other words, "…experiences find their most adequate articulation in narratives." Tellingly, Foucault (1988, p93) uses a similar argument in writing about power and construction of truth:

> *…in any society, there are manifold relations of power which permeate, characterise and constitute the social body…and these relations of power cannot themselves be established, consolidated nor implemented without the production, accumulation, circulation and functioning of a discourse. There can be no possible exercise of power without a certain economy of discourses of truth which operates through and on the basis of this association.*

***Summary***

In this research I use critical gerontology as a theoretical framework to better understand the barriers and facilitators of service user and carer involvement. I use narrative gerontology as a tool for generating and analysing the stories produced by people with dementia, carers and CMHT staff.

## 3.4. Involving people with dementia and carers: the research advisory group

In this section I describe the rationale for creating a research advisory group and the process by which I recruited people to the group. I also provide an overview of the work advisory group members were involved in over the course of the research. I have devised a number of diagrams

depicting how group members were recruited (diagram 3-3), the research activities in which they were involved (diagram 3-4) and the suggested dissemination strategy devised by the group (diagram 3-5).

**Diagram 3-3: Recruitment strategy for the advisory group**

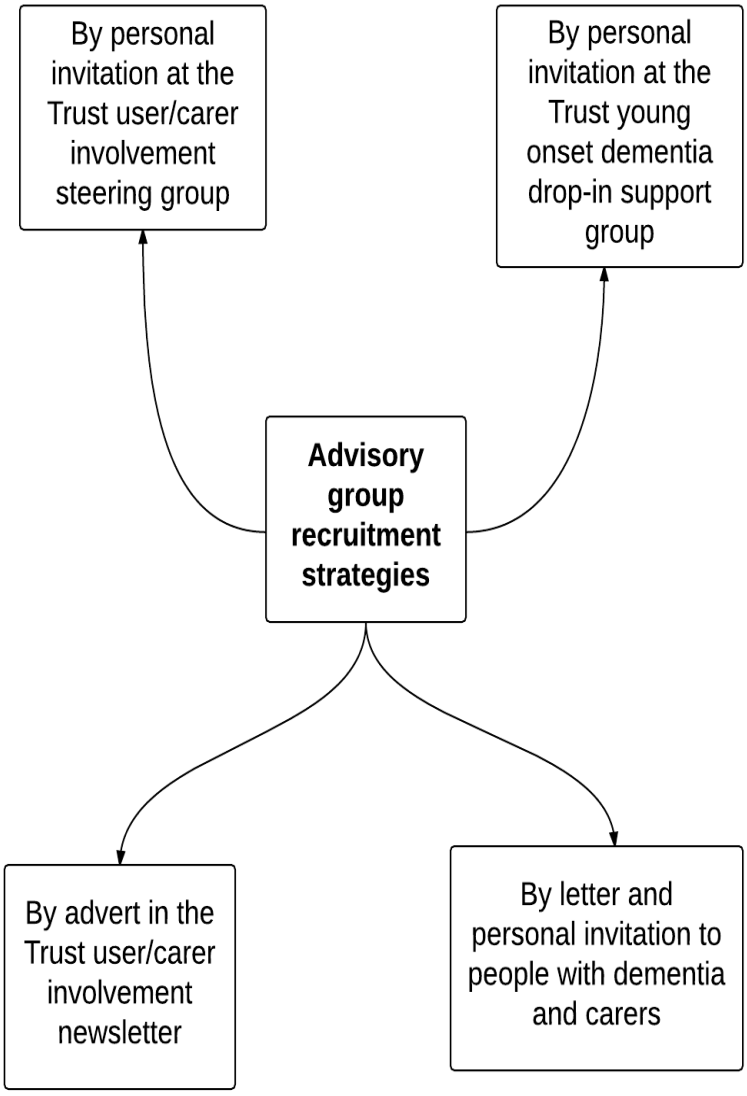


**Diagram 3-4: Research activities of advisory group members**

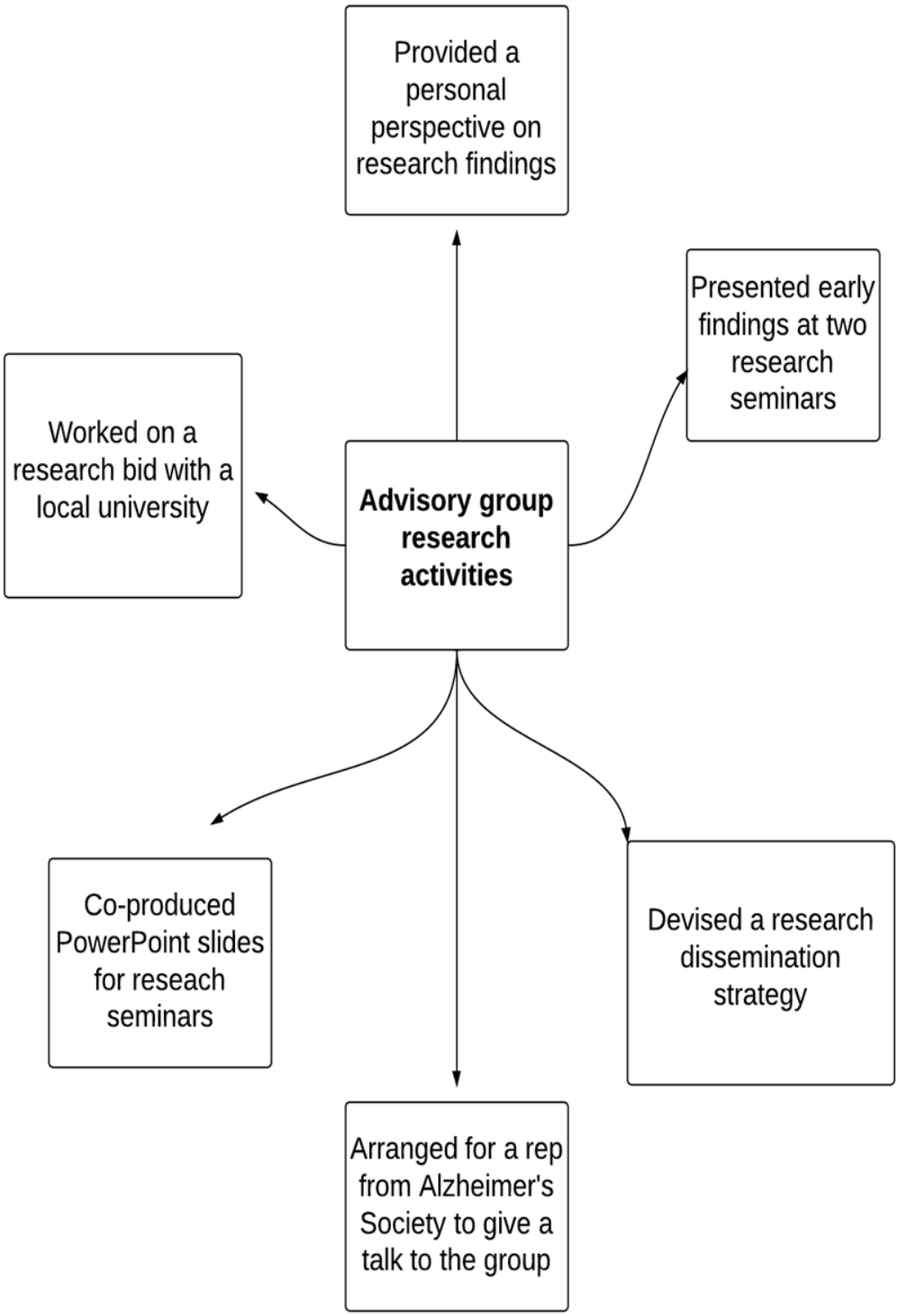
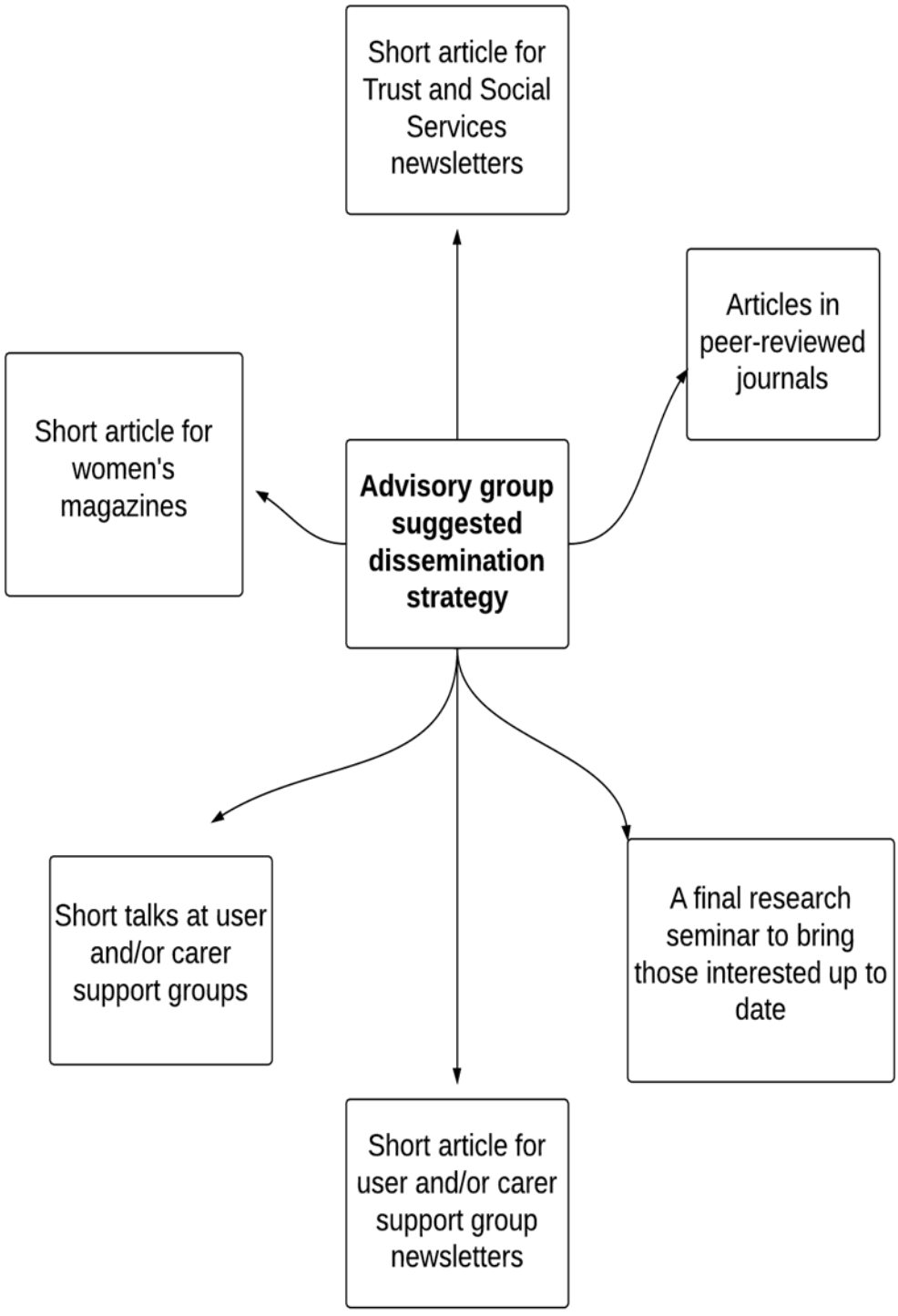


**Diagram 3-5: Dissemination strategies devised by advisory group**



Stakeholder involvement is an increasingly important part of NHS research and development and a key requirement of NHS research governance (INVOLVE, 2012). A considerable part of my initial NHS ethics submission was related to how I would involve people with dementia and carers in my research and how the process would be managed. INVOLVE's model for involving members of the public in research identifies the key stages for meaningful involvement. Although I was able to include CMHT staff in the development of the research protocol, it was not possible to involve people with dementia and carers as I was unable to approach them until after I had secured permission and ethical approval from an NHS ethics committee. I had hoped to involve people with dementia and carers in the management of the research via membership of an advisory group early on in the data collection process. However, it took time to work out the best way of contacting possible group members. The Trust had started a user/carer involvement steering group at the same time as I was thinking about how I could recruit advisory group members to guide my research. I was introduced to the development worker who facilitated the group at a conference hosted by the Trust and at which I was presenting a paper on my research. I asked if I could attend the next meeting of the involvement group with the purpose of presenting the research and recruiting people to the group. At the meeting I was successful in recruiting several people to the advisory group. In addition, in the initial letter of invitation to people with dementia and carers, I asked if participants would like to take participate in the advisory group, one couple responded positively. The

advisory group comprised five people with personal experience of dementia. One group member was diagnosed with dementia, another was the spouse of the person diagnosed with dementia, another had nursed her husband until his death the previous year, another was the spouse of an older woman with advanced dementia, another was a social worker working as a development worker promoting patient and service user involvement in service development in mental health services. To meet the requirements of the NHS ethics committee, an older carer with whom I had conducted research previously, helped me to facilitate the group by helping me meet and greet and make refreshments. All those who volunteered to join the advisory group were given a participant information document which outlined their role in the research and how it might develop (Appendix 2). Members of the advisory group were involved in various aspects of the study including: devising a dissemination strategy, co-presenting seminars on the research, generating topics for future research. They also became involved in advising university staff on a separate research proposal. The first meeting of the advisory group was held in September 2010. Thereafter the meetings were bi-monthly for a period of one year.

User-led organisations such as Shaping Our Lives are critical of involvement meetings that have been initiated by services rather than service users but also recognise the value such meetings have if they are sensitively managed and facilitated and provide the space (i.e. cultural, physical and emotional) for:

- Service users to have a good time;
- The provision of good, free food and refreshments which are culturally appropriate;
- The provision of a comfortable, safe and supportive environment;
- An opportunity for people to gain knowledge, awareness and understanding from the events or meetings (Beresford, 2013, p10).

In facilitating the advisory group meetings, I strove to ensure all these benefits. Additionally, since my study was concerned with the involvement of people with dementia and carers in research and service development, I was interested in testing out Branfield and Beresford's (2006) thoughts on the utility of small groups and networks as a way of involving people in the day-to-day work of services. Finally, I was interested in developing research capacity locally and reasoned that if my advisory group became skilled and experienced in contributing to research, they may wish to become involved with other initiatives in the future.

### 3.4.1. *The role of the advisory group in developing the dissemination strategy*

An important consideration in this methodology chapter relates to the question of the early dissemination of the findings from the study. Advisory group members were involved with devising a dissemination strategy for the study. Part of the strategy was to share aspects of the study while it was still in progress. This was to encourage the

development of local networking and shared learning opportunities. I facilitated two public seminars so that interested parties could track the progress of the research and for everyone involved with the research to share their experience and developing skills. The seminars were used to share provisional findings from the research and to ask for ideas on the best way to take particular issues forward. In this way, opportunities to generate research capital were expressly linked with the development of the research project rather than a distant outcome at the end. Furthermore, one of the advisory group meetings was dedicated to producing a research dissemination strategy. Group members suggested that in addition to the potential for writing articles for peer-reviewed journals, the dissemination strategy should include writing short articles for local Trust and Social Care newsletters/forums, local support groups, local newspapers and for local radio. Given the success of the two research seminars, group members suggested facilitating a number of talks for local support groups.

A discussion of the advantages and disadvantages of facilitating the advisory group can be found in the concluding chapter of the thesis (8.4.6).

## 3.5. Reflection and reflexivity as research tools

Oxford Dictionaries Online (2010) defines reflection as, “serious thought or consideration” and reflexivity as, “taking account of itself or of the effect of the personality or presence of the researcher on what is being

investigated." Reflection is often linked with practitioner development (Schön, 1987) and reflexivity with ethically sound research methodologies (Bourdieu and Wacquant, 1992; Yin, 2013). Although almost synonymous with qualitative research, reflection and reflexivity are not unproblematic and their integration into naturalistic research methodologies is not straightforward (Finlay, 2002). In this study I have used the process of reflection to monitor my professional conduct before, during and after the activities of data collection and analysis, and the process of reflexivity as a way of making sense of my emotional and intellectual response to the data. More information on this aspect of the study can be found in the discussion chapter at section 7.13.

## 3.6. The process of gaining ethical approval in the NHS

In this section I describe the process by which I gained ethical permission to conduct the study in the NHS. This section includes details of why I chose the research site and how I gained access to the site together with an overview of the process of gaining ethical permission to conduct the study in the NHS.

### 3.6.1. *Selection of the research site*

A number of issues affected the selection of the research site. The decision to focus on a single team was based in part on a comprehensive search of the literature that revealed only a small number of published studies involving people with dementia and carers in service evaluations of dementia services. It seemed appropriate, therefore, to develop an in-

depth study of the people and work associated with a single dementia service. Regular caring responsibilities and limited access to transport encouraged me in approaching an accessible CMHT.

### 3.6.2. *Negotiating access*

I began the process of negotiating access to the research site by emailing the clinical services manager of the mental health service for older people (MHSOP) to arrange an appointment. Although, he was unable to meet with me, I was offered an appointment with the acting team manager. I sent both managers a copy of my research proposal and asked them to think about how the proposal could be developed so that the mental health service could benefit from the research. I met with the acting team manager on several occasions to discuss the research proposal in detail. Engaging in this process undoubtedly helped me to gain access to the Trust, as over the course of several meetings, I became a familiar and trusted figure. During this process, a number of decisions were taken including that the Trust would pay every person with dementia and every carer an honorarium of £20 plus travelling expenses for each advisory group meeting they attended. The Trust also offered the advisory group the use of a spacious meeting room and a free buffet lunch. We also worked out a sampling strategy (later carried out by the CMHT team leader) for identifying participants for the research interviews. I was also able to identify key meetings to attend that would be beneficial for developing my understanding of how the MHSOP worked and how the memory service fitted with other services provided by the Trust, including

team meetings, Trust governance meetings, caseload supervision meetings between care home liaison staff and the consultant psychiatrist, service user and carer involvement meetings, young onset dementia drop-in meetings and a Trust conference.

It came to light during my discussions with the acting team manager that the MHSOP was in the process of being re-accredited by a local university. The accreditation process investigated a number of issues, including how well the Trust involved service users and carers in the everyday work of the service. At the previous accreditation the only aspect of the assessment the mental health service had failed was on service user involvement in research and service development. My study was therefore viewed as timely as it was hoped that, together with a range of other involvement initiatives the Trust had started, it would contribute towards a successful re-accreditation.[15]

When the final version of the research proposal was accepted by the general manager of the mental health service and I was given permission to work with the CMHT, I applied for ethical approval from the University. I also applied for a research passport for research in the NHS[16][17] and had

[15] The Trust was successfully re-accredited.

[16] https://www.dur.ac.uk/hr/policies/research/respssprt/

[17] Due to the amount of identifying information included in the research passport, I have not included a copy in the appendices.

the research proposal independently reviewed by a recognised expert in the field (Appendix 3).

### 3.6.3. *Submitting to NHS ethics*

Once the various checks and the amendments suggested by the external reviewer were completed, I then began the process of applying for permission to conduct research in the NHS. This was an extensive process that involved completing a lengthy online application form, applying for permission from the local research ethics committee (Appendix 4), the local Trust (Appendix 5) and two social service departments. As I was in the process of gaining ethical approval via the NHS, I did not need to apply to social services separately. I was informed by email that they would be happy to accept the recommendations of the NHS ethics committee. The final step in the process was to defend my application before a research ethics committee. The whole process took approximately nine months.

## 3.7. Sampling strategy

In case-based qualitative research, the sampling strategy is all-important. This is because researchers are interested in the everydayness of ordinary life; in discovering how people, "… function in their ordinary pursuits and milieu …" (Stake, 1995, p1). Qualitative research is not about generalisation; it is more about illumination, rich description and the generation of ideas and insights. Because of this need for detail, purposive sampling is used to identify people best placed to describe the

phenomenon under investigation. Building upon the work of several qualitative researchers, Teddlie and Yu (2007) developed a typology of purposive sampling strategies that are helpful in terms of thinking more deeply about different approaches to purposive sampling available to qualitative researchers (Table 3-1).

**Table 3-1: A typology of purposive sampling strategies**

| |
|---|
| **A. Sampling to Achieve Representativeness or Comparability** |
| 1. Typical Case Sampling |
| 2. Extreme or Deviant Case Sampling (also known as Outlier Sampling) |
| 3. Intensity Sampling |
| 4. Maximum Variation Sampling |
| 5. Homogeneous Sampling |
| 6. Reputational Case Sampling |
| **B. Sampling Special or Unique Cases** |
| 7. Revelatory Case Sampling |
| 8. Critical Case Sampling |
| 9. Sampling Politically Important Cases |
| 10. Complete Collection (also known as Criterion Sampling) |
| **C. Sequential Sampling** |
| 11. Theoretical sampling (also known as Theory-Based Sampling) |
| 12. Confirming and Disconfirming Cases |
| 13. Opportunistic Sampling (also known as Emergent Sampling) |
| 14. Snowball Sampling (also known as Chain Sampling) |
| **D. Sampling Using Combinations of Purposive Techniques** |
| (Teddlie and Yu, 2007, p81) |

In this study, I employed multiple techniques to maximise opportunities to recruit individuals with the requisite knowledge, skills and experience. For people with dementia and carers, I employed the following sampling techniques:

- Typical case sampling. Every person who matched the inclusion criteria was invited to take part in the research.

- Maximum variation sampling. I made every effort to include people from a range of ethnic backgrounds, gender, age and type of dementia. But, due to the low numbers of people with dementia who were available to take part in the study, this strategy quickly became irrelevant. I suspect this had something to do with the time of year I was contacting people (June, July, and August) as many had made, or were making, plans to go on holiday. At the time the study was being conducted, only one couple from the black, Asian, minority ethnic (BAME) community was identified by the sampling techniques. Although sympathetic to the aims of the study, they were not in a position to take part.

- Opportunistic sampling. I attended the young onset dementia drop-in group and asked if anyone would like to take part in the research. I also attended the Trust's User Involvement Steering Group in order to recruit people to join the advisory group.

In terms of staff recruitment, every member of staff working in the CMHT and two senior managers from the MHSOP were invited to take part in the study.

### 3.7.1. *Research population*

Morse and Field (1996, p65) proposed that 'appropriateness and adequacy' are the guiding principles of qualitative research. Appropriateness is linked to the identification and involvement of participants who have a deep understanding of the phenomenon being researched and the ability to develop the theoretical requirements of the study. Adequacy is about ensuring that enough data is generated to ensure a rich and full description of the phenomenon. Morse and Field's definitions of appropriateness and adequacy were fulfilled by recruiting people with dementia and carers who had experience of using the memory services provided by the CMHT and staff who were currently employed by the Trust to work within the CMHT and/or within the MHSOP[18] and conducting enough interviews so that data saturation was reached.

[18] This was to ensure that I was able to capture data from senior managers and clinical staff who worked across several areas in MHSOP.

### 3.7.2. *Sampling selection*

I worked with the CMHT leader to identify a sample of people with dementia and carers. This was achieved by identifying people with dementia and carers who had used the memory service within the time period June-August 2009 and who were still active to the CMHT.

I did not have permission from NHS ethics to access patient information before participants agreed to take part in the study, so the CMHT Leader searched the database and identified those who had used the memory service 12 months previously and who were still active to the team. Details of all potential participants were forwarded to the appropriate memory nurse who made contact with the family. If the individual with dementia and/or carer agreed to be interviewed, I met briefly with the memory nurses to make a note of the family's contact details and discuss any special needs the family may have in terms of communication.

The sampling strategy for staff was in the form of a written invitation to all staff working in the CMHT and senior members of staff from the MHSOP (Appendix 6). The letter of invitation was accompanied by a consent form (Appendix 7) and a participant information document (Appendix 8).

### 3.7.3. *Inclusion and exclusion criteria*

When someone receives a diagnosis of dementia, taking part in a research study about dementia may be the last thing they want to do. I was keenly aware of this issue and took care to minimise the risk of inflicting undue stress on people with dementia and carers. I consulted

with the acting team manager before inviting participants to join the study. My primary concern was to ensure that people with dementia and carers who were in crisis were not exposed to further stress. Those deemed to be in crisis were excluded from the study. I also decided that only people with mild to moderate dementia should be included. Despite my years of professional experience, I nevertheless felt it would be difficult to discern if and when a conversation with a person with severe dementia was truly consensual. Also, as I was interested in what people with dementia thought about the service they received from the CMHT and how dementia affected their lives, it was important that participants were able to communicate with me either verbally or non-verbally. Although people with severe dementia were not included in the study, carers of people with severe dementia were invited to participate in the study, not as proxies, but as participants in their own right.

To summarise, people with dementia and carers in the sample were i) past or current users of the young onset dementia service or older people's dementia service provided by the CMHT, ii) not in crisis iii) and, their involvement was agreed by senior members of the CMHT. For those people with dementia who were living with a spouse or partner and who were experiencing significant challenges with communication, their carers were approached first to ensure that taking part would be something their spouse/partner would ordinarily be happy with.

### 3.7.4. *Sample*

A total of 49 participants completed 51 research interviews between April 2010-July 2011: 9 people with dementia, 12 carers (of which ten were spouses and two were relatives), 1 family support worker and 28 staff members from the CMHT for older people. There were four spouse/carer dyads and two relative/carer dyads. All were white European. Not everyone in the study had a differentiated diagnosis. A breakdown of the type of and number of interviews completed with people with dementia and carers can be found in table 3-2, participants' diagnoses in table 3-3, characteristics of carers in table 3-4 and CMHT staff interviews in table 3-5.

**Table 3-2: Type/number of interviews: people with dementia and carers**

| **Type of interview** | **Number of interviews** |
|---|---|
| Joint: spouse/carer | 4 |
| Joint: relative/carer | 2 |
| Single: individuals with dementia | 5 |
| Single: spouses who were carers | 8 |
| Single: relatives who were carers | 1 |
| Single: family support worker | 1 |
| **Total** | **21** |

**Table 3-3: Diagnosis of participants with dementia**

| | **Number of people with dementia** |
|---|---|
| Alzheimer's: early onset | 1 |
| Alzheimer's: late onset | 2 |
| Vascular dementia | 1 |
| Dementia | 5 |
| **Total** | **9** |
| Male | 5 |
| Female | 4 |

**Table 3-4: Characteristics of carers**

| | **Number of carers** |
|---|---|
| Caring for a spouse with young onset Alzheimer's disease | 4 |
| Caring for spouse with late onset Alzheimer's disease | 2 |
| Caring for a spouse with vascular dementia | 1 |
| Caring for a spouse with non-specified dementia | 3 |
| Caring for a relative with non-specified dementia | 1 |
| **Total** | **11** |
| Male | 6 |
| Female | 5 |

## Table 3-5: A breakdown of CMHT interviews

| | Participants | Interviews |
|---|---|---|
| Medical staff | 2 | 2 |
| Medical Secretaries | 1 | 1 |
| Memory Nurses: late onset | 4 | 5 |
| Memory Nurses: young onset | 1 | 1 |
| Managers | 3 | 4 |
| CPNs: Tadham | 2 | 2 |
| CPNs: Wickham | 2 | 2 |
| CPNs: hospital liaison/Tadham | 1 | 1 |
| CPNs: care home liaison/Tadham | 2 | 2 |
| CPNs: care home liaison/Wickham | 1 | 1 |
| Healthcare Assistants | 1 | 1 |
| Physiotherapists | 1 | 1 |
| Occupational Therapists | 2 | 2 |
| Clinical Psychologists | 1 | 1 |
| Anglican Priest | 1 | 1 |
| Social Workers: Tadham | 2 | 2 |
| Social Workers: Wickham | 1 | 1 |
| **Total** | **28** | **30** |
| Male | 6 | |
| Female | 22 | |

With the exception of a memory nurse and the clinical services manager who were interviewed twice, all CMHT and MHSOP staff were interviewed once. People with dementia and carers were offered the opportunity to be interviewed either together, separately or both. One married couple chose to be interviewed both separately and together, creating three research interviews. In two families, husbands with dementia chose to be interviewed jointly with their wives, while the wives also requested a separate interview. Two couples chose to be interviewed together and did not want the option of being interviewed separately. One woman in her 80s was interviewed with her son present. Three people with dementia living on their own at home were interviewed alone but with a family member or friend in a nearby room.

## 3.8. Data collection

Holstein and Gubrium (1995) have argued that it is rare for qualitative researchers to provide information on the processes and/or strategies they use to shape the interview process both at the beginning and throughout. I myself did not fully understand the way in which I influenced the whole process until months after the last interview was completed. As a result, I did not always record the preamble to each interview. Every interview, however, was prefixed by a preamble in which I outlined the aim of the study and contextualised my involvement. When interviewing people with dementia the preamble was extensive as I carefully reviewed the currency of informed consent before moving on to the interview proper. Issues of consent are discussed in more detail in section 3.9.1.

The section begins by acknowledging the popularity of the research interview in qualitative studies before moving on to a discussion of my attempts to create an environment in which those I interviewed would feel comfortable with the topic under investigation and confident enough to ask questions as the interview progressed. As will be made clear in section 3.11, this is of critical importance, as the 'narrative environment' in which data are produced is influential in determining the criteria for a good story and a good storyteller (Gubrium and Holstein, 2009).

### 3.8.1. *Strategies for reducing the researcher-researched divide*

None of the people with dementia or carers participating in this study had previous experience of research or service development. Few CMHT staff had been involved with research either, but most had been involved in some elements of local service development. In conducting interviews, I tried to create an atmosphere in which people felt knowledgeable and relaxed. I did this by disclosing something personal about myself and my interest in dementia, and then asking people to tell me a little about themselves. I believe this device contributed towards the quality of the communication that was established during the interviews, influencing, as a result, the quality of the data produced. In developing rapport I was attempting to build connections in the interview process, for the purpose of bridging the potentially harmful gap between researchers and 'the researched' identified by Sullivan *et al.* (2001).

Other strategies I used to diminish the divide included developing a respectful relationship with people with dementia during the interviews. For example, I decided not to cut across someone when they were talking; even when it became clear they had not grasped the question asked. Instead, I waited until there was a natural pause in the conversation and rephrased the question. I was more interested in developing a conversation and was less worried if my initial questions were misunderstood. If participants appeared distressed, I offered to stop the interview. Although this happened several times in conversations with people with dementia and carers, they invariably wanted to carry on. On one occasion when I bent down to turn off the digital recorder, a carer gently pushed my hand to one side indicating that she wanted to carry on with the recorded interview.

### 3.8.2. *Setting for the interviews*

Staff from Tadham were interviewed in a room at the CMHT base that was regularly used for quiet discussion and/or clinical supervision. The room was decorated in pastel colours and furnished with a sofa and comfortable easy chairs. It was situated slightly away from the main offices and as such provided a good space for the research interviews. All CMHT staff from Tadham chose to be interviewed at the CMHT base. Interviews with staff from Wickham took place in various comfortably furnished seminar rooms in a large, purpose built day hospital in Wickham or at the CMHT base in Tadham. Although CMHT staff from Wickham did not have the benefit of having their Interviews conducted in

a small, private room, this did not appear to have any effect on the quality of the data produced. Interviews with people with dementia and carers took place either in their homes or at the CMHT base. Most of the carers who attended the drop-in session for people with early onset dementia were interviewed at The Royal while the support group was in progress. This was for mainly practical reasons. Being interviewed while the group was in progress meant the person with dementia was in a safe and stimulating environment, freeing carers to take part in the interview without feeling stressed or worried. It was also one less appointment to keep – a case of 'killing two birds with one stone', as one carer pointed out. Agreement for this arrangement was worked out with the memory nurse who facilitated the drop-in sessions.

### 3.8.3. *Interviewing people with dementia and carers*

In an attempt to reduce the stress people with dementia and carers might feel during their interview, I created two pictorial interview guides, one for people with dementia (Appendix 9) and one for carers (Appendix 10). Each guide consisted of a laminated A4 sheet of paper with brightly coloured speech bubbles. The speech bubbles represented topics that I was interested in pursuing, rather than set questions. I made it clear from the start, however, that if people wanted to discuss a topic that was not listed on the board, I would be very happy to talk about it. I also explained that printing the topic areas out on a laminated sheet was as much about reminding me of areas I thought may be useful to the study as it was about guiding the course of our conversation. These guides were

successful on two levels. Firstly, they acted as a set of prompts throughout the interviews. It was not unusual for someone to check the board as they finished a conversation to see what they had covered. Even people who experienced difficulty reading were able to make sense of the simple sentences included in the speech bubbles. The guide also served an unexpected purpose, to create a physical barrier between me and the person being interviewed. For example, when some participants became emotional they shielded their faces with the board while they re-composed themselves. This was really helpful to me as occasionally people became upset when we were not talking about an obviously emotional issue. As soon as I saw people staring hard at the board, or lifting the board to hide their face, I stopped the conversation and waited quietly until they were ready to continue. After a few moments, the board would return to its resting position and the interview would continue.

### 3.8.4. *Interviewing CMHT staff*

When interviewing CMHT staff, I devised an interview schedule (Appendix 11), which while not adhered to slavishly, was useful in guiding the interviews overall. Interviews were semi-structured in that there were particular areas I was interested in investigating in some detail, such as how the recent service changes in the MHSOP affected the CMHT, the memory service and the staff who worked in them. As in Willis' (2009) study, the interview schedule was refined iteratively as fieldwork progressed. This allowed me to tailor questions to the differing

responsibilities of CMHT staff and to pursue topics raised in earlier interviews.

### 3.8.5. *Recording the interview*

Everyone who took part in the study consented to the use of a recording device during the interview and to the use of their interview data in the thesis. In the preamble to each interview, I asked everyone again if it they were happy for me to record their interview. Each interview was recorded using an Olympus DS-40 digital voice recorder. Two copies of the interview were made on CD. One copy was given to each interviewee and I kept a copy for transcription. I took the unusual step of giving everyone an audio copy of their interview data on CD as I knew from conversations with people with dementia that most would find it difficult to read a transcribed manuscript or even a summary. I also made sure that everyone knew they could have a copy of the typed manuscript as well. Returning the data to everyone who took part in the research was an important acknowledgment of the co-ownership of the data produced.

### 3.8.6. *Transcribing the interviews*

Every research interview was transcribed verbatim. This allowed me the opportunity to use the interviewees' original data, or an abridged version, depending on the coherence of sentences or phrases. There are, however, a number of issues related to transcribing interview data, particularly when transcribed data are presented as quotations in the final text. For example, it is important to be aware that once text is stripped of

contextual information it can seem somewhat diminished or flat. But, writing in the context of narrative gerontology Baars (2012, p8) has argued:

> *The special quality of narratives as a direct event in the presence of the speaker, is their vividness: a directness and richness of expression in specific situations, where spoken words are accompanied by non-textual forms of expression such as facial expressions, gestures or the unique voice of the speaker.*

I therefore try to ensure that I provide enough contextual information to convey the emotional and other non-textual elements of particular quotes. I also annotate the text, for example to denote laughter and use exclamation marks to denote when the narrator was getting excited and raised his/her voice.

### 3.8.7. *Participant observation*

To complement the research interviews, I drew upon the tradition of ethnography to observe and participate in a number of groups related to the provision of the dementia service within the Trust. The purpose was less to 'collect data' and more to help me understand the structure, language and culture of the CMHT. I negotiated access to a number of meetings that I attended regularly throughout the period of data collection (i.e. April 2010 – August 2011), for example, governance meetings, research planning meetings, general CMHT meetings, user and carer involvement meetings, clinical team meetings and the young onset dementia drop-in meetings. Attending the meetings helped me to understand the day-to-day language of staff working in the CMHT and

MHSOP, which meant I could ask more pertinent questions during the interviews, particularly in relation to complex financial matters. Participation in the various meetings meant that my profile within the Trust was high for the duration of the study.

### 3.8.8. *Research diaries*

Research diaries have been identified as a source of rich nuanced data in ethnographic studies generally (Zimmerman and Wieder, 1977), in research with older people (Jacelon and Imperio, 2005), with older carers (Parker and Hamill, 2011) and in research with people with dementia (Bartlett, 2012). At the beginning of each interview, I asked people with dementia and carers to consider keeping a research diary for one week. The purpose was to capture the experiences of their everyday lives. Few people, however, were interested in keeping a diary and only one person completed one. I reflect on my learning in relation to this aspect of the research methodology in the concluding chapter (8.4.7).

### 3.8.9. *An audit trail via field notes, reflective notes and memos*

Field notes, reflective notes and memos all play an important role in qualitative research (Yin, 2011). Field notes, despite their name, are not always made in the field (Mack *et al.*, 2005). In my study, I wanted be 100% ‘present‘ during the research interviews, partly as a sign of respect for the research participants and partly because I dislike people taking notes when I am being interviewed as it makes me feel insecure about what I am saying. Consquently, I made very few notes during interviews.

Instead, I began the process of making field notes directly after the interview. When possible, I completed notes that same evening, including notes on the ‘narrative environment’. For example, I wrote a description of the rooms staff were interviewed in and of the room in which the advisory group met. I also wrote down my immediate impressions of how staff interacted during meetings I observed. I also made a note of comments made by staff on their ‘encouragement’ to take part in the interviews by the clinical servcies manager as it provided me with insight into how positively the research was viewed by the senior management of the MHSOP.

I also made numerous reflective notes, some of which contained value judgements, that unintentionally crept into my early thesis writing. While these notes helped me to write, in some cases they were a distraction and so were later removed. A typical example occurred when I was writing up the methods chapter. I had written of the processes I had implemented to ensure people with dementia and carers took part in the research because they wanted to and not because they felt under pressure to do so from me. I had concerns, however, that due to the close relationship they had with their memory nurses, people with dementia and carers may have taken part in the research to please them. Part of the process of my learning to write academically was remembering not to layer a factual account (what actually happened) with a reflective gaze (how I felt about the issue).

I used the memo facility in NVvo to make countless memos about the data as I was reading. This was an essential part of my beginning to understand the data and of making links between the interviews and the wider literature on dementia and involvement. Writing in the context of nursing practice, Birks *et al.* (2008, p68) noted that memoing was rarely used outside of grounded theory approaches and argued for the utility of memoing for research from all genres:

> *Memoing serves to assist the researcher in making conceptual leaps from raw data to those abstractions that explain research phenomena in the context in which it is examined.*

The memos I made tended to be extensive as I used the process of memoing as a way of clarifying my thinking. Each time I read an interview transcript I added to the memo, rather than developing separate memos, simply dating the new addition. Sometimes, I made the memos while listening to the audio file of the interview as I found I remembered more of the mental notes I made during the interview that way. In order to provide a transparent account of this process, I have included a copy of Sophie's interview transcript[19] (appendix 12) and the memos I wrote when I read through her account (appendix 13).

[19] Sophie has been diagnosed with dementia

## 3.9. Ethical issues

Ethical concerns related to completing case-based qualitative research are the same as those facing researchers completing work in other research genres. Namely, that the research protocol provides evidence of a structured approach to data collection and analysis and that each step in the research process has been scrutinised for possible ethical dilemmas. Yin (2011) argues that one of the most important ethical components of qualitative research is the personal integrity of the researcher. Yin's (2011) discussion of ethics in qualitative research, therefore, unsurprisingly begins with a comprehensive listing of the skills of a good researcher such as the ability to: i) adapt to uncertainties in the field, ii) be a good listener (no preconceived ideas), iii) be flexible, open and alert to the possibility of serendipitous opportunities, iv) have a good understanding of the issues under investigation, v) deal with sensitive information and vi) recognise and avoid bias. Further, Yin (2013) recommends going beyond that which we are mandated to do in terms of: i) ensuring informed consent, ii) protecting people from harm (including from deception), iii) protecting people's privacy and confidentiality, iv) taking extra precautions for especially vulnerable groups and v) ensuring equitable access to the study in terms of fair inclusion and exclusion criteria.

Although I did not have access to Yin's (2011) suggestions until I was half-way though conducting my fieldwork, I nevertheless prepared myself for the task by reading around issues related to involving people with

dementia and carers in research, including the best way to support people with dementia who may not be able to communicate verbally. I tried to stay alert to serendipitous opportunities and looked for opportunities to talk to people (outside of my study) about their experiences of dementia. I was particularly interested in the contrast between the views of people without dementia who frequently said that if they found out they had dementia they would want to kill themselves and those with a diagnosis of dementia who invariably developed elaborate strategies to manage their symptoms.

### 3.9.1. *Consent and capacity to consent*

Under the terms of the Mental Capacity Act 2005, a person with dementia is deemed to have capacity to contribute to decisions affecting their lives unless and until proved otherwise. In relation to gaining consent in research, researchers need to be confident that a person with dementia has capacity to consent both at the beginning of the research process when someone is first approached and at all further points when they actually participate. To assist researchers in this process, Warner *et al.* (2008, p168) developed a protocol for checking that individuals are capacitious at the different stages of the research process:

- Provide sufficiently detailed, salient written and verbal information to potential participants in a form they can understand;

- Repeat the information as many times as necessary and call upon carers if needed to ensure clarity;

- Allow sufficient time for understanding and retaining the information;
- Test to ensure the information has been received and understood;
- Ensure potential participants are able to assess the information they have been given and are not being coerced.

In my research, I felt one of the most significant ethical challenges would be in ensuring people with dementia were given adequate time, space and information to give informed consent. It was important that no one felt under pressure to take part in the study and that they understood the service they received from the CMHT would not be affected in any way by their participation in the study. It was important that people with dementia and carers had someone they knew and trusted to explain the broader aims of the study and how they could take part. I therefore asked their memory nurse to broach the subject initially. I also made every effort to ensure that people with dementia and carers understood that they could decline or withdraw from the study at any time, for any reason, without repercussion. The majority of people with dementia and carers had developed a close relationship with their memory nurse, who often came to be seen as a friend and confidante. The importance of memory nurses, therefore, in recruiting participants cannot be underestimated.

It was agreed that after potential participants were identified, their named memory nurse would contact them to talk about the study in broad terms. If the person with dementia and/or carers agreed to take part in the study,

they were sent a formal invitation to join the study (Appendix 14), a consent form (Appendix 15) and participant information sheet by post (Appendix 16). One to two weeks after receiving the printed information, I rang to confirm they were still interested in taking part in the study and if they were, I made an appointment to talk to them in more detail and to carry out interviews, or if needed, made a further appointment.

This approach, whilst ensuring continuity of informed consent, lengthened the data collection period considerably. However, it was important to give people time to think about the study together with opportunities to opt out before they met me. In practice, few people declined to take part in the study and no one opted out once they had agreed to take part. Two carers and one person with dementia changed their mind and decided to opt into the study after first declining. This was not because they discussed the matter further with the memory nurse or me, but because they had time to think it over. Interestingly, when I thanked people for agreeing to take part in the study they said that the reason they took part was because they wanted to be able to contribute to a study that they felt could help people in the future. One carer went further and said she wanted to take part because she did not want other people to go through what she and her husband had experienced. Even though they knew it might prove an emotional experience for them, people with dementia and carers felt that the benefits of the study compensated for any negative effects they might themselves experience. This latter point is important on

a number of levels, not least given Yin's (2013) admonition to avoid doing unnecessary research that may cause emotional distress to participants.

Writing about the involvement of people with dementia in research, Dewing (2002) argued for the need to acknowledge any pre-existing directives or expressed wishes of individuals with dementia to ensure that taking part in research was something they would normally have agreed to. This was an issue uppermost in the minds of carers in the study and they frequently said, unprompted, that this was the 'kind of thing' their spouses or partners would have been interested in before they became ill with dementia. A level of biographical knowledge of people with dementia is crucial for researchers if they are to be confident of having gained informed consent. Coleman and Mills (2001) additionally argue that researchers need to develop therapeutic, non-coercive relationships with people with dementia in order to be confident that they feel able to withdraw from research.

To integrate some of these ideals into the research process, where possible I met with carers and/or family members to gather some background information about the family and about the person receiving services before I began interviewing. I did this for several reasons. Firstly, I felt it was important to know if the person with dementia had particular communication difficulties and if so, which communication prompts worked best for them. Secondly, I wanted to ascertain if the carer and/or family member felt the interview should be conducted verbally or verbally with visual prompts. Finally, I wanted to know if there were behavioural

cues that might indicate that the person with dementia was getting upset during the interview, in order to avoid causing them undue distress. I believed that by gathering some biographical and personal information about the person with dementia before the interview process began, I would be able to understand, albeit incompletely, when the process of consent was 'in progress'. Crucially, I also wanted to be alert to any indications that interviews were losing a sense of partnership and becoming an imposition (Cowdell, 2008).

In an attempt to ensure consent was ongoing throughout the time people with dementia were engaged with the research, at the beginning of each interview I spent time going through the purpose of the study, what people could expect to happen during the interview and what would be done with their words afterwards. On occasions, carers supported this process by rephrasing the information in a way the person with dementia could understand. Interviews were conducted at an unhurried pace but I actively encouraged people with dementia to stop me if I spoke too quickly and to ask their own questions. Participants tended to laugh when I said this and suggested it would be more likely that I would have to stop them from 'going off on a tangent'.

The process of obtaining consent from younger people with dementia[20] and carers was complex and started with an invitation for me to attend

[20] People who are diagnosed with dementia under the age of 65

the fortnightly drop-in session for people diagnosed with young onset dementia and their carers. At the beginning of the session, I was able to speak to the group as a whole and then with individual group members. I used my time in the group to give people more details about the study together with information on how they could get involved. One person agreed to participate in the study during the first session I attended. Later, I asked the memory nurse who facilitated the drop-in to ask group members if I could attend the group as a participant observer during the data collection phase of the study. I assured group members that I would not be taking notes during meetings and that I was happy to talk about the research I was conducting if they wanted more information. In the months that followed, three other people also agreed to participate. Altogether, four members of the young onset dementia group (four carers and one person with dementia) agreed to participate in the research by being interviewed. One other person, who was subsequently diagnosed with mild cognitive impairment (MCI), had initially agreed to be interviewed. But, when he was discharged from the memory service he decided to withdraw from the study without being interviewed.[21]

[21] Once people receive their diagnosis, those who are diagnosed with MCI are no longer eligible to receive support from the memory service, including the young onset dementia service.

### 3.9.2. *Managing issues of confidentiality*

The MHSOP followed a strict Trust-wide protocol on the use of patients' personal data. In practice, this meant that I could not write in my paper diary the name or address of the person with dementia or carer I was interviewing. This was to ensure that in the event of my diary getting lost and/or stolen, a person's identity could not be linked with the service. All interview files (audio files and original typed interview manuscripts) were uploaded to a password protected online storage facility at Durham University.

In making use of the data, where including biographical information about an individual adds an extra dimension and I felt confident that to do so would not compromise identity, I have included details such as age and diagnosis. Pseudonyms have been used throughout the research narrative. The identity of the NHS Trust that hosted the study has been concealed by giving it a fictional name and by avoiding reference its location or identifying attributes.

## 3.10. Data analysis

This section on data analysis begins by stressing the importance of theoretical coherence by explicitly linking the aims of the study with the data analysis tools. I then move on to address issues of 'narrative adequacy' (Gubrium and Holstein, 2009) through a discussion of the criteria for good stories and good storytellers. I then present an overview of the processes I undertook to develop the analytic themes, code data,

triangulate data and finally member-check the data. I then identify how I integrated processes of reflection and reflexivity throughout the research process. This is followed by a brief description of the use of NVivo to store and code the data.

There are many different ways to analyse narrative data. Atkinson (1998), for example, suggested that some accounts may require no more analysis than an introductory paragraph while others may require a deep, thoughtful, situated, discipline-related analysis. Much depends on the original aims of the research. The most important consideration is how good a fit the analytic tool is with the theoretical underpinnings of the study. In this research I was interested in understanding how narratives about dementia produced by people with dementia, carers and mental health practitioners can extend what we know about the experience of having dementia and the use of dementia services. But what are the criteria for a 'good' narrative? What constitutes a 'good' story? And who can be a 'good' storyteller? It is to these issues that I now turn.

## 3.11. Narrative adequacy: assessing the quality of narrative data

Gubrium and Holstein (2009, p199) note that within the social sciences validity, reliability and objectivity are the, "…evaluative cornerstone of research methodology." Their purpose, they argue, is the application of abstract principles across a range of disciplines and topics. While noting the more flexible and contextual nature of qualitative research, Gubrium and Holstein (2009) nonetheless point out that qualitative research is

likewise embroiled in debates that attempt to pin down what is ‘good’ qualitative data. Narrativity, according to Gubrium and Holstein (2009, p200) has also accrued evaluative criteria including that a good story is, “rich, complete, and insightful” and that storytellers are, “knowledgeable, honest, and forthcoming.” It should have, “protagonists, inciting issues, and culminating events.” Narrative interviews likewise must be scrutinised for rapport (between the researcher and the interviewee), rich narrative and for responses that are, “spontaneous, rich, specific, and relevant” or, “deep, detailed, vivid, and nuanced” (Rubin and Rubin, 1995, p76). The results of the research should be, “fresh and real” and conclusions should be, “balanced, thorough, credible, and accurate” (Rubin and Rubin, 2012). Gubrium and Holstein (2009, p200) argue, however, that like validity, reliability and objectivity, none of the criteria applied to narrative adequacy can be applied in a context free manner and, “…that research standards tend to mimic commonsense standards where narrative adequacy is concerned.” Gubrium and Holstein (2009) also argue that the best way to discern whether a story is a good one or the narrator a good storyteller is to turn the whole process around and to approach the subject of narrative adequacy from the perspective of the storyteller and the listener. What do storytellers believe is a good story? How do listeners decide who is a good storyteller? And, how do they apply commonsense criteria to the process? This has the effect of shifting the focus of the analysis to, “…the indigenous practices applied to produce and assess what are considered good stories and storytelling” (Gubrium and Holstein, 2009).

### 3.11.1. *What is a good story?*

Gubrium and Holstein (2009) begin their account of what makes a good story by challenging the argument that narrative data has to be rich, deep and insightful. Instead they argue narrative accounts are 'good enough' if they serve the purpose for which they were solicited. Their argument is that there is little point in attempting to extract rich, deep data when it would be more appropriate to obtain less detailed accounts. A good story does not depend only on how finely or richly nuanced the research data are. Moreover, the narrative environment in which the story is told also has an important role to play. In his research on the descriptive organisation of senility, Gubrium (1986) attended a number of support groups for carers of people with dementia. He noted that there appeared to be four sets of criteria by which stories were judged to be true. The first related to the relaying of finely grained accounts that listeners could relate to. The second was linked to whether the account was in some way compelling or entertaining. In this respect, it did not seem to matter if accounts were embellished slightly for the listeners as everyone knew what was going on. The third rested on the ability of the storyteller to provide a comprehensive account of an issue. People, it seemed, were interested in knowing more not less of the detail. Conversely, the fourth criteria Gubrium identified was related to the ability of the storyteller to 'get to the point.' While these criteria made good principles, Gubrium noticed that stories, no matter how engaging or detailed, did not always travel well. Some stories can lose their credibility and, when told in a

different setting, their authenticity. From this Gubrium argued that the narrative environment in which a story is told is as least as important as the story itself and that, "…answers to the question of 'What is a good story?' need to be figured in relation to local understandings" (Gubrium and Holstein, 2009, p206). Listeners who value factual, concise accounts, for example, may be unwilling to listen to a lengthy account of one person's trials and tribulations. In other words, there is an unwritten code in every narrative environment that determines how well a story will be received and judged 'good enough'. The local codes and everyday practices that shape narrative environments are, however, apt to change over time in response to updated information and learning. Gubrium, for example, discovered that support groups that had been exposed to knowledge of the five stages of grief as formulated by Elizabeth Kübler-Ross (1969) were intolerant of carers who talked about the need for carers to demonstrate undying devotion 'until the end'. Such carers were deemed 'unrealistic' or 'in denial'. What emerges from Gubrium's analysis is that goodness criteria cannot be applied *carte blanche*. Goodness criteria are worked out on a moment-by-moment basis within the context of local knowledge, expertise and experience. What may serve as goodness criteria at one point in time may serve a different purpose the next, leading Gubrium and Holstein (2009, p210) to comment that, "…codes and other standards of adequacy are resources for, not determinants of, the work of formulating quality control in narrative matters."

Viewing the analytic qualities of stories in terms of how stories are produced in local narrative environments and in terms of their relevance to listeners has a democratising effect on the research environment. If stories can be thick or thin, if they can be adequately conveyed in a couple of sentences or in a book, if their changing nature is recognised and encouraged, then stories of every type can play a role in knowledge production. Stories produced in this research demonstrate how both rich, nuanced accounts and slender sentences contributed to answering the research questions.

### 3.11.2. *Who is a good storyteller?*

If, as it appears, goodness criteria for stories are worked out on an individual basis during everyday practice, who, then, qualifies as a good storyteller? Gubrium and Holstein (2009) noted that in common with goodness criteria for stories, commonsense evaluations of storytellers are in plentiful supply. Commonsense criteria for a good storyteller include that he/she has the ability to connect with the audience, is well informed, ready to learn, listen and participate. S/he is confident and authentic, easy to like and non-threatening. S/he makes things simple and knows how to reinforce key points[22]. Gubrium and Holstein (2009, p211) add that the storytellers are usually viewed as credible, as experts or as trustworthy. In relation to research methodology, ideal research interview

[22] http://www.inc.com/kevin-daum/7-things-really-amazing-communicators-do.html

subjects were viewed as being, "…cooperative, well-motivated, eloquent and knowledgeable." While no doubt useful quality criteria, Gubrium and Holstein (2009) remind us, however, that even the most eloquent storytellers speak from a particular perspective. In other words, they are motivated to express a point of view that may not always present 'the whole story'. Sometimes listeners need to supplement what they hear with physical evidence. Findings from research into counselling techniques for troubled families found that staff at therapy centres, for example, at times completely discounted family members' spoken accounts of their relationships, drawing instead on behavioural cues of individuals as they spoke (Gubrium, 1992). Mulhall (2003, p307) also argued the importance of gathering behavioural data, "The way people move, dress, interact and use space is very much a part of how particular social settings are constructed. Observation is the key method for collecting data about such matters."

Gubrium and Holstein (2009, p217) observed that in the course of telling their stories, storytellers themselves build in a number of 'authorization devices' that help to secure the storyteller's status as a 'good' storyteller. For example, storytellers can use presence and immediacy, 'I was there, at the time'. They also draw upon personal experience 'it happened to me' or, once removed, 'that happened to someone I know'. They can also draw upon witnesses if necessary, e.g. other family members or friends to corroborate their story. All these authorisation devices or strategies help ensure the credibility of the storyteller, especially when the story being

told puts another person in a bad light, such as when reporting inadequate care or poor practice.

If a story has more than one storyteller, it is likely that, in an effort to 'get the story straight' storytellers will correct each other's version of the story until the final version of the story is agreed. This process of correction for the purpose of authenticity can be observed in the data excerpts presented in the findings chapters. For example, on one occasion Louisa, a carer, complained that since his sessions with the physiotherapist had stopped, Nevin, her husband would not engage in any exercise. Nevin's response, "I've got a scooter!" demonstrated how he was not prepared to accept the authenticity of the story that Louisa was trying to share and he quickly cut in with his version of what was going on. Nevin's excitable response coupled with Louisa's heavenward look at the end of the exchange signalled the likelihood that this conversation was far from over and that the 'truth' of the exchange would probably be contested every time the scooter was taken out of the garage.

This process of story verification is an important aspect of storytelling, as inauthentic accounts are less likely to be believed. Goodness criteria for storytelling, therefore, are, "…interactionally and situationally established" during and after story production (Gubrium and Holstein, 2009, p219).

To summarise: goodness criteria for storytellers are not only contingent upon the ability of the storyteller to 'tell a good story' as the narrative environment also has an important role to play. Good storytellers provide

good enough information to ‘get the job done’ and their stories ring true with their listeners. The narrative adequacy of the stories and storytellers in this research can be judged in chapters 4, 5 and 6 which present findings relating to each of the research questions of this study.

### 3.11.3. *Generating themes and data coding*

Holstein and Gubrium’s (1995, p4) analysis of the meaning-making process in qualitative interviews identifies the interview process as not only active but interactive, “Both parties to the interview are necessarily and unavoidably *active*.” The first stage of this interactive, meaning-making relationship begins in the research interview as interviewer and interviewee co-produce the research narrative. The second stage of meaning-making takes place as the interview transcripts are read and re-read. It is inevitable that some interviews will produce more relevant data (in terms of what the researcher is looking for) than others. However, even less fruitful interviews provide insights into the process of data production. A discussion of my own challenges in this area can be found in the concluding chapter of the thesis. The third stage in the meaning-making process takes place as decisions are made on how data should be presented in the research report. The fourth stage is related to the work of making linkages between ideas generated from interview excerpts, from the literature, from the pre and post-interview chats and the countless observations that influence the process of reflection. The fifth and final stage of the process takes the form of tentative conclusion drawing.

In this study, I analysed the research interviews using adapted forms of Conventional Content Analysis as described by Burnard (1991) and Hsieh and Shannon (2005), both of which are adaptations of Glaser and Strauss's (1967) grounded theory approach to data analysis. Both approaches utilise a system of open coding where codes are generated from the interview transcripts and grouped and regrouped under emergent themes until the researcher is satisfied that all the data has been coded or accounted for. Unlike grounded theory, this approach to data coding does not generate theory, it generates a comprehensive description of the content of the interview transcripts. A flowchart depicting the stages of data analysis I undertook can be found in table 3-6.

**Table 3-6: Stages of data analysis undertaken in this study**

- Wrote up field-notes.
- Transcribed interview data.
- Imported interview transcripts into NVivo.
- Read transcripts: with and without audio files
- Wrote memo(s) after reading/listening sessions.
- Began to look for patterns in the data, i.e. did more than one person say the same thing? Did one piece of data contradict another? CMHT staff experience and the experience of people with dementia in relation to standardised occupational therapy assessments was a good example of this.
- Re-read transcripts and began coding the data using NVivo coding function.
- Lots of smaller analytical categories produced, e.g., living well with dementia, early diagnosis and supports, dimensions of care planning, care planning and care-giving, involvement in care planning, aspects of involvement, i.e. what does it look like? Raising awareness from the perspective of the person diagnosed and from the perspective of carers, power and social exclusion and more.
- Began the process of subsuming these smaller categories into larger meta-categories.
- Several meta-categories were developed and discarded, e.g., at one point the data were subsumed under the first four objectives of the National Dementia Strategy for England (Department of Health, 2009).
- Finally, the analytical categories devised during an evaluation of the Croydon memory service (Willis *et al*, 2009) were used as the study's analytical framework. These categories proved to be a good fit for the data I had collected.

The overall process of making connections in the data was iterative with some steps proving more fruitful than others. For example, although I did not find it difficult to develop initial categories, I struggled to subsume some of data under larger 'catch-all' headings. At first I tried using 'service success' or 'involvement' related themes as meta-headings. At one point, I subsumed data under the first four objectives in the national dementia strategy, i.e. i) raising awareness and understanding, ii) early diagnosis and support and iii) living well with dementia. But, none of those meta-categories was a good fit for the data. However, I later identified an effective approach reflecting analytical categories devised by Banerjee *et al.* (2007) in an evaluation of the Croydon memory service. The team later published an account of this process and how they involved people with dementia and carers in the research. The analytical categories identified in the paper by Willis *et al.* (2009) proved invaluable in guiding my future analysis.

### 3.11.4. *Triangulation of the data*

Although data triangulation plays an important role in research it has a particular function in qualitative studies. Data triangulation in qualitative studies should be an, "…attempt to map out, or explain more fully, the richness and complexity of human behavior by studying it from more than one standpoint" (Cohen *et al.*, 2000, p254). In this study, I have attempted to triangulate the data shared by participants by drawing upon theoretical concepts of critical gerontology and narrative gerontology that illuminate how structural oppression and cultural processes contribute

towards our understanding of ageism. I have also drawn upon theoretical insights gained from discussions of power and their relationship to service user involvement. I have also provided multiple examples of the issue under scrutiny, so that issues could be explored from more than one angle. In this way, stories shared in the research are linked together by theoretical coherence and via the personal experiences of participants. Data triangulation was further enabled by drawing on the accounts of different groups of people with differing experiences of dementia and of dementia services.

### 3.11.5. *NVivo as an aid in data analysis*

NVivo was used throughout the data collection and analysis phases of the study. During data collection, typed manuscripts were uploaded to NVivo for safe storage. NVivo was subsequently used to code sections of the data. Coded sections were saved in separate documents and it was these documents of coded data that were used extensively throughout the interpretative phase of the research. I also made extensive use of the memo and search facilities in NVivo.

### 3.11.6. *Member checks*

Member checks are a common feature of qualitative research. Creswell (2013, p53), for example, argues that member checks, alongside triangulation, help to ensure rigour in ‘good’ qualitative studies. Harper and Cole (2012) write that interviewees can be asked to check their data at any point in the data analysis process. They can, for example, be given

a summary of what they said, a draft of the section of the report in which their data appears, or they can be given the whole report so that they can see their contribution in context with what others have said. The purpose of member checks in my study was to allow everyone who had contributed to the study to ensure they had been quoted accurately and to give them an opportunity to correct or withdraw data. This process began when I gave everyone a copy of their interview on CD. On completion of the first complete draft of the thesis, I made arrangements with the CMHT leader, to contact all participants and offer the opportunity to at least read the data chapters of the thesis, so that they could see how I had used their data, and convey comments and/or concerns to me. For a number of reasons, it was not possible to contact everyone. For example, some members of staff had moved on to other jobs outside the organisation and one was on long-term sick leave. I was able to contact all but one member of the advisory group personally, who, due to the progression of his illness, was unable to engage further in the research. People with dementia, carers and family members were contacted by their memory nurse to see if they were interested in receiving a copy of the draft thesis. No one requested a copy. I cannot be certain how many CMHT staff read the thesis, but in a follow-up telephone conversation, the clinical services manager, reported that it had generated much discussion. One member of staff asked if a quote could be re-worded.

## 3.12. Chapter summary

In this chapter I have provided an explanation for the selection of a case-based qualitative approach to data collection and analysis, the theoretical framework of the study and the research design including the research tools used to generate the research data.

Before ending this chapter, I provide an outline of the approach adopted in presenting the findings of the study. These are presented in three chapters. Chapter four presents data from people with dementia and carers on their initial experiences of dementia. Chapter five presents data from people with dementia and carers on the dementia service they use, together with their views on a range of other health related services. Chapter six presents data from CMHT staff and reflects the strategies they employed in creating a service to meet the needs of people with dementia and carers while also meeting policy driven targets.

In each of the findings chapters literature that helps to provide context for the data is integrated into the preamble for each data excerpt along with details conveying the context in which the data was shared. This is an analytical strategy recommended by Gubrium and Holstein (2009) to ensure interview data are not diminished by the process of transcription. A further strategy is the addition of emotional cues, i.e. laughing, crying, anger, etc. When appropriate, I have incorporated both of these strategies throughout the findings chapters. I attempt to maintain the integrity of the data by clearly separating the data from my analysis and

interpretation. The purpose of presenting the data largely 'untouched' by researcher intervention is to subtly reinforce the strength and clarity of the data. Despite the scepticism of some researchers about the reliability of data produced by people with dementia, i.e. Blackeby and Quarmby (2005, p118),[23] my study generated thoughtful and deeply insightful data.

[23] People with dementia were excluded from this evaluation, even though its aim was to assess levels of service user satisfaction, because it was assumed they would produce unreliable information, and that it would be upsetting for them to take part in the evaluation if they did not remember all the details.

# Chapter Four: The initial experience of dementia

## 4.1. Introduction

In this chapter I present interview data from people with dementia and carers on a range of issues they identified as being important to them. Data in this chapter represents the first of six analytical categories in a model of service evaluation devised by Willis *et al.* (2009, p27) to develop a 'rigorous' qualitative model of service evaluation for dementia services. Data from the remaining five analytical categories are published in chapter five of the thesis. Issues raised in the research interviews are presented here chronologically. This reflects the decision of people with dementia and carers to tell me their stories 'from the beginning'. Data in this chapter includes information on how and when people first began to suspect there was something wrong and the support they received after a diagnosis from family, friends, neighbours and others. This is followed by an exploration of the experience of living with dementia from the perspective of people with dementia and data on the spouse's reaction to becoming a carer and, flowing from that, their caring responsibilities and the burden and/or stress they experienced. The chapter is brought to a close with some 'top tips' on managing the daily challenges of dementia from people with dementia and from carers. A summary of the findings from this chapter is included in table 4-1.

## Table 4-1: Summary of findings answering RQ1

| **Data stream one**<br>Corresponds with analytical category: The initial experience of dementia<br>Findings answer research question one | |
|---|---|
| Early symptoms of dementia | Symptoms were 'undementia-like,' including loss of confidence, excessive tiredness, skill-loss, withdrawal. |
| Support from family and friends after the diagnosis | For some families this was not an issue, for others family members and friends gradually deserted them. Leaving them alone to cope in very difficult circumstances. |
| The experience of having dementia | Made people feel furious, frustrated and sad. It was upsetting to lose the right word and then for it to come back later when they didn't need it. Felt under pressure to keep the diagnosis a secret. Some people retained friendships and networks for a long time. Others were treated as though they were already dead. |
| When does 'forgetting' become dementia? | It was unclear when the forgetfulness became dementia. Everyone is forget at times. How can you tell the difference? |
| On becoming a carer | Spouses experienced extreme shock at the diagnosis. No one 'knew what to do.' Most had never been in the position of carer. Experience of total bewilderment. Caring for an adult dependent was challenging emotionally and physically. |
| Caring responsibilities | Taking care of your spouses' needs was a full-time job. Needed to develop the capacity to 'see around corners' in order to ensure all needs were met. Spouses felt as though they were always on 'guard duty.' The pressure was unending. Never had time for oneself. |
| Carer's strategies for managing stress | Get a dog! Get out at least once every day. Make the most of every day. Try to keep up some hobbies. |
| Top tips on living well from dementia by people with dementia | Do not dwell on the diagnosis. Live every day as though it is your last. Never turn down invitations to go out. Face your fears. Make notes to remind you of what you enjoyed. Stay in touch with friends. Keep busy and active. Develop strategies for remembering. |
| Top tips on living well with dementia by carers | Get out of the house every day. Create joy-filled moments. Learn to create diversionary tactics when situations look 'hairy.' Be thankful for what you do have. Confide in others. Learn to communicate. |

### 4.1.1. *Early signs and symptoms of dementia*

Most people associate dementia with memory loss - unsurprising given that memory loss is a key feature in all types of dementia. Dementia, however, is much more than memory loss. Dementia also affects people's behaviour and their ability to carry out simple, everyday tasks (Department of Health, 2009). In the following excerpt, Anna talks about the early days when she first began to suspect that something was wrong:

*Well, we saw signs of it whilst his mum was still at home but we hadn't realised…we put that down to tiredness. We can trace it back to when you think about what actually he wasn't doing right… He was forgetting how to add up and he was forgetting how to measure things but again we put it down to tiredness because he was working seven days a week. (Anna – spouse and carer)*

Anna was not the only carer to confuse early signs of dementia with tiredness. Helen, who cares for her husband Will, also believed he was simply over-tired from working too much:

*Well, I think a good two year before he was finally diagnosed things had been very strained between us. He was putting in an awful lot of hours at work, sixty/seventy hours a week. He was getting, it felt, as though he wasn't listening when you were talking to him because it didn't matter what you said he never remembered anything. And when he came home all he did was sleep. (Helen – spouse and carer)*

It is only with the benefit of hindsight that Rex is able to identify the early signs and symptoms of dementia that Julia his wife was showing. At the time he was simply too busy trying to cope, too busy to think clearly about what might be happening:

*And I suppose that I never thought a great deal about that and it is only with hindsight that you try and put it into some sort of context. (Rex – spouse and carer)*

In addition to forgetting how to carry out simple everyday activities, Rex noticed that Julia his wife was also beginning to struggle with more complex/skilled activities that she had engaged in previously for many years:

*I really became concerned when she crashed the car twice and she'd been driving since she was seventeen and had never had an accident in her life and on both occasions that she crashed, she hit a stationary vehicle. I began to get the, sort of, feeling that she just wasn't, for the want of a better expression, she wasn't connecting. (Rex – spouse and carer)*

Looking back, Bill is also able to pick out a series of incidents that looked innocuous at the time, but with hindsight were probably among the earliest signs and symptoms of his wife's dementia:

*Betty has been diagnosed with dementia for just over a year now… But in hindsight, I think she had been developing it a lot earlier than that. In fact, I would have said at least three years…that I could tell. When she was doing things she was slowing down and slowing down and slowing down…to the point where, from an accounting point of view, she was getting mixed up with the figures, decimal points and this sort of thing. (Bill – spouse and carer)*

Bill also took notice of the struggle Betty had in working the controls of their recently purchased car, realising now how significant it was in terms of the development of the disease:

*Well, Betty used to have her own car…and I bought her a new one with a different sort of gear box and she couldn't get away with it. And she was blaming it on the car but it wasn't the car. (Bill – spouse and carer)*

Like Bill and Rex, Helen noticed that her husband Will began to struggle with making the necessary connections to complete tasks he had completed countless times before:

*We bought a Corvette and he [Will, her husband] was going to work one day and the radiator blew… Normally, Will would have been there sorting it, but it stood in the yard for months and months and he didn't do anything with it. And then when he did go he didn't seem to know what he needed to do. He asked a friend could he give him a hand because he didn't seem to know what he needed to do. I mean, Will had worked on cars all our married life. I mean, we have never put a car into the garage for any work. (Helen – spouse and carer)*

Among the most common signs and symptoms of dementia reported by families in my research was that of forgetting how to carry out simple everyday activities, such as handling money. Here, Adam talks about how he and his mother Erica first began to suspect that something might be wrong:

*We started noticing that Michael's memory was being affected. Just little things like he started to forget how to sign things so when he was going to the bank he couldn't remember how to sign a cheque or things like that. He couldn't remember his bank account number, his sort code for his credit card. So, gradually things got to the point where we had to, well we couldn't let him go out with credit cards and lots of money because he was like, losing his wallet and things like that. (Adam – family carer)*

Sometimes, the changes that dementia cause are so gradual, that spouses and family members do not realise something is wrong and/or that they might be linked to dementia. This is particularly true in the early stages of the disease when symptoms result in relatively minor language slip-ups or a growing hesitation in social situations rather than a dramatic change in behaviour. Here Rex explains further:

*I began to notice that… silly little things that you don't pay any attention to at the time. As a spouse or the other partner then you just up your game to compensate for it and at times I would think, 'Well that is a silly thing to say,' you know, [but] thought no more about it. But she was becoming more and more, withdrawn is the wrong word, but reticent to contribute to a conversation or a discussion. And, had got to the point over a gradual period of time where she wouldn't make a decision about anything, she always deferred it to me all the time. If we were in a group of people and there was conversation and someone spoke to her, before she ever answered the question she would look at me. (Rex – spouse and carer)*

For some, it was only when day-to-day life became completely unmanageable that they finally decided to visit their GP. Here Rex talks emotionally about the day he and his wife Julia finally decided to seek help:

*Between 2002 and 2006 it was apparent that she [Julia] was deteriorating and we had some difficult times. Me trying to get her to see a doctor, and her refusing to see a doctor. Until in the end in October 2006 we had had a particularly bad day and I can't think why it was a particularly bad day. But we had had a particularly bad day. And she said to me, 'This is no good I need to see a doctor.' That was all I needed because I picked the phone up almost immediately and made her an appointment to see my GP. (Rex – spouse and carer)*

Helen also recalled that it was only when her husband Will (a long distance lorry driver) could not find his way back home from a delivery job, that they finally realised he needed professional help:

*And then he came home one day and he said, 'I had an awful experience yesterday.' He had been in the lay-by that he used, that he had been using for years and years and years. And he woke up one morning and he didn't know where he was. Hadn't a clue. Got out of his wagon and went to the edge of the lay-by and still couldn't figure out where he was. He managed to get hold of one the lads [via CB radio] that he worked with and he had to follow him. He didn't know how to get home. (Helen – spouse and carer)*

Mary only began to consider that something was seriously wrong when Lewis lost the ability to recognise the value of money, but even then only fleetingly linked it with dementia:

*I can remember it was just after Christmas. He came in with a handful of money and he was counting pounds as if they were hundreds and that really set alarm bells ringing. But when we went to the doctors, straight away he said, 'We will do the tests, but it could be Alzheimer's.' I never, ever thought of that happening to us, never, ever entered my head. (Mary - spouse and carer)*

Although spouses such as Louisa and James had suspected for years that 'something' was wrong, for some families dementia was the last thing they thought could be causing the problem, consequently the diagnosis was both shocking and unexpected:

*But she [the Consultant at the hospital] was fantastic. She did a scan where he had to go in and stay in for the day. And he was injected with stuff so that they could read the brain better. And then we had an appointment to see her. Both Katie [their daughter] and I went and for all we were, suspecting that there could be something quite serious, when she showed us the scan and the back of Will´s head…there was no brain activity at all. It is all just a black mass. And then, she diagnosed the Alzheimer's, you know, it was…quite a, shock, to both of us. We were both in tears. (Helen – spouse and carer)*

Sometimes extended family members did realise something was wrong but decided not to say anything at the time:

*And then people will say to you, and have said to me, members of my family have said to me, 'Well, we knew there was something wrong but we didn't like to say anything.' (Rex – spouse and carer)*

Sometimes people with dementia noticed they were having problems before anyone else. Betty for example, a successful and busy

accountant, began to experience difficulties with word finding and with calculating simple sums:

*I know what actually first kicked in on my head was, I was making some cheques out and I thought, 'Get the cheque book out.' And, I was trying to spell something very, very easy and I thought, 'Oh, it doesn't matter, just leave it a minute,' you know, because sometimes it does, doesn't it? And you think, 'You stupid sod' and you go on. Well, it didn't work so I left it for the day and then the next day I still couldn't do it. (Betty – person with dementia)*

Lyn, a retired business owner, was also the first to notice things were not quite right. A once avid knitter, Lyn began to struggle with even the simplest knitting techniques:

*It's like two years since it started and I hadn't been knitting for quite a while and I have always done a lot of knitting. Anyway, I went over my friends and I says, 'Peggy, can you show us how to start it.' And she said, 'What are you on about?' I said, 'I just haven't a clue how to do it.' And that was when I realised something was wrong. (Lyn – person with dementia)*

Harry, a retired Civil Service Scientist felt his symptoms came on suddenly and without warning:

*It happened on a Sunday years ago. I woke up…I could only remember [his son's name] name and nobody else's, or lots of things. (Harry - person with dementia)*

After months and sometimes years of uncertainty, a diagnosis, even a diagnosis of dementia came as a relief to some as it offered an explanation for the previously unexplainable and somewhat frightening 'random' signs and symptoms they had experienced to date:

*I thought I better look it up…and that was when I knew I had to say something to [the GP]. It was quite a relief actually, once I had told him. (Betty – person with dementia)*

### 4.1.2. *Support after the diagnosis*

Possibly the most important issue facing people affected by dementia is the fact that once diagnosed, they (and to a lesser degree their family members) are treated as non-people (Kitwood, 1997). It is an issue that bloggers (Taylor, 2012, Thornton, 2011), diarists (Henderson, 1998) and authors (Bryden, 2005, McGowin, 1994) with dementia have wrestled with for some time and one that people affected by dementia alluded to in this research. For example, James, spouse and carer for Eva, felt very frustrated that friends and even family members treated his wife differently based solely on the fact that she has been diagnosed with young onset dementia:

*My wife has got two sisters and I have actually asked them to their faces why they don't phone her and why they don't talk to her. They said that if Eva asked them an embarrassing question [they] would be so embarrassed about trying to answer. And I said, 'Well, you are talking rubbish. Eva can question and answer, it's her memory retention that has gone, but she can sit and talk. She is not going to jump on the table and rip her clothes off or anything.' (James – spouse and carer)*

James also feels frustrated that their daughter Tessa is reluctant to spend time with her mother. Even when she does visit, James feels that Eva is side-lined while the conversation revolves around their daughter's problems:

*She [their daughter Tessa] comes into the house and she will maybe be 10 minutes, 20 minutes, whatever it may be, half an hour, and all the time she is talking about her, not Eva. She is not talking about what has been*

*on the news or… It's how her feet are aching because she has been on her feet all day or her back's aching because she's… And Eva is sitting there with this incurable bloody disease, this condition and she is prattling on about how she feels sorry for herself and I feel like smacking her. (James - spouse and carer)*

James was not the only person to find that family and friends did not maintain meaningful contact after a diagnosis of dementia. Anna, spouse of and carer for Jim (Jim is now in long-term care) found herself coping alone but for entirely different reasons. Her children knew all too well what a future shaped by dementia held for them and they decided to escape by leaving home. Jim was diagnosed with young onset dementia only a year after his mother died from late onset dementia. Anna had cared for Jim's mother in the family home until just before she died and although the children really loved their nana, the whole family was traumatised by the experience. When their father was diagnosed with young onset dementia just a short while after the death of their nana, the children were still emotionally fragile (one son later had a mental health breakdown) and could not face going through it all over again. Despite feeling hurt at their reaction, Anna never blamed the children for their decision:

*When Jim became ill they [the children] couldn't cope with it. They ran. They knew what was going to happen because they'd seen their nana and… I'm not blaming them. It is just the way that they coped and they couldn't cope seeing their dad as well like it. The first time with nana they all pulled together but with their dad, because he was so much younger, they ran. (Anna - spouse and carer)*

The issue of diminishing support when a family member becomes ill with dementia is complex to unravel. Each of the carers I interviewed

attempted (in their own way) to justify why friends and family disappeared just when the person with dementia and their spouse/family needed them most. Rex, a retired businessman whose wife has young onset dementia, shared his thoughts on why support may diminish post-diagnosis:

*When Julia became obviously unwell most of [our friends] just disappeared, with the exception of two or three couples. Only one of which we see now on a regular basis. I think that with mental health…people are frightened of it. I mean, my brother who was very close to Julia has never seen Julia since she went into care. He won't go and see Julia when he comes to visit mum…he doesn't want to go and see her. My mum won't go and see her because she says, and you know, it is not a criticism of her, 'I'd rather remember her the way that she was rather than how she is now.' So, you find to some extent that you are coping with it on your own. I was lucky because Leanne [the memory nurse] was a great support to me. (Rex – spouse and carer)*

Rex had never personally encountered anyone with dementia before his wife became ill. Nor was it a topic he remembered hearing very much about. He had no idea that it was a disease that could affect younger people like Julia:

*Fortunately, the GP that we had over there [name of GP] was only in her early thirties and was aware of, if you like, early onset dementia, which was an expression I had not come across at the time of course, because I think, like a lot of other people, you think of dementia and Alzheimer's as an old people's disease. (Rex – spouse and carer)*

There is a high emotional price to pay for coping with dementia alone. James a burly ex-soldier, admitted that he often finds himself angry at the circumstances he and his wife Eva are in and increasingly finds himself becoming frustrated with Eva as her ability to understand their life together inevitably declines:

*Well, up until quite recently I was coping quite well, I thought. But now I find I am on edge all the time and although Eva seems to have bucked up a bit in the last couple of months, she is, like, really acting different, is what I am trying to say… She still does things which I can't get her to stop doing and they really frustrate me. Frustration is a big thing because I will ask her to do something that a year ago she was more than capable to do. And I will ask things like, I hate talking about her like this, make a cup of tea or… and I have to take over because I am afraid she's going to scald herself with the kettle and things like that, you know. (James – spouse and carer)*

Rex confesses that before Julia was finally admitted into hospital for assessment – several years after she first started showing signs and symptoms of dementia, he was often overwhelmed in his role as carer for his wife and struggled with feelings of anger, frustration and stress which were exacerbated by the cumulative effects of sleep deprivation:

*It's the lack of sleep as she became progressively worse before she went into [hospital] for assessment. She was becoming incontinent, so I was changing beds every night, almost. I was existing on about three/four hours sleep. And then it was never what you would call proper sleep, sort of, always half awake. (Rex – spouse and carer)*

Several years on from his wife's admission into fulltime nursing care, Rex is rebuilding his life one day at a time. He continues to attend a drop-in for people diagnosed with young onset dementia so that he can offer encouragement and support to others on the same journey as himself and his wife. All three carers found taking part in the interviews a deeply emotional experience.

Not everyone's social circle grew smaller because of a diagnosis of dementia. Bill and Betty Jackson talked at length about the good relationship they had with their friends. Betty in particular continues to get a lot of satisfaction from her life-long friendships with several local

women. Bill is a lot older than Betty and many of his friends have passed away. Perhaps, for this reason Bill was keenly aware of 'being alone' with the illness and in particular of not having children around to keep a watchful eye on them both:

*When you don't have a family and you don't have any children and something goes wrong, there is just the two of you, right? And you may or may not be computer literate [in terms of finding out information] so that when something like this happens, you are in for a bit of a shock when there's just the two of you. (Bill - spouse and carer)*

Michael, who has dementia and is in his eighties, also has a comprehensive support system made up of family and friends. Each and every family member is committed to understanding what Michael needs to enjoy life at home. Michael and his partner Erica summed up his current status with a contented smile:

*Maybe people help him too much, I don't know. But, he knows that we are there for him, don't you? (Erica – partner)*

*No, we can't grumble like. I can't grumble. To be honest like with everything that is going on at the moment. As far as I'm concerned everything is going alright…I feel pretty good like, you know. I sure know when I am well, I tell you. (Michael – person with dementia)*

### 4.1.3. *The experience of having dementia*

The experience of dementia is different for everyone. What is viewed as frustrating by one person will not necessarily be the same for another. In the following excerpts, Sophie and Will talk about aspects of the disease that frustrate them the most:

*It really, really makes me so furious when I can't get it when I need it and then it will come back again when I don't need it and it is bloody annoying. (Sophie – person with dementia)*

*Sometimes, everything seems fine and then all of a sudden somebody will ask me something silly. And I can't… Yes I know what that is, but I just go round looking for it. Losing tools in front of you like [that were] within your reach, looking for glasses. You've seen them, but they haven't registered. The beep hasn't gone. And then I will go back and I'll say, 'Well, where did I have them last?' 'Where did I have them?' And even down to scrapers and diggers. Little digger things that we use to plant and then if you go and have a cup of tea and then come back, you know, 'Where did I put them pots?' (Will - person with dementia)*

*Sometimes I do stutter a bit, but it is, mostly just when I can't [remember something]. One thing, if it stops me and I can't remember it then that makes me upset. It makes me upset because I would love to remember all the things. (Sophie – person with dementia)*

*I'll do some things out of context. I will go walking down somewhere and I will turn around and say, 'Well, what the hell am I walking down here for?' If my mind is not clicked on what I am doing then I might have a little walk where I haven't been before and then I will turn around and say, 'Ah! I know where I'm going. I'm going back home.' (Will – person with dementia)*

*I know so much and I can't always get it out and so it's [like] with the buses it will take two hours… God, it just goes in a bloody flash and it stays there and it laughs at me out the window. (Sophie – person with dementia)*

*I might meet someone else who is doing something, you know. And they'd say, 'We are doing so-and-so and so-and-so,' 'Oh, yeah? Very good.' You would chat about that for about five or ten minutes and then… it's gone. (Will – person with dementia)*

Will also talked at length about his father (who died before he reached

Will's age), wondering if perhaps he too had been ill with young onset

dementia:

*My dad had a memory problem, always lost his glasses, always, always lost his things. I can remember that he used to go; I won't tell you the rude bits, but he used go down our street and he used to say, 'I've got*

*everything mother, I'm away.' That's what he'd say, that's his [illness], you know. (Will – person with dementia)*

Betty and Lyn, on the other hand, spoke about the need for discretion when telling family and friends about their diagnosis of dementia:

*You do not tell somebody in the village unless it's a good friend because otherwise it is around the village in five minutes. 'Betty Jackson has got Alzheimer's, did you know?' (Betty – person with dementia)*

*I don't tell anybody. There is only Lilly, our Madge and April that know for a certain fact. They won't tell anybody else. My cousin, she knows what's the matter with us, well, two cousins actually. (Lyn – person with dementia)*

The pressure to keep the diagnosis a secret meant there was a need to engage in a certain amount of subterfuge when interacting with the neighbours. Like most people I interviewed, Sophie, a retired PA in her late seventies, felt she managed to hide the fact she had dementia when chatting to neighbours - as long as she kept the conversation simple:

*Nobody knows that I have got this problem mostly because when I am out and I am talking, just plainly out in the street and not picking up all the things that have happened to me, then nobody would know that I have got a problem. Because I can talk to them and say, 'Hi, how are you doing?' and, 'Isn't a lovely day today?' and, 'How are you getting on with your garden?' (Sophie – person with dementia)*

Attitudes towards devalued people vary, especially if they behave in a way that draws attention to their weaknesses. By way of illustration, Sophie shared the following story of an incident that occurred while travelling on a local bus:

*I was at the front of the bus as I was going to get out at the next stop and…unfortunately my trolley tripped up, right in front of the guy who was driving the bus. So I said to him, 'Oh my God, I am really, really sorry.'*

*Because, I mean, you know, it was all over the floor at the front there. So he said, 'No, you just put everything back.' And then…the people at the back of the bus started saying, 'Hurry up! We want to get off the bus. We've got shopping to do and we want to get out.' And then that turned me into tears…I was so upset about it. I was really crying buckets and nobody seemed to be saying anything to me. The driver of the bus was very kind, he said to me, 'Don't worry love. Don't bother about them.' But I did because when you've got people shouting at you, 'Hurry up and get off' you know 'We've got to go places,' it makes you really stressed. (Sophie –person with dementia)*

Ironically, given Sophie's experience, people with dementia in my research demonstrated a tender compassion towards other devalued people generally and people diagnosed with dementia particularly. Lyn, a retired businesswoman knew several people diagnosed with dementia and enjoyed nothing more than encouraging them to keep going and to stop worrying about forgetting a few things. Here Lyn explains how she tried to cheer up her life-long friend, Lucia:

*Viv's mother-in-law [Lucia] is very forgetful, but she's good fun like is Lucia. I mean, she knows what's the matter with her. I think it is some sort of dementia. Like Christmas, Viv always invites Lucia and Tom up and we always go over for our Christmas dinner. We always have a lovely day because Lucia, you know, she's a laughy person. Yeah, we always have a good day. But last Christmas she was going on and on, 'I am so forgetful Lyn. I am. I'm so forgetful!' 'Oh Lucia, don't think about it!' I said, 'If you forget you will remember some time or another.' (Lyn – person with dementia)*

Although Lyn found it difficult to break the news of her diagnosis to her children, she encouraged them to try and adopt a similar attitude as her with regards to the possibility of the illness running in the family:

*I worry for my family. I mean, when I was first diagnosed with it of course I told Mark and Jan and I think Jan's words were, 'Will I get it mum?' and I said, 'Well, I don't know,' I said, 'It is just one of these things.' But I said, 'Don't think about it.' So, that's us off worrying a little bit, you know? (Lyn – person with dementia)*

Lyn enjoys spending time chatting with friends. When she found out that someone she knew from the past had been admitted into a local care home because of dementia, she immediately arranged to visit her. The following excerpt is taken from a longer conversation Lyn had with a relative of her old acquaintance prior to the visit:

*Now, I was talking to a relation of Edith. 'Oh Lyn, there is no point in going because she doesn't know you.' And I thought, 'I will have to go and see Edith.' Well, as soon as I went in she says, 'Oh, it's Lyn. Come on, we shall go to my room.' She knew me straight away. (Lyn - person with dementia)*

This level of thoughtfulness was evident throughout my interviews with people diagnosed with dementia. In fact, the people I interviewed were not only interested in the lives of other people diagnosed with disease; they also demonstrated a deep concern for the circumstances that had brought them to this place in their lives. Michael and Erica for example were troubled about the circumstances that culminated in Michael's brother Alec being admitted into full-time nursing care. The following conversation is one of several they shared with me. It was (perhaps), as much about Michael and Erica finding closure about a decision they disagreed with as it was about re-tracing the steps of Alec's troubled marriage and his eventual admission into long-term care:

*We went to Scotland [on holiday] and she [Alec's wife] started crying. And I said, 'What's the matter? 'Oh, it's him, it's him.' Michael said, 'I'll have a talk to him.' He said, 'What's going on? Why is she crying?' He [Alec] said, 'I don't know.' And he really didn't know. I tried to talk to her. I said, 'What is the matter', and she said, 'Well, he doesn't talk to me. He's ignoring me.' But, that is part of the illness, isn't it? I knew that was part of the illness because my brother had it you see. (Erica, retelling the story with Michael)*

In contrast to carers, people with dementia who took part in my research frequently adopted a '*que sera sera'* attitude towards their diagnosis. Here Betty explains her rationale for living life boldly, taking each and every day as it comes:

*He [her husband Bill] was trying to stop me doing things which I was going to do…because he was, sort of, thinking into what it said in the book [handbook about dementia], that it would happen the next day. I have never read what it says and what I don't know, I don't have to worry about. So I didn't read that book. Because I didn't want to wake up every morning thinking, 'Dare I put my feet on the floor? Will I end up on the floor?' So I don't bother, I don't read it, up to present I have not. (Betty – person with dementia)*

Betty's husband Bill felt he had to know what she was doing and where she was at all times. Bill explained that this was not because he wanted to control her life; rather he was worried that without proper supervision Betty would have an accident, therefore he believed he needed to keep a dutiful eye on her. It was obvious Bill took his responsibility as Betty's carer very seriously. Bill's over-protective attitude towards Betty was a source of irritation to her:

*He is the thing that aggravates me most. His continual, 'What are you doing? Why are you doing that? And he goes on all the [day]. And I'll say, 'What are you getting bad-tempered for?'…that annoys me. (Betty – person with dementia)*

Lyn, a pragmatist at heart, also shared Betty's *'whatever will be will be'* approach to her diagnosis of dementia, pointing to the futility of trying to fight something that cannot be changed:

*No, it doesn't worry us. Just take life as it comes. What is the good of worrying? It doesn't help matters does it? I mean, it certainly doesn't*

*worry us, because what I think to myself is, one day, if I can't look after myself, I will just have to go into a home. (Lyn – person with dementia)*

### 4.1.4. *When does 'forgetting' become dementia?*

The difficulty of distinguishing between what is a normal part of getting older and the signs and symptoms of dementia is one of the complex aspects of dementia that professionals, carers and those diagnosed with dementia struggle to fully appreciate. It was an issue that both Betty and Bill touched upon at different points during their joint interview. In the first excerpt, Betty was talking about her failing eyesight (which was corrected with surgery), which at first she put down to a progression of Alzheimer's disease. In the second one, Bill was talking about the confusion he felt over what 'normal' was, in terms of forgetting. In the third excerpt Betty points her that, on occasions, her friends forget things that she remembers and she cannot help but wonder, when does normal forgetfulness become dementia?

*I always know what the number is, it has to be at so-in-so. But you see, while I had the cataracts you see, because I have had this one done just a few months ago, well, I couldn't even read my bank statement because I couldn't find the point. And I thought it was to do with the Alzheimer's and, of course, it wasn't. (Betty – person with dementia)*

*The most important things, from my point of view was, the identification of the problem, that, I thought there was something wrong but I didn't personally take it any further, I just used to think it's old age, you know. (Bill – spouse and carer)*

*When I listen to some people or when you do listen to people I think well, 'I wonder if she has got it because she must have.' And it is like people like Dot, she will say, 'Can you remember who so-in-so was?' Because she wanted to know what she needed to know and I will say, 'Well yeah.' She said 'I don't know what is happening this week. I have been trying to figure out who certain people are and I can't.' And I have done, but I shut*

*it, and I say nothing. But that is, they are put down as 'old age' where is it alright and where is it old age? Where does it click in? (Betty – person with dementia)*

### 4.1.5. *On becoming a carer*

The shock associated with suddenly becoming a carer was expressed by everyone in different ways. In the following excerpt, Bill muses about the challenge of walking in the Consultant's door a husband and walking out a carer. To this day he struggles with understanding what his role is and admitted that sometimes he gets things wrong:

*There's no specific instruction on how to function as the carer and what might happen. All of sudden you are faced with this situation and then you tend to be over-reactive…being a carer is stressful and the older you get you are less able to handle it. Because your mind runs away with itself you start imagining all sorts of things even to the point where you sometimes think that you've got it yourself. Because of the stressful situations you forget to do things yourself. (Bill – spouse and carer)*

Trying to understand the reach of dementia was also a major issue for carers. How for example can you know if the person you are caring for is able to correctly answer health-related questions? What if they answer wrongly? It was something that troubled Bill greatly:

*I'm thinking what is she going to say to the opticians for the tests? If she misunderstands letters, characters and figures [and] right from left, is she going to get the wrong prescription for wearing glasses? (Bill – spouse and carer)*

All the carers who took part in my research were either still caring for their partner/spouse or had been caring for them for many years before they were admitted into fulltime nursing care. Some, like Anna, had also cared

for elderly parents or in-laws and had children at home. Without exception, all expressed the following sentiment in various ways:

*I didn't realise it was going to be as hard as it has got lately. Over the last couple of years it's got really hard. You know, it has got really hard. (Nick – spouse and carer)*

Nick goes on to explain why things are so hard:

*I mean I do every mortal thing she's a nine stone 6 months old baby. I mean I do everything, I clean her, every mortal thing that you could think...I do. She does nothing now, just sit there quite happy until I lift her up, get her dinner, sit her at the table, cut the big bits up and put her salt and pepper on, and that sort of thing. But it is, total, total, she can do nothing for herself, unfortunately. I wish she could, but I mean she can't even get dressed. Odd times she'll fasten a zip, when she does that, you know, it's brilliant. I mean, it means nothing to you, nothing, but to me yeah. But if she is getting in the car and I'll say, "Oh fasten your seatbelt love" and she'll get it. Not every time but the time that she does of course, it puts a big smile on her face. People up the street think I'm mad. (Nick – spouse and carer)*

The fact that caring for someone with dementia was a difficult and stressful job was also something that troubled people with dementia. Here, Will talks about how much he enjoys attending the young onset dementia drop-in and how both he and his wife benefit in differing ways from attending:

*It gives you a different sort of, outlook. The way people talk to each other and some of them are good friends and some of them are, you know, whatever. It's a good thing, I mean it has… It also takes a lot of burden off Helen. Because, I mean, it must really get pretty hard for her, at the end of the day. And, that is what really, that should, ease up a bit. Because it is not easy; definitely not easy for a carer; because it is there all the time, 24/7. But, as we say, we have to go on. (Will – person with dementia).*

### 4.1.6. *Caring responsibilities*

Given the physical, mental and emotional toll of caring for someone with dementia, it is unsurprising that Cooper *et al.* (2009) found so many carers willing to admit they sometimes abused the person they cared for. A more recent study by Kishimoto *et al.* (2013) on the prevalence of carer abuse towards people with mild dementia in Japan reported similar levels of abuse. Many of the carers I interviewed in my research were living on the edge mentally, emotionally and physically. Some wondered just how much longer they could go on. Because of lack of support, there was a constant busyness to people's lives, a sense that there was an unending list of jobs to do. Nick, who has been caring for his wife Maria for eight years, put it like this:

*Well, it's fulltime, fulltime. 24/7 no 25/7 because I don't get time off for dinner…my mother never stopped and it is like that now there is always something to do, always, always. (Nick – spouse and carer)*

Louisa was newly retired when her husband Nevin was diagnosed with vascular dementia. Initially, he was misdiagnosed and for two years received treatment for a condition he did not have. The medication made him dizzy and weak which led to a large number of falls. Nevin was seriously injured several times while falling. Nevin is now much stronger and no longer falls as much as he did. The stress, however, of feeling that she always has to know where her husband is and what he is doing, is at times difficult for Louisa to manage. It is a pressure she believes she will never come to terms with:

*I am constantly on the alert. What is he doing? You know. I'm never going to get over that. That is not going to go away. (Louisa – spouse and carer)*

Always having to be 'on guard' was a feature of caring for someone with dementia that other carers mentioned as well. Bill, for example, likened being a carer for his wife Betty who has Alzheimer's disease to being a policeman:

*The biggest challenge, I think, is being able to second guess what is going to happen. I'm probably not explaining it very well. But basically, it's like being like a policeman, I think, more than anything else…on the lookout. Continually on the lookout. (Bill – spouse and carer)*

Ewan, whose wife Liza was diagnosed with young onset dementia several years ago, looked upon it as developing the ability to see around corners:

*With Liza being as she is, you look closely, you know, we are still learning to look round and see round corners. Some days we actually do but, other times you don't. (Ewan – spouse and carer)*

For some, the pressure of never having a single moment to oneself was one of the most difficult challenges of the disease. Mary and her husband Lewis are both retired teachers. They taught at separate schools and although they loved spending time together, they were also used to spending time apart. Here Mary shares her frustration on the emotional stress of never having time alone:

*From the moment I wake up it is getting all his clothes out, getting his tablets, getting this and that and I do find the business of him not being able to do anything on his own very hard work, very hard work. You know, if I just want to sit down and read the paper, I could be reading it for five minutes and then he is standing there. (Mary - spouse and carer)*

This issue, of not having a single moment in the day for oneself was also raised by James, who felt this was the single biggest contributor to his growing levels of stress:

*I'm stressed because of the fact that I don't get a break…getting Eva's breakfast, making sure she has had her medicine, take her and the dog for a walk, come back again, have a coffee, go out for a couple of hours, maybe have a lunch meal. If I don't have a lunch meal, come back, cook lunch. If there is a bit of washing or something, you know, get that on, bit of ironing to get done, start getting the tea ready, have the tea, wash up after tea, you know…then I sit and watch television with her and quite honestly I am so bloody tired that I'm falling asleep. (James – spouse and carer)*

Anna also talked about the pressure of caring for her husband Jim 24/7 and of never having a single moment alone:

*Mentally and physically I was so worn out. Because he used to stand behind me crying twenty four hours, as soon as I got up on a morning there would be crying. But he would be right behind me. I couldn't go to the toilet. I couldn't have a shower. I couldn't go from the kitchen to the living room. He was always behind me. And that was his fear; of being left alone. (Anna – spouse and carer)*

It was not simply about having time to oneself – although that was viewed as important by everyone, it was also about the fact that it was impossible to get on with jobs around the house. Here James attempts to explain how the cumulative effect of always trying to be on top of every situation is putting his relationship with his wife under stress:

*If I had something to do, like a bit of decorating, I could use that hour to get a bit done, you know. I mean, I can't even do things now like. I'm going to cut the grass and I lock the front door because Eva has wandered, and I'll cut the grass and or something and I go back in. I have to call for Eva and she is reluctant, for some reason. I don't know if it's because she can't hear me or she just doesn't know how to respond because I will call her name about two or three times and then I will*

*actually have to shout it out and then I get a reaction. But I have now got into, it is probably my fault, that I have now got into the habit of when I'm talking with her now to get the meaning across, to get a response, I shout. And when that happens, like it did this morning, that gets Eva upset at the beginning of the day and that is not a good thing. And I want that to stop but I am always, I am suffering from stress. (James – spouse and carer)*

In the following excerpt, Rex shares his thoughts on the mental and physical toll of caring for his wife Julia who is diagnosed with young onset dementia:

*Going shopping was a nightmare in the end because she would go off with other people and put things in other people's trolleys and it was an absolute nightmare…those were the sort of physical things. Then there were the mental things, the stress of trying to cope with it. Not really knowing how to cope with it because this is something that you have never experienced in your life before. (Rex – spouse and carer)*

### 4.1.7. *Carers' strategies for managing stress*

People experienced the stress of care-giving in a number of ways. For example, four years ago Bill suffered a heart attack and although he made a full recovery, when Betty became ill with dementia he began to experience chest pains again. This was a frightening experience for Bill as he immediately began to worry about what would happen to Betty if he died before her, given the fact they did not have children or close family to keep an eye on things in his absence:

*I've got a heart problem, right? And blood pressure and what-have-you for which I'm taking tablets. I was starting to wind down, if you like. But, once this problem with…Betty is concerned, I started to get these stressful symptoms again and I went to my GP and he organised x-rays and what have you but the conclusions everyone came to was that my problems were stress related. (Bill – spouse and carer)*

Sometimes, as Bill explains in the following excerpt, the most stressful part of caring for a spouse/partner with dementia is simply the changing nature of the relationship between them:

*You see, I meet a lady who walks a dog occasionally on a morning…and she's in the sad situation where her husband has Alzheimer's…and he doesn't know her and is in a home. And I think of that situation developing with Betty and that is what upsets me and I think that is why I want Betty to have everything that pleases her. And that is why I get upset when she gets very touchy if I'm over-reacting, you know? She never, never, ever used to get sharp with me, but she does now. (Bill – spouse and carer)*

Learning to cope with the stress of caring was therefore an issue of great importance to Bill and the other carers I spoke to. In the following excerpt Bill talks about what he does to stay balanced and positive:

*Well, most of the unwinding is done every morning. I am a very early riser. I [go] down to the woods [with the dog]…and I will be down there for an hour or so, walking miles. Listening to and seeing the wildlife, listening to the birds and watching the deer and so on…you can unwind with that. I used to play golf but I can't manage that now. But other than that, I like reading, like watching sport on the telly. (Bill – spouse and carer)*

Taking the dog out for a walk was a lifesaver for Anna too. To Anna's mind, if carers do not already have a dog, they should borrow one:

*Getting out in the fresh air for exercise was the way I coped. If I hadn't have been able to go out every day with the dog for a walk, I would just have gone nuts. So, for people who haven't got a pet or for people who don't go out they need to find something because you do…need to try and find something to sort of, try and switch off from it all and pretend it's not happening. (Anna – spouse and carer)*

In addition to getting out in the fresh air every day, Anna also acknowledges the important role her personal circle of support played in helping her out on a day-to-day basis:

*As I say, I was able to go to Mind and have my friends so eventually that was the support that I had. And, as I say [the memory nurse] used to pop in every now and again but I know that if I had wanted to ring her she would have come and seen me. And the girls at the [care] home as well, the staff at the home they used to… if I had a problem… they would support me. Because, you know, it's part and parcel of their job. So, I was lucky I guess, there's a lot of people out there who haven't got what I had. And if they don't, I don't know how they are coping. (Anna – spouse and carer)*

### 4.1.8. *Top tips on living well with dementia from people with dementia*

People with dementia who took part in my research were keen to share their thoughts on how to live well with dementia. Their top tips revolved around keeping their lives as close to their usual routine as possible and avoiding dwelling on what they had lost. Betty for example, an energetic and recently retired, self-employed accountant decided from day one that she was not going to live her life in the shadows of dementia:

*Well, when you first [get diagnosed with dementia], it is like, you think, 'Oh my God,' don't you? And I just thought, 'Oh.' I was sort of looking at myself and thinking, 'Well, because he was reading all the…horror and things. I said, 'I am not reading that.' But he got so far through and I said, 'You can pack that in and you can throw it away.' Because he is expecting all these things of what can happen. Which isn't good, well I don't think so. Because there is nothing you know…you can't stop it, so why look at it? (Betty – person with dementia)*

True to her word, Betty seizes every opportunity that comes her way to enjoy her life to the full. She does this in the understanding that if you continually turn down invitations to dinner/days out, then eventually the invitations will dry up, something that she has no intention of letting happen:

*I just go on as I was, yeah, I don't give in to anything and if anybody rings and says, 'Would you like to go to so-in-so,' I will say, 'Yes! I will be ready in two minutes.' Because if you don't, if you say 'no' again they won't ask you. And then you get so you don't see people, you don't talk to people and I don't know what you would do. So I don't! I mean, if Emma my friend said, 'Come on, there is a thing we can go to Betty,' say around about Christmas time and I will say, 'Yes.' Because I wouldn't think, 'Oh well, I might be dead then.' I would say, 'Oh yeah, I will go.' Because [otherwise] you miss out don't you? (Betty – person with dementia)*

Harry, a retired Civil Service scientist, continues to put his research skills to good use by scanning his daily newspaper for health tips on staying healthy, in the hope this will be helpful in managing and the symptoms of his dementia. Harry also believes that by keeping his brain active with brain training games such as Sudoku, he is helping himself to live as well as possible with the disease. Harry wryly referred to his game playing as 'brain help.' Harry also carries a notebook around with him every day. He uses the notebook as a memory jogger. In the following excerpt, Harry explains how he uses the notebook to remember what he enjoyed eating earlier in the day:

*What I do, is I write everything. So, you know if I have [something] to eat nice in the morning. And I can look at this and find out what it was. (Harry – person with dementia)*

Keeping a thankful attitude for what you retain, rather than continually grieving for what you have lost was an important part of living well with dementia for Lewis, a retired teacher:

*Anyway, I mean, I am 78 and…I'm not worried about you know, not having what other people have. I've got my wife, I've got my daughter, I've got myself and we are all still together, and we are all happy most of the time. I can still…I have still got my hands and I've still got my eyes, I've got everything…I have got everything but my memory. (Lewis – person with dementia)*

For Lyn, one of the most important things for her was to stay connected to her friends. Staying in touch was, she believed, one of the ways she survives not only the symptoms of dementia, but an unhappy marriage:

*I went to Cleghole School. And then I met Samuel and we got married and you know; I have regretted it all my life. (Lyn – person with dementia)*

*Pat and I are very good friends…I go to Pat's every day, not many days I miss. And then I go up to Clara's and she is a girl from Cleghole. I knew all [Clara's] family, she lost her partner and so I started going up there… Sometimes I will go over to Anne's and then on the way back I will say to Samuel, 'I'll be ten minutes' and then go and see Edith. I just like to keep up with people. (Lyn – person with dementia)*

Maintaining friendships was important to Michael as well and was one of the things he thought helped him to live well despite having dementia:

*I go to the club yeah a couple of times in the week. I have friends I like to sit with and play like, you know and that I see, very often. (Michael – person with dementia)*

For the majority of people I interviewed, keeping busy and active was, they felt, the key to living well with dementia. Here Nevin talks about his love for messing around in the garage:

*Things I like to do now, I mean…well, as I say, happy to get in that bloomin' garage and mess about. (Nevin – person with dementia)*

Happy to mess around in his beloved garage, Nevin was quite clear that living well with dementia did not necessarily extend to engaging in anything more strenuous than that:

*Louisa:* *When that stopped [Nevin's physiotherapy sessions] the whole thing, the whole exercise thing stopped. And you won't do them at home on your own, exercise I mean. They*

*have told you to go out for walks and when was the last time you went for a walk?*

*Nevin:* *I've got a scooter!*

For Betty, keeping busy and active was about continuing to do her share of the household tasks:

*I did some of the garden yesterday. I did the washing. I did the meal and all that. I mean, so, I really…I know there is something wrong, but I can't say that I have anything that I think, 'Oh God, I am not going to do that.' I haven't anything like that because I try to just go on as I was. (Betty – person with dementia)*

For Will, in addition to working on the allotment, playing with his grandson and walking the dog featured heavily on his list of strategies to live well with dementia:

*We take the grandson for a walk and the dog, so that is quite cracking. We will go round and have a play with the dog and that's good, I enjoy that, things like that. And the dog is good mind, he never asks any questions. (Will – person with dementia)*

Betty shares Will's dry sense of humour:

*Bill:* *Betty used to be a self-employed accountant…and she had been doing that for many years.*

*Betty:* *[laughing] that is probably what drove me mad!*

For Harry, living well with dementia was, in part, about continuing to attend art classes, something he has done for many years:

*I have my daughter as well - she's very good. She takes me to art class on a Friday and she and I are best friends…I mean, all these pictures [pointing to the paintings that cover every wall in the living room] are*

*mine. I've painted these. I have been painting for years, for thirty five years I have been going to art classes. (Harry – person with dementia)*

Harry attributes his good mental health to the fact he is able to get out and about easily. Harry lives in a small country village in rural Wickham and is of the opinion it is probably the best place for an older person to live bar none. Here Harry talks about the many and varied activities he is able to take part in every week:

*On a Tuesday I go to the town Café where old people go, you know. We go at ten o'clock in the morning, we have coffee, we play dominos and get a lovely lunch and tea and that's on a Tuesday. On a Wednesday, I am in the pensioners club and I get a lunch at the pensioners club. Our lunch, at a café down there, that's on a Wednesday. On a Thursday an ambulance vehicle comes along, picks up old people, me and an old lady and they take us into Castleton for lunch and that's on Thursday. It is a wonderful place for old people. (Harry – person with dementia)*

In addition to having a full and varied diary, Harry also employs someone to clean his house. The support Harry has at home means he feels safe, enjoys an active life and (importantly for him) is not spending his hard earned income on care home fees:

*I have a lady who comes in and cleans my house and she hasn't come today, so I have had to do all my housework, you know. And so, when I am doing the washing up and that, I drop things and when I'm doing the cooking I maybe burn my finger…I mean, thanks to her, having her and having my son Joseph, it saves me having to go in to a care hotel which would cost me six hundred pounds a week! (Harry – person with dementia)*

Learning to cope with the frustrations of memory loss was an issue that most people touched upon and each had their own way of dealing with it. Here, Will shares his tried and tested method for remembering where he last saw something:

*I call it 'shake me head.' You know, you have looked for something for so long and then you walk back in and it is standing there looking at you. And that annoys me. I've passed it three times and I haven't actually, nothing has sort of, stimulated me to think, 'Ah! There it is!' No, that can get me cross. And then, I'll just go and sit down and I'll say, 'I will have a couple of hours just doing nothing.' And that sometimes helps. And I will go back out there and I'll say, 'Oh, there it is.' That can be temper though I think, in the mind, of saying, 'Yeah, you silly old goat,' you know what I mean? But, other than that you just say, 'Ah well, never mind.' (Will - person with dementia)*

### 4.1.9. *Top tips on living well with dementia from carers*

In this section of the chapter, I present 'top tips' from carers on how to live well with dementia. For example, the need for routine was mentioned by almost everyone, including Bill who felt that without an established routine, things would quickly begin to slide at home. Additionally, getting out of the house for at least part of the day was deemed essential for keeping frayed tempers at bay. In the following excerpt, Mary and Lewis talk about how they plan their day:

*Mary:* *We leave the house every day. Every day we go somewhere. If it is only into town for a coffee, we go out. But then in the afternoons he will go in the garden, won't you?*

*Lewis:* *Yeah.*

*Mary:* *He spends a lot time tidying up in his room, don't you?*

*Lewis:* *My room is the best kept room in the house.*

*Mary:* *But, he can never find anything in it.*

*Lewis:* *[laughing] It can be difficult!*

Even when things looked ‘hairy’ Nick found that with a few diversionary tactics up his sleeve he was able to quickly recreate a happy, joyful atmosphere:

*As I say we are never in. You know, like, when the weather is fine, we would be off about half past nine ten o’clock, to the coast. Or up the dales, she likes the Dales, Get the dog in the river. You see a lot of what we do, you see, apart from getting her out, is to keep the dog happy. It is a challenge, to try and keep them both, I mean, Maria we obviously keep Maria happy, smiling, don’t want her to get down. Cos once she goes down it can be a bit hairy you know, she wants her mom, she wants the kids, she wants to go and collect them from school.*

For Bill, this idea – of creating joy filled moments throughout the day, was one that he also relished and he actively looked for ways to bring joy and happiness into his wife’s life:

*For example, we went to Northampton this week and she is going to her goddaughter's wedding and she was going through her jewellery - all of it. But, she hadn’t anything to match the rig out that she’s got. I realised it’s her birthday on the first of October and it will be our golden wedding next April. So, I am thinking, ‘I'm going to do something before then.’ So, I took her with a friend…into the jewellers…and bought her some new jewellery to match the rig out and what have you. That’s one of the things where I want her to enjoy it now when she can enjoy it. (Bill – spouse and carer)*

Finding joy in the everyday was not just about buying his wife new jewellery, Bill also knew how to take pleasure in the little things of life:

*We’re doing a lot of things together now, which we’ve got to now because Betty hasn’t got a car anymore and she hasn’t got that much amount of independence. So, she relies on me taking her, but I love doing [that]. There is nothing nicer than getting in the car and popping down to The Tea Rooms and having a nice cup of tea and coffee and toasted tea cake and a bit of a chin wag and Betty will have a walk around the garden centre and that sort thing. (Bill – spouse and carer)*

Ewan talked about his gratitude for all that his wife had done for him before she became ill with young onset dementia. In his eyes, Liza had looked after him before she became ill with dementia, so he felt it was his was his turn to look after her. Top tips from Ewan included getting things sorted out as quickly as possible:

*I am in a fortunate situation that I am able to… keep Liza more in less in the lifestyle in which she has become accustomed to and I don't see why she shouldn't. I mean she looked after me for a long time… I make things pleasant and comfortable so why shouldn't she enjoy it? That's my take on it. I mean whatever she needs we sort out. I mean, she [Christine, Liza's support worker] only says, 'Oh, I could do with so-and-so' or 'We haven't got this.' Someone has an idea, you know, it is just sorted out as soon as possible because that is just who I am. (Ewan – spouse and carer)*

Although carers found it a difficult thing to do initially, when they did confide in the neighbours, their support proved to be invaluable. Louisa said that learning to let other people help had 'saved' their lives. Here, Louisa talks about the difference talking to a neighbour made to her and Nevin:

*The lady over the road is a care worker of some description and I went for her one night because he had fallen and he had ripped all his arm. And I went to her to see if she had any dressing because I didn't just want to put a plaster on. Anyway, she came over and she said, 'I will have to look at it' and she said, 'No Louisa, I am going to phone the 24 hour nurses,' which I didn't know anything about. So she called them out didn't she? And they came out and then she said to me, 'You need help as well Louisa. You can't cope. You can't carry on coping like this.' And then, once the nurses came we filled a load of bumph in with one thing and another. The dressings you want and then the nurse and the district nurse were coming to change your dressings, this was due to all these falls. And then, one contacting another and then the other put us in contact with somebody else. And we had streams of social workers coming and everything seemed to click into place to help me to help him. (Louisa – spouse and carer)*

Carers spoke insightfully on the lessons they had learned over the years in relation to communicating with their spouse with dementia. For many, the lessons had been hard won and came about after a period of trial and error. Learning how to communicate effectively was however something many carers felt was key to both of them living well with the symptoms of dementia. In the following excerpt, Bill talks about how he learned to change the way he communicated with his wife Betty:

*Bill:* *I think that…they've had a chunk of their earlier life [taken away] and what you have got to do is to try and put that back…Betty now realises that and she comes and asks a question which she would never do before. She used to try and figure something out for herself. So, that is one thing I would say that I would try and make sure that the individual has confidence to come and ask the question and be shown without taking offence. No, that contradicted what I said earlier on, but there are certain things, now, that Betty realises that she can't do and she will come and say, 'Can you come and do this?' and that is very, very important. And the other thing that I have learned…don't talk down to them. You know. Don't, even though they've lost some of the...training as a child, don't treat them like as a child, I am not explaining that very well, am I?*

*Ethna:* *You are. You are explaining that very well.*

*Bill:* *Well, that's…*

*Ethna:* *It is about treating people with respect, isn't it?*

*Bill:* *Yeah. The best analysis I could say to that is that it…you may be explaining a childish thing but you need to do it on an adult basis. That's important you know. But, in the earlier days I would say, 'Get out of the way, I'll show you how to do that,' you know? But now, I'll [say] 'You do it, I'll show you,' rather than being dominant about it. 'Are you sure that's right?' this sort of thing. Whereas, once upon a time, I mean, I was very abrupt and that sort of thing. Patience, patience is important…but it is very difficult to put in to practice sometimes…particularly if you are under stress.*

Finding innovative ways to help their spouse feel physically and emotionally safe and secure was at the top of every carer's list of top tips. Rose, in the final data excerpt of the chapter, shared with fellow advisory group members the 'cover story' she invented to ensure her late husband Marcus did not feel threatened by her presence in the family home during the later stages of his illness:

*Towards the end of Marcus' illness he would on occasion forget who I was. I would be standing in the kitchen in the evening, tidying up, doing dishes, that sort of thing and Marcus would come into the kitchen and say, 'Who are you? Where's my wife? What are you doing here? And then he would demand I leave immediately. The first time he did it, I grabbed my coat and keys and quick as a flash I replied, 'That's okay, I'm just leaving.' I opened the back door and shut it after me. When I could see that Marcus had gone back into the living room, I went round to the front of the house and let myself in the front door, saying loudly, 'It's me, Rose, I'm home Marcus, would you like a nice cup of tea?' I can't count the number of times I had to do this and, thank goodness, it worked every time. (Rose – spouse and carer)*

## 4.2. Chapter summary

In this chapter I presented data from people with dementia and carers on their initial experience of dementia. Topics covered in the chapter included: recognising the early signs and symptoms of dementia (4.1.1), support after the diagnosis (4.1.2), the experience of living with dementia from the perspectives of people with dementia (4.1.3), the challenges associated with becoming a carer (4.1.5), caring responsibilities (4.1.6) and carer burden (4.1.7) and finally, people with dementia (4.1.8) and carers (4.1.9) shared their 'top tips' for living with dementia.

I now turn to the second findings chapter in which I present data from people with dementia and carers on the dementia services they use, together with their views on other health services including GPs, opticians, dentists, and the district nursing service.

# Chapter Five: Reflections by people with dementia and carers on the dementia service and associated services

## 5.1. Introduction

In this second findings chapter I present data from people with dementia and carers on the dementia service they use and other health-related services. Interview data are presented under the five categories of service evaluation identified by Willis *et al.* (2009), i.e. service experience (5.1.1) including data on the experience of receiving the diagnosis, using occupational therapy services, support provided by the consultant psychiatrist, reflections on memory drugs, memory assessment tests, the young onset dementia drop-in support group and targeted therapy groups and other health-related services that people with dementia and carers used. This is followed in section 5.1.2 with data on helpful interventions including: counselling support and community-based resources such as MIND, adult day centres and horticultural projects. In section 5.1.3, I present data on how people with dementia and carers attempt to normalise their experience of dementia. This includes data on: adapting to the diagnosis, overcoming fear, managing other people's attitudes, renegotiating relationship boundaries, working through everyday battles and skirmishes and finally making peace with the diagnosis. I then present data on issues related to communication (5.1.4). The chapter is brought to a close with data reflecting perceived gaps in the dementia service and other services (5.1.5). A summary of the findings from this chapter is included in table 5-1.

**Table 5-1: Summary of findings answering RQ2**

| **Data stream two**<br>Corresponds with analytical categories: service experience, interventions, normalising the catastrophe, communication and service gaps<br>Findings answer research question two | |
|---|---|
| Service experience | Includes data on: the experience of receiving the diagnosis, of using occupational therapy services and the support provided by the consultant psychiatrist. This section also includes data on other health-related services that people with dementia and carers used. Both positive and negative experiences reported. |
| Interventions | Service interventions included: memory drugs, memory assessment tests MMSE, a young onset dementia drop-in support group, targeted therapy groups, counselling support and community-based resources such as MIND, adult day centres and horticultural projects. |
| Normalising the catastrophe | Includes data on how people with dementia and carers attempt to normalise their experience of dementia. This includes data on: adapting to the diagnosis, overcoming fear, managing other people's attitudes, renegotiating relationship boundaries, working through everyday battles and skirmishes and finally making peace with the diagnosis. |
| Communication | Includes data on the importance of effective communication. The importance of the memory nurse being there for the person diagnosed with dementia and the carer. Memory nurses and support staff became family friends. People with dementia and carers felt supported by the service. CMHT staff described as approachable, down to earth, responsive, 'never in a dash,' round pegs in round holes, helped carers when they needed to make difficult decisions. |
| Service gaps | Few people could identify service gaps. However, people's narratives reveal, a lack of connectivity between health services, simple service needs were not met leading to 'horrendous' situations. Lack of support for carers post-diagnosis. Carer assessments not being completed. Lack of organised respite for carers. No targeted support groups for people with dementia, i.e. memory management, skills development or for carers in relation to understanding dementia or in caring for an adult dependent. |

### 5.1.1. *Service experience*

One of the primary aims of the national dementia strategy (Department of Health, 2009) is for people to get their diagnosis of dementia early so they can receive the individualised support they need. People with dementia and carers in my study shared a range of diagnosis experiences. Bill and Betty's experience of receiving their diagnosis was a positive one, but there were others whose experience was not good and who felt their diagnosis was delivered in a cavalier and off-hand manner, something (they thought) would not happen if their spouse/partner had been given a diagnosis of cancer. This issue was also raised by Nikki, CMHT Leader, who pointed out that dementia is a terminal illness and as such people diagnosed with the disease deserve to be treated with the same respect and dignity as cancer patients and other terminally ill people.

The section on service experience begins with Louisa and Nevin recounting their experience of receiving a diagnosis of dementia. It illustrates some of the difficulties they experienced when Nevin first became ill with vascular dementia. It traces their journey from the first conversations they shared with their GP through to their meeting with the Consultant Psychiatrist from the CMHT. Louisa and Nevin's story illustrates the wrong way to receive a diagnosis of dementia and the long-lasting effects this can have upon the family and the important role of the dementia service in providing an accurate and speedy diagnosis and treatment. Louisa and Nevin retold their story together and at times they

became overwhelmed by emotion. I asked them several times if they would like to stop the interview but they were adamant they did not. They felt that if telling their story meant other people would not have to go through the same ordeal that they did, the painful experience of sharing it would be justified. Louisa and Nevin both feel that it was only after their meeting with the consultant psychiatrist from the CMHT that they began to see light at the end of the tunnel:

*Louisa:* *He collapsed completely out of the blue one day and I phoned the ambulance. We took him to hospital and they didn't find anything wrong. Because he has emphysema they thought it was his breathing that was at fault. I did mention to the doctor then, what was in the back of my mind because I had an idea, what it was [that it could be dementia] and I was pooh-poohed, 'It was his breathing. Go home and don't think about it. It will never happen again.' Exactly a month later, this was in 2008…we were in bed and it happened again, he collapsed again…he was fitting. So I rang the paramedics again. And this is when they decided they would do a CAT scan and MRI scan and then we had to make an appointment to see the Neurologist at the hospital.*

*Nevin:* *It was all in my head, wasn't it?*

*Louisa:* *Yes. Yes.*

*Nevin:* *Yeah, but they didn't find anything out.*

*Louisa:* *No, well they did. They did that and then we had to make an appointment to see the Neurologist at the hospital. So, we went to see the Neurologist and he said, by these scan pictures it was hardening of the arteries in the brain that were causing the epilepsy. So they put him on [anti-epilepsy medication]. And we had to increase it on a fortnightly basis till he had reached two grams a day. So, this went on for a while and I thought, he is getting worse, it was dreadful. He didn't know which way up he was, he was sleeping hours and hours. He was spending 13 hours a day in bed and the rest asleep in the chair. So I went back to the GP and I said,*

*'This isn't right. Perhaps the medication has been making him toxic.' So, off we go to the blood tests. And no, it wasn't making him toxic. But there was no monitoring whilst I was increasing this [anti epilepsy medication]. I did say to the GP, 'Doesn't he need monitoring?' and he said, 'No, there is no need for that,' so, it was all in my hands. There should have been monitoring. I think if we had gone to the GP once a fortnight and instead of, 'How've you been Mr Brown? How has he been? What has he been doing?' we wouldn't have, he would never had reached the stage he was. I mean, when he was having all these falls, he had seven falls in one month. He was battered and bruised to death. Mind, they maybe just think she is a fussy wife, she is making a fuss. Anyway, the upside of it all was that…he was falling all over the place, he couldn't stand upright he didn't know who he was, where he was until one night I was desperate and I phoned the GP and I said, 'Can I have a second opinion?'…I did say to the GP on the phone, I said, 'Has he got dementia?' and he said, 'Yes.' But they were treating him for epilepsy.*

*Nevin:* *Even that woman up there she said go and get him an appointment!*

*Louisa:* *So, we made an appointment to go and see Dr. Noble [the CMHT Consultant Psychiatrist]. She saw the same set of scans that they had in the hospital because she sent for them and within five minutes of being in her office she said, 'It is vascular dementia.'*

*Nevin:* *And, she showed us the blood tests.*

*Louisa:* *So, she said to our GP, 'I want all his medication changing and I want you to do this, this, this and this.*

*Ethna:* *Has it made a difference?*

*Louisa:* *You wouldn't believe the difference. I mean, he is normal.*

*Nevin:* *I didn't come off them straight away did I?*

*Louisa:* *No, because we had to bring you off slowly. And this is where Clare [the memory nurse] got involved. But we have never been back to [the CMHT office] to see Dr Noble since. Because she's got him stabilised and they keep doing blood tests until they have reached the level of the*

*drug that suits him. He hasn't had any more falls, no more memory lapses, but he has still got vascular dementia.*

*Nevin:* *Well, she did say it wouldn't get any better didn't she? I don't know.*

*Louisa:* *It was horrendous, absolutely horrendous. What annoys me though, I've known Nevin since I were one year old. And I told the doctor, I said, 'Whatever is happening up here [tapping the side of her head] has been coming on for the last three years, because I have noticed the change in him.' The family had noticed a change in him. He was doing daft things, things that were totally out of character. I even went as far as keeping a diary every day for six weeks. I took it to the GP, I said, 'When you have got a minute, can you read that?' I never heard a thing. There was no comeback whatsoever. I did tell him afterwards, I said, 'I am angry.' Because I was really angry, I said, 'You have taken 18 months away from us two through a misdiagnosis.'*

Louisa and Nevin's experience of not being listened to was not unique. James, who cares for his wife Eva who has early onset dementia, faced the same challenge:

*I went to see [the GP] because she wasn't feeling right. Eva mentions to him, that there is a history of dementia in her family, her father had it, her gran had it and one of the aunties had it. 'No', he said, 'It's nothing like that.' My daughter went once with Eva, same thing, she says, 'Don't you think my mum should go for some of the tests, just to find out if there is anything.' And he said, 'There is no need. No need.' I go in and says, 'Are you sure this is stress my wife has, or is it early onset Alzheimer's?' 'Don't worry it is not anything like that. But, we can't be 100% remember,' you know, putting an umbrella up to make sure nothing landed on him. (James – spouse and carer)*

Like Louisa and Nevin, James felt very angry at the length of time it took for Eva to get a diagnosis of dementia. He feels that it contributed directly to the high levels of stress he and Eva experienced prior to the diagnosis.

In the months leading up to Betty's diagnosis of dementia, Bill and Betty

Jackson could not have been more pleased with the way they were

treated by their GP and staff from the CMHT:

*Our impression of the system, from the moment [the GP] relayed the information and the reaction from Ted [the memory nurse] and Dr Noble [the Consultant Psychiatrist] and the further examination can't really be faulted because it was very, very good indeed. Well they all are, you know, they all are. And I think that they should be praised for it. (Bill – spouse and carer)*

*But the thing that I appreciated was when the ball was set rolling from the GP and each stage we had a visit. We went to see Dr Noble and that is something else, the staff there are very good, right? Unlike when you for example go to the eye clinic in the [name of hospital] you get an appointment and you are there for hours, right? You go to [the CMHT office] and a lady comes up to you and says, 'Can I help you? And would you like a cup of tea?' You don't get that in the [name of hospital]. You don't. (Bill – spouse and carer)*

Moreover, Bill and Betty are keen to stress that providing an excellent

service is not something staff at the CMHT 'have to do', in their mind,

staff provide a first-rate service simply because they want to:

*Bill:* *But, I suppose they've got to behave in that manner at [the CMHT office].*

*Betty:* *No, they don't have too!*

*Ethna:* *What do you mean?*

*Bill:* *The ordinary staff over there don't know what an individual's problems are, right? All they know is whoever is going over there has some sort of a mental problem, right? And I think they feel they need to be more sensitive to the situation.*

*Betty:* *I mean, the people who are helping you, are not really instructing you, but they are keeping you…up to date and on the right path, well then you are quite happy.*

### *Occupational therapy*

The work of other CMHT members was also highly valued. Nick and James for example were very pleased with the support their families received from the Occupational Therapy Team:

*For a long time, I was lifting her [Maria his wife] in and out of the bath and then of course it got a little bit too much. And then one of the young ladies said, 'Oh, I'll get you a board to go across,' which is brilliant. Just sit her on the board, swing her legs round, lower her into the bath and then push it out the way… And, of course, as you finish you sit her up, shove the board underneath and swing the legs out and it is a lot safer, a lot easier. So, really, anything we want, sort of, anything we have asked for up to present they've always been… Like the rail, the rail up there, you know, to help her up the stairs, little things like that, you know. (Nick – spouse and carer)*

*[Liz and Abbie] are helping a little bit by taking Eva away for an hour and I think that helps Eva tremendously, because she is sitting talking and I think Abbie [the CMHT OT] must be bloody good at her job because she questions Eva and pulls out answers from her, you know, by the way she questions her. (James – spouse and carer)*

Betty was the only person with dementia to talk about her experience of the CMHT occupational therapy team. For Betty, it was not an altogether positive experience:

*Betty:* *And then a lady came […] and so she said, 'Oh we are going to see whether or not you can look after yourself,' well this was a scream. So she said, I'll bring some stuff and see if you can make a meal.' So, she came and she got out this bag and she had there was some jam, a spoon and all this things and I thought, 'she is going to do toast. I best tell her because I hate it.' She said, 'So, I have bought a machine in case you don't.' I said, 'I always toast in the oven.'*

*Ethna:* *Right.*

*Betty:* *Which I do because it's quicker and you can get more bits on.*

*Ethna:* *Yeah.*

*Betty:* *'Oh' she said, 'You will have to do it.' So, I put it together and that was all sorted out.*

The conversation continues, but Betty is now talking about the fact she has never used a toaster before as she always pops the bread under the grill to toast:

*Yeah, so...and of course I am looking and I keep thinking, 'Oh God. I wish I had the instructions. I said, 'well, if you have never used one, they usually tell you in the instructions how to put it on'. So, I put it on and the toast came out so she gave me a plate and said I had to put the jam and the butter on and cut it into two slices. Well, if you'd seen the butter and jam, she had a little scabby thing and the butter was beyond belief and the jam was a bit yuck, and I said, 'Will we scrape it onto this piece of paper and then you can throw it all away.' And I don't think she liked it, but it was filthy! Because I mean, butter when it goes like that, I mean, it's horrible, isn't it? So, I don't know how long she has had it...and then the next time I had to make a cup of tea. [Then] she didn't come anymore. (Betty - person with dementia)*

Part of Betty's frustration with the standardised occupational therapy assessment was linked to the fact that, at that point, she was still taking care of the majority of the housework and the cooking, only needing help from Bill on using the timer or lifting heavy things. Here she explains how the day before, she had taken care of most of the day-to-day work of the household:

*I mean, I did some of the garden yesterday. I did the washing. I did the meal and all that. (Betty – person with dementia)*

***Consultant support***

For most families, contact with the CMHT was primarily via their memory nurse, support workers or the occupational therapy team. The current

CMHT Consultant Psychiatrist – Dr Craig Adams, also holds a caseload and his work with people with dementia and carers was also very much appreciated. Nick, for example, described Craig as, 'good as gold,' a sentiment echoed by just about every staff member of the CMHT. The following are just a few of the many positive comments that were made about him:

*When I first met him, I didn't, we didn't get on first of all, because he was asking me questions and I said, 'I am fine thank you. I don't want anybody to worry about me, I am absolutely fine.' And…he was saying to me, 'Well, I want to find out things and that sort of thing…Now I call him [by an affectionate nickname], because I have got so…I think he is really nice and everything. (Sophie – person with dementia)*

*And obviously Dr Adams has always been very good…He's lovely to work with. (Dot – care home liaison nurse)*

*We've got Dr. Adams and he is very good and very supportive as well. (Liz – memory nurse)*

*And, you know, even Dr. Adams will come and say, 'Have you heard about this [new research/findings]' and you know, we would go to him and other medics…it's nice that way. (Andrea – memory nurse)*

*I've worked with Craig Adams and Anita Noble [another Consultant who has moved on] as a Consultant for a good while…I think we've been very, you know, advantaged from the point of view that they're good team players. They are open Consultants to work with. They are open to suggestion. It very much feels like, you know, you are part of a team rather than an 'us and them' in terms of the old hierarchies that used to be about in the health service. (Ted – memory nurse)*

***Memory drugs***

At present there is no cure for dementia of any type. There are, however, four drugs licensed for use in the UK by the National Institute for Health and Clinical Excellence (NICE) for the treatment of Alzheimer's disease.

These are, three cholinesterase (AChE) inhibitors – donepezil (Aricept), rivastigmine (Exelon) and galantamine (Reminyl) for mild to moderate Alzheimer's disease. Memantine is recommended as an option for managing moderate Alzheimer's disease for people who cannot take AChE inhibitors and as an option for managing severe Alzheimer's disease (National Institute for Health and Clinical Excellence, 2011a). Treatment for vascular dementia is the same as for high blood pressure and high cholesterol levels. Many of the people interviewed had been either prescribed a memory drug or had their drug regime revised post diagnosis. When asked whether they thought taking the new drugs had made a difference in their everyday lives, reactions were mixed:

*Well, it is getting a bit better because the memory nurse has organised a pill, a memory pill for me…I take it last thing at night and it is beginning to work. (Harry – person with dementia)*

*Well, I canna say that I have made any improvement that I know about. You know? I mean, there probably is an improvement that I don't notice, you know? (Lyn – person with dementia)*

*Well, I can't say that there was any difference really, because I still don't have any, sort of, memory, you know. I [still] forget things. (Lyn – person with dementia)*

*But what [the memory nurse] said when he came in, I think it was November, is that there didn't appear to be any major loss in memory between the last [memory assessment] and the current one, so it [the memory drug] seems to be, sort of, holding its own. (Lesley – person with dementia, recounting the story with Chris her son)*

*Ethna:* *Do you think that taking the drugs is helpful to you? To you think it making a difference?*

*Sophie:* *I think so. But as I, as I say, it came, I don't know. I don't know what would have happened if I stopped. Because one day I did miss it and I didn't seem to be any different much on that particular day or the day after, but I thought I better get on with them. I have been told to take them, so I don't know, actually the only way to find out if it did, is to, is, er,*

*stop taking them, I might find the difference then. But, er, you know, I just wonder what, what amount I could find back in the...because I am always asking Tim because things in my background…I feel that I am better and I take it quite happily and quite willingly but it goes in spasms. I am sorry I have forgotten your name now.*

*Bill:* *We are in a situation now where, we have been told that this drug is not a cure but it could hold off.*

*Betty:* *Which [the memory nurse] implied that it had done so far, which quite pleases me, because I didn't feel any different once the tablet kicked in.*

*Ethna:* *Is the medication working for you, does it, is it, having a good effect?*

*Betty:* *Well, I would say so, yes…as I say I just feel the same as I was. I may get tired a little bit more but then I will not sit still. So that is my own fault, isn't it?*

Nick and Maria's experience of being prescribed the memory drug was catastrophic. Nick explains why:

*Ethna:* *Did the memory drugs help?*

*Nick:* *No.*

*Ethna:* *No?*

*Nick:* *No…The first one Dr Craig Adams put her on it turned her into a shell. She got a lot worse and she [had to be admitted to hospital] for a fortnight.*

After a fortnight in the in-patient assessment unit, Maria's health deteriorated. She lost (and never regained) the ability to speak and became withdrawn and depressed. Nick made the decision to take her home, despite a recommendation by hospital staff to admit Maria into fulltime nursing care:

*The in-patient assessment unit is a lovely place, don't get me wrong, but she was frightened there, she was petrified. I mean there were two or three lads with their heads stuck on the chests, you know, so, she, I*

*mean you can't blame her. I think she was frightened of them. So, anyway, in the end I said I would take her home at the end of the fortnight. (Nick – spouse and carer)*

Despite the mixed results, those who did not experience any ill-effects from the drugs said they were happy to stay on the memory drug even if they did not notice a difference in their everyday skills and abilities. Nevin, who made considerable health gains when he was finally diagnosed with vascular dementia by the Consultant from the CMHT, was (much to his wife's amusement) hoping for rather more from the change in his drug regime. The following is a conversation that took place between Nevin and his wife Louisa:

*Nevin:* *I mean, if I go up the steps I am all of a dither and thinking I'm going to fall and I do and you are hanging on to my steps, legs and…*

*Louisa:* *But you are not shaking like you used to…*

*Nevin:* *No. Anyway they are saying that I will get no better. But if I get no worse I will be alright.*

*Louisa:* *Nevin! You won't, you are a lot better. You are 80% better than you were. You want to go back to what you were 20 years ago and you are getting older all the time and you can't do that!*

*Nevin:* *[Laughing] No, that annoys me!*

### *The Mini Mental State Examination (MMSE)*

The Mini Mental State Examination (MMSE) (Folstein *et al.*, 1975) is used to detect memory problems and monitor progression. Simard (1998, p12), however, identified that in mild, or early stage dementia, its lack of sensitivity can produce 'ceiling effects' which may produce a false negative, while 'floor effects' make its use problematic with people severe

dementia. Test scores are also thought to be unduly influenced by a person's cultural, educational and ethnic background. As a result, it is recommended that the MMSE is used alongside other more sensitive assessment tools (Simard, 1998).

When I asked Betty for her views on the MMSE, she expressed irritation at the types of activities she was asked to perform in order to assess her memory, pointing out that some activities were irrelevant:

*I mean, the things that they normally ask you are the things that you don't use. And, then you have to it backside first…well, I don't really need that, I mean, I can do it the other way, the way that you use it. So, I don't quite get that neither. They seem a bit odd, some of them, I mean some of them are straight forward like, go around a clock and you have to put the figures in, well, yeah I can do that and that sort of thing. And there is another thing I do and I think, 'Well who wants to know that?' (Betty – person with dementia)*

Lewis and Mary have just been talking about what kind of help they receive from their memory nurse. This leads to a discussion of the six-monthly memory assessment which Lewis finds stressful.

*Lewis:* *I love Jessica, I mean, sorry pet.*

*Mary:* *I know what you mean.*

*Ethna:* *You get on well together?*

*Lewis:* *We get on well together, she's a very, very lovely person and yeah, you know, I like her coming and she's very pleasant to me, and she, whatever I want, etc etc.*

*Mary:* *You don't like her giving you the test!*

*Lewis:* *The test?*

*Mary:* *When she asks you those questions. How to spell WORLD backwards.*

*Lewis:* *Oh yes, yeah things like that.*

*Mary:* *You don't like her when she does the tests.*

*Lewis:* *Yeah, the tests, the tests...*

*Ethna:* *How often do you have the tests?*

*Lewis:* *Huh?*

*Ethna:* *How often do you have the tests?*

*Lewis:* *Not very... [trailing off looking uncertain].*

*Mary:* *Once every 6 months. She comes three-monthly.*

*Lewis:* *[Remembering now] she hasn't been for a long while has she?*

*Mary:* *She is due next week, actually.*

*Lewis:* *Yeah, I thought she was coming today?*

*Mary:* *No, this is Ethna who is coming today.*

*Lewis:* *Sorry! [looks at me smiling ruefully]*

*Ethna:* *It's okay [smiling back].*

Lyn also mentioned the memory tests, although she associates the test with the overall service her memory nurse provides, rather than viewing it as a stressful event.

*Ethna:* *What kind of help does Clare give you?*

*Lyn:* *She just talks to us. Gives us little tests.*

*Ethna:* *Yeah.*

*Lyn:* *I think last time she came. She had, she says, give us three words, or something. I think I did pretty well at that.*

*Samuel:* *[Before Lyn asked him to leave the room] you got two!*

*Ethna:* *Did your tests become better when, the tests that Clare did, did they improve once you started taking the drugs?*

*Lyn:* *The last time Clare was here it was sort of just shapes, you know? And, while I didn't get top marks, they weren't bad marks, you know. Clare seemed quite, you know, quite pleased about them.*

*Samuel:* *She is not as good as me, I am on morphine now.*

*Lyn:* *Oh Samuel, shut up!*

***The young onset dementia drop-in support group***

Ewan's wife Liza was sectioned under the Mental Health Act 2005 while she was attending the [now defunct] hospital day service. Ewan found out about it after the event and was angry at the decision. The stay in hospital proved to be disastrous for Liza:

*They wanted Liza to come in for a couple of weeks and that's when she stopped speaking, you know? And he [Ewan] said she didn't look as if she'd been bathed, or had her hair done or anything and he just fetched her home. (Christine – paid carer)*

The unexpected sectioning of Liza frightened Ewan and as a result he cut off all contact with the mental health service at the hospital. It was Liz the memory nurse from the CMHT that helped to change Ewan's mind about accepting services again:

*Well, it is probably all down to the sectioning thing, you know, when something…you are not comfortable [with what happens] you avoid it and then I think Liz started to visit…and made an impression and encouraged us to go [to the young onset dementia drop-in] and we thought, right, we will give it a try and then it just snowballed from there. (Ewan – spouse and carer)*

The young onset dementia drop-in facilitated by Liz was a relatively new addition to the support offered to people with dementia in the local area. It was highly valued by everyone who participated in this study. In fact, those who attended counted themselves as lucky:

*I guess I was lucky, in that, I came to the service when the young dementia service was being set up, because prior to that, as far as I understand…it was probably being tagged onto the end of elderly dementia and hadn't been established or recognised as a separate entity. So, I suppose I was fortunate…that I was…involved in that from the very beginning. (Rex – spouse and carer)*

For Will, attending the young onset dementia drop-in meant meeting other people, some of whom had worked in the same industry as him:

*Well, like, some people have actually worked in the transport industry and they are there as well…I don't know if it is catching like, but it is that sort of thing. And, even when I went in there, I says, 'I know that bloke, and I know that bloke.' And it is not [just] through being in the transport industry, you know, it has just worked out that way. (Will – person with dementia)*

In addition to getting an opportunity to meet up with men that he knew previously, being part of the drop-in gave Will a sense of security, a safe place where he did not feel judged and opportunities to take part in conversations without feeling stressed or under pressure:

*Well, you don't have to go…you go where there's some guys who are all losing the same things, and doing the same things, and you don't quite feel so odd if you get the meaning…because it seems to be something that happens, for what means or reason…I will go and sit and listen and then when something catches my ear that I know a little bit about or not enough about really to have a tackle at it but I will go into it, with both feet and see if I can tackle it…I don't have a problem with getting into a conversation if I wanted to, if I heard it. I would wimble my way around to get in. And you know, just chat away…That's the only thing that sort of keeps the old ticker ticking, you know? And I don't feel threatened or anything in any way. (Will – person with dementia)*

For some families, attending the drop-in was a calendar 'must-do'. Families attended not to just get something out of the service, like Rex they also wanted to give something back:

*Oh yeah… the drop in. We didn't used to bother with it that much, now we go every time. Christine and Liza are in better attendance than Liz [the memory nurse]. I go [as well]. Christine says, 'It's better if you go because*

*you'll brighten things up a bit.' Right well yeah, I'm quite good at that. (Ewan – spouse and carer)*

***Targeted therapy groups***

Targeted therapy groups are provided by the OT team. No one who I interviewed in my research had been invited to attend any of the previous or current groups, so there is no data to present in this area. The work of targeted groups is discussed by OTs in section three of the chapter and has been identified as a service gap.

***Services used but not provided by the MHSOP or CMHT***

People with dementia often have complex health needs. People taking part in my research for example were receiving active treatment for Type 1 diabetes, benign tumours, cataracts, heart disease and a range of other serious health conditions. Managing the various conditions meant attending appointments with other health-services such as Ophthalmologists, GP surgeries and Dentists. Getting someone ready for one of these appointments was, according to carers, akin to executing a military exercise. Because of this, carers deeply appreciated those professionals and services that went the extra mile to ensure that the person they cared for was not kept waiting around unnecessarily. GPs and dentists, for example, were highly praised for ensuring that people with dementia were treated speedily and with dignity and respect. In the following excerpts, people with dementia and carers talk about the excellent services they have received from both GPs and dentists:

*Our GP, he said, 'Don't ever just bring her down. Ring me to let me know she is coming down and bring her down. Don't bother about making appointments'. So, you know, how many GPs would say that? (Nick – spouse and carer)*

*Oh yes! Right from the very beginning from the GP's point of view he wants complimenting because he could have said, 'No, you are all right', or something of this nature without following it through. But he followed it through to the point where there was two [other] problems and both these problems were identified. (Bill – spouse and carer)*

*Well, I went with a list of three you see and he was laughing at me. I said, 'I've got a list' and he went, 'Oh God.' Because I don't often, I mean, if I'm desperate I go… (Betty – person with dementia)*

*We had Liza at the dentist just recently. Christine was a bit concerned about Liza's gum or sensitive tooth and wanted to check it out, this was the Thursday. You know how busy these bloody dentists get. He said, 'Well, would you be able to manage until Tuesday? And he said, 'What time would you like to bring Liza in on Tuesday'? I said, 'Half past ten is not a bad time.' We went down, Christine and I and Liza and we parked right outside the door and I went in…she didn't go in the waiting room, just went straight in. On to the chair and she just opened her mouth for him! Couldn't believe it! I was dreading it all weekend, because that could have turned into anything. (Ewan – spouse and carer)*

GP receptionists also played an important role in supporting people with dementia. Just before she was diagnosed with dementia, Lyn had started to regularly miss appointments. The GP receptionist took note of this and gently challenged Lyn the next time she phoned:

*One day, I phoned Daisy about an appointment and she said, 'Lyn, you are forgetting quite a few appointments.' 'Hey,' I said, 'I am not.' And she said, 'Yeah, there are quite a few that you have missed.' And she said, 'I am going to have a word with the doctor.' The doctor said that it was dementia. So, that was how it all started. (Lyn – person with dementia)*

There were also stories demonstrating the need for dementia-focused education in some areas. Nick for example, needed to go into hospital to have a cataract removed, he contacted the District Nursing team to see if,

while he was recovering, someone could come out and administer his wife's insulin injection. Nick felt it was a less than positive experience for both him and Maria:

*I had to go off [to hospital] for this cataract, so I had to get the district nurse to come out just to do her dinner time needle. She rung me and she said, 'Have you got the prescription' and I said, 'No, I don't need it,' like, it is only at dinner time. 'It doesn't matter what her blood readings are you just give her two units. Two units that's all you do. Two units, do the blood but it doesn't matter what they are. Two units.' 'Well I can't do that.' 'Well why not like?' 'Well, I need a prescription from the doctor.' I said, 'For what purpose?' I said, 'I don't get one.' Anyway, I said, 'Look, you maybe better forget it.' 'Okay then.' And she just put the phone down. So I thought well, 'If that's your district nurses.' (Nick – spouse and carer)*

Nick's second contact with the District Nursing team was also problematic:

*Then when she was in the respite unit for those two weeks I was bad, no, one week that I was bad…the mess the district nurses made of her! I mean, I never bruise her. I mean, I'm an old plain man, and they, these are supposed to be compassionate. I mean, she was black and blue! (Nick – spouse and carer)*

People with dementia also noticed an edge in people's attitudes. Betty, a retired accountant, recalls her experience of buying glasses from a well-known high street Optician:

*We went to [name of Opticians] on Tuesday. Got them tested and because this eye, without glasses on I couldn't see at all. So, I got all the tests got it all sorted out, all done up, right? 'Go and choose your glasses.' There was that and then the lady said, 'Oh, these glasses hmm.' How I didn't say something I don't know. She said to me, 'Do you use a computer?' in that voice, you know. And I said, 'No, I don't.' 'Oh', she said, 'I thought you didn't.' And I thought, if Bill hadn't been there I would have said something like, 'No, I just add it up in me head.' I don't need one. (Betty – person with dementia)*

### 5.1.2. *Helpful interventions*

#### *Counselling*

Counselling is an umbrella term for a range for talking therapies. It is thought that carers could benefit from counselling to help them come to terms with the sadness and grief they experience at their spouse/partner's diagnosis. Until recently, it was thought that people with dementia would not benefit from talking therapies, however, according to Alzheimer's Society (2012), this view is beginning to change. None of the people I interviewed had been offered counselling, but one carer, Louisa, went to her GP and asked for it. Louisa talked about the effect of Nevin's misdiagnosis on her own health and the role counselling played in her getting better. Louisa has just been discussing how Nevin received his diagnosis. She is still visibly upset, eyes blurred with tears:

*Ethna:* *That has been quite a traumatic experience for you I think, those 18 months, hasn't it?*

*Louisa:* *Yeah. And I was in a bigger mess than he was. Basically.*

*Ethna:* *Psychologically…?*

*Louisa:* *Yeah. Because I wasn't getting help I wasn't getting any further forward. I did go for counselling because I asked the GP, I said 'look, I am not coping with this very well, at all.' I spent months in tears didn't I? Crying at a drop of a hat. I am just starting again now [as tears slide down her cheeks, I bend over to turn off the digital recorder, to stop the interview. Louisa stops my hand and with a slight shake of her head, continues talking]. And I just went and I said, 'I am just not coping with this. I need somebody to talk to.' So, he put me in touch with a counsellor and I went, I think I went for 10 sessions.*

*Ethna:* *Was it helpful to you?*

*Louisa:* *Very, very helpful. She did tell me that, she couldn't do anything she couldn't advise me, she could just listen to me. And I just used to go and talk and cry and cry and talk. So, basically it stopped it all building up, so yes, it did help a lot.*

***Community resources: MIND***

Anna's story also illustrated the difference good quality, timely support can make. In this instance, it was the practical help Anna received from Jenny, a support worker employed by the local Alzheimer's Society – a service that is no longer available in that area. Moreover, after Jim was admitted to fulltime care, Jenny continued to support Anna and it was her on-going and timely interventions that were instrumental in helping Anna recover:

*Our Jenny from the Alzheimer's got me enrolled at Mind and computer classes. I used to go there once a week. I got a qualification from there in computing. But I also had a chance to meet other people who weren't in my situation, though some were, they had different issues. They might have had health issues of their own, but it helped me to sort of cope with having Jim in the home, you know what I mean? They helped to get me better. (Anna – spouse and carer)*

***Community resources: day centre***

Adult day care centres help older people maintain their independence by helping them to improve their daily living skills and by enabling older people to extend their social network. They also offer respite to carers by enabling them to have some alone time. Nevin has recently started to attend a Day Centre. Due to the stigma surrounding day centres for older people, Louisa was not, however, overly excited about Nevin attending. It was Clare their memory nurse who finally persuaded them to give it a go:

*Louisa:* *Clare mentioned going there to give me a break, because initially, when we were going through a bad patch they mentioned getting sitters in. I told the social worker, 'I don't want him to go to the day centre. I have seen people with Alzheimer's and there is a lot, lot worse. Nevin is one of the lucky ones…I thought, he wants stimulating he doesn't want sitting in a corner with people worse than him. So, I told her that I said no, I didn't want him to go. If he goes anywhere, I want him stimulated, not knocking back, if you know what I mean. Jen Miller from [the day centre] rang me up and I told her, 'I don't want him to come to you.' And she said, 'Why don't you come for a visit? So, we both went, didn't we? Can you remember?*

*Nevin:* *Yeah, I think so.*

*Louisa:* *I said, 'We are just going to see what they do, to meet the people and we will take it from there.' And, I was quite impressed. Actually, I changed my mind completely…you really do enjoy it, don't you?*

*Nevin:* *Yeah, I must do.*

Even though it was something she found difficult to do initially, Louisa is very pleased with their decision to support Nevin attending the Day Centre one day a week. As Betty and Helen have already pointed out, learning to live with the symptoms of dementia is bad enough, but learning to share your life 24/7 with your spouse after a lifetime of work-imposed absence was (they felt) much more difficult. Living well with dementia therefore meant carving out some 'me' time for both the person with dementia and their spouse:

*We both look forward to Thursday because basically, you know, being together 24 hours a day 7 days a week is torture for any couple. Isn't it? It has got to be. [looking towards Nevin] You don't understand when I say that to you. (Louisa – spouse and carer)*

***Community resources: gardening project***

The therapeutic effect of gardening has been known to gardeners for millennia. In recent years, though, its beneficial effects have been put to good use to enable ill or socially disadvantaged people improve their health, communication and thinking skills. Davis (1998, p3) argued, "There is a special connection between people and plants, between people and the gardening pursuit, and between people and natural surroundings." Social and therapeutic horticulture builds on these naturally occurring relationships to teach people new skills in a safe and nurturing environment. Horticultural therapists work on a one-to-one and small-group basis to help people achieve their own goals. Will attends a gardening project on his local allotment a couple of times a week. He has been going for some time now and while he enjoys all aspects of the experience, Will says it is the banter he gets from 'the lads' that really make his day:

*Mark, cracking bloke, he comes over and you know, it's our allotment like, to have a bit of a chat and what-have-you…just on about different things that happen…and then you get back on with your job again. It is just the craic you have with the lads, each other, you know, and then...because I have dug their whole allotment, at this time, the old fellow came up, 'Ay, Mark he is showing you up.' And Mark says, 'He's not.' And he says, 'Ay, Mark he has dug all that in one day.' He says, 'We'll have to get rid of him now,' he says. And it is just things like that...banter. (Will – person with dementia)*

Keeping busy was a strategy used by most people to minimise the effect of a diagnosis of dementia. Will believes that for him, his work at the allotment, has been a life saver:

*As a rule, I am with the same person. I am working with more or less the same [people]. There is not a lot of people there now… I´m working on an allotment, helping them… planting and weeding the place and keeping it clean and… so that keeps me busy and it does help me. I must admit it does help me. That I am not, like, sitting here [pointing to his armchair] or just working in the house, or doing something like that. For me, you get down there and do something else, that's grand. I don't even mind weeding. I dug the whole place over when I was first working there. And it's just, just to, think I'll just do something down here. (Will – person with dementia)*

Will's wife Helen thinks the reason working on the allotment is so beneficial is that Mark treats Will like an ordinary person and not as a person with dementia:

*Helen:* *Mark is like me, he can see [when Will's confused about an activity] but you know he will let him forget about that and set him on with something else. Mark is very good in the way that he reacts to Will. You know, he doesn't get angry or cross or… It makes me feel happy that he is doing something that he enjoys and he gets some peace out of it and Mark is very good with Will, he doesn't make an issue out of, if Will forgets anything.*

*Will:* *He [Mark] forgets things as well! He is just as bad!*

Will enjoys the fact that Mark doesn't give him any special treatment because he has dementia. Sometimes though, Will admits that a bit of special treatment would not go amiss:

*Mark sometimes moves them, you know. How could he with me? How…I said, 'Don't move them pots there.' He says, 'Why?' I says, 'I just put them there.' He says, 'Well, I was taking them away,' and that sort of thing, but that is just normal I suppose. (Will – person with dementia)*

### 5.1.3. *Normalising the catastrophic*

#### *Adapting to the diagnosis*

A common thread running through almost every interview with people diagnosed with dementia was the issue of adaptation. Just how much do you change your life in response to the diagnosis? Should you adapt at all? Should you fight the disease? How to pick which battle to fight? For people such as Betty the decision was simple and clear-cut. She thinks the best way to live well with dementia is to accept that some things will change and there is nothing you can do to stop it. You should simply accept the changes and move on with your life:

*I have never been a very good speller and that has now gone out the window. I just don't bother. It used to worry me. But I can't, so I can't, so that's it. End of story…You see, the idea is, you know you can't do it, which I do know I can't do it. So why go on saying to yourself, 'Well, I should be able to do it. I should be able to…' when you know perfectly well, you can't, so why spend your time talking to yourself? To me, I think, that is, it has gone Betty and be thankful for what you have got…Why battle with yourself? You don't know if you are making yourself worse. (Betty – person with dementia)*

Sophie on the other hand, finds she often draws on inner resources she developed in response to difficult times earlier in life to help her manage the symptoms of dementia. She wonders occasionally whether dementia is a result of the stressful situations she has experienced in life and if she could have done something to protect herself. But mostly, Sophie uses her life experience to face down the annoying symptoms of dementia in order to regain a sense of equilibrium:

*I have had quite a hell of a time in my life, but I have managed to get through each and every one of them, you know, I just won't give in… And I just keep on saying, 'Come on' and just laugh about it because it is funny. You know. If I miss a word or something like, 'Oh! Bloody hell! It's gone again!' (Sophie – person with dementia)*

Accepting help from other people was a difficult aspect of living with the symptoms of dementia. It was something that Michael struggled with in the beginning. Yet, as Michael's partner Erica points out, asking for help is an important part of living well with any illness, including dementia:

*Erica:* *Well it hasn't worried me up 'til now. You know what I mean? Anything that has happened hasn't worried me. Except maybe…*

*Michael:* *If I don't remember anything anymore.*

*Erica:* *I think it is worrying him more. Because like, if he does anything he says he is sorry and I say, 'Well, look, it is nothing,' you know. I think it worries him more than me, do you understand what I mean [looking over to Michael] don't you? Because, I mean, he was such an independent man, you know what I mean? But you have to let people help you, don't you?*

For Lyn, adapting her life meant letting go of things that were of little or no importance to her anymore:

*I like my home. I like to keep it clean, maybe not as clean as it used to be, but never mind. (Lyn – person with dementia)*

Sophie echoes Lyn's sentiment about accepting that you do not actually need to do everything, that it was okay to let some things slide:

*I used to make cakes and do cakes, but I don't do that much now because you can buy cakes quickly and it is not really [worth it]…I have had to get all of the stuff out and do it and that sort of thing, but I can still*

*cook quite well and I can get myself a meal and things. I haven't got a problem like that. (Sophie – person with dementia)*

For most of the families I interviewed, in addition to considering the needs of the person with dementia, other family members also needed a lot of support. Lyn for example, takes care of her husband Samuel. Samuel has a number of physically limiting conditions that require a cocktail of daily medications – including morphine. In addition to caring for him physically, Lyn also takes care of Samuel's medication. Samuel's deteriorating physical health has had a serious impact on Lyn's ability to run the family home as she depended on Samuel doing his share of the work. The stress of coping with his difficult behaviour, of an increased physical workload and the day-to-day management of her own dementia-related challenges, mean that she sometimes finds herself becoming stressed. In the following excerpt, Lyn explains how she attempts to live with the stress and strain of daily life and her advice to others on overcoming those challenges daily:

*Well, I have found it hard, you know, sort of, doing all the messages [running errands] because Samuel used to do quite a bit, you know. If I wanted anything from up the shop, well he had the car and he would just pop up the store, go down to the butchers and things like that. But I have found it hard. He is not a very good patient. He soon loses his head and then I will lose mine. Just, you know, you just take each day as it comes, that is all you can do. (Lyn – person with dementia)*

A difficult issue to come to terms with for many people with dementia was the issue of a perceived loss of freedom. For some, this was one of the most difficult aspects of living with the symptoms of dementia. Betty for example, was used to driving into town whenever she needed anything.

Losing her driving licence was a big blow as it meant she became reliant on her husband Bill for transport. Here Betty tries to explain the subtleties of losing the freedom to shop unaccompanied or with a friend who 'knew the rules' of shopping:

*Last year it was very, very cold and icy, wasn't it? And everywhere I went Bill came with me. And I loved to go round town on my own, I always have. Because if you are looking for something, say if you go with a friend, instead of talking, you look for it don't you? So, I prefer to do that, particularly at Christmas time… Well, we hadn't gone to town [for a while] and then when we did; Bill was always there. (Betty – person with dementia)*

Regardless of which partner lost their driving licence, losing your licence was a major blow to many of the families I interviewed. We have already heard how Samuel's inability to drive due to illness affected Lyn's workload. Nevin also keenly felt the loss of his driving licence:

*I mean, I could have chopped both me arms off. Bloomin' 'eck, well they might as well have done! (Nevin – person with dementia)*

For Nevin's wife Louisa, having to drive again after a break of over forty years, was a nerve-wracking experience:

*Louisa:* *That is another bone of contention, you see, because he had to surrender his driving licence. That was a big thing…with both of us. We came to the conclusion that it was just a year at that point, you see, so I said, 'Right I can cope for a year.' I will just have to do it, to go to GPs, hospitals and all the rest of it.*

*Nevin:* *[and] shopping.*

*Louisa:* *Yeah, and it has just gone on from there. But that is why the 'P plates' are still on the car, I won't take them off.*

*Nevin:* *Yeah, she got the green ones on.*

*Louisa:* *That is my insurance and it…makes you unhappy sitting in the passenger seat and letting me do the driving. I don't like it. You like it even less. And it must be hard because he has driven all sorts of vehicles and he just can't even drive a car now.*

*Nevin:* *[Laughing] No, I know. I can still drive you mad.*

*Louisa:* *[Smiling] Well, yeah, that's easily done. That is easily done.*

***Feeling the fear and doing it anyway***

When faced with a diagnosis of dementia, it would be all too easy to simply fade into the background, allowing other people make decisions for you (as was the case with Rex's wife) and to let go of your usual routines and activities. No one would really know whether an increased reticence on the part of the person with dementia was a progression of the disease or simply a loss of self-confidence when faced with such staggering news. Betty, a keen observer of people, understands only too well the inherent danger of simply 'letting go' and in the following excerpt she pleads with people newly diagnosed with dementia to fight the stereotype of the disease and to believe that they should continue living their lives as before:

*Well, when I first went into [name of shop] I was terrified. Because I had never been in a shop for months. And I thought that this is what happens when you stay in and you are not walking out, because I had a list, I had all sorts I wanted. I thought, right, so there was a lovely fellow came and said, 'What are you wanting?' and I said, 'I want this, this and this,' Right, come with me.' And, he found all sorts for me and then I said, 'I want some cream that would make my face look really lovely,' and he said, 'That is not my department, Madame. If you go and ask that lady over there.' But, they were so nice and once I had come out I was all right and I thought, 'Yeah, I can do that now.' But I don't know what I would have*

*been like if I had let it go and go and go. I would have been frightened, which I was then, but I wasn't going to walk out. And now, I don't think about it, I just go, but that's part of it…you have got to do it for yourself. (Betty – person with dementia)*

A loss of self-confidence is an issue that Lewis battles with on a daily basis. In the following excerpt, Mary and Lewis are having a discussion about the possibility of someone coming into the house to spend time with Lewis with the purpose of supporting him to engage in his favourite activities. It is a stressful conversation for both of them as the issues are not easily resolvable:

*Mary:* *I mean, we have got a pool table in the in the stable there and it is just getting, you know, someone who would come and be happy coming…*

*Lewis:* *[cutting in] But er, sorry pet…*

*Mary:* *No, you go on, you go.*

*Lewis:* *But at the same time I don't…when you mentioned, let's say about the thing up there? [the pool table in the stable] …get somebody, get somebody in.*

*Mary:* *Yeah, you don't like the idea, do you?*

*Lewis:* *I don't like the idea. It's like, you know, pushing, pushing somebody.*

*Ethna:* *Feels a bit intrusive does it?*

*Lewis:* *Yes. Yeah.*

*Mary:* *If someone did come to do anything to do anything with you, you would soon get on with them Lewis because you do get on with people.*

*Lewis:* *Oh…I don't know. I don't know.*

*Mary:* *He is worried about it because he was worried about you [Ethna] coming yesterday, you see.*

Lewis: [Nodding in agreement] *All right yes, yes, I was, I was and I'm not now.*

### *Learning to manage other people's attitudes*

For many carers, in addition to managing their loved one's complex needs, the stress of coping with other people's attitude towards dementia was a big challenge. Here Rex talks about the challenges of taking his wife to activities outside the family home:

*I think, for the [drop-in support] group to go as a group, you know, did arouse… One or two things that came to mind such as bowling at [the leisure centre] and there was no way Julia was going to… It was too noisy it was too crowded it was just, you know, too much. And we had, sort of like, a Christmas lunch and things like that. All were stressful situations, you know, I think because of the public attitude to people with mental health. If you are taking people out as a group into a public arena, you are aware of more pressures. I mean, there are more things that you have to think about and deal with and cope with. (Rex – spouse and carer)*

Having to take into account other people's reactions to the person with dementia also worried Mary as she did not want to cause other people to feel uncomfortable, saying that she thought, *'It might be awkward for the other people as well.'*

### *Renegotiating relationship boundaries*

Without doubt, one of the most difficult aspects of managing the symptoms of dementia was related in some way to the changing relationship between the person with dementia and their spouse/partner.

Dealing with the symptoms of dementia meant learning to relate to each other in a completely different way. For many reasons, some people found that easier to do than others. The section opens with a spirited discussion between Helen and Will as they try to explain why Will no longer has a key to the family home:

*Will:* *If Helen's not in and I want to go out, I can't, I haven't got a key, see? I'm a key loser.*

*Helen:* *He has lost two, so I wouldn't let him have another one.*

*Will:* *I didn't lose the second one.*

*Helen:* *Will!*

*Will:* *I am sure I am going to find it somewhere.*

*Helen:* *I am sure. I think it is in the house, but you know, I haven't come across it when I've looked for things, so what he has done with it, I don't know. It could be anywhere!*

*Will:* *Yeah, it is in a keep place.*

*Helen:* *So, consequently I just said, 'No, you are not getting another key,' because I can't afford, because these keys are £5 or £6 a time, with it being double-glazed doors and I said, 'You can't keep losing keys.' So, now he is not allowed one.*

Shifting responsibilities was an issue for most of the people I interviewed. For Anna, whose husband Jim was diagnosed with young onset dementia, the pain of watching her husband struggle with everyday tasks was almost too much to bear:

*When he is searching for his wallet because he has hid it again somewhere else, or his glasses. And you are going out for an appointment at the hospital and he can't find any of it. You spend an hour*

*searching for it all. So, you have got to get ready an hour before your appointment before you can even set off because you know you are going to have to start looking for something that he needs, that he has put somewhere. Things like even being able to go and make a cup of tea because he doesn't know what order he is supposed to make a cup of tea in. Or make a cup of coffee. You know. Do you put the coffee in a cup? Or do you just put it in the bowl with the sugar? It's trying to get your head round watching them doing things that are…that even a child doesn't do. But they do. And trying to get to the reason that this is happening. You know what I mean? (Anna – spouse and carer)*

It was an issue that Bill also struggled with on a daily basis. Bill's wife Betty was used to leading an independent life and for reasons described earlier, Betty found Bill's close supervision invasive and unwelcome. But, as Bill points out, although the attention he pays his wife is perhaps overwhelming for her, he views it as the natural reaction of a husband who wants to protect his wife:

*The other side of the coin, as far as I am concerned, is that I feel that it's my responsibility to keep an eye on Betty, to make sure that something doesn't go wrong. I may be going over the top, but I think that is typical of a husband who is concerned for his wife. (Bill - spouse and carer)*

For Louisa and Nevin, working together was an important aspect of managing the symptoms of the disease. Friends since childhood, Louisa and Nevin decided early on in the process that the best way to stay sane would be to face the challenges of dementia together. This means that, for example, when the couple needed extra support at home they had a discussion about the possibility of sitters, so that Louisa could leave the home to run errands, etc. Like Lewis, Nevin did not welcome the idea of strangers in his home:

*Louisa:* *There was a point where I wouldn't go out and leave him. If I had to go out I used to make sure somebody was here with him. You didn't care for that either, 'I'll be all right, I'll be all right' and I thought yeah I know! And what will I come back to? You know? So, for safety sake I didn't dare go out and leave him on his own. And then she [the memory nurse] suggested sitters anyway, we did discuss it but you didn't want a sitter. You didn't like that idea did you?*

*Nevin:* *What?*

*Louisa:* *About getting somebody to come and sit in the house while I went out. You didn't like that idea at all.*

*Nevin:* *No, I don't!*

An area that sometimes caused friction between couples was the tendency for people with dementia to think that their everyday actions or mistakes were being perceived as 'dementia-related.' In the following excerpt, Will explains how he deals with stressful situations. Helen his wife also shares her thoughts on the same situation:

*Will:* *Yeah, just go out and come back, it's all right. I don't get uptight and things like that anymore, it doesn't pay.*

*Helen:* *He does, but he doesn't realise he is doing it. I mean I can see it, when he is getting into a state, but if you ask him what's wrong, 'Nothing, I'm fine, there is nothing the matter with me.' Will's never been one that has been able to discuss and be able to talk about his own feelings, he has always made a joke or everything is funny, so, he finds it difficult with the Alzheimer's to be able to express himself, because he's always had to make a joke about everything. So, even when he is getting confused and not sure what is happening, I mean, I can see it on his face, when he is like that and I'll say to him, 'I know, I am just doing this, or I am just doing that,' you know. Especially, if you are out and he loses sight of you…and he is looking round and you can see he is confused, 'Where's Helen?' or whoever is with him. And you will say, 'Will, I am here.' [and he says] 'I know, I'm just coming.*

*Will:* *That is when she is in Ferrari mode.*

*Helen:* *But, because I sometimes, myself personally, feel that it is his way of coping. He doesn't want to say, 'Yeah. I was confused,' or 'I was...' if he doesn't admit to it, it didn't happen. He thinks I'm wrong, but that's what I see will happen with him.*

*Will:* *Fair comment. It just depends, but as a rule, I haven't lost you. I know you are in that shop, I can relax a little bit and then you've gone round the corner and out of sight and I think, 'Well, there is only another two blocks and it's there.'…I just go to the entrance that she came in and I stop there.*

*Helen:* *Now he says that, but when it happens, he doesn't. He doesn't do what he is saying.*

Betty understands that her husband has concerns regarding how she is managing to cope with the symptoms of dementia. Nonetheless, it irritates her that everything she does is viewed through a 'dementia lens.' Sometimes, Betty points out, dropping a piece of cutlery while preparing a meal is just dropping a piece of cutlery and not a sign she has lost another chunk of herself to the ravages of the disease. So irritated is she with Bill's constant supervision that on occasion Betty admitted with a wry smile that when Bill calls to her while she is in the kitchen (checking she's okay), she sometimes pretends not to hear him:

*It is the question, 'What are you doing?' Or… if I drop a fork or something, you know, you do in the kitchen. 'Are you all right?' And then…I don't answer [purposely] and I think, I could be laying on the floor, you know? I could be bleeding to death but he's never opened the door. So I think why are you asking me? And then he will shout, 'Are you deaf?' It is just a game I think. (Betty – person with dementia)*

Learning to become more directive in their relationship with their spouse/partner with dementia was an issue that all the carers I

interviewed struggled with. On the one hand, carers felt ill at ease taking an overly directive role and yet they understood only too well that if they did not, their life together would be thrown into chaos. In the following excerpt, Louisa and Nevin describe the process they went through with regard to Nevin managing his own money. The couple have been discussing how much they both get out of Nevin attending the Day Centre one day a week. Louisa has just finished talking about the day out in town she enjoys with her girlfriends while Nevin is at the Centre:

*Nevin:* *[Smiling] I let her spend money like, she doesn't go empty-handed.*

*Louisa:* *This was another thing. He had a problem with money, didn't you? Then again with him doing the work he did, I always did the finances. You were quite happy for me to sort out all the finances. Nevin doesn't do bills. He never did.*

*Nevin:* *Never signed a cheque.*

*Louisa:* *Never signed a cheque or anything.*

*Louisa:* *And then one day… we had been out for our lunch and we had been out for petrol and we came home and you said to me, 'I think I have handed two £20 notes over.' I used to get them out of the cash point and they are always new notes there. And you have got to watch yourself haven't you? And I say, 'Why? What have you done?' and he says, 'I have got no money left.' And he says, 'I think I have done it twice, when I went to pay for the petrol and when I went to pay for the lunch.' So he said, 'You will have to take it off me' he says, 'I can't cope with this.' He says, 'I don't need money' and I says, 'You don't because you don't go out.' If we did go out it was me that paid. And basically that's been the same until the last few weeks and you said to me, what did you say? Well, he needed money for something, I said, 'Really Nevin, I think you can cope with it again now.' There is no reason why you can't have your pocket money back. And he said, 'No, I think you are best keeping hold of it, we*

*will carry on as we have been.' [glancing towards Nevin] You have always got a few pound in your pocket.*

*Nevin:* *I haven't now!*

*Louisa:* *No, well, you have spent it all! It is little things like that, that's difficult, because I mean, you, as I say, you initially said to me, 'Don't give me any more money because I don't know what I am doing.' And I thought, 'God, he has worked hard all his life and this is what it has come to. You've got nothing.'*

*Nevin:* *No, I'll be all right. Won't I?*

*Louisa:* *Oh yeah! We will both be all right! But it is just little things like that and it builds up and builds up and it is really not nice you know? It isn't.*

In addition to finances being an area of stress for many couples, the other (and possibility most significant) area of change that most people commented upon was the deep sadness and (seemingly) unresolvable grief that accompanied the gradual loss of skills that the partner with dementia experienced, sometimes on a daily basis. In the following excerpt, Anna tearfully shares the agonising experience of watching her husband of over twenty years gradually lose the ability to care for himself:

*Accepting that this was happening to my husband it was… he was no longer really… he was no longer able to function as the man I married. But, he was going back to being very, very dependent on another person as in a child. And accepting that, you don't want to accept, you fight against it. You think, 'No, it's not happening.' I could cope initially with doing things because you do. You do it mechanically because you become a parent but then that that shifts your relationship from being a wife, lover… a partner, soul mate, everything. That shifts your relationship to being a parent. And… you can't get your head round it. You really can't get your head round it, but you have to… you have to sort of switch yourself off from being the wife, but you still miss the husband. (Anna – spouse and carer)*

### *Everyday battles and skirmishes*

Sometimes, living well with a spouse who has dementia was about choosing which battles were worth fighting. In the following excerpt, Louisa talks about how (in the beginning) she tried to make Nevin wear his hearing aids and how, after a while she decided it was one battle not worth winning. The conversation is taking place because Nevin has just been explaining that he often gets messages mixed up on the phone because he cannot hear the caller very well:

*Nevin:* *There was somebody on the phone and I said [looking towards Louisa] where were you at?*

*Louisa:* *I don't know. Why?*

*Nevin:* *Well, I said, I don't know, I said - just say it was, I don't know a woman's name and I said to you, was it a bloke though? I said a woman.*

*Louisa:* *I can't remember Nevin.*

*Nevin:* *It was something I told you.*

*Louisa:* *Well, because you don't hear very well on the phone that is why you won't… he has got hearing aids but he won't wear them.*

*Nevin:* *Yeah… anyway.*

*Louisa:* *We have a gadget for the television but he won't use it.*

*Nevin:* *I do! But you took it away!*

*Louisa:* *Yeah, because it lay there for months unused and I tidied it up. You don't like your hearing aids and I just think, 'Oh, he has got enough to contend with, you don't have to wear them,' I just shout at him.*

Learning to choose which battles to fight was also an important issue for Chris whose ninety-four year old mother, Lesley, recently moved into a care home. Lesley spends almost all her time in her room and does not really like having visitors (with the exception of Ted her memory nurse and close family). Chris has tried to persuade his mother on a number of occasions to pop downstairs once in a while, as he knows she would probably enjoy the company and the stimulus of conversation would do her good. Lesley, however, is simply not interested in doing that, preferring her own company to that of the other residents. After a number of thwarted attempts, Chris decided it was not a battle worth upsetting his mother for:

*Well, she has been here 18 months now and she has now become a creature of habit. She knows what time people come and what time she is going for lunch and all this type of thing and if that's altered in anyway, you know like people coming to visit her, I mean, no disrespect to you or anything like that but… as it is getting towards the witching hour she gets herself very twitchy and things like that. So, I mean, I have said, ever since she moved in, if she just went out for a coffee afternoon or something and mixed with people, but she doesn't want to do it, so I don't make an issue of it. (Chris – son and ex-carer)*

Michael is in his eighties and has dementia. He lives with his partner Erica who is physically disabled and Erica's adult son Adam. Adam has been Michael's carer for several years. Michael's family has a strong history of dementia. Michael's brother Alec has been diagnosed with dementia and is living in a residential care home. Several of Michael's brothers and uncles were diagnosed with dementia before they died. Erica comes from a large extended family. She had one brother who was diagnosed with dementia before he died. The family are close-knit and

enjoy spending time together. Although Michael has had dementia for some time, his family encourage him to go to the club he has attended since he was a boy of fourteen a couple of times a week and support him to take part in whatever is going on in the family. Adam is on hand to handle the day to day issues that arise between the couple. Daily frustrations are ironed out quickly by Adam who puts these minor skirmishes down to the age-old challenge of living together in retirement, rather than dementia:

*There might be a problem like if I wasn't here because mother would give moany faces all the time. And, 'What are you doing?' because she just… Old people do that, don't they? They just can't help it. Like little things become [big]. (Adam – family carer)*

***Making peace with the diagnosis***

Learning to make peace with a diagnosis of dementia was an important issue for many carers and was a critical element in whether the couple were able to live well with the disease or not. Making peace with the diagnosis was not so much about total acceptance as it was about trying to make sense of a particular aspect of it on any given day. For Anna, whose husband Jim is now living in fulltime nursing care, making peace with the diagnosis was something that happened gradually – but not without a fight:

*It is also a case of that you have got to accept that it's happening and as long you are not accepting that is happening you don't want to go anywhere near these places [to get help] because in your head it's not happening. You know, you are fighting against the fact. It took me two or three years to accept that it was happening in the first place, you know, when he was first diagnosed I still said, 'No, it's not. No, no it's not*

*Alzheimer's. No, no. And yet it had been diagnosed but no, it's not Alzheimer's. You kick against it. When I have been talking to other carers they have all said the same, they didn't want to accept it. (Anna – spouse and carer)*

For Helen, making peace with the diagnosis was an on-going battle. On the one hand Helen understands the best way forward for her and Will is, 'To learn to live with it and get on as best you can,' in reality she struggles to understand their life together and feels angry with the way their lives have turned out:

*It has been getting used to having Will here 24/7 which has been very, very difficult. Because Will's always worked away [from home] you kind of make your own life. And at first and still now sometimes, it just feels as though he is interfering in my way of life. The little niche that I've done for myself, you know? And of course he sees and feels that I do too much [for the family] and possibly I do, but that is my nature and he is constantly going on and on and on and having little digs at the kids because the grandchildren, you know, about us. But, I mean… you see people with the stickers in the window, 'grandma's taxi' and all this and… I just expect that and get on with it. But Will finds it hard. Whether… he feels I should be spending more time with him and well then, he should have thought of that before he went back on the lorries and then we could have had more quality time when we were younger. I feel that, he chose his way of life, making me choose mine and he has got to learn to live with it now. It causes a lot of friction but I don't feel that I want to stop doing my way of life just because Will's at home. I do sometimes but, oh it is very difficult. (Helen – spouse and carer)*

Louisa also found the change imposed on herself and Nevin difficult to deal with initially but understood the importance (for both of them) of accepting that things had changed and making the necessary adaptations to her life:

*When I packed in work, I was going to do computer courses and I used to go line dancing and I was going to go as a befriender for Age Concern - believe it or not. Go and sit with people, lonely people. And I was doing a course on… First Aid and all the rest of it and then of course when all of this happened, I said, 'I can't do any of this' so, I dropped it all and now I*

*miss contact with people. I am a people person and I miss contact with people… Some days I could have just stood and screamed, I thought, 'Is this me for the rest of my life?' It has calmed down a lot, all of that. And now I just think, 'Ah well, it could be a lot worse'…The turning point [was] when we got you on the right medication, we talked to everybody there was to talk to and I just thought, 'Well, you will just have to settle yourself down Louisa, this is as good as it gets.' Because you sort of, kick against all this because it is completely alien and then I thought, 'Don't make any plans for tomorrow until tomorrow comes. Just get up and deal with today.' And I said to all the friends and family who said, 'Do you want to do this or that', and I said, 'No, we will wait until tomorrow.' I don't do tomorrow today and I was always one for plans. I always knew exactly where I was going and what I was doing, but I don't do any of that now. I just think, 'No, we will deal with today' and I think, basically, from my point of view, it is just settling down. I still kick against it. There are still traces and I still get frustrated but I have learned to cope, as I say, I am just thankful that he is still here. (Louisa – spouse and carer)*

It was Nick who touched on the crux of the matter, in order to live well with dementia, somehow, someway, people with dementia and carers need to find peace among the heartache. Nick found peace by doing his best to fill his wife's days with joy, Bill by treating his wife to jewellery and toasted tea cakes and Louisa by letting Nevin win a few battles now and again. But, how do you find peace when your partner is now living in a nursing home? Here, Anna shares her secret for finding peace among the heartache:

*Anna:* *So, I don't go to see him every day because it was too much for him and too much for me. I go every other day and sometimes if I am having a bad day and I haven't been to see him the day before I don't go and see him the next day either, because he feeds on my moods…but then sometimes I'll go every day for a week. It just depends.*

*Ethna:* *On how you are and how things are going.*

*Anna:* *And how he is and if he is really, really poorly I go every day. You know, like, he was quite poorly over Christmas and everything, I go every day then. Or, as much as I can, do you know what I mean? He has just got a wheelchair*

*and I took him out in it the other day and I'm going to take him out this afternoon. It is good being able to take him out again.*

*Ethna:* *Yeah?*

*Anna:* *Because last year he was able to walk around the gardens but they said to me, 'Don't get a wheelchair too soon Anna, because he will become reliant on it.' So, the only place I would take him was round the block or round in the gardens because he couldn't walk very far and to take him anywhere else would have meant a wheelchair. And it was a walk and I wanted him to keep his mobility and to get the fresh air but then he became really poorly just before Christmas and since then his mobility has gone. He needs assistance now to walk around in the home with two people. So I said, 'Right! It is time for the wheelchair, isn't it?' For me, it's freedom for me to be able to see him without being in the home setting. And for him to get the fresh air and just to be with him. Not as we once were because we will never be that but…*

*Ethna:* *Just you and him…*

*Anna:* *Just me and him…*

Finding peace among the heartache was not always easy, but when found, it helped to infuse a sense of fun and purpose back into a relationship beleaguered by the demands of dementia. Here, Mary and Lewis talk about a short break they went on recently that included a game of mini-golf:

*Lewis:* *It's competitive. And I kept saying, telling her, 'No, sorry you have missed that.' But, I had a game and it was enjoyable, I enjoyed it immensely.*

*Mary:* *Yeah, we had a nice time, didn't we?*

*Lewis:* *Yeah, I would like to go to a place like that night after night.*

*Mary:* *I know you would!*

### 5.1.4. *Communication*

Knowing how to communicate clearly and with respect for both the person diagnosed with the disease and their carer was seen as important by everyone. Effective communication took many forms including being honest, friendly, responding to issues quickly and without fuss, being approachable, knowing when to listen, making time, being sensitive when carers needed to make difficult decisions and going the extra mile. Anna talks about the support both she and her husband Jim received post diagnosis and the important role her memory nurse played in enabling both Anna and Jim to talk through issues as they arose:

*Mainly she [Leanne the memory nurse] just came out to check and ask how we were getting on. She would give us advice about things like labelling things in the kitchen and what have you and trying to give us [advice] on how to do certain things that would suit Jim, coping strategies and that sort of thing. But mainly it was just chatting you know, which was good because it was… it was just being able to talk to somebody who knew how you were feeling. And, Jim being able to talk to [someone], who knew how he was feeling. (Anna – spouse and carer)*

While everyone who was interviewed spoke highly of their memory nurse, Louisa and Nevin's relationship with their memory nurse – Clare, got off to a bit of a rocky start when Clare unknowingly scuppered Louisa's plan to not tell Nevin about his diagnosis of dementia:

*Louisa:* *Mind, I could have killed Clare the first time we met her, I really could.*

*Ethna:* *Why?*

*Louisa:* *Clare came out first, and she sat there doing this memory test and discussed it with our two sons. Because we all knew what was happening. And I said, 'We won't tell your*

*dad. We won't tell him, he doesn't need to know what is going on. We will keep it from him.' And Clare comes in and she says, 'Right, about this vascular dementia' and I thought, 'You sod! I could have smacked her.' You [turning to Nevin] didn't pick up on it did you? What she had said? And I thought, well if we are going here and talking to that one and seeing that one, he is going to wonder what is going on, I am going to have to tell him. And that was the hardest thing I have ever had to do.*

*Nevin:* *Well, she [Clare] told you, didn't she?*

*Louisa:* *She told you but you didn't pick up on it. And I thought well if we are going down that route then I am going to have to come up front and tell you and I sat there and I cried my heart out.*

Louisa knows that sharing the diagnosis with Nevin was the best thing to do for them as a couple, admitting that the stress of not telling Nevin had been unbearable. As a couple they had shared everything in life, so keeping Nevin's diagnosis a secret was a heavy burden, one that thankfully she no longer carries:

*I was keeping it all secret, that was difficult. But as I say, it is all right talking about it [now] it is all out in the open. We have never, ever, had secrets from each other and I hated it. (Louisa – spouse and carer)*

For Lesley, in her nineties and now living in a care home, regular visits from Ted, her memory nurse, were about more than simply doing routine tests and check-ups, according to her son Chris, Ted's regular visits brightened her day:

*I have got to admit that her eyes light up when Ted Ball walks in the frame. (Chris – son and carer)*

For Sophie, regular visits from her memory nurse are a chance for a nice cup of tea and a chinwag:

*She [the memory nurse] is very, very good. Oh… we just sit and have a chat and that sort of thing and she says to me, 'How am I getting on?' And we talk about books you know, all of these sorts of things and art and stuff like that and everything. (Sophie – person with dementia)*

For others, regular contact with the memory nurse enabled day-to-day life to be relatively hiccup-free:

*Well, if she stopped coming once a month it would be quite disappointing because there are one or two things that I think, 'Oh well, Liz will be here next week, we will pass that in front of her, whereas you wouldn't bother making an appointment with someone, because you think it is not that important. Like other times in the past, there have been a variety of issues that have been put in front of her to which…she answers straight away or if she doesn't she will find the answer, she will do a bit of research for you. I would be very disappointed if that stopped. (Ewan – spouse and carer)*

While Bill and his wife Betty had high praise for every member of the CMHT they came into contact with, they felt particularly appreciative of Ted, their memory nurse and Ed their support worker:

*They are the right quality and I think they've got round pegs in round holes. Whereas in some places we've got square pegs in round holes. Some of the nurses that you come across, it is a job and they are getting a wage. Other nurses you come across it is more than a job. (Bill – spouse and carer)*

This sentiment, of having the right people in the right job, was also echoed by Christine who shares caring responsibilities for Ewan's wife Liza:

*Yeah, she's very approachable and down to earth and she's just a nice person. I think they've got the right person for the job. I don't think anybody could do it any better actually. (Christine – paid carer)*

In addition to supporting families day-to-day, memory nurses also supported carers when they needed to take the difficult decision to have

their loved one admitted to hospital for assessment. Despite a number of crisis situations, Rex resisted having his wife Julia admitted into hospital for assessment for a long time. It was Leanne, their memory nurse who finally persuaded Rex to consider not only Julia's health and well-being, but also his own:

*Julia went into hospital for assessment on the first of April 2008. She was only going in for assessment at that point because her medication had been all over the place and her actions had changed radically. I mean, for instance, she was getting very rough and angry with the cat and she used to kick the cat and she would never have done that. She would try and pull the curtains down and things like that. And I'd sort of, put off the fact that I knew that she was going to have to go into hospital. Leanne said to me, 'You know, I think we need her get into hospital and get her stabilised and get some sort of assessment done.' And I was very reluctant to do that. And I, sort of, put it off for about three weeks and then it got to the point where I really couldn't do anymore. Ultimately, Leanne said to me, 'If you don't do this Rex, you are going to end up as the patient. And who does that help at the end of the day?' So, she went into hospital on the first of April and they were able to stabilise her. By the beginning of May, we knew she wasn't coming home. (Rex – spouse and carer)*

Leanne worked closely with Rex to help him find a suitable care home for Julia and continued offering support for long as Rex needed it after Julia was admitted. In fact, the two families became good friends, something which continues to this day. Rex was not the only person to experience this level of support and friendship with members of the CMHT. Louisa also felt that her relationship with staff from the CMHT was based on mutual respect and genuine friendship:

*She brightens up your day [Clare the memory nurse] because she's… Yeah, she is lovely. She is lovely. That is why I say all these nurses and people they have all ended up as friends, you know. (Louisa – spouse and carer)*

One of the things that carers valued about the support they received from their memory nurse was the knowledge that there was someone standing in the wings, ready to help them whenever the need arose:

*I mean she's got plenty to do and when she comes she is sort of never in a dash, you know, always has time. (Ewan – spouse and carer)*

*Well, Liz is always there. I mean, that's one thing I do like about Liz, if you have any problems. I mean, she will literally try and drop everything and see. And she does organise things, I mean she'll phone up… like when we had problems with this swallowing and drinking and that, she was straight in there. (Christine – paid carer)*

*I was concerned that we were not going to be able to be given the prescription on time because Ted [the memory nurse] was emphatic about… taking the pill every day and I thought she is not going to have one and that was when I was worried. But, the beauty of it was Ted said, 'Any problem [get] on the phone. If you can't get the pills, I will make sure you get them.' So, I was happy at that. So really, a good contact is all you want really. (Bill – spouse and carer)*

*Yeah, that was a help to know that there was somebody there. It was just a question of picking the phone up and saying, 'I need some advice… I am not sure what to do about this, what do you think?' (Rex – spouse and carer)*

*Dr Adams says, 'You know where I am'. Megan [the CPN] said the same 'Don't ever be frightened to phone.' Just you let us know. (Nick – spouse and carer)*

*[The CMHT dementia service] has been good as gold. Amy the [CMHT] receptionist also is good as gold. Everybody we have dealt with can't do enough. They have bent over backwards. (Nick – spouse and carer)*

### 5.1.5. *Gaps in service*

People with dementia and carers were reluctant to talk about gaps in the dementia service they received. Everyone was happy with the contact they had with the team and with the knowledge that help was only a phone call away. When I asked if they felt the service could do any more,

people, like Adam, were genuinely at a loss to know what else could be done:

*I don't really think there is anything anyone could really do that would improve the situation dramatically. Because we have a good family so, do you know what I mean? We have plenty of people [family members and friends] coming in so, what more could anyone really do? It's a memory problem basically so… you have to, sort of, keep them active and involved in the day-today things that you do, don't you?(Adam – family carer)*

Others, like Nick, did not want to contact the team too often, perceiving himself to be a burden. A sentiment he repeated five times during his interview:

*We manage you, see. We don't really need a lot of help because we manage.*

*As I say, we take each day as it comes. We don't need too much help. We don't have to ask for help.*

*We haven't really needed anybody else. So, I couldn't really tell you about other services.*

*Luckily we manage as we are, we don't need much help. Just things like that rail [pointing to a newly installed stair rail], to help her get up the stairs and of course the little thing that goes across the bath. Little things like that you know, that is all we've needed. We haven't needed anything else.*

*People say, do you get help? You know, because we don't ask, we don't. We manage. We are big enough burden to ourselves and we don't want to be a burden on anyone else. And we are not.*

***There was a lack of communication between health services***

Bill and Anna, did though, share their thoughts on gaps in the flow of information between health services. Bill, a systems analyst before he retired, was sceptical about the ability of the processes currently in place to share information on his wife's health between services. He was able

to point to multiple points in the system where he felt Betty was vulnerable:

*Bill:* *It became quite obvious to me when Betty was having her cataract operation done that the nurses weren't aware of her condition. All they were aware of was that she was there to get her cataracts removed, right? It took so long, I had to come home and I thought I am not leaving Betty on her own in the hospital, right? I'm worried of what she is going to say because she can get things out of context and mix things up and so on. So, I just had a quiet word with the nurse I said, "Betty has got a dementia problem and she may get confused." I think that information should have been available in some way, shape or form. It was further exacerbated when I went to [another hospital], because they weren't aware of what had gone on [at the previous hospital]. I made sure then that I was with her when she went back to the re-assessment after the cataract operation. I sat in, because I wasn't sure what answers she was giving to the questions from the nurse, right? And it became further obvious that there is no, no knowledge of Betty anywhere else, other than...*

*Ethna:* *From you…*

*Bill:* *From me. So I went this week to the optician with her, right? And again I'm thinking, what is she going to say to the opticians for the tests, if she misunderstands letters, characters and figures? Right from left... Is she going to get the wrong prescription for wearing glasses? So, again, I had to tip off the optician that Betty has a form of dementia and may confuse things and may even be dyslexic and so on.*

The following data excerpt is a vignette illustrating the stress experienced by a family when services demonstrate a lack of initiative, sensitivity and/or common sense in meeting what should have been a relatively simple support need. Like Bill and Betty's story, it is the lack of communication between services that causes a relatively simple issue to become an overwhelming one. The vignette begins with Anna talking about a service funded by the Alzheimer's Society that existed in the past

and which she personally found to be of great benefit. Anna is talking about an incident that happened when her husband Jim was still living at home.

***Anna and Jim's story***

*"That's gone now [the service from the Alzheimer's Society]. So there are a lot of people losing out there. The support worker from there, she used to come and support me sometimes when we were stuck. It was daft things like when he became incontinent and you couldn´t get the pads from anybody… I got in touch with the hospital. I got in touch with the chemist. Can I buy them? No. They didn't do bigger sizes. I got in touch with the doctor and, 'No, we don't do them.' And I kept getting fobbed off. All I had to do was go through the district nurse but nobody said. And I was past myself. It was the year where it rained all summer, like last year…I mean he was fully incontinent and on a night time I was having to strip all the beds and I couldn't wash the duvets because they were too big to go in the washing machine. They were having to go to the laundry. I wasn't able to get to the laundry because I don't drive. So, I was having to go and buy a new one from [the shop] and I bought three in one week. And I was still getting no help and by the end of that week, I couldn't get the bedding dry even though I had a tumble dryer because as fast as I was putting it in to wash, do you know what I mean? I was past myself. And I mean, talking about it now, it was something simple but you imagine it snowballs. I got in touch with Jenny [the support worker] from the Alzheimer's and she came running round in her car and said, 'Right. I*

*will get this sorted.' And she off went down to [name of Day Centre] and borrowed some from them and came here with them and then said, 'Right. We need to phone a district nurse.' So, why did nobody else tell me that? Because I had phoned the doctors and everything and they had all fobbed me off and said, 'No, it is not us you need to find.' Phoned the district nurse, she was going to do a plan that I'd have to fill in to see how… And I said, 'No, come on.' I had just told her what had happened all week and she said, 'We won't bother with a plan and she we went out to the car and got the pads brought them in and said, 'We have got some more on order and you will be getting them delivered every month.' But it took all of that and all that stress that we didn't need, you know? Horrendous, absolutely horrendous."*

***Support for carers***

The Department of Health (2007, p16) acknowledges that caring for a person with dementia, "…will certainly arouse a great many conflicting emotions." Which emotions carers will struggle with will depend on their relationship to the person with dementia. Spouses, for example, will struggle with different issues to adult children caring for a parent. Young children will struggle to comprehend the needs of a parent diagnosed with young onset dementia. Much depends also on the quality of the relationship between those affected before a diagnosis was made. Moreover, the needs of carers will change as the cognitive abilities of the person they care for fluctuates and/or declines. Carers have talked about the stress of caring responsibilities (Bowes and Wilkinson, 2003; Hoskins

*et al.*, 2005; Papastavrou *et al.*, 2007), with some reporting they have started to experience the effects of stress even before the first visit to the memory clinic (Rosness *et al.*, 2009). Findings from a study investigating whether memory clinics supported carers found that, “Carers' knowledge of dementia was poor” (Logiudice *et al.*, 1999, p629). Despite the time lapse, findings from my study confirmed those earlier findings. In the following excerpt, Anna identifies that it is not just an understanding of dementia that carers do not have, they do not have the practical skills to care for an adult dependent who is losing the ability to engage in their usual activities:

*Anna:* *All carers should have the opportunity of learning how to care for somebody at home for their personal needs.*

*Ethna:* *Does that not happen then?*

*Anna:* *No, and is totally, it is common sense really! But you don´t have common sense when you are caring. If you were taught how to wash somebody whilst they are sitting on a bed and dress them while they are sitting on the bed and you didn’t have to have the fight in the bathroom and how to dress somebody when they are on the toilet. You know, they can be sat, you can wash their face, and what have you, and you can start putting the clothes on from the bottom. And you are not fighting to pull the clothes up.*

*Ethna:* *Yeah.*

*Anna:* *And do that on your own... if you are taught all those skills that the carers are taught in a care home you would cope much easier. I wouldn’t have had the fights that I used to have with Jim when he was putting a pad on because I would have been able to get him to hold his hands onto the sink and then do it. And I would have persuaded him to do that. Or I would have said put your hands in the water and wash your hands and whilst he was doing that I could have had the pad on. But I didn’t have those skills of how to distract him to keep him busy so that I could dress him. And if carers were taught like they are in care homes, like the*

*staff are taught how to care for people. It would be so much easier. So much easier.*

***Targeted groups/memory management groups***

None of the people with dementia or carers that participated in my study had been offered an opportunity to take part in either a targeted group or in a memory management group. The following is the continuation of a conversation where Mary and Lewis are talking about the support they receive in-between their six-monthly visits from the memory nurse.

*Mary:* *There is nothing really to offer, is there?*

*Lewis:* *For what?*

*Mary:* *For you, there is nothing for Jessica to offer us, really. Lots of people, lots of places have these memory clinics now that people can go to and get stimulation from but...*

*Lewis:* *[Emphatically] We haven't got any, have we? Haven't been to that.*

## 5.2. Chapter summary

In this chapter I have presented data under the five service evaluation categories devised by Willis *et al.* (2009). Utilising Willis' (2009) analytical categories, data were subsumed under the following headings: service experience (5.1.1), including experiences of receiving a diagnosis of dementia, occupational therapy support, support for people with young onset dementia, Consultant support, memory drugs and memory assessments (MMSE). Helpful interventions (5.1.2), including: counselling services, community-based resources, i.e. MIND, day centres for older people, horticultural projects. Normalising the catastrophic (5.1.3),

including learning to adapt to the diagnosis, overcoming fearful situations, managing other people's attitudes, overcoming daily battles and skirmishes and making peace with the diagnosis. Communication (5.1.4) and finally gaps in service (5.1.5). I now turn to the final data chapter in which I present data from the staff working in the CMHT and the MHSOP.

# Chapter Six: Reflections by CMHT staff on their work as practitioners and as a dementia service provider

*The thing that defines success for me in reality is, and I don't get the time to do it anywhere near as much as I used to, is actually spending time with patients and just getting their stories, you know? And people saying, 'Thanks very much, you've made a real, you've made a difference.' That, to me, defines success. (Ben – clinical services manager)*

## 6.1. Introduction

In this final findings chapter I provide an overview of the work of the dementia service provided within the CMHT. The mental health service offered by the CMHT had, at the time the interviews took place, recently undergone a radical transformation. For example, one of the two day hospitals provided by the Trust in the area had been recently decommissioned. The CMHT had been reshaped to reflect the growing number of dementia referrals to the service and the way that people suspected of having dementia were diagnosed, assessed and reviewed had been overhauled. In order to capture the detail of these changes, the chapter begins by identifying the drivers behind the change in the way the MHSOP delivered services to people diagnosed with mental illness and/or dementia (6.1.1). This is followed with data reflecting some of the challenges to the new system raised by practitioners (6.1.2). I then identify drivers for change in the development of the CMHT generally and the new dementia service in particular (6.1.3). I then present data demonstrating how the changes affected everyday practice within the CMHT, i.e. via the implementation of standardised assessments and

careplans (6.1.4), the closure of the day hospital service and the emergence of targeted therapy groups (6.1.6). This is followed by data on how well the needs of carers are being addressed (6.1.5), how the process of change is viewed as an opportunity to provide a better service and not a threat (6.1.7), building service user and carer involvement into the system (6.1.8) and the important role dementia champions play in keeping the service both focused and forward-thinking (6.1.9). The chapter is brought to a close with data reflecting how the service responds to problem-solving (6.1.10), how the service may develop in the future (6.1.11) and the development of a 'no-blame' culture in the service (6.1.12). A summary of the findings from this chapter is included in table 6-1.

**Table 6-1: Summary of findings answering RQ3**

| **Data stream three**<br>Presents data from CMHT staff on the strategies they devise to keep the service patient-focused, while surpassing all government set targets<br>Findings answer research question three | |
|---|---|
| Drivers for change in the MHSOP | 'New Ways of Working for Psychiatrists' was the driver for change at the level of the MHSOP. This resulted in the responsibility for new assessments being shared with CPNs. |
| Challenges to the changes from practitioners | There was resistance from medical staff to the changes as they were viewed as 'unsafe.' These issues are worked through by the team. Some hesitation from nursing staff due to increased workload. |
| Drivers for change in the CMHT and the development of the memory service | Clinical services manager felt the team was not offering a specialist service, even though they claimed they were. Some staff over-burdened. Desire to set high standards for targets on first appointments. |
| How service changes have influenced professional practice | More emphasis on professional staff completing assessments. Support staff delivering care packages. Some staff expressed concerns about becoming de-skilled. Others were happy with the changes. Day hospital service closed. Targeted groups instigated. Problems remain with througput and therapy outcomes in groups. |
| Change as opportunity | Change was viewed positively. Achieving targets was stressful and time-consuming. |
| Building service user involvement into the system | Payment by Results seen as an important tool for modernising mental health services. Within this, the mental health clustering tool was viewed as a way to build service user involvement into the day-to-day work of the service. |
| The importance of dementia champions | The importance of having a 'dementia champion' in local service to ensure the needs of people with dementia were consistently foregrounded. |
| Problem-solving | The importance of viewing service pressures as an opportunity for change and of not 'throwing staff' at a problem. Taking time out to think things through. |
| Future service developments | Working with local service to create new services to meet current and future demand. |

### 6.1.1. *Drivers for change: MHSOP*

*Generally our philosophy is, we grumble about it, but we just get on with it. What's the point? You know, we are told to do and we do it because if we don't Ben will tell us off. And that's a very good incentive, you know. It sounds childish but you get a gentle bollocking from Ben. (Craig – consultant psychiatrist)*

Organisational change is complex, multi-faceted and difficult to manage (Senior and Fleming, 2006). Yet, despite its complexity (or perhaps because of it) change is the lifeblood of any organisation that wants to remain ahead of the game. It is of course possible to talk about the principles of change and what should happen; the National Dementia Strategy is a good example of that. But, when change is demonstrated via exemplars that show real people grappling with real-world challenges, the possibilities for change to excite/motivate and propel others into action is, I believe, increased. The CMHT is going through a period of intense and sustained change which (happily for me) provides a number of opportunities to understand how it responded to the challenge of implementing public policies that, at times, seemed far removed from the everyday life of people with dementia, carers and the staff who support them.

Sometimes, even when a member of staff understands the need to work differently, the security of working within a familiar environment occasionally prevents them from doing so. The story shared by Dr. Craig Adams is a case in point. Craig is currently the in-patient Consultant Psychiatrist with responsibility for patients at the two research sites. Although he could not have known it at the time, the difficulties Craig

experienced working within the MHSOP became a catalyst for one of the biggest changes in the way the service operated. At the time, Craig and his colleague Dr Anita Noble shared the medical lead for inpatient and community services in the north of the county. Due to a workload that resulted in them having to work ten and eleven hours a day and a weak infrastructure that meant they did not/could not make time to support each other properly, Anita and Craig became mentally and physically fatigued. Anita eventually left the service and Craig became unwell not long afterwards. Prior to the events which led to Anita's resignation and Craig's ill-health, the Royal College of Psychiatrists published a document warning of the dangers of Consultant burnout. The document entitled New *Ways of Working for Psychiatrists*[24] (Royal College of Psychiatrists and National Institute for Mental Health, 2005) was unequivocal about the need for change within mental health services. It advocated for example that:

- Consultant Psychiatrists should no longer be responsible for every patient; other members of the team could (and should) assume responsibility for patients with less complex needs;
- Consultant Psychiatrists should use their knowledge and skills to treat patients with the most challenging and/or complex needs;

[24] Hereafter referred to as New Ways of Working

- The number of Consultant-led clinics should be slashed and abolished when possible.

Despite the report's obvious appeal and the pressing need for change in the service, Craig and Anita carried on working in a situation that slowly became untenable. Here, Craig explains why, in the beginning, *New Ways of Working* was not embraced as fully as it could have been:

*As it happens, the nature of the change has been driven by something called New Ways of Working… which has said because of the difficulty of recruiting Psychiatrists and retaining them and Psychiatrists burning out that they can't keep doing this, it's impossible. So, they said that other people in the team could be involved and the doctor wasn't responsible for everybody in the team. That was a big change because until about five years ago the doctor was considered responsible for everybody that anybody had, which was crazy, but that was the system. So, using that model we have gradually moved over the past five years to a position where the nurses are doing a lot more of the new patient assessments. The doctors are doing fewer of the new patient assessments and concentrating on the complex patients, patients who the nurses were having trouble with or the doctor heard and thought, 'I need to see this person.' And, we became quite adept at that but there was still, I suppose, my reluctance to completely give up that role and also a nursing reluctance because of course, their role [and] the amount of work they have had to do…has increased. (Craig – consultant psychiatrist)*

Even after Anita's resignation, Craig was unwilling to fully implement the recommendations spelt out in *New Ways of Working*. The pressure of trying to cope within a system that had not worked well for many years resulted in Craig having to take time off sick. In his absence, staff working within the service began to fully implement the recommendations in *New Ways of Working*. When he returned to work, Craig found everything had changed:

*My team was very good and they basically switched into a full New Ways of Working in my absence and [that] took the load off [me], so I was just*

*left doing the New Ways of Working… So, we've gone from a very medically-led to a very nurse-led model and this is not just in the community. We've been working at this for some years in the hospital, inpatient setting and when we had a day hospital we were also working that way in the day hospital as well. (Craig – consultant psychiatrist)*

### 6.1.2. *Challenges to the new system*

Not everyone believed the new arrangements were an improvement. Lily, for example, worried at the speed at which changes were being introduced and also in relation to nurses carrying out the initial patient assessment instead of medics:

*There was no preparation time. It was like, 'Now, we are doing this.' There was no concept of, 'We are about to change this service.' It was, 'Now we are doing that and now we are doing that.' My role changed and the doctor role changed, which I didn't like, because obviously some didn't think it was a safe change… in that, suddenly you stopped doing patient assessments and were doing follow up assessments and diagnostic assessments… Sometimes that would make sense if it was just a simple case of Alzheimer's but it didn't make sense if it was a patient that was being referred by the GP because they couldn't manage their medication and they needed a clearer diagnosis and clearer medication management. And so you went from one extreme from the doctor seeing every new patient to the doctor seeing no new patients. I felt that was too extreme… I think that it's important to have more medical input earlier sometimes. You can miss things… It is actually very hard going out to diagnose someone who you have not done the initial assessment for. Especially if you don't feel that initial assessment is adequate. (Lily – specialist registrar)*

Lily's comments reveal a number of concerns, one of which was related to the fact that the role of medics has changed from being 'first on the scene' to completing the follow-up assessment. From her comments, it is clear that Lily does not think all CPNs have the requisite skills to carry out the initial assessment. This view directly contradicts Craig's view that medics, particularly junior doctors, do not have the skills to carry out initial

assessments and that, in fact, CPNs are highly skilled in that area. Lily, in her role as a Specialist Registrar, does have the skills, knowledge and expertise to complete initial assessments, but the service-wide change was introduced because junior doctors do not. In the day-to-day work of the CMHT and/or MHSOP, there are fewer Specialist Registrars than there are junior doctors, so the argument for change is a strong one. One way of understanding Lily's resistance to the change is perhaps to understand that, she, as an experienced mental health medical practitioner, is competent to carry out initial assessments, but because her more junior medical colleagues are not, she has had the assessment role (which she enjoyed) taken away from her. In other words, her resistance may be linked to her changed role, rather than to the change *per se*. Lily could then be reacting to the way the change impacted her working life. She framed the change as unsafe, because things might get missed, whereas Craig framed the change in terms of providing safer care. Lily expressed her concerns to Craig, her clinical supervisor, and to Ben the Clinical Services Manager and although the direction the service was travelling did not change, she was satisfied that her concerns were listened to respectfully:

*I get on well with the manager Ben. I've been able to discuss these service changes with him… I suppose one thing is, [in] the beginning I didn't understand his attitude and why he was coming in and saying… now I understand where he is coming from. I understand much more his reasoning. But I don't think that was explained brilliantly at the beginning, when it all started to change and I was like, 'This is terrible. What is going on here? Why are you destroying a good service and making it into a not good service?' But now I am, kind of, understanding where he is…coming from. I think that the trouble is there is always change and nothing seems to stay still. (Lily – specialist registrar)*

As mentioned earlier, Craig believes that one of the great strengths of moving from a doctor-led service to a nurse-led service lies in the skills, knowledge and expertise that CPNs bring to their new role. CPNs are specialists in mental health issues and the majority of CPNs working in the MHSOP are very experienced mental health practitioners, something that junior doctors are not:

*We have a number of doctors around but not all of them are very well trained and the juniors we have on the ward don't know any psychiatry when they come onto the ward. So you can't send them out into the community to do competent assessments because they actually haven't got a clue, it would be unreasonable for the doctor, the patient as well. (Craig – consultant psychiatrist)*

Despite her initial reservations about the shape of the new service, Lily sees the potential benefits of fully adopting *New Ways of Working* and the inherent flaws in the old way of working:

*It is interesting that my next service is a very traditional service and I can already see the disadvantages of that. I think this [service] works well now [but] I think it needs a bit more tweezing. (Lily – specialist registrar)*

In his role as Consultant Psychiatrist for the CMHT Craig understands the concerns medics may have in relation to ever-changing patterns of service delivery and of changing roles. Here for example, Craig talks about the challenge of persuading doctors to work more cooperatively with the Trust in terms of using a new data-capturing IT system PARIS, an essential tool in the Trust's toolkit to ensure they are complying with the government's performance agenda:

*Basically doctors don't like change. They really don't. They hate changing and they're more comfortable doing what they have always done, thank*

*you, this is the best way because I do it and I know it best. I did some work with Ben's PARIS IT group with Consultants when I was an ACD [Assistant Clinical Director], going round talking to Consultants, trying to persuade them to use it, and this was after they should have been doing it for six months, twelve months. People were still finding reasons not to use it and it appalled me really. It appalled me. So, my senior doctors, I have to tell them to speak to Ben and Ben winds them up sometimes because Ben gives them a completely different perspective on life that they can't cope with. But, that is just another way of looking at things - from a business point of view - and it usually takes a year for them to be able to see the sense in what Ben is saying and why he is doing things and what the Trust is about. It takes quite a long time for senior doctors, who are challenged by our change to get their head around it. (Craig – consultant psychiatrist)*

Lily was not the only member of staff to express concerns on the issue of unwanted role change:

*As an occupational therapist I don't feel as though, I give full reign to my skills that I have actually trained to do. Because they now, we are, I'm more focused, focused because of the way that the Trust has aligned, for assessment work, rather than, therapeutic graded activity, which was part of why I did my training, you know. I enjoyed that side of working with people on a day-to-day basis. (Gina – occupational therapist)*

The issue of prioritising initial assessments, rather than engaging in graded, therapeutic activities, was also noted by Jilly:

*We pass most of the stuff on now to the support workers because we found we are that busy with the new assessments we don't really have time to do that graded work. (Jilly – occupational therapist)*

*I find when we get really hectic, the follow-up, kind of slides a bit. I think we always keep up with the assessments and everything else... (Jilly – occupational therapist)*

### 6.1.3. *Drivers for change: CMHT*

*New Ways of Working* may have been the driver for making changes to the wider mental health service, but it was not the main driver for

changing the way the CMHT operated. Here Ben explains the rationale behind the changes:

*The main driver for me for the changes over the last twelve months, in this locality, has been around we sell ourselves as a specialist service, yet we were asking people to perform a very, very generic role in how they delivered their care. So, we had CPNs who basically did a bit of all sorts. So, they would have some people with depression, they would have someone with bipolar, they would have quite a few with dementia and then we had this group of patients who were on the dementia drugs, two hundred and fifty/two hundred and eighty people and one person had responsibility for managing them. And I kept thinking there's something wrong, seventy five/eighty percent of our work is being carried out by less than ten percent of our workforce…So, we took the decision to split our community service. Instead of having lots of generic people aligned to GPs, we made the decision that what we would have is a service aligned around patient's needs. [So] we have got community services for people with dementia and we've got a community service for people with functional problems. (Ben – clinical services manager)*

The idea behind the new changes is that some CPNs assume the role of memory nurses (organic mental illness), while other CPNs work with older people with functional mental illness. For a number of reasons, however, this is not a straightforward split. In the same way that medical conditions coexist alongside a diagnosis of dementia, functional mental illness can coexist alongside a diagnosis of dementia. Moreover, because the incidence of dementia increases with age, more and more people with functional mental illness will also be diagnosed with dementia in later life. The caseload split also becomes less clear when people are re-referred to the service as they are sometimes referred to the practitioner they worked with previously, even if, in the case of the couple that Mel (a CPN) is supporting, they have been diagnosed with dementia and not functional mental illness:

*Two [of the three patients with dementia on her caseload] of them are a married couple who have refused any interventions and they don't really want to engage with the service but they both have quite significant memory impairment but no insight into the extent of it really. It just got opened to me again because she was admitted to hospital. It was the carers that had alerted me…her partner was left at home. So as I was the last person involved it got opened back up to me. (Mel – CPN)*

As the dementia service is fairly new, there remain a number of issues to be fully worked out in relation to supporting people with functional illness who are then diagnosed with dementia. So, although it may be a question that can be better answered in the future, for now Mel thinks the service will remain needs-led, rather than service-led:

*Until the actual, the depression or anxiety was over and it was… clearly a memory problem that was overtaking, then I think it would go to a more specialist service. But up until that point it would be very much… needs lead. (Mel – CPN)*

In relation to the team split, at least one CPN (who previously managed a mixed caseload) revealed they felt that by focussing on one client group, they run the risk of becoming de-skilled. Here Hetty talks about the process of referral allocation:

*I think on the downside there is a chance you can lose your key skills in certain areas as well. (Hetty – CPN)*

In addition to people with dementia being referred to CPNs because they were once on their caseload, CPNs will also pick up referrals when the workload of the team reaches a critical point:

*Ethna:* *Is someone then routinely referred on to your caseload because the other nurses, the memory nurses, their caseload is full?*

*Hetty:* *Not routinely. Nikki will come along and say, 'Can anybody take this one?' you know. Or, you, you look at the pressures of the team.*

*Hetty:* *[We are] a tiny team and, you know, I am not going to turn around and say, 'I am only going to work with that.' If something urgent comes through, you don't, you just go ahead and do it. Whoever has got capacity to do it, you know? I don't know if they are the right answers but...*

*Ethna:* *…there are always going to be crisis points or critical points where everyone is going to have to… take all sorts of cases and I guess that is why you're worried that you might lose out in terms of keeping those key skills if you are not seeing people regularly enough.*

*Hetty:* *Yeah. I think it works both ways, as well, you know, because I suppose people on the organic team feel they lose some of their counselling skills, as well.*

Other members of staff viewed the organic/functional divide as a positive one that will reap benefits in terms of the development of core nursing skills:

*I think this move over the past few months has been good because it is helping to focus on building more strength on expertise and knowledge and awareness to do with the dementia pathway that is coming in, and where we are going with that. And, I think you keep yourself more up-to-date on one specific area and domain of, you know, what you are working with as opposed to generic, you know, people with some anxiety problems, depressive problems, and memory difficulties, someone with a bit of psychosis and a bit of a mixture and really you are dipping your toe in and out of different areas. (Ted – memory nurse)*

### 6.1.4. *Standardising care via standardised assessments*

One of the positive aspects of the media storm around dementia, is that more people are becoming diagnosed resulting in an increase in referrals to the CMHT. The effect of this shift on members of the team has been far-reaching. Occupational therapists for example have experienced a

significant shift in the way they work with people with dementia. At one time they were responsible for completing both the assessment and the therapeutic intervention. This has now shifted towards the completion of more complex (i.e. more finely graded) assessments with the hands-on therapy being delivered primarily by occupational therapy support workers. Because assessments are, as a matter of priority, dealt with immediately, a backlog of interventions inevitably develops. The pressure to complete ever more complex assessments, does of course offer proof that CMHT staff are providing a highly specialist service in terms of assessment, but they are providing less hands-on care, something which Gina believes newly qualified occupational therapists have been socialised into accepting:

*Someone who has come from university… and then gone into post, I don't think would fight for any sort of therapeutic interventions, I think they would just go along the line of assessment, because that's what's expected. (Gina – occupational therapist)*

Jilly also noted the shift in role and, like Gina, says she misses one-to-one interventions:

*I remember when I started here I used to do a lot more intervention whereas now I find that my work is a lot more assessment and I pass on a lot of the interventions to the support workers. So, that's changed. (Jilly – occupational therapist)*

*That's the nice bit of the job [working with people on a one-to-one basis], so you do miss out on that and I think I like to do a few of my groups because you get the intervention… (Jilly – occupational therapist)*

*I would like to offer the whole package from an OT perspective, you know, the assessment, you know, you have got to get your assessments*

*right. That is an important part…I would like to play a bigger part in providing the therapeutic intervention. (Gina – occupational therapist)*

### 6.1.5. *Support for carers*

Carer support is an issue that has been raised at several points throughout the data chapters. Ted, a memory nurse, felt that the needs of carers were frequently overlooked probably due to the high caseloads:

*Ethna:* *Do you do any targeted support then for the carers?*

*Ted:* *At the moment no. I have got to say I think, reflecting on the number of referrals that we have got going through, I mean, all of that work that I have just described, getting us to the point where we do the delivery, the treatment and what-have-you, there is very little time for the carers.*

For Ted reflected that his greatest challenge in relation to the influx in new referrals is related to carer support, which he acknowledges is almost non-existent:

*Ted:* *It [a carer's assessment] is in our core assessment, but I, I do feel that we are, really, ill-equipped to...*

*Ethna:* *If a carer did say to you well…*

*Ted:* *Do a carers assessment? Yeah. I do feel, you know, it is a bit of a struggle at times because I sit there thinking what am I supposed to do? If they say yes I am really pointing them to give the social services a ring but from the mental health, and our service side of things, there is nothing much I can really offer.*

Elena is a CPN support worker with the CMHT in rural Wickham. Elena sees her role as supporting both the individual with dementia and their carer. Here Elena talks about the problems of persuading individuals with

dementia to use available services and the potential effect that has on carer health:

*Elena:* *Sometimes we can have difficult patients that won't consider anything that you offer. I go out just to, to as I say, to build up rapport and try and get somewhere with offering some respite for their carers.*

*Ethna:* *So, is it a problem, sort of, is it a wide spread problem that people are a bit resistant to...?*

*Elena:* *It is yeah. Because people, a lot of people, if we have people with dementia they have no insight to their problems and they think they can manage and they are doing everything and family are under a big strain because they can't and they, their lives is, sort of, on hold, on hold because the person won't go to day care, they won't go to respite if they want to go on holiday and the person can't be left.*

*Ethna:* *So that is a big problem for the carers.*

*Elena:* *It is yeah. Especially in this [rural] area because people tend to look after their own family for a long time, so sometimes we don't get referrals until people are quite bad. Which we see more of that now.*

Elena spends a long time getting to know the individual with dementia and their carer and/or family members. She views the process of relationship building as a critical first step in the provision of support for carers. Here Elena is talking about the small social group she and a colleague facilitate in the local community for people with dementia:

*Elena:* *It is a bit more of a personal thing as well because the carers get to know you really well. They might be really hesitant of asking you questions or being quite truthful about what's happening but, as time goes on and you build up a relationship, they are quite open in saying, "Well, actually, I am struggling and things aren't going so well." And, "This is getting worse." They are quite comfortable to sit and even cry in front of you, where...that takes...*

### 6.1.6. *Transitioning from day hospital services to targeted care*

One of the very first changes to take place within the mental health service for older people, was the closing down of the day hospital in Tadham. The service was closed for a number of reasons including that it had become more of a social event than an opportunity for active therapy, that due to a lack of throughput, the service could only meet the needs of a small number of people and that the model created dependency. The change aroused mixed feelings among CMHT staff, who while philosophically supporting the idea, nevertheless noted the effect of the closure on people with dementia and carers was significant. Part of the conflict is in relation to the fact that people with dementia said they enjoyed the social networking that opened up to them at the day hospital, while carers said they enjoyed the respite from caring responsibilities. The problem was that the day hospital was mandated to provide targeted therapy, not social support and respite care. Further conflicts arise because the level of support provided by the day hospital, in terms of social networking and respite, has not been replicated in local communities. And, even in areas where community-based opportunities exist, because of the problems they experience travelling independently, people with dementia have difficulties accessing them:

*One point was transport, a lot of the people with the dementia had difficulties accessing transport and we do a lot of work with people in that area but some of them just, still, can't access that independently. So that was where we were, kind of, stuck really. (Jilly - occupational therapist)*

Two of the ways that occupational therapists have moved their practice on from the day hospital model is via the development of more sophisticated graded assessments and the provision of targeted groups. Here Jilly talks about a group for men that is currently running:

*I had read a bit of research about how gentlemen generally don't access services as much as, maybe, the women do. They are quite reluctant to get engaged in, in tasks… a couple of the gentlemen I was working with one-to-one had given up really and resigned to sitting alone in a chair and watching telly and becoming quite socially isolated. And you mention the likes of a day centre to them and like, 'I am not going there and playing bingo with old ladies.'' So we set the group up and it is led by them really. And we just meet up once a fortnight and they have a trip out, so like a walk in the park or go to a museum or out for lunch. It is to build confidence and motivation and increase the social stimulation. And we have found that once they have got involved with those kind of groups that they enjoy, they are more likely to try other activities. We have moved people on then to some of the day centres that they weren't, maybe, so keen on or it has given some of them confidence to think, 'well, actually I can do some of these things again and I am going to go and start doing my garden again.' Just because they have had that bit of confidence, so, that is why we set that up and it is working quite well. They quite enjoy it. (Jilly – occupational therapist)*

As Gina and Jilly talked about the work of the targeted groups, it became clear that the development of the groups was not unproblematic. For example, Gina pointed that the closure of day hospitals was linked (philosophically and practically) to providing more one-to-one care. Yet, due to pressures of work, it is rarely possible to offer that level of care. Targeted groups, therefore, provide a way to deliver support in the way that therapy groups in the old day hospital used to:

*Ethna:* *Do you think that [targeted group-work] is one of the ways you get round the system then? By developing good groups? Do you think that is your way of trying to...if you can't beat the system then use it as best you can?*

*Gina:* *It is. It is, yeah. Uh huh. Yeah.*

The irony of this was not lost on Gina:

*Because of the amount of referrals that we get, assessment is, assessment has to be, your first port of call. This is why we do groups because then we feel as though we can capture a few people with similar problems. Even though they have been identified [as not being] person centred, are you with me? You know, we are actually grouping people together when we should be working with people on a one-to-one basis. (Gina – occupational therapist)*

Although the purpose of offering time-limited targeted therapy groups is to ensure more people (than before) get access to services, even in the new targeted services, throughput remains a constant challenge:

*We have got some people who we have had for much longer because we have found it difficult to move them on for whatever reason. But, generally we try and keep a flow, otherwise it gets a bit stuck. (Jilly – occupational therapist)*

Another criticism of the day hospital was related to it being viewed as a social activity rather than a therapeutic activity. According to Jilly, it is an issue that has not been completely resolved with the development of more targeted services:

*We are looking at the function of that [group] at the minute and possibly bringing that to an end and start some new groups because I think that has turned into more of a social group. (Jilly – occupational therapist)*

Gina, on the other hand, acknowledges the social function the groups provide, viewing it as an important component of the care provided:

*Yeah. Definitely. And I think, you know, that [the social element of care provided in more traditional services] was, I think was really good and I think that was what the type of people who we were working with needed.*

*And that is the thing that is missing now I suppose. (Gina – occupational therapist)*

The issue of day hospitals creating dependency was one of the reasons given for their demise. It is an issue that has not been altogether resolved with the introduction of targeted therapy groups:

*I have been more aware of the groups and keeping them timely because I think with some of them, through our own fault, we created a bit of dependency. We had a lady and she has written me several letters about how she misses the group and how much she loved it and that was the highlight of her week… I feel sorry that she misses it that much because but we didn't want to create a dependency. (Jilly – occupational therapist)*

Issues related to transport were a recurrent theme throughout the interviews with Gina, Jilly and Elena and were, according to all three, one of the main reasons that people with dementia are unable to access community-based services:

*Like I said, a lot of it is transport issues… the day centres, they provide transport but a lot of the groups, don't [provide transport], [because of that] some people find it difficult to access and that is why they love coming here. (Jilly – occupational therapist)*

*…we try to get people to go to another organisation but transport is a huge issue… at least coming here, you know, we have the transport. (Gina – occupational therapist)*

*We have got no transport. So, people who live further afield, unless they have got a family member who would pick them up, fetch them in and take them home, it is difficult for them to attend. We have got two ladies who come by taxi that live in the town. They pay for the taxis themselves. (Elena – CPN support worker)*

Elena works [and lives] in rural Wickham where transport issues are an even greater challenge. Elena knows that if she and her colleague do not personally intervene, many people with dementia will be unable to benefit

from the weekly drop-in service they offer. In response to this, Elena and her colleague have set up a complex social bartering scheme whereby CMHT staff, friends and families raise money, not only for transport but other vital resources, including trips away and meals out. Here Elena explains how her system works:

*Elena:* *We are not financed by the NHS. The Chief Exec does pay the twelve pound a week for the rent and then after that it is left to us.*

*Ethna:* *So how do you find the money for it then?*

*Elena:* *Beg, steal and borrow. We had a patient whose wife attended. She had a severe stroke… she used to come to the group. We used to fetch her up…she has since died and her sister-in-law started making cards to sell for the group. She made no profit whatsoever… what we sell we can keep the money for. So that gave us quite a boost. Because we tick along with next to nothing, you know, with tea, coffee, milk, sugar, biscuits, we sort of, manage with that. Initially, the Trust did initially give us a thousand pound. That was seven years ago; we have had nothing else off the Trust since. Somebody else that used to attend, they died and the money from the collection, from the funeral came to us.*

*Elena:* *On Saturday I helped out with the fair that we had here [at the day hospital]. So I donated that card money that I sold, to [the day hospital] and they've guaranteed that they will help us out, whatever we want. Also the treasurer of [the day hospital] has offered to do some transporting for us. Free of charge.*

*Ethna:* *[laughing] You are a right Del Boy aren't you? A little bit here a little bit there.*

*Elena:* *[laughing even harder] You just have to! So, anyway, he is going to pick a couple up for us and the families agree to, sort of, give him, two, two fifty, three pound. Because he is a volunteer driver he would get probably five pound if he was taking people about. So, if he, if he picks two or three up and they all give him some money, then it just helps towards the petrol really*.

*Elena:* *At Christmas we take them out. For them… you see, a lot of people wouldn't get out anywhere else because with them being forgetful and, you know, they need somebody there to look after them. And we know them quite well… sometimes a husband or wife comes as well on the trip because it gives them a break… the same with the Christmas meal, they come to that. And then it's just the staff and any carers that want to help that come along. So, it all goes quite smoothly. I keep saying every year I am never going to do it again. Because it is a nightmare trying to find something that's suitable for them. And that is not too far. So, yeah we've had a few good trips.*

*Ethna:* *Sounds excellent. Sounds absolutely brilliant!*

*Elena:* *You know, we couldn't do that if we didn't beg, steal and borrow for the money… It is something that is not seen, I suppose, by the Trust as being that important, but I think it is in this area.*

### 6.1.7. *Embracing change as a strategy for meeting targets*

Embracing change and seeing it as an opportunity to get creative is, according to Craig and other members of the CMHT, one of Ben's many strengths. And, although not insensitive to the obvious frustration his staff feel at the unending stream of changes imposed upon them, Ben views his strategy of embracing change, as opposed to simply accepting change, as fundamental to the future success of the service:

*If we don't change and we don't develop there's a couple things going to happen. If when Payment by Results and stuff like that comes in [and] we're not hitting our targets and we don't all do what we need to do… I am going to find something taken out of my budget. To try and get them to understand that, you have got to get hold of them and say, 'Look, if that's the scenario we're in at the end of the financial year, which one of you doesn't want a job the next year because that's what it means… At the end of the five percent is a band six [nurse]. That's actually a bit more than, a top of a band six. So one of you lot is not having a job. And all that means is one of you isn't employed anymore and the rest of you are doing the work that that person isn't doing.' So it's really [about] getting*

*smart and trying to work through ways to make it easier. (Ben – clinical services manager)*

Ben has a strong focus on the benefits that meeting targets brings to the team (in terms of retaining valuable resources). CMHT staff, however, often struggle with the day-to-day reality of spending up to 25% of their time engaged in the paperwork trail necessary to prove targets are being met:

*The downside of my typical week would be the amount of time spent on paperwork. I would say possibly 25% of my day is spent sitting on the computer, because you go out…you make notes as you're speaking to people, you're filling out your assessment forms, but when you come back you've still got to repeat all that by putting it on the computer… occasionally, I've had to take a day out of my week to catch up. That's not often, but maybe once a month I'll have a day in the office, catching up, finishing off assignments, making sure things get sent to the GP or wherever. (Dot – memory nurse)*

Clinical staff were not the only ones who struggled with the reality of meeting paper targets; management staff also found the volume of paperwork difficult to justify. Here Nikki expresses her frustration at what she sees as an obsessive focus on the process of care, rather than patient-centred outcomes:

*I was at a conference not so long ago about dementia… and you know all of the things that came up are exactly the same things that always come up. And I do think, 'How the hell are they going to put that right then? Been doing it long enough.' And whenever you ask people about how they would put it right they would talk about a process but actually what we need to put right is [the] fundamental ethics of it. There is stuff like, you know, have space between the patient and the staff member… and making sure that people understand that. And about wearing your uniform, what does that mean to people? etc., and not using those as tools of power in a relationship if someone is already vulnerable. And it is about people understanding that and I don't think we do that… That is the stuff we should be doing, not ticking boxes and having systems and telling people, I don't know, make sure you label where you put the*

*stapler. We need to talk about the fundamentals here, about relationships. (Nikki – CMHT leader)*

### 6.1.8. *Building service user and carer involvement into the system*

Nikki's concerns in relation to people focusing on process at the expense of outcomes are shared by the current UK coalition government. And, in an attempt to move away from the large block contracts that typified the commissioning strategies of the previous government, the current government have introduced a new commissioning tool - Payment by Results (PbR) (Department of Health, 2012d). The idea behind PbR is that the government will specify what kind of service they want and providers will be paid if they produce the specified results. Ben views PbR as an essential part of modernising mental health services, believing it will help drive up the quality of services:

*If you give me a block contract and said, 'There's your block contract, there's your money, get on and do it. One, you might give…two teams a million pounds each. One team, for the million pounds might see fifty new patients a year; the other team might see four hundred new patients a year. Something wrong. (Ben – clinical services manager)*

Block contracts are straightforward to administrate, PbR is much more complex and as a result calls for a sensitive approach to commissioning if it is to succeed where the block contracts failed. Ben thinks the Mental

Health Clustering Tool (MHCT)[25] could just be the answer to the problem. Here, he explains how:

*What payment by results is going to mean, is that we start linking outcomes as part of the cluster. Now, part of, particularly for people with dementia, those outcomes are not going to be purely around a score from a medically derived tool, whatever that may be, MMSE or whatever, I think those outcomes are going to be about key markers in time, events taking place in a certain time sequence and about satisfaction from the patient, where they are able to [give it] and certainly from carers where they are involved. I think that's where we can focus in on the day-to-day stuff and if we get that right all the other strategy stuff almost should be reflecting what we're doing, as much as setting the agenda. (Ben – clinical services manager)*

One of the things that Ben understands very well is that even under the coalition government, targets are not going to go away. They may not get quite so many new targets to meet, but the likelihood is that the old ones are here to stay. The issue then becomes one of finding innovative ways to use the performance agenda to promote the involvement of people with dementia and carers. Before becoming the Clinical Services Manager, Ben worked as a CPN for many years; he also had personal experience of caring for a family member with dementia. He understands therefore the importance of seizing every opportunity to involve people in their care, despite the demands of the service. Here Ben shares how he thinks the MHCT can not only work for involvement, but can actively create opportunities for people with dementia and carers to be involved in

[25] A tool used to standardise patient needs into broad categories of need that are aligned to finance.

care planning right from the very beginning of their journey with the service:

*If I go back to the clustering bit, that bit about outcomes and the bit about being able to measure for the individual's [need], irrespective of what the diagnosis is really. Because you've identified the patient's level of need, by default that will then give you, in terms of interventions… the box with all the needs in. We know that this box will support that group so you end up with a toolkit of interventions. But then there is also a bit about, there is a box of choices there as well for the patients. I think that's when PPI will be something that we just do… So, we shouldn't be going out and saying, for example, 'We've done our assessment, this is what we are going to do.' We will be coming out and saying, 'We have done our assessment this morning and this is what we found, these are the choices, where would you like to go with this? What would you like us to do?' I think that once we get to that point I think that's when we will have embedded the principles about what PPI is about into our day-to-day work. (Ben – clinical services manager)*

In addition to strategies for involving people with dementia and carers in the day-to-day work of the service via care-planning and the judicious use of the modernisation and performance agenda, the MHSOP also had a user/carer involvement steering group that fed into the work of the Trust Board. Penny is the involvement officer for the MHSOP in the areas in which the research took place and her role is to create opportunities for service users and carers to get involved with the work of the Trust both at the level of the individual and strategically. When the role was first created, a lot of time was spent helping staff understand how they could incorporate opportunities for involvement into their everyday work. While there was some enthusiasm for involvement at the time, Penny noted there were also some challenges:

*When I first started doing the job there was quite a bit of resistance in terms of, 'Well, we know how to do our job,' kind of thing… 'We've been*

*doing it for years.' If a service user or a carer makes a suggestion it can be interpreted, maybe like, the wrong way. (Penny – PPI officer)*

It was acknowledged that there was a need for people who used the Trust's services to get together in a supportive environment to learn about developments in the service and to offer advice and support to each other. After talking to people to understand what they wanted from the new service, the first service user-led/carer-led coffee afternoon for older people's services was developed. In time, members of that group were encouraged to get involved with a new group that was in the process of being developed. This group, unlike the informal support group, would (eventually) feed into various meetings facilitated by the directorate management team. The new group, the User Involvement Steering Group, has been successful on some levels but not on others. It has been successful in terms of enriching the lives of people who are involved with the group enabling them to participate in training events (such as leadership courses), getting involved with various projects and contributing to conferences and seminars facilitated by the Trust. In this way, it has contributed significantly to the growth and development of a rich stream social and human capital in the local area. It has also been successful in providing opportunities for involvement group members to listen to senior managers from the Trust sharing new ideas and service plans, while giving their feedback on them. It has been less successful as a mechanism by which the directorate's management team can get timely feedback on particular issues affecting the service. Here Penny explains why:

*I think in terms of how that fits into the management structure [it] isn't very good. I think some of that is down to the reporting side of it, turning it around in a month and getting the stuff in, you know, what we've discussed, getting it all written up, getting it all sent out, I find that quite a challenge really. (Penny – PPI officer)*

Chloe, General Manager for older people's mental health services in the North of the Trust was very much aware of the challenges of facilitating the User Involvement Steering Group and while disappointed with progress so far in relation to feeding into the work of the directorate, was nevertheless cognisant of the many aims of such a group, both stated and unstated:

*They have kind of gone off on a tangent and talk about, quite rightly, talk about things that are important to them. What we are trying to do this year, is align their discussion more with what we are talking about as a directorate so we get more coherency between the two because I think at the minute that is not quite there for a lot of reasons which are predominantly historical, so that's, kind of, the task for this year. (Chloe – General Services Manager)*

Although very much in favour of the involvement group (and regularly in attendance as an invited contributor), Ben noted the difficulty of using small groups as a proxy for a much wider population:

*I think the other thing we need to be very careful with as well with… having your PPI groups and stuff is that it often brings the same people with their issues, not always fetching carers with carers issues. And, I think we have got to be really careful that we don't end up with going down a route that is about meeting the needs of a small group of people. We have to keep it in the back of our minds that this is actually about, for Tadham, a thousand people. It is not just about those two or three or those half a dozen or who are actively involved. Although they are very, very important…they contribute a lot… you [still] have to be careful… (Ben – clinical services manager)*

In the spirit of equity and access to services, Penny also worked with service users and carers to create a range of easy to read information sheets so that everyone, regardless of where they lived, could have access to the same level/type of information:

*Information is always one of those things that come up but at the time we…had a mixture of stuff where people were either getting told one thing or not getting told something or getting told something completely different. So, we did a lot of work at an individual level, working with service users and carers and we produced a pack and it explained all kinds of things like… what does it mean when you are seeing a Consultant… a social worker, the care services? So it was all those kinds of things. (Penny – PPI officer)*

The MHSOP facilitated the development of an involvement database which lists all the available opportunities for involvement in the service, together with details of upcoming conferences, workshops, seminars, etc. When members of staff would like to have user or carer involvement on a project they are working on, they advertise their projects via the involvement database which distributes a monthly update to its many subscribers. In this way, there is the possibility that a diverse range of people can become involved in a wide range of activities.

When asked directly about how they would involve people with dementia and carers in service development, staff found the question difficult to answer, partly because it was not an issue they had thought about and partly because (in the case of Chloe) they had put a lot of thought into it, but they had not been successful in attracting people.

*Ethna:* *If you were wanting to involve the team and the staff and families and people with dementia in the care homes in thinking about how they could develop and make the*

*service better, how do you think you might able to go about that? Get their input into developing the service?*

*Jessica:* *I don't know to be honest. They really only have one way into the service at the moment, that is speaking to the actual CPN when we go in to see the relative and I don't know what more. I've never actually given it any thought as to what 'more' we could offer.*

*Ethna:* *Could you think of how you could involve people with young onset dementia and the carers in the development of the service in the future or in the evaluation of the service in the future?*

*Liz:* *I don't know really. Because I don't know how they would do that. As I say, I know in the past, they've sent like questionnaires out for people, what they want, is there anything else we can do, this that and the other, but apart from doing things like that I don't know what we could do because regarding the, the development of the service a lot of that depends on money and that is out of our power.*

*Chloe:* *I don't know. We've struggled with this for ages and I really don't know what it is. You try arranging things in a variety of ways, asking them, you know, if we put something on, when would you like it? What's is the best time for you to come? Would you be willing to come? What topic would you want to talk about? How would you want the format? Or that kind of thing and you put something on and they still don't come.*

The final words on service user and carer involvement are from Ben who conceded that although service user and carer involvement may be happening at the level of individual practitioner dyads and triads, it had yet to become embedded in the everyday work of the service, which may go some way to explaining why staff found the involvement question a difficult one to answer:

*I would say we are starting a journey, we are nowhere near the end of that…there is still something there that PPI is very much something that we are mandated to do and we still haven't really got there. It is something that we do and I think we do reasonably well but, I still think we have got a way to go. (Ben – clinical services manager)*

### 6.1.9. *The importance of dementia champions*

It is because of the skills, knowledge and expertise that Ben brings to the MHSOP and his ability to understand how targets can work for the service, that Craig believes the importance of having a 'Ben' in every service cannot be underestimated, here he explains why:

*We've had Ben looking after us who wheeler deals and we have done very well by Ben. He is very shrewd, he is a business-man. And that is what we needed and it is really Ben who has helped to drive the service change we've got and almost pre-empt people by saying we will be the first pilot to do this or that. We've got a history of piloting things first, things that have come and gone and failed and been fashionable for six months and then disappeared but we've always done early pilots which is usually the best place to be. You are not the last person to be told to do it… Ben has used our resource, I have no idea how he does it but it doesn't matter, he has fixed it for us. And he's done pretty well. People get irritated with him because he seems a bit vague, but he's an ideas man. He comes up with ideas and he is honest about it. He's got a vague idea of how he wants it to look but it is really for us to try and work something out. We as a group will get cross with him because he hasn't told us exactly what to do and we have to work it out for ourselves…You need Bens in the organisation to sort it and if you don't have Bens then a bit of the organisation is a loser. (Craig – consultant psychiatrist)*

Ben's role as change agent was viewed by other members of the CMHT as foundational to the success of the service and its ability to continue delivering high-quality patient-centred care. Ben himself was only too aware of the critical need for a sensitive dementia-focused commissioning strategy. Ben admits to engaging in a certain amount of 'wheeler dealer' activities to ensure that he get what he thinks the service needs and commissioners, it seems, are more often than not on the receiving end of his entrepreneurial endeavours. Here Ben explains how he managed to 'find' the finances to fund the new young onset dementia service that people with dementia and carers spoke so highly about:

*We managed… to do a bit deal with the PCT, so we ended up getting a little bit more money than they thought. They thought they were going to fund us for part of a post, but I actually managed to convince them to do thirty grand a year. I said, "You said you would put that in". They said, "Did I?" "Yeah, yeah, yeah, definitely, well you better have because I have recruited to the post". "Oh, hell! What, what?" And so, in came the money. Well, you know, shy bairns get nowt. (Ben – clinical services manager)*

Ben was happy to admit that he sometimes bends (though never breaks) the rules to ensure his service gets the resources it needs to keep on growing and developing. Ben has a lot of respect for his commissioning colleagues in the PCT and is deeply thankful for the support the MHSOP receives from people such as Alana - a PCT commissioner:

*We have a very, very good commissioner in the PCT - Alana, she's very pro-mental health services for older people… she's very focused on trying to do the right thing and trying to secure stuff. I'm optimistic this year we will get some fairly significant additional funding, which will be additional to the contract so… it won't just be a one off fund it will be a permanent increase in revenue. (Ben – clinical services manager)*

### 6.1.10. *Creative problem-solving*

One of the ways that Ben is able to ensure the service stays lean, focused and efficient is by constantly thinking about the current pressures the team are facing. Not prepared to simply 'throw staff at a problem' Ben encourages his team to solve their current problems by looking carefully at why the pressures are occurring in the first place and dealing with that, rather than the symptom of the problem, which could be blocked beds, unacceptably long waiting lists or unmanageable caseloads. Despite being challenging for staff to think like this, Ben believes this is a much more productive way of reacting to and/or managing service pressures:

*I'm a great believer of just throwing staff at a problem doesn't solve a problem. Understanding what the problem is and a lot of it is about systems and processes, particularly in things like waiting times, response times and stuff like that. It's invariably about how you use what you've got, not the amount of what you've got. I've been cautious to not just fill vacancies like for like, so every time we have a vacant post we walk away and we sit down and we'll think, 'What do we actually need? What would we want from this? What are we short of? Where's the big pressures coming from? Who's the staff that are really, really under the cosh?' (Ben – clinical services manager)*

Always keen to make processes work for and not against involvement, Ben and the team decided to change the way they allocated new referrals. Like most of the Trust processes, there are targets that have to be met around how quickly new referrals are actioned. Ben and the team understand that the quality of the relationship (and therefore the potential for future involvement) between staff and patients hinges to some extent on how quickly someone is seen by a member of the team. Given the levels of family anxiety around being referred to the CMHT, a quick and friendly response to a new referral speaks volumes in terms of how the service respects (and therefore treats) people with dementia and carers. The current Trust target is for 80% of new referrals to be seen within six weeks, 100% seen within eight weeks. Here Ben explains how the team literally smashed that target:

*The other thing we have brought in is we used to do weekly allocation, we now go to daily allocations and that is just around speeding up the time from being referred to being seen so it's rare for any of our patients to wait longer than four weeks for a first appointment, very rare. (Ben – clinical services manager)*

Ben wants to see those referral times come even lower:

*There are elements we are struggling with at the moment with medical cover [there is still only one Consultant Psychiatrist for the MHSOP, instead of two] and that's creating some pressures in certain bits of the service but in general for first appointments, four weeks. I would like to get it down to two… My personal time would be, I would want eighty percent of all the patients referred to be seen within one week and the other, the hundred percent to be seen within two. I haven't told the team that yet because of, I think, they would all go aaahhh! (Ben – clinical services manager)*

Sometimes doing the best for the person with dementia is not about keeping them 'on the books,' it is actually about discharging them. Staff struggle with the thought of discharging people with dementia as they know people will need support for the foreseeable future. While people in receipt of memory drugs would never be discharged, Ben makes a clear case for discharging others, once the assessment and/or crisis period is over:

*They are now starting to see that actually keeping patients open to our service potentially does have disadvantages because there are things out there in the community that they are actively excluded from if they are known to us. To put it crudely, in intermediate care for example, if a patient, one of our patients needed intermediate care they are in doom. For whatever they have been in the acute trust for, they don't really care. If they found out that that patient belonged to us, then that patient wouldn't get intermediate care. Because they are obviously barking mad lunatics because they are all in the mental health services. So, there's a benefit [to discharging people]. (Ben – clinical services manager)*

### 6.1.11. *Possible futures for the service*

The importance of treating people quickly when they are admitted into hospital for assessment and/or treatment was an issue of critical

importance to the CMHT and the MHSOP. Here Ben talks about why it is so important:

*There's lots of evidence out there that people who go into hospital with dementia usually spend twice as long than those people who don't have dementia. The longer they are in, the quicker we deskill them, the quicker we take away their independence. There is almost, sort of, a breaking point, I would say, in my experience, probably between the ten to fourteen day mark. Once you start getting over fourteen days we are really almost actively deskilling people even though we are not wanting to do that, we do that. I think there's a big chunk of work about making sure if somebody hits the ward they get in, we have a very robust mechanism for reviewing that very quickly from the point they come in. So, is this the right thing for that patient? Is there a different way we can support them? And if there is; let's get them out and give them that support. (Ben – clinical services manager)*

In an effort to keep people out of hospital for as long as possible, the CMHT is currently working alongside Social Services colleagues to develop a specialist dementia home care service, which Ben hopes will be able to support people at home for longer. The CMHT has offered its services in terms of offering experiential placements so that home care staff can gain experience working with people with higher support needs. Ben is aware that this will still leave a service gap. Here, he explains how that gap will be closed:

*There is still a bit of a gap about what we do in our day-to-day work and what they will be doing. So we are looking to the under-spend to recruit some intensive support at home for those people bubbling up and coming to the point where we think we might need to admit them. [It will also be about] getting them out of the ward quicker and getting them a really good robust package in to support them for the first week or two at home. So I suppose really an intermediate care service, though I would never ever call it that. But that type of a service but purely for our patients. (Ben – clinical services manager)*

Never one to shy away from a confrontation if it results in a better service for people with dementia in his local area, Ben once talked with the local management team about the possibility of losing the majority of the service's dementia assessment beds. Although keen to point out that some people will always need access to in-patient services, Ben is adamant that the in-patient resource could be used more effectively elsewhere in the service:

*We talked about our bed usage and I was… well, I thought I was going to be put on the ducking stool and be dropped in the pond because I said, 'Well, why have we got dementia assessment beds? I said, 'Well, why have we got them? Do we need them? If I took all the staff who are currently working on the dementia assessment unit there for those twelve beds, I could provide a community service… which would provide, excluding our current community service, four staff in a morning, four staff on a day shift and three staff on a night shift. They could keep an awful lot of people out of hospital. It is about understanding, really understanding what the issues are. (Ben – clinical services manager)*

### 6.1.12. *Creating a no-blame culture*

The final data excerpts are related to the kind of culture the MHSOP have tried to develop across the service. In many ways, these final data excerpts explains why, despite almost continuous service change, CMHT staff are able to provide a service that is highly regarded by people with dementia and carers and, according to staff, is a good place to work:

*Craig:* *I think that I personally make an impact because I have a particular style, an open, accepting style and I don't see mistakes as mistakes, you know, we deal with it in a different way.*

*Ethna:* *Just something to learn from and move on.*

*Craig:* *Yeah. Yeah. What have we done here? You know, it could have been me or you that makes the error. It could have*

*been somebody else. I have a culture where we can acknowledge that we didn't get things right and it is okay to be wrong or to do something drastic and, and I am not going to shout at them.*

*Ethna:* *You don't see that culture in many places. There is a blame culture in many NHS organisations.*

*Craig:* *There can, there can be and it can operate at different levels and it will just get passed down the chain to the bottom but we've tried to avoid that. I think we've been fairly successful with that. And I think, I think to my credit, when I came, I changed the culture so that this could happen.*

The final data excerpt of the chapter is an extract from a field note made immediately after a meeting I was invited to observe. The meeting is a caseload supervision between Craig, the consultant psychiatrist and the two care home liaison nurses. The meeting begins with a report from Paula, one of the two nurses that, she had to admit a care home patient into the hospital assessment ward on a Friday afternoon. Paula is very upset by this as this is something the team try very hard to avoid as it contributes to bed-blocking. Paula is feeling frustrated and upset as she understands the resource implications of bed-blocking. Craig listens attentively to her story and when she stops talking, he begins. He spends a considerable amount of time reassuring Paula that she did everything possible to avoid this situation, that she followed protocol and therefore has nothing to reproach herself for. It takes a while for Paula to feel settled with the situation. She really cares that her decision has affected the performance of another part of the service and that Craig will have to deal with the situation after the weekend. The scenario provides a good example of how supportive members of the team are with each other,

how they respect each other's workload and how they do not attribute blame.

## 6.2. Chapter summary

In this chapter I have provided an overview of the organisational changes taking place within the MHSOP and CMHT generally and the dementia service specifically. The chapter began with an overview of the drivers behind the changes in the MHSOP (6.1.1), some of the challenges associated with that (6.1.2) and the drivers for change behind the transformation in the way community mental health services were provided for older people (6.1.3). I then provided an overview of how those service modifications influenced professional practice, i.e. via the implementation of standardised assessments and careplans (6.1.4) and the move away from hospital day care towards targeted therapy groups (6.1.6). Data highlighting the importance of support for carers and the lack of time to engage with this aspect of service delivery properly (6.1.5) is followed by data reflecting the philosophy of the service in terms of viewing service change as an opportunity not a threat (6.1.7). I then presented data on how CMHT staff believed service user and carer involvement could be built into the system (6.1.8). Following this, I presented data that supported the idea of a 'dementia champion' in every mental health service (6.1.9) and the role of creative problem-solving (6.1.10), some ideas on how the service might develop in the future (6.1.11) and data on the development of a 'no-blame' culture in the service (6.1.12).

# Chapter Seven: Discussion of the research findings

## 7.1. Introduction

In this chapter I draw together the findings presented in chapters 4, 5 and 6 to develop a critical analysis of the data and address each of the research questions. In doing this I develop links between the research findings, the evidence and theoretical arguments presented in the literature review together with evidence from other relevant literatures.

The chapter is divided into four sections. The first section discusses issues related to the first research question: To what extent can knowledges produced by people with dementia and carers challenge negative stereotypes of dementia while extending our knowledge on how to involve them in research about dementia and in service development?

This is achieved via an analysis of initial experiences of dementia which includes: i) a discussion of the experiences of the 'undementia-like' symptoms of early dementia, ii) support from family and friends following the diagnosis, iii) the public portrayal of dementia as fearful and unknowable, iv) challenging public portrayals of dementia, carer's journeys, v) the 'problem' of medically driven accounts of dementia, vi) the need for personal responses to dementia, vii) ways of challenging the system via personal responses, viii) a discussion of the role of people with dementia and carers in the production of knowledge and ix) linked to the previous section on knowledge production, a discussion of social

divisions including gender, identity and relationships, as identified in the stories shared by people with dementia and carers.

The second section discusses issues related to the second research question: What criteria do people with dementia and carers use to evaluate the memory service they used?

This is achieved via discussions of issues related to: i) service experience, ii) helpful interventions, iii) normalising the catastrophic, iv) communication and v) gaps in the service. At the end of this section I provide an interpretative summary of the criteria by which people with dementia and carers judged the memory service and associated services to be valuable. These criteria included: being listened to, being believed, being viewed as a person not a diagnosis and 'going the extra mile'.

The third section discusses issues related to the third research question: What values, attitudes and practices among mental health practitioners and service-level managers facilitate the development of high-quality services and the effective involvement of people with dementia and carers?

This is achieved via discussions of issues related to how the values, attitudes and practices of mental health practitioners and other professionals working within the CMHT facilitate effective service user involvement. This is carried out via an analysis of how members of the CMHT responded to a radical change in the way mental health services

for older people were delivered locally and the leadership style adopted across the service.

The fourth and final section provides a reflective account of my own role in the process of data generation and analysis and the role of critical gerontology as a tool to frame and inform the study.

## 7.2. RQ1: To what extent can knowledges produced by people with dementia and carers challenge negative stereotypes of dementia while extending our knowledge on how to involve them in research about dementia and in service development?

In this section I discuss data under the first analytical category devised during the evaluation of the Croydon memory service by Banerjee *et al.* (2007) and subsequently published by Willis *et al.* (2009): initial experiences of dementia. Narratives by people with dementia and carers in this category comprised their reflections on when they first began to suspect 'something was wrong'. These reflections are discussed within the context of their ability to sensitise those without a diagnosis of dementia to the challenges faced by those who do.

## 7.3. Initial experiences of dementia

### 7.3.1. *The 'un-dementia-like' symptoms of dementia*

For many people, the most confusing aspect of what would later be diagnosed as dementia was that the cognitive changes they experienced did not bear any resemblance to anything they had seen or heard of before. This may have been because most people tend to think of

dementia as something that happens to the very old and/or physically and mentally frail. No one in my research could relate those images of dementia to the otherwise healthy, vigorous person they had known for decades. Dementia is popularly associated with memory loss and symptoms such as losing confidence in social situations, or a failure to complete complex tasks were not initially associated with dementia. Anna and Helen, for example, both put their husband's changing health down to work-related stress and tiredness due to working excessively long hours.

Little is yet known about the links between stress and the onset of dementia, however, a longitudinal study of Swedish women exploring common psychosocial stressors by Johansson *et al.* (2013) reports a correlation between social stressors and the onset of dementia. Although, it is not possible to claim a direct link between stress and dementia, interest in the role of stress and the onset of dementia has led the Alzheimer's Society to fund research to investigate the subject more thoroughly.[26] A study by Leino (1989) predicting symptoms of stress precipitating musculoskeletal disorders identified 18 different possible symptoms of stress, including: loss of appetite, difficulties in falling asleep or awakening during the night, headache, lack of energy, fatigue or feebleness, anxiety or nervousness. It is not difficult to see why spouses

[26] Re: http://alzheimers.org.uk/site/scripts/news_article.php?newsID=1243

and people with dementia themselves would confuse stress with the early signs of dementia. To complicate the picture further, the Department of Health (2009) identified that in addition to stress, symptoms of fatigue and depression can also mimic the early signs and symptoms of dementia.

It is widely presumed that people delay going to visit their GP with worries about memory as they attribute the symptoms of dementia to simply getting older (Department of Health, 2009). But, no one in my study spoke of mistaking the changing health and behaviour of their spouse/partner for the changes that naturally occur with growing older. Spouses and people with dementia themselves did notice that things were 'not quite right' for many years before a diagnosis of dementia was made, but it was as if people took a mental note of any strange incidents when they occurred and simply filed them away. As a carer, Rex pointed out that he simply 'upped his game' to compensate for Julia's deteriorating skills and confidence levels. For the majority of those who took part in my study, it took a critical incident of such magnitude that it could not be ignored to convince families they needed help, for example, Will not being able to find his way home from work, Lewis miscounting the money, Michael forgetting how to use the ATM, Julia being abusive to her cat and tearing down curtains. Betty, who has a diagnosis of Alzheimer's disease, talked about the issue of recognising 'everyday slip-ups' and when they begin to point to cognitive decline. This raises an important question: at what point does 'everyday' forgetting begin to foreshadow the more sinister forgetting that is associated with dementia? Or, as Betty

reasonably asks, how can you tell when dementia 'clicks in'? In a study investigating how people diagnosed with Alzheimer's disease or MCI resisted social disenfranchisement, Beard and Fox (2008, p1513) reported that:

> *Although all respondents acknowledged forgetfulness, they had difficulty balancing the ''everyday nature of forgetfulness'' with the new ''reality'' that rendered what was previously considered normal, a symptom of disease.*

Langdon *et al.* (2007) interviewing 12 people with early stage dementia to elicit their views on how other people viewed their diagnosis, also found that some people in their study spoke about how and when forgetfulness became dementia and, like Betty, they compared themselves to others in an attempt to normalise their experience and to work out their own place in the grand scheme of things.

### 7.3.2. *Support from family and friends after the diagnosis*

In relation to support from family and friends, people with dementia and carers reported a mixed picture of support post-diagnosis. For some, like Betty and Bill and Michael, Erica and Adam, a diagnosis of dementia did not make a perceptible difference to the number or type of friendships they enjoyed, although Betty remained cautious in sharing news of her diagnosis. For others, however, everything changed. Rex, for example talked candidly about how their circle of friendships dwindled from a large circle to just one couple. He also reported that his brother and mother broke off their relationship with Julia once she entered the NHS

assessment unit. James talked about the attitude of his daughter towards his wife Eva, and of how Eva's two sisters refused to even talk to her on the phone. Anna talked about how her young family, already devastated by the experience of caring for their grandmother who had dementia, simply 'ran away' when their father was diagnosed with the disease just months after the death of their grandmother. The experience of people with dementia and carers in my research was similar to findings from research conducted by Alzheimer's Disease International (2012): once a diagnosis of dementia is received, the whole family is affected by a loss of friendships and ties. The Alzheimer's Society (2013) reported that almost two-thirds of people with dementia surveyed in a recent poll reported feeling lonely and depressed, while the remaining third said their friendship circles had decreased. Given these findings, it is unsurprising that those who participated in the advisory group in my research said that although they enjoyed taking part in the research, they equally valued the social networks they developed as a result of attending the meetings and the camaraderie they experienced during group meetings. These findings are important as they point to the importance of social contact and maintaining valued roles once a diagnosis of dementia has been made. The systematic involvement of people with dementia and carers in local research and service development initiatives could play an important role in alleviating the loneliness people say they feel after the diagnosis, contribute to the development of research capacity locally and improve the quality of services.

### 7.3.3. *Dementia: perceived as fearful and unknowable*

Many of those interviewed believed fear was at the heart of relationship breakdowns: fear of the future, either because they 'knew what was coming' or fear because they did not. These findings reflect those reported by the YouGov (2012) poll reporting that fear of dementia was greater than fear of cancer. Research by Corner and Bond (2004) eliciting the views of older people on dementia, found that some older people were fearful of a possible diagnosis of dementia in the future, uncomfortable talking to relatives or friends with dementia, and reluctant to contact health professionals with memory-related anxieties. A recent poll by the Alzheimer's Society[27] found that this situation has not changed much in the 10 years since Corner and Bond's study with up to 54% of people delaying going to the GP with worries about their memory because they were fearful of receiving a diagnosis of dementia.

In their research investigating help-seeking behaviours in people with cognitive impairment, Hurt *et al.* (2012) reported that people who did not seek help tended to distance themselves from others, attributed their memory problems to non-medical issues and engaged in emotion-based coping strategies. This evidence lends support to Lazarus' (2006) contention that people who do not believe their situation can be changed by intervention are unlikely to seek help. In order for people to feel less

[27] http://www.alzheimers.org.uk/site/scripts/news_article.php?newsID=2038

fearful about a diagnosis of dementia, they need to hear from people who have been diagnosed earlier in the disease process, as that will provide them with opportunities to hear more positive stories of dementia (Department of Health, 2013c). Findings from research by Manthorpe *et al.* (2013) into patient and carer perceptions of the diagnostic processes in dementia suggested that by listening to the experiences of people with dementia and carers, primary care practitioners would be able to offer support that was more sensitive to their needs. The irony in this situation is that people delay going to their GP because of their fear of dementia and what a diagnosis may mean for them and their family. But, fewer people being diagnosed early means fewer stories of people sharing stories of adaptation and support. A 'state of the nation' report on dementia by the Department of Health (2013c, p45) put the case succinctly:

> *These perceptions of dementia stifle the ability of people with the condition to live well. Promoting understanding of the condition and a living well message, showing how people with dementia can continue to make choices in their lives, is critically important.*

The importance of researchers involving people with early stage dementia in research on dementia and in service development in the early stages of the disease cannot be overstated. Stories from people with dementia in the early stages of the disease can play a vital role in persuading people to visit their GP early and being able to contribute to presenting a more balanced view of life with dementia. Such stories can

act as a powerful antidote to the more prevalent view of dementia as frightening and unknowable.

### 7.3.4. *Challenging stereotypes of dementia*

This view of dementia as frightening and unknowable is perpetuated because the lives of people diagnosed with the disease are shrouded in mystery and because even the word dementia causes those without the disease to recoil and withdraw. George and Whitehouse (2010, p343) argue that dementia is viewed as frightening because, “Losing one’s mind to dementia is, for many, the worst imaginable illness.” Kitwood (1997) argued that the most frightening aspect of dementia for most people was that when they looked at the person with dementia, it was as if they saw a foreshadowing of their own future. This view of the lives and worth of people with dementia as disconnected from the ‘real world’ is very much at odds with how people diagnosed with the disease viewed themselves in my research. Via their stories, people with dementia demonstrated a deep, abiding desire to stay connected to the world they inhabited and to the people they shared their lives with. They illustrated that people with dementia lived rich, full lives, engaged entirely with the here and now and in no way ready for the ‘long goodbye’. In particular their stories demonstrated a sustained and energetic determination to make themselves understood within the context of who they are as people of experience - as Betty, Lyn, Sophie and Will’s stories so aptly and poignantly illustrated. They were, moreover, acutely aware of the effect of their diagnosis on family, friends and neighbours and actively refrained

from sharing their diagnosis with people who they felt could not be trusted with the news. In a qualitative study canvassing the views of people with dementia on how other people reacted to their diagnosis, Langdon *et al.* (2007, p989) also reported that people with dementia were reluctant to share their diagnosis with people outside their immediate circle and they wanted those they did share it with, "…to respond authentically and honestly to them." People with dementia in my study chose to 'play down' the disease, something that for the most part they felt they were successful in doing as long as they steered the conversation away from complex topics, something that Sophie felt she did well. Sabat and Harré (1992, p446) have written about the self once people have been diagnosed with dementia and they argued that although the disease process may affect aspects of an individual's personality, loss of self occurs primarily when people without a diagnosis of disease 'other' the person with dementia, thereby stripping them of their ability to construct and reconstruct social selves:

> *Consequently the social recognition, or lack thereof, of a given self will have profound effects upon the ways in which the person's behaviour is viewed and the ways in which the person is then treated by others.*

Betty, Sophie, Lyn and Will's stories illustrate just how hard they worked to sustain their sense of self. Moreover, and despite a number of anxiety-inducing setbacks, they continually renewed their attempts to stay connected with the everyday activities of life and experienced deep

sadness coupled with frustration when people without the disease did not respect their input in a given situation.

People with dementia who took part in this research had experienced the symptoms of dementia for many years prior to taking part in my study, although some, like Betty and Lewis, only received their formal diagnoses one year earlier. Everyone was cognitively impaired, some moderately so. Lewis was 'moderately impaired' when I interviewed him, but by the end of the study Lewis was severely cognitively impaired and no longer able to communicate meaningfully with anyone other than his wife Mary[28]. It is highly instructive, therefore, that people with dementia who took part in the research were able to share stories of how they managed the symptoms of the disease and other people's attitudes towards them. Moreover, Lewis and Mary took part in two research seminars as part of the early dissemination of findings during which they shared personal details and i) how dementia affected them and ii) their involvement in the research.

### 7.3.5. *Dementia: carers' journeys*

Carers too shared experiences of oppression and exclusion because their spouse or partner was diagnosed with dementia. Their stories included

[28] Lewis and Mary were members of the advisory group. Lewis and Mary spoke at one of the two research seminars about their experience of dementia and of taking part in the research.

instances of being left to cope in ‘horrendous’ situations which over time sapped their strength and their ability to take care of their loved one and themselves. They referred to the stress involved in renegotiating relationship boundaries and shared stories that revealed their fear of sharing their spouses’ diagnosis. Stories of how they attempted to support their partner’s independence were balanced by stories of when unpopular decisions, such as taking away a spouse’s driving licence were made. The heartbreak, anguish and devastation that travelled alongside the reality of skills lost to the disease were captured and emotionally recounted by carers. Despite the fact that sometimes they were recalling events that took place several years ago, carers’ accounts of lives lived with a partner diagnosed with dementia, were often tearful and emotionally charged. For some, the exquisite nature of the pain they experienced was made yet more unbearable by the withdrawal of family relationships and friendships at the very time they needed that support most.

### 7.3.6. *The problem of medically driven accounts in protecting and caring for people with dementia*

From the perspective of critical gerontology, the stories shared by people with dementia and carers perfectly illustrated why modernist (medically driven) accounts of health dismally failed people diagnosed with a disease for which there is no medical cure. Bruens (2013), for example, argues that by focusing on interventions, medically driven accounts of dementia neglect the person. This places people with dementia in a

doubly dangerous position. For if the model of ‘care’ under which they receive services treats people with dementia as non-people, other people will do the same. This perhaps offers us one clue as to why the YouGov (2012) poll found so few people interested in learning more about dementia. Why learn more about a disease that cannot be cured? Better perhaps to just get on with life and forget about dementia and by extension forget also about those afflicted with the disease.

Stories shared by people with dementia and carers in this study consistently reflected a modernist mind-set that rejected them as people with a contribution to make, viewing them instead as a drain on ‘the system,’ not a real people and worryingly, as socially dead (Sweeting and Gilhooly, 1997; Brannelly, 2011; Barry and Yuill, 2012). In sharing stories of their everyday lives, people with dementia and carers exposed, in a remarkably non-judgemental and matter-of-fact way, the moral landscape of the communities in which they live. But why is this important? Byrne (1998, p121) writing about the links between premature death and social exclusion sums up the significance of the societal challenges facing people with dementia and carers:

> *It matters intellectually because it provides such a clear illustration of how the social and the individual intersect, and how the nature of that intersection is best understood in terms of the dynamics of far from equilibrium nested systems. It matters politically because it is wrong.*

### 7.3.7. *Dementia: the need for a personal response*

Stories shared by people with dementia and carers provide us with an opportunity to cross over into their worlds, to see things from their perspectives. See, if you like, where they intersect with the social. For some of the people who took part in the research, the meeting of the social and the individual was marred by the symptoms spelt out in Kitwood's (1997) theory of malignant social psychology that articulates the ways in which people with dementia are denied personhood. I argue that it is absolutely necessary for us to know about these social reactions, important for us to realise they are not single, one-off experiences in an otherwise perfect system, but are experienced widely by people with dementia and carers.

For decades, critical gerontologists have worked to identify the sociological processes by which older people are marginalised, discriminated against and excluded. De Beauvoir (1972), for example, drew upon the humanities, social sciences and personal reflection to identify the structural inequalities that generate ageism in the West. Her writing, unapologetically provocative, was written with a purpose: to bring about social change. Townsend (1981), similarly, wrote of the effects of political posturing that resulted in policies that progressively devalued older people. Others have written in the same vein, while applying the principles in differing contexts e.g. Baars (1991), Biggs *et al.* (2003), Estes *et al.* (2003), Baars *et al.* (2006), Katz and McHugh (2010), Wild *et al.* (2013), Bruens (2013) and Zeilig (2014). Their explanations of the

social processes are valuable because they sensitise us to the many layers and types of oppression older people in general and people with dementia and carers in particular face. Accounts by participants in this research also show the power of slipping (quietly and without making a fuss) into the shoes of people with dementia and carers. Their stories sensitise us to the multiple and interlocking layers of societal oppression they face on a day-to-day basis. Being jeered at while travelling on a bus because her shopping trolley tipped over (Sophie), having someone question her ability to use a computer when in reality she could run rings around them mentally (Betty), being unhappily married to a truculent and invalid spouse who took pleasure in boasting he was 'sicker than her' (Lyn), being told by your GP that dementia is related to low educational attainment when you have dedicated your life to the teaching profession (Lewis) and being afraid to tell people you have been diagnosed with dementia because of their possible reaction (everybody), are important illustrations of the faces of social oppression experienced by people with dementia who took part in this research.

Braye and Preston-Shoot (2003) caution of the danger of discussing issues of power and powerlessness as though we were not part of the problem and therefore, not part of the solution. Lukes (1974/2005) does the same, arguing that invisible forms of power are the most powerful and most insidious. Taken together, both warnings provide us with a powerful reminder that we need to take account of ourselves because, if left unchecked, we will 'other' society, depersonalising the many and varied

processes and strategies at work. We will treat society as something that can be subjectively observed, rather than an organic system we actively or passively participate in (Berger, 1970). In reality, not only do we swim in, are nourished by and help to sustain the great ocean of life that is society, we also, innocently or otherwise, collude with its many rules and regulations, becoming self-aware only when our own lives are touched by dissonance or discord (Berger, 1970). Better perhaps, to take ownership of the exclusionary forces we read so much about, so that we can get past Becker's (1967, p239) question, '…whose side are we on?' And, realise (finally), there are no sides: there is only 'us'.

### 7.3.8. *Challenging the system: the work of a lifetime*

Identifying the social structures and cultural processes that oppress people with dementia and carers may be the everyday work of critical gerontology. Writing about those structures and processes as they affect the lives of people with dementia and carers may be the work of narrative gerontology. Dismantling those structures and processes layer by layer is, however, the work of everyone. It is also the work of a lifetime. Perhaps this is why when we first become cognisant of issues of privilege and of power, the hardest thing we have to do is not related to the work involved in mounting a life-changing campaign – few of us are called to do that. Rather, our most difficult task is to keep the reality of the oppression at the forefront of our thinking and of our lives (Johnson, 2005). Because of the way stories by people with dementia and carers so powerfully illuminate societal intersections, both those that liberate and

those that oppress, they are ideal tools for teaching a new generation of critical gerontologists what theory 'looks like' in the lifeworlds of people with dementia and carers. Stories by people with dementia and carers are able to both illuminate theory and generate theory. Indeed, their explanatory power may just be unequalled.

### 7.3.9. *Knowledge production: it's a learning curve*

In addition to casting a light on how theory plays out in practice, knowledges produced by people with dementia and carers also played a valuable role in sharing understandings of their experience of dementia services, the importance of which, according to Manthorpe *et al.* (2013) should not be underestimated. Blackeby and Quarmby (2005, p118) did not involve people with dementia in their evaluation of a memory clinic because they thought, "…the nature of their condition may mean that the responses they gave could be unreliable." Similarly, in a study evaluating the clinical effects of an integrated multidisciplinary diagnostic facility (a memory clinic in The Netherlands), Wolfs *et al.* (2008, p304) selected proxies to provide qualitative evaluation data because:

> *…of the longitudinal nature of the study, the complex health problems of the study population and the anticipated progressive global deterioration of intellect and personality of the study population.*

People with dementia were not invited to give feedback on the services they used, but they nevertheless provided data for the researchers via the provision of three sets of MMSE scores over the course of one year. Not

involving people with dementia because their condition might be worse in the future, neatly side-steps a discussion of ways they could be engaged now. Holstein and Gubrium (1995, p8) refer to this kind of participation as epistemologically passive and that those who take part as, "…not engaged in the production of knowledge." There are undoubted challenges when involving people with dementia in qualitative evaluations of memory services. For example, researchers need to be well informed about the area they are researching, they need to be good communicators and able to practise empathy. They must be patient and considerate and, because of the tendency of people with cognitive impairment to wander off point, they need to be skilled in getting them back on track. None of these challenges are insurmountable and if researchers are open to viewing the event as a learning experience: then learn they will (McKillop and Wilkinson, 2004). Despite the severity of cognitive impairment experienced by people with dementia in my study, they, alongside carers, were able to provide valuable data on many aspects of the service they received. It is to those data that I now turn, beginning with a discussion of social divisions, particularly gender and identity, and their impact on the relationships between people with dementia and carers after a diagnosis of dementia as well as implications for CMHT staff.

## 7.4. Gender, shifting identities and relationships

In this section of the discussion chapter I review issues of gender, identity and relationships, social divisions of great interest to critical

gerontologists. It is not possible for me to review issues of ethnicity or race in relation to the data I collected, as, common to many studies into dementia, the people who took part in my study were all white European. Nor do I discuss issues of poverty, as that was not a subject I raised with people with dementia or carers, nor they with me. Although, the lack of social diversity could be viewed as a limitation of my study, it is, nevertheless, an accurate reflection of the ethnicity and background of people using services for people with dementia in the Trust that hosted my study where less than 1% of people with dementia and their carers were from a black, Asian or ethnic minority background.

Gender has been of central interest in analyses of carers and caring roles. Miller and Cafasso (1992) identified that care work is gendered work with two-thirds of all care-giving activities performed by women. Twenty-one years later, the Office of National Statistics (2013) reported similar findings in England and Wales, identifying that in 2011, 57.7% of carers were women and 42.3% were men, with women aged 50-64 providing most of the care although the gender inequality gap closes as people grow older, with retired men more likely to provide care than women. Russell (2007) has argued that, due to stereotypical images of the division of labour within the home, men continue to be viewed as not 'real' carers. Miller and Cafasso (1992, p498) believe this way of viewing caregiving has evolved because published articles investigating gender and caregiving have tended, "…to emphasize statistically significant gender differences, ignoring findings of no difference."

According to Russell (2007, p299), conceptualising men as 'getting it wrong' has diminished the visibility of male carers and the caring work they do rendering, "…the quantity and quality of care provided by men…as deficient." Russell (2007) furthermore argues that the literature on caregiving deals with the issue by either ignoring it or by down-grading the emotion-work men do. In an effort to provide a balanced account of the experience of caring, in this study I have presented female and male narratives of caring. These have provided rich, detailed accounts of not only the physical work of caring, but also the emotion work. Male carers talked just as freely as female carers about how the act of caring was much more than just doing the 'right thing'. Caring, rather, was viewed as an act of love with each act of caring seen as a declaration of that love. Far from being viewed as deficient, the work of male carers was presented no differently to that of female carers, resulting in complex descriptions of care-giving that poignantly revealed both the tender and tough side of love and caring for a spouse with dementia.

In their meta-analysis of gender difference in caregiving, Miller and Cafasso (1992) argue that given the lack of significant differences between female and male carers, comparing how women and men perform their caregiving roles (as a way of identifying who provides 'better care'), either via instrumental work, i.e. helping with or taking over the practical activities of daily living (Keady and Nolan, 1996), body work, i.e. helping someone with bathing and personal hygiene needs (Twigg, 2000) or emotion work, i.e. being there for someone emotionally, supporting and

encouraging them (Thomeer *et al.*, 2015) is less helpful than understanding their individual experience of caring. In my research, I was interested in understanding how carers drew upon their gendered experiences and how those experiences influenced their relationship with the person they cared for.

Given the gendered life experiences of women and men, it should come as no surprise that women and men do perform care differently (Miller and Cafasso, 1992). This could be linked to the idea that female and male carers draw upon different 'cultural scripts' to both learn how to 'do' care and also how to express what they are doing to others. Additionally, the language: or cultural scripts that care-givers and care-receivers use to express their ideas about the caring experience may also differ. According to Goddard and Wierzbicka (2004, p153) cultural scripts, "..refers to a powerful new technique for articulating cultural norms, values, and practices in terms which are clear, precise, and accessible to cultural insiders and to cultural outsiders alike." Key to understanding the significance of cultural scripts is the acknowledgement that language not only enables us to express how we think and feel, but, according to Goddard and Wierzbicka (1995), language influences how we think. These are critical issues to consider in relation to people with dementia, who progressively lose the ability to express their own thoughts, wishes and desires linguistically and who come to depend upon others to articulate those ideas for them. For the people with dementia and carers who took part in my research, this was one of the most challenging

aspects of dementia. Finding the balance between care and control was something that required the development of sensitive negotiation skills as living with the symptoms of dementia added an additional layer of complexity to the capacity of language to do the work of expressing need. What is interesting about the narratives in my research is how the experience of dementia, both as a care giver and a care receiver, challenged taken-for-granted ideas on gender, identity and relationships, forcing those involved to write their own cultural scripts delineating what it is to be an older person in Britain today giving or receiving care.

### 7.4.1. *The gendered context of care*

Findings from a content and visual textual analysis of six popular magazines, led Clarke *et al.* (2014, p26) to argue that images of late masculinity are largely missing from popular culture and when they are available older men are, "…depicted as experienced and powerful celebrities or as healthy and happy unknown individuals." The absence of older male role-models facing and overcoming everyday challenges creates a situation in which there is a dearth of male scripts for older men to follow. Clarke *et al.* (2014) argue that the few that are available are of powerful, virile, lean, good-looking men abseiling and yachting into the sunset, spending their disposable income on time-shares and fine wines. These images, far removed from everyday life, bear little resemblance to the life of older men generally and to the lives of older male carers in particular. According to Blytheway (2011, p80), unrealistic images of ageing are problematic as they, "…create expectations of what it is to be

a person of a particular age." Images of carers (women or men) performing everyday caring activities do not feature in many advertising campaigns. Unsurprisingly, neither did they feature in any version of a future envisaged by those who took part in my study. For Betty, diagnosed with Alzheimer's disease in her early seventies, and her husband Bill, the reality of living with a long-term and degenerative condition is far removed from their expectations of life after retirement. Bill talks about the experience of walking in the door of the GP surgery a husband and walking out a carer and the lack of experience (or training) he had for the role. Rex, whose wife Julia has young onset dementia, also spoke about how ill-equipped he felt to manage Julia's illness, as it was not something he had either come into contact with previously or had even thought much about. Not only was there no 'male script' for Bill and Rex to follow, their experiences were alien, frightening and left them feeling out of control.

Early studies into carer burden, such as the one by Barusch and Spaid (1989), reported that men had a tendency to report less carer burden than women. Almost a quarter century later, in research investigating the support needs of 15 older men caring for spouses with dementia, Milligan and Morbey (2013, p2) reported that older men are still less likely than women to ask for help and frequently only ask for assistance in a crisis. In my study, female and male carers spoke equally of the difficulty of asking for assistance, admitting that it took a crisis for them to seek help and even then, it was often outsiders who took the initiative. Anna, for

example, shared her story of the period during which Jim her husband became incontinent during the night. Anna became so overwhelmed with the practical tasks of washing soiled sheets and duvets, that it took a support worker from the Alzheimer's Society to take control of the situation and get support in place. Rex shared how he and his wife Julia almost had a complete breakdown before they asked for help, while Louisa reported that it was during a crisis situation, in which Nevin had injured himself during a fall, that a neighbour finally convinced her to seek professional intervention. Nick's interview was particularly instructive. At multiple points during our conversation, Nick ended a sentence by repeating variations of: *we're okay, we're doing okay, we don't need much help, we don't ask for much help, because we don't need much.* A later conversation with the Consultant Psychiatrist from the CMHT revealed that due to the advanced nature of Maria's illness, and the subsequent toll of caring for her at home, he advised Nick to consider finding a nursing home placement for Maria two years previously. It was a suggestion that Nick was still ignoring at the time of the interview.

It was not just the caregiving spouse who struggled with changing roles in the home. Betty struggled with Bill's change of role from at-work professional-to-retiree-to-carer in unexpected ways. Independent and resourceful, Betty learned to be content with Bill working long days and playing golf in his time off. An Accountant with a large circle of girl-friends and an active social life, Betty carved out a life for herself in Bill's absence. When Betty retired, Bill's continuous presence in the house and

his interference in her everyday life began to become a serious problem for her. Before taking early retirement, Betty had total responsibility for managing the household and freedom to live her life as she choose. Although, as Betty pointed out, in the beginning, this was not so much a choice but the sequelae of Bill rarely being at home before his retirement. When Betty began to need help with everyday activities, particularly when she could no longer drive, she began to experience Bill's presence as troublesome and his decision-making as interference. She became angry that Bill thought he could 'just walk in' and take over her life and the activities she enjoyed with girl-friends: shopping with Bill, Betty explained, was not the same as shopping with girl-friends. Betty and Bill's difficulties arose out of their shifting roles in the home after retirement and Betty's diagnosis of dementia. Betty gives the example of Bill constantly asking her if she is okay when she is working in the kitchen, particularly if she drops something. Betty perceives this as controlling and tries to re-gain control by not answering him, pretending she hasn't heard and even going so far as to drop something on purpose. Bill views his actions as something a man who loves his wife should do and he struggles with Betty's reaction to his protective stance. In Betty and Bill's complex relationship, both draw on their gendered experience of being in the world and both struggle with the shifting boundaries of their new identities as care-giver and care-receiver and the subsequent shift in roles. Russell (2007) suggests that society lacks a vocabulary to adequately express the care work done by men. Perhaps this goes some way to explain why

Betty (who does not have access to these alternative male scripts either) experiences Bill's actions as control rather than care.

In relation to the role of identity and the of loss of self in Alzheimer's disease, Sabat and Harré (1992, p443) argue, "The primary cause of the loss of self is the ways in which others view and treat the Alzheimer's sufferer." At the heart of their argument is the acknowledgement of the key role played by language in the construction of social reality, which introduces the idea that other people can construct (and therefore limit or enlarge) the life experiences of people with dementia. Sabat and Harré (1992) argue strongly that there is a self that remains whole and intact, despite the severity of Alzheimer's disease. In their research exploring the relationship between identity and cognitive and functional abilities, Caddell and Clare (2012a) also argued for a non-linear relationship between the decline in cognitive functioning and identity. In other words, there is evidence that elements of self are preserved even during later stages of dementia.

In a study investigating differences in identity between people of the same age with and without early stage dementia, Caddell and Clare (2012b) found that with the exception of one element (people without dementia reported higher levels of identity-related stress than those without dementia), there were few difference between the groups in the way that identity was perceived and/or understood. In my research Sophie, Betty, Nevin, Will and Lyn demonstrated high levels of awareness in relation to how other people viewed them and they revealed

complex strategies for protecting their identity, including deciding who to tell and how much to tell them. Sophie explained that she actively constructed an image of herself as capable and in control, particularly when relating to outsiders, while Betty felt it was important to present an image of herself as always willing to go on a social outing. Lyn demonstrated great sensitivity towards her daughter who had asked: *will I get it (Alzheimer's disease) as well?* In these and in other ways, managing identity was implicitly linked to managing relationships, either for the purpose of keeping outsiders at bay, maintaining friendships or for offering comfort to family members.

In their study exploring the impact of early-stage dementia on identity, Caddell and Clare (2011, p379) suggested there was a paradox at play whereby people with dementia experienced both identity continuity and change. This was an issue that Betty spoke about at several points during her interview using the example of spelling. Betty's spelling has deteriorated since her diagnosis. At first this caused her great angst. In time, however, Betty decided that it did not matter to her that she could no longer spell as well as she used to as there were still many other things that she could do. Betty used this example to encourage other people with dementia not to fret over what they have lost, but to rejoice in the things they can still do, otherwise, Betty noted: *you could drive yourself mad!* Her thoughts on managing her illness resonate with Beard's (2004, p415) observation that, "Despite normative expectations and the rhetoric of loss, respondents deliberately manage their

interactions to make sense of their lives and preserve themselves." It is an observation also reported by MacRae (2010, p293) who, in her study examining the impact of the illness on identity, found, "…that, given the necessary resources, persons with Alzheimer's can live meaningful, purposeful lives and creatively manage to protect and preserve identity."

Despite a lack of evidence that people with dementia lose their identity once a diagnosis of dementia has been made, for those who took part in my research, presenting that self to others was problematic, perhaps because as Sabat (2001) pointed out, much depends upon the maintenance of a complex, reciprocal agreement with those around us. We need the cooperation and consent of others. We need other people to agree with the version of self that we want to present. In their research exploring the experience of living with dementia in the community, O'Sullivan *et al.* (2014, p483), found there was a, "…conflict between living positively with dementia, and enduring the negative attitudes that typify the dominant social discourse." This finding, although discouraging is not new. Kitwood (1997), for example, argued that it was the negative social positioning of people with dementia that effectively hampered their efforts to live well with the disease. Kitwood's theory of malignant social psychology builds upon research by Brody *et al.* (1971) into 'excess disabilities' wherein the experiences of people with dementia are curtailed more by those without dementia than by the limitations of their illness. Sabat (2006) extends the ideas of Kitwood (1997) and Brody *et al.* (1971) arguing that we can understand the effect (both positive and negative) of

social positioning on the lives of people with dementia by analysing their social interactions with others. For in doing so, we are able to understand better how people with dementia experience the symptoms of dementia, the strategies they employ to ameliorate their damaging effects and the way they find and make meaning in their everyday lives.

This presentation of self has become something of a battleground for Betty and Bill. Betty wants to present a version of self that is strong, capable, independent, organised and in control. But, perhaps to help him understand and play out his new role as carer, Bill tries to construct a version of Betty as someone 'in need'. This lack of cooperation and consent between the couple on their new roles in the home, causes them both distress. Sabat and Harré (1992) warn that if carers, such as Bill, persist in their construction of the person they care for as lacking, i.e. in their skills or abilities, then people such as Betty will eventually acquiesce, playing the role of the 'Alzheimer's patient' until such time as they no longer have to fake the self they present and the new fake self (the one that is lacking) becomes the dominant and only self that others see and they are capable of presenting.

In their qualitative study of male carers, the support they give and they support they need, Milligan and Morbey (2013) reported that engaging in caregiving activities challenged men's gender identity. In my study, Bill's account of how he had to re-think his communication strategies with Betty, reveals that initially, in his day-to-day communication with her, he drew upon the male script he was most familiar with: being dominant,

controlling and bossy. That he should, is not surprising, given how little information there is about doing masculinity as an older man (Clarke *et al.*, 2014) and as an older carer (Russell, 2007). In time, however, and with the benefit of experience, Bill reported that he is learning to communicate with Betty in a way that validates her contribution. He is learning to view her declining skills not as deficiencies, but as opportunities for them to connect. Since Betty's diagnosis of dementia, Bill's view of what constitutes masculinity has broadened to include being kind, patient, generous and nurturing. In the absence of a male script to follow, Bill created his own and in doing so, gave himself permission to be emotional, nurturing, demonstrative and joy-seeking: aspects of himself he had not developed or encouraged before. Bill's story resonates strongly with Russell's (2007) argument that common perceptions of male carers as less caring or less demonstrative than female carers are misleading and that male carers are nurturing and innovate.

In his qualitative study investigating the distinctive strengths and weaknesses of 14 older male carers caring for a spouse with dementia, Russell (2001) identified that the men who took part in his study demonstrated a style of caring that drew upon aspects of management and nurturing. While Russell's findings were a welcome addition to the knowledge about male carers at the time, I argue that utilising a management/nurturing style of caregiving is not linked specifically to gender. In my study both female and male carers provided powerful accounts of caregiving that illustrated their utilisation of a caregiving style

that encompassed aspects of both management and nurturing. Ribeiro *et al.* (2007, p307) identified power and control as, "…a contextual condition of marriage" and suggested it posed particular challenges for male carers, who may have a need to tightly control situations. In my study, female and male carers both spoke about the need to tightly control every aspect of their lives as, without such organisation, their daily lives dissolved into chaos. For them, managing and nurturing were not two different things. For the carers in my study, management was nurturing. Ewan, for example, described getting his wife Liza ready for a doctor's appointment as akin to planning a military operation. However, he viewed his actions as an act of love, of him trying to do the best for his wife, just as she did for him before she became ill. Bill viewed being organised as the best way to cope with daily challenges. Nick viewed solid organisational skills as key to the couple getting out and about and linked to this: making (and keeping) Maria happy. Through these (and many more stories shared in the research), issues of power and control were linked to keeping things together, to protecting each other from harm and providing joy-filled moments and were not explicitly linked to gender.

In their research exploring the ways gender might influence caregiving, Calasanti and Bowen (2006) identified that both female and male carers crossed gender boundaries in order to maintain the household, give care and as a way of maintaining the gender identity of the spouse with dementia. Calasanti and Bowen (2006) believed that this crossing of gender boundaries was most often invisible and took the form of multiple

small acts of compassion aimed at maintaining the identity of their loved one. The unique ways in which carers negotiated these shifting gender boundaries was illustrated in my research by Louisa's tearful account of how she attempted to promote Nevin's masculinity by supporting him to take care of his pocket money. That this attempt failed was devastating to Louisa who understood that looking after the money was linked to Nevin's role in the house as the financial provider and money-manager. The loss of this role brought home to Louisa the reality that Nevin was ill and he was not going to get better. Louisa grieved for the loss of Nevin's role in which he could be 'the man of the house'. She grieved for Nevin's loss, at the unfairness of dementia and for herself. She grieved also for the impact of these shifting gender boundaries on their relationship which she experienced as being stressful. Anna also shared her experience of watching her husband Jim lose the ability to look after himself and spoke emotionally of the pain of watching her husband, lover, father of her children and best friend become ever more incapacitated, until he could no longer understand how to make a cup of tea. For Anna, this shifting of gender boundaries, was something she felt she tackled afresh each day with Jim's gradual loss of independence. The grief Anna experienced watching Jim lose the roles through which he expressed his masculinity rendered the grief ongoing and almost incomprehensible. Anna asked quietly, more to herself than of me, *how it is possible to deal with this aspect of Jim's illness?* Bill and Nick also talked extensively about the difficulty of negotiating shifting gender boundaries. For Bill, this was linked to Betty's loss of independence and manifested most clearly in the

loss of her driving licence. For the first time in their marriage, Betty had to rely on Bill for social activities and for simply getting out of the village. Betty's role as money-manager and house-manager was severely challenged with the onset of Alzheimer's disease and even though she understood she needed assistance with these aspects of her life, Betty resented the implication that she was helpless. Nick also had to assume the role of money-manager and house-manager. Interestingly, although they expressed surprise at the amount of work to do and the unending nature of the work, at no point during their interviews did Bill or Nick express resentment at taking over the roles their wives had previously occupied in the home.

Abel (1990) noted that in relation to research on caregiving, most researchers tended to focus on caregiving activities and caregiver stress that, while important, presented a one-dimensional view of caring as burdensome and stressful. It seems that with respect to reporting the view that caring is first and foremost burdensome, not much has changed. For example, in a study examining links between the mental health of carers and the coping strategies they use, Snyder *et al.* (2014) reported that caregivers most frequently reported viewing caring as a burden. In my study, however, while both female and male carers spoke candidly about their caregiving experiences, about the challenges they faced and the setbacks they endured, they also spoke about the joy of caring, of caring for their spouse as an opportunity to pay them back for a

lifetime of love and care, and as an opportunity to connect in ways not previously explored.

In their article reporting on the results of a field study of the 'descriptive organisation' of caregiving, Gubrium and Lynott (1987, p279) argued that moving beyond mere description of caregiving tasks and carer stress to a description of the experience of giving (and receiving) care opens up a new vista, one in which our sense of humanity is strengthened and our lives enriched:

> *Caregiving was something to behold, to be proud of, a sign of effective human stewardship. Success and effectiveness were not simply a less-negative outcome of the care equation as commonly understood; rather, they were realizations of an entirely different sense of human straits and obligation.*

Like the carers who took part in Gubrium and Lynott's (1987) study, female and male carers in my study viewed their experience of caring as challenging in terms of the way it forced them to re-think who they were (and who they were becoming), so that they could be the best version of themselves for the person they cared for.

Understanding the importance of identity, gender, relationships, ethnicity and other social divisions is critical for the development of services that meet the needs of people with dementia and carers. Investigating how they affect the lives of people with dementia and carers, both positively and negatively, could provide a strong foundation for CMHTs to begin the process of involving them in the development and evaluation of dementia services. The Center for Creative Leadership and The King's Fund

(2014a) argue that an organisation's culture is shaped and revealed with every single interaction including how staff talk to patients and to each other. These everyday interactions are a powerful litmus test of the values underpinning the service. From stories shared in the research it was clear that people with dementia and carers developed strong, positive relationships with CMHT staff and that CMHT staff highly valued these relationships, frequently moving beyond a professional relationship to one of confidante and friend. People with dementia and carers spoke movingly of the support they received and CMHT staff spoke passionately about the needs of the people they support and the strategies they engaged in to ensure that support was delivered. In many ways it seemed as though people with dementia and carers judged the quality of the service they received by the strength of the relationship they had with CMHT staff.

A careful reading of the research narratives by people with dementia and carers reveals that once diagnosed, the service they received from the CMHT tended to revolve around the development of a relationship with just one or two members of the CMHT. Although these relationships were valued by everyone involved, carers, were not routinely offered a carers' assessment or made aware of the fact that they may profit from a welfare benefits check. Moreover, CMHT staff themselves identified that, due to pressure of work, they rarely took into account the needs of the carer. When asked directly about the services they received people with dementia and carers reported that they were not offered access to

memory or skills training workshops, and were not always offered information on local services or resources. One of the Advisory Group members was a development worker who worked for the Trust, but in a different geographical area. Through her contribution to the group we learned that people with dementia and carers in their service were systematically signposted to local dementia cafes and other local services in a way that, with the exception of the rural community of Wickham, people with dementia and carers in my study were not. It is clear from the narratives created by CMHT staff that they had a strong commitment to values-based practice, and in many instances, went out of their way to ensure people with dementia and carers felt valued and cared for, key aspects of the work of collective leadership as espoused by the Center for Creative Leadership and The King's Fund (2014a, 2014b). It is also clear, however, that CMHT staff could become more proactive in connecting people with dementia and carers to support groups and other local resources and ensuring the needs of carers become a central feature of a multiagency assessment process. Working on an inter-agency basis is a critical aspect of collective leadership, as it ensures that every part of the patient journey is underpinned by staff working within a shared value base. The Center for Creative Leadership and The King's Fund (2014a) argue that the delivery of high quality care can only be achieved when organisations work closely together, sharing their skills, knowledge, expertise and other resources. Tanner (2011) acknowledges that within a social work context, issues of identity and how they relate to people with dementia have only just started to be addressed. She argues,

moreover, that the skills, time and commitment required for work to significantly impact social work practice can only happen within a supportive organisational context. It is likely that the development of a culture of resource-sharing and respect for the role other organisations play in the health of people with dementia and carers could play an important role in elevating good quality care to high quality care. Developing stronger relationships with other community-based organisations, actively looking for ways to connect people with dementia and carers with local resources, proactively investigating ways that people with dementia and carers can be involved in this process and supporting staff to do their job well, could all play a role in the continued development of dementia services offered not just by CMHTs but the wider network of dementia services.

## 7.5. RQ2: What criteria do people with dementia and carers use to evaluate dementia services?

In this section I discuss data related to the five remaining analytical categories devised by Banerjee *et al.* (2007) during the evaluation of the Croydon memory service and later published by Willis *et al.* (2009). The categories are: service experience, helpful interventions, normalising the catastrophic, communication and gaps in the service. Data in this section comprised reflections by people with dementia and carers on their experiences of using the memory service, the CMHT and other services.

## 7.6. Service experience

> *Nothing is more likely to focus the mind on the impact of decisions on patients than to listen to patients' experiences. The most important cultural change should be to require all who work there to place the patient perspective at the forefront of their minds and deliberations in all they do (House of Commons, 2013a, para: 1.110, p63)*.

With only a small number of qualitative evaluations of memory services involving people with dementia as interviewees - and no published studies involving them as advisory group members - there is little existing knowledge of individuals' experiences of using memory services. The narrow knowledge base includes studies by: Cahill *et al.* (2008) and Innes and McCabe (2012) in which people with dementia were interviewed on aspects of a memory service and by Manthorpe *et al.* (2013) who reviewed the diagnostic experiences of people with dementia and carers and in studies providing feedback on all aspects of memory services such as by Willis *et al.* (2009), Morgan *et al.* (2009) and Dixon *et al.* (2012). Carers have been involved in the evaluation of other specialist dementia services, such as the Admiral Nurse Service which provides support for carers who are caring for people with dementia receiving highly specialist or end-of-life care (Woods and Algar, 2009).

My own experience of seeking to understand how people with dementia experienced the memory service was an instructive learning experience for me. When asked about their experiences of the memory service, the majority were unaware of 'the memory service' but they were aware of visits from their memory nurse or other CMHT professionals. When I explained that memory nurses worked as part of a larger memory service,

they seemed puzzled. I quickly realised that it was necessary to ask participants to comment on their experiences of the service they received from a named practitioner. Once I established an effective way to ask people about the service they received, they had no difficulties providing feedback.

### 7.6.1. *Overall satisfaction*

Overall, people with dementia and carers expressed high satisfaction with all CMHT staff, including reception staff, office staff, nursing staff, medical staff and allied health professionals. In fact, some people with dementia and carers could not sing the praises of the CMHT staff and some GPs highly enough, saying things like, ‘we’ve become lifelong friends’ ‘they were as good as gold’ and so on. Positive accounts of GPs are counterbalanced with several negative accounts. Betty and Bill’s experience of their GP was exceptionally good. In addition to referring Betty to the CMHT, their GP also diagnosed two other health-related issues that were promptly dealt with. Nevin and Louisa’s account of receiving their diagnosis was so traumatic that Nevin was seriously ill for several years afterwards and Louisa became ill with stress. They only started to recover their health when Nevin was finally referred to the CMHT for cognitive assessment and treatment. Every person with dementia and every carer expressed high levels of satisfaction with all aspects of their interaction with the memory service including, the speed with which they were assessed, the way their diagnosis was communicated and the six-monthly visits following initial assessment.

Carers of people who had been diagnosed with young onset dementia, were particularly happy with the service they received, praising the quality of information they received in response to day-to-day issues, the speed of response and the level of support they received post-diagnosis, including monthly visits and access to the fortnightly young onset dementia drop-in service.

High levels of service user/carer satisfaction on the services provided by a memory clinic were also reported by Lee *et al.* (2010),[29] who reported that 84% of respondents expressed satisfaction with the service and thought it a valuable addition to the care provided by their family doctor. Findings on service user/carer satisfaction reported in my study were similar to that reported by Willis *et al.* (2009) in that overall people with dementia and carers rated staff interventions highly, even using the same words 'the right pegs in the right holes' as carers in the study by Willis *et al.* (2009, p31). However, there were aspects of the service people with dementia and carers were more ambivalent about, for example, being prescribed memory drugs. The majority of people with dementia I interviewed were unsure of whether the drug made any discernible difference, but were, nonetheless happy to take them just in case they made a difference they were not aware of. As both Lyn and Sophie pointed out, 'How would I know if the drugs made a difference, I have

[29] This was a paper-based survey that solicited brief, but useful responses

dementia don't I?' Only one person, Harry, felt the drugs were making a difference, but he was unable to say how.

### 7.6.2. *Cognitive assessments offered by the memory service*

The use of the cognitive assessment tool: the MMSE, was disliked by Betty, feared by Lewis and accepted without any problems by Lyn. Betty's criticisms of the MMSE were related to the fact that some of the questions were irrational in relation to what a retired person would reasonably need to know. This was not a blanket dislike of the tool, just of particular questions. Betty understood the significance of taking the test and was happy to take it. Lewis, however, feared the test and would become anxious when he knew the appointment was drawing near. Lyn viewed the test as just another part of the work she and her memory nurse did together. As such, she did not feel anxious about taking the test. The current MMSE has been in use, unchanged, since 1975. Given the feedback from people with dementia in my study and from other studies, i.e. Beckett *et al.* (2013), it is perhaps the right time to work with older people, with and without dementia, and mental health practitioners to ascertain the kind of questions that would more accurately reflect their experience of ageing in the 21st century.

### 7.6.3. *Activities of living assessments offered by OTs*

An insightful comment by Betty raised a concern in relation to the use of standardised occupational therapy assessments. Betty was asked to prepare toast when she was still preparing the family's' meals (with

assistance from Bill with setting timers and lifting heavy pans). Not only was this confusing to Betty but it focused on a deficit rather than a strengths model invalidating any accurate assessment of Betty's needs. Betty's account of her occupational therapy assessment demonstrates the importance of implementing standardised assessments within the wider context of people's everyday lives. It also highlights the importance of using a strengths-based model which makes the best use of the skills individuals with dementia still have (Yarry *et al.*, 2010). This will help to ensure that people with dementia are not offered assessments that fall below their current skills level.

Writing in the context of nursing practice, Dahm and Wadensten (2008) identified that if the practitioner is inexperienced, standardised care plans (produced from standardised assessments) may not reflect the actual needs of the person being assessed. During one of the two research seminars, I talked about Betty's reaction to the occupational therapy assessment. A member of the audience was an occupational therapist and she said it was an issue the profession was aware of and even though it was 'embarrassing' to have it raised as an issue in a public seminar it was an issue that needed to be discussed openly.

## 7.7. Helpful interventions

Turning now to evaluations of specific interventions, I discuss the interventions reported by people with dementia and carers in the study. The Croydon memory clinic evaluated by Willis *et al.* (2009) worked in an

integrated way with local adult day care centres or with the local branch of a not-for-profit organisation such as the Alzheimer's Society. This level of partnership working was not evident in the memory service in my research. The services identified by Willis *et al.* (2009) were used by people in my study, but not always as a result of a referral by memory staff. All of these services offered valuable support for both the person with dementia and for carers. Louisa and Nevin talked about the adult day care centre that Nevin attended once a week. Both Nevin and Louisa were happy with the type and level of activities that were offered during the day and both were happy for the placement to continue for the foreseeable future. Anna, a carer, talked about the support she received from the Alzheimer's Society whose knowledge of local services and how they operated proved invaluable. It was through the Alzheimer's Society that Anna accessed MIND and took a number of courses which she enjoyed.

Will, who has early onset dementia, talked about the gardening club he attended at his local allotment. Will found the gardening club hugely valuable for a number of reasons, i.e. he enjoyed the manly banter, learning new skills, getting out of the house for a break and not being treated as Will the person with dementia, but Will the gardener. Given how beneficial people with dementia and carers found these other services, it would be helpful for the memory service to have closer links with them and other opportunities and make this information available to individuals when they are referred to the memory service.

During the period of my research, CMHT staff offered two types of targeted groups. The first type was a young onset dementia drop-in support group which met fortnightly at the CMHT base. People with young onset dementia attended the group with their spouse or carer. Group members were offered light refreshments and used the opportunity to catch up with others in the group. The group was facilitated by a memory nurse and an occupational therapist. Group members could also talk privately with staff if they needed to.

During the time I attended the group, one person was discharged as he had recently received a diagnosis of mild cognitive impairment (MCI). Discharged from the service, he was no longer eligible to join the session. Eric (the man who was discharged) had been a regular user of the day hospital and he was in attendance at most of the young onset drop-in meetings. During one of the meetings I asked him what he appreciated most about the meeting. Eric replied that it was the social aspect he enjoyed most, especially being able to meet up with other people in the ‘same boat’ as him. He also appreciated the opportunity to chat with staff about any day-to-day worries he had.

The targeted therapy groups facilitated by the occupational therapy team were aimed at providing targeted support to older people with mental health problems rather than people with dementia. There were two groups in progress when the research was taking place. One group was ‘a men’s group’ and the other was ‘a ladies group’. The purpose of the groups was to build confidence and develop skills. Targeted therapy

groups replaced the work of the day hospital in Tadham, a service that had been highly valued by people with dementia and carers. Feedback from the occupational therapists (OTs) suggested the day hospital service had been valued by older people with mental health problems and by people with dementia because it offered them a place to go where they could learn new skills, meet new people and take a break from just being at home all day. Carers had said to day hospital staff that they valued the service because it provided them with a short break from their caring responsibilities. The day hospital service was closed as part of a wider organisation of the MHSOP as it was felt that the service encouraged patient dependency, lacked throughput and was not focused on health-related treatment or support. However, data from the OTs suggested that the issue of patient dependency and low throughput remained, with patients being allowed to continue attending the groups for much longer than the prescribed six or eight weeks as there was a lack of alternative services that met their needs in the local area. OTs noted that the social aspect of the targeted groups was highly valued by all those who attended. One person who had been discharged from a group, wrote to the team repeatedly to say she missed the opportunity for social interaction. This kind of feedback from patients was viewed by staff as having created dependency. Writing in the context of targeted memory groups Hazell and Punshon (2003) questioned whether the social support people experienced by attending the groups was actually more valuable than the interventions delivered. This did seem to be the case for the targeted groups offered by the OTs.

In terms of accessing services that were available in the local community, OTs identified lack of transport as a major barrier for people with dementia. This issue was also identified in a consultation exercise conducted by the Office of the Deputy Prime Minister (2005) which reported that lack of accessible transport for older people played a key role in their social isolation. OTs reported that few of the people with dementia they worked with had the confidence to travel alone on public transport, relying heavily on others in this area. OTs reported that one of the reasons the targeted groups provided by the CMHT were so appreciated was that transport to and from the group was arranged by CMHT staff. Lack of transport to groups in the local area resulted in people with dementia facing seemingly insurmountable barriers to access them. As highlighted by Willis *et al.* (2009), the value of targeted support via small groups was noted by everyone who used them, but the question of where people with dementia can access social support after the groups have finished needs to be addressed by the CMHT.

As highlighted in the previous section, the majority of people with dementia and carers found it difficult to say whether taking memory drugs made a discernible difference to their cognitive health. So it is difficult to conclude if the intervention was a positive one or not.

## 7.8. Normalising the catastrophic

This category is related to how useful people with dementia and carers found the interventions provided by the memory service and other

services and whether it helped them to find a way of living with a diagnosis of dementia. In relation to the young onset dementia drop-in support group, people with dementia and carers both found the drop-in very beneficial. At least one carer (Rex) continued to attend the group after his wife was admitted into fulltime nursing care, due to the friendships he had made. Another carer also attended the group for many months after his wife had died, although he did not attend during the time I attended group meetings. Will, who has young onset dementia, said he valued being in a group were he was accepted and did not feel under pressure to 'perform' for others. Helen and Ewan, both carers, also commented on the support they experienced by attending the group. Carers attended the young onset dementia drop-in not just to receive support, but to give it. On one occasion, Ewan (a working farmer) was too busy to attend the session with his wife Liza and her family support worker Christine, prompting Christine to say, "*It's better if you go because you'll brighten things up a bit." "Right well yeah, I'm quite good at that."* A reciprocal attitude towards membership of the group was noted by everyone.

In terms of the benefit of other organised groups, Anna said she also found it very helpful to meet other people who had gone through other kinds of difficult situations. Anna admits, it was during her time at MIND that she finally began to heal. In the study by Willis *et al.* (2009) people with dementia reported on the value of attending groups and other dementia-related services provided by the memory service. In particular,

they appreciated having somewhere to go where they could meet like-minded people and somewhere they could just be themselves. In my research, people with dementia and carers also found the groups they attended beneficial in terms of making new friends, learning how to manage the disease and getting support when they needed it.

People with dementia and carers in my study also talked at length of the personal strategies they devised to 'normalise the catastrophic'. This included complex strategies for communicating with neighbours and friends who did not know of the dementia diagnosis to ensure they did not find out. It also involved re-starting activities that had been put on hold. Betty talked about this extensively pointing out the importance of doing things even if you felt afraid and of never saying no to an invitation to go out in case people stopped asking. Normalising the catastrophic was also about finding a way to accept the change in other people's attitudes and letting go of family and friends who did not want to remain in contact. Carers spoke of creating joy-filled moments and of learning to appreciate the small things and of making the most of everyday activities. For couples, one of the most challenging aspects of normalising the catastrophic was the in relation to the subtle relationship adjustments that had to be made, sometimes on a daily basis. This was challenging on a number of levels, including spouses assuming responsibility for tasks previously undertaken by the partner and which they now found difficult, e.g. driving. It was also challenging because losing skills was a reminder

that the disease was degenerative which brought new challenges in terms of grieving.

## 7.9. Communication

There can be little doubt that effective communication between professionals and between professionals and the people they care for is at the heart of high-quality care (O'Daniel and Rosenstein, 2008) and that ineffective communication threatens the quality of care (House of Commons, 2013a). In my study, people with dementia and carers reported high levels of satisfaction with communication, from the speed with which they received their diagnosis (once the CMHT received the referral), to the way in which the diagnosis was given, the respect with which they were treated at their appointments (the cups of tea were particularly appreciated) and the level of communication at subsequent appointments. Information given by team members was reported as being given in a sincere and empathetic manner. Once diagnosed, people with dementia and carers were seen primarily by a single, named worker. Only in emergencies would non-named workers respond to a call for assistance. This contributed to the development of therapeutic relationships that were highly valued by people with dementia and carers. All who participated in my research were told of their diagnosis of dementia as soon as that information was available. One carer, Louisa, had thought that her husband Nevin who has hearing difficulties had not heard what the consultant psychiatrist had said when she was explaining the diagnosis. She decided not to tell him, but later discovered Nevin had

heard and understood. Nevin was given his diagnosis of dementia at his first appointment with the consultant psychiatrist.[30] Although the news was difficult for Louisa, she explained that the relief at knowing what was wrong was, for her and the family, an overwhelming, but positive experience. All study participants felt their named worker supported them on every level, including emotionally and reported that CMHT staff 'bent over backwards' to ensure their needs were met. These findings contrast with those from the evaluation of a dementia pathway in Leeds by Beckett *et al.* (2013), that reported good rapport with people with dementia, but mixed findings on the emotional support offered to carers, with some staff not viewing carer support as part of their role. All carers who took part in my study felt that their named worker was easy to get in contact with. Bill and Ewan in particular noted how reassuring it was to know someone was just on the end of a telephone. And, on the occasions they did call, they were very happy with the rapid response they received. People with dementia and carers spoke warmly of all staff employed by the wider service (including receptionists and medical secretaries) describing them as 'round pegs in round holes' with Christine (Liza's family support worker) going as far as to say, she did not think anyone could do the job better than their memory nurse.

[30] The consultant already had access to the results from several scans that had been requested by a local neurologist.

Although people with dementia and carers expressed high levels of satisfaction in relation to the way CMHT staff communicate with them, when I first asked them to talk to me about the memory service, they were unaware that they were receiving a 'memory service'. This issue raises an important point in relation to how people with dementia and carers think the memory service operates. If people with dementia and carers do not know that the memory service comprises a range of professionals, including social workers, this may prevent them from asking for advice on issues they think are non-nurse related. The information needs of people with dementia and carers has been well documented (Department of Health, 2007; National Institute for Health and Clinical Excellence, 2011b; Newbronner Liz. *et al.*, 2013), as has the burden and stress of having a diagnosis of dementia and of being a carer for someone with a diagnosis of dementia. People who are overwhelmed with stress are likely to experience difficulties identifying and/or prioritising their health and/or social care needs. Memory services, therefore, need to be proactive in that respect by providing written information on the memory service and how it fits with the CMHT. This could be in the form of a booklet giving information about the role of other professionals working in the CMHT together with examples of the type of help people could request, physiotherapy, and support with daily living skills or counselling.

## 7.10. Gaps in service

Although the overwhelming message from people with dementia and carers was of high levels of service satisfaction with the service they received from the CMHT and a reluctance to identify gaps in the service, deeper readings of interview transcripts revealed some suggestions for improvement from carers. I was also able to identify one issue as a result of attending the young onset dementia drop-in support group. In this section I discuss the issues identified.

### 7.10.1. *Communication between services*

Bill, a carer, spent a considerable amount of time in his interview talking about the issue of communication between different parts of the health service. While his partner Betty was in the process of being diagnosed with Alzheimer's disease, their GP picked up on two other health-related issues. This resulted in a number of hospital appointments with two different specialists and a range of professionals. During the course of keeping these appointments, Bill became very concerned that no one, other than himself, had any idea that Betty had been diagnosed with dementia. Although Bill tried to ensure that he was with Betty when she was asked questions about her health this was not always possible and he became worried. Bill felt that there should have been a central record that health professionals could access, so that they understood Betty's unique health-related needs. My research interviews took place just as summary care records were being piloted. They are designed to contain

information such as details of prescription medications, allergies and any drug allergies or reactions. One way of overcoming the problems Bill and Betty identified would be to include a brief summary of the dementia diagnosis, together with emergency contact details of someone who knows the person well.

Anna, a carer, also talked about a lack of communication between the different branches of the health service. Her concern was linked to meeting the information needs of people with dementia and carers. She had found herself being passed from service to service to find the information she needed. Finally, it was the Alzheimer's Society that sorted everything out with just one or two calls. The value of the Alzheimer's Society was mentioned by a number of carers, yet there is no longer a branch of the society in the area.

### 7.10.2. *Targeted therapy groups*

Although the CMHT facilitated targeted therapy groups, they were used mainly by people with functional mental illness, i.e. depression, psychosis and none of the people with dementia or carers in my study were offered access to them. Participants spoke at length about the challenges of living with a diagnosis of dementia, including the lack of information on what dementia was, how to care for someone with a cognitive impairment whose skills were constantly changing and memory management tools. During interviews with memory nurses and OT staff I did not directly ask them why they were not providing targeted groups for people with

dementia or their carers, so I do not know the rationale for the lack of provision. The CMHT is ideally situated to facilitate these courses.

Another issue in relation to the targeted therapy groups was in relation to their secondary role of social support. The OTs facilitating the groups recognised how valuable the groups were in this respect and in some cases people were allowed to continue in the groups for longer than was originally intended. Given public acknowledgement that people with dementia experience loneliness and social isolation (Department of Health, 2009), and social support for families diminishes rapidly after a family member is diagnosed with dementia (Alzheimer's Society, 2013), on-going social support is a priority that could be addressed by memory services working in partnership with other service providers such as the Alzheimer's Society.

Lack of support was particularly noticeable for people like Eric who was diagnosed with mild cognitive impairment (MCI) and discharged from the memory service once his diagnosis was confirmed. This left Eric unable to access support offered by the memory service. As 10-15% of people with MCI will go on to develop dementia[31], it seems clear that an opportunity is being missed to establish support systems for people diagnosed with MCI who go on to develop dementia.

[31] http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=120

### 7.10.3. *Counselling support for people with dementia and carers*

The role of counselling in supporting people with dementia and carers after a diagnosis of dementia is becoming more widely recognised. For example, the value of psychotherapy for the person diagnosed with dementia was identified by Bender and Cheston (1997), Bryden (2002) and Yale (2013), while the value of all kinds of talking therapies for people with dementia and carers was identified by the Alzheimer's Society (2012). Counselling is thought to be able to play an important role in helping to normalise the experience of dementia by i) helping people with dementia and families understand what dementia is and how it could be affecting the person diagnosed, ii) giving the family an opportunity to confront and come to terms with the many emotions that accompany a diagnosis of a terminal illness and iii) by helping people with dementia and families address some of the more challenging aspects of dementia in terms of how other people will react to the diagnosis by tackling issues such as identity loss and stigma, the process of which can help people with dementia adapt to their new identity[32]. The implication is that counselling services could usefully be added to the range of services made routinely available to people with dementia and carers. This could take place either via the memory service directly or via the GP. Who

[32] http://www.counselling-directory.org.uk/dementia.html#howcancounsellinghelppeoplewithdementia

provides the therapy is less important than ensuring people are actually offered the opportunity to receive this support.

While it was clear that CMHT staff generally and memory service staff in particular played an important role in helping people with dementia and carers feel supported, there was still a clear gap in the support offered to carers post-diagnosis. Ted, a memory nurse, acknowledged this gap, admitting they were overwhelmed with work and unable to give this aspect of their work sufficient attention. Beckett *et al.* (2013) also reported on a lack of support for carers post-diagnosis. Given i) the important role carers play in the continued good health of people with dementia and the financial resources that could be saved by preventing people with dementia from being admitted into hospital (National Audit Office, 2010), ii) the right for carers' to have their needs assessed under the Carers and Disabled Children Act 2000 and iii) the duty of local authorities under the Carers (Equal Opportunities) Act 2004, to assess the ability of carers to provide care, even if they have not asked for it, the memory service could work more closely with their social work colleagues to ensure carers of people with dementia are routinely offered a carer's assessment.

## 7.11. An interpretative account of the evaluative criteria discussed by people with dementia and carers

The following sections present an interpretative account of the stories shared by people with dementia and carers. Their stories illustrate the difference between being listened to and not being listened to, of being believed and not being believed, of family, friends and staff who saw the

person not a diagnosis and who went the extra mile to make them feel valued. In sharing their stories, people with dementia and carers highlight the core values that services need to embody if they want to provide services that are valued by people with dementia and carers. Cook and Miller (2012, p1) argue that, “In a climate of limited resources, being clear about what makes a difference to individuals is more important than ever.” Berwick (2009, p562) argues that understanding the needs and wants of individual patients can, and should, form the building blocks of public policy:

> *…becoming responsive to individual needs and wants can give us the information we need for informed social choices to be made where they mostly belong: at the level of public policy*.

### 7.11.1. *They were listened to*

People with dementia and their carers identified the importance of being listened to. There are, however, different kinds of listeners. There are those who, though listening, are yet busy formulating a ‘quick-fix’ to whatever is being discussed. And, there are those who are able to sit quietly and simply be present with the person talking. It was this second type of listening that people with dementia and their carers found valuable. This could be because many of the challenges dementia brings to the lives of those affected by it are not amenable to intervention.

I argue that thoughts, even troubling ones, need to be spoken about and integrated into the dementia narrative that people affected by the disease need to create. This means that creating the family’s dementia narrative

could be as critical to the health of the family as any other type of intervention as it is through the creation of narrative that people with dementia and carers may be able to make sense of what they are going through. Holstein and Gubrium (2000, p3) alluded to this mysterious melding of memory and biography when they wrote of a self that is consciously and unconsciously constructed through the re-telling of stories, “Not only is there a story of the self, but it’s been said that the self itself is narratively constructed.” Narratives change in response to the changes wrought by the disease, yet the experience of facing, speaking about and being respectfully listened to, enables people to make sense of their lives with dementia. Although I make no claims that this process of re-integration through mindful listening is a universal one, it was clear from the stories people with dementia and carers shared, that those who had access to partners, family members, friends or professional helpers who consistently saw them, and treated them, as people of experience found living with the symptoms of dementia a less depersonalising, less isolating experience than those who did not.

Michael and his family provide a good example of how being respectfully listened to sets up the conditions necessary for involvement to flourish. Michael, for example, had a number of anxieties in relation to his brother Alec who also has dementia, but who is now in a care home. Michael, Erica and Adam believed Alec was admitted into care long before he needed to be in order to meet the needs of his terminally ill wife and their daughter who works fulltime. Michael visits his brother regularly and

although he knows Alec is resigned to his lot in life, knowing his brother does not really want to be there, coupled with the knowledge that he is unable to change the situation, causes Michael to feel conflicted and stressed. This on-going state of inner conflict causes Michael to have frequent nightmares about going into a care home, something he does not want to happen. The stress of Michael's inner conflict is, to a large extent, ameliorated by Erica, Adam and other members of this large, happy family. They facilitate Eric's visits to his brother and they actively encourage him to talk about how he feels about the situation, especially when he starts to become stressed. In this way, the whole family is able to live with the stress that inevitably accompanies a life lived with a diagnosis of dementia. This way of coping was what Holstein and Gubrium (2000) referred to when they proposed that in creating and re-creating narratives, what we are doing is actually creating and re-creating ourselves.

### 7.11.2. *They were believed*

Being believed was of great importance to people with dementia and carers, particularly at the beginning of the illness. Some of the stories shared in the research highlighted the need for professionals (especially GPs) to simply believe their patients' stories when they present at the surgery and to acknowledge that, when it comes to dementia, they, as professionals, did not always know best. The consequences of not being believed are uncompromisingly demonstrated in Eva, James and Tessa's story, the pain of which continues to resonate through their lives. They

are also demonstrated in Louisa and Nevin's account of his journey to a diagnosis of dementia. One issue highlighted was the failure of some GPs to recognise the early signs and symptoms of dementia and the subsequent delay or failure to refer the family to their local CMHT for appropriate treatment. Even after the GP realised that Nevin probably had dementia, he continued the treatment for epilepsy and did not refer Nevin to the CMHT. Failure to refer to specialist support can result in people with dementia not receiving the early treatment and support they need and carers becoming stressed and in need of active support for years after the initial diagnosis and probable admission into long-term care earlier than need be for people with dementia (Department of Health, 2009). This is a critically important issue given that an Impact Assessment carried out by the National Audit Office (NAO) identified that delaying admission into long-term care by as little as a week could realise annual savings in the region of, "…£130 million from 2013-14 (a net saving of £533 million over ten years)" (National Audit Office, 2010, p5). Moreover, if admitted into hospital, a lack of appropriately skilled nursing and medical staff means that people with dementia are more likely to stay in hospital longer, become more confused and dependent, be prescribed antipsychotic medication they do not need and be discharged into a care/nursing home (Alzheimer's Society, 2009).

Stories from people who were believed when they shared their anxieties about their own failing mental powers or those of their spouse/partner, were consistently positive, despite the challenges of living with dementia

day-to-day. Professionals' responses to accounts of people with dementia and carers as reliable and truthful representations of what they were experiencing were highly valued. Betty and Bill provide a poignant example of how, despite the day-to-day reality of living with a disease that ebbs and flows, experiences of being believed, supported and encouraged by their GP and later by their memory nurse provided a protective shield against the stresses and strains of living with dementia now.

### 7.11.3. *They saw a person not a diagnosis*

The ability of others to view the lives of people with dementia and carers as simply that – lives lived with the symptoms of dementia, was a critical factor in whether people affected by the disease lived well or otherwise. The buffering effect of positive interaction was so restorative that even when family and friends let them down, people with dementia and carers could still find ways of living well with the disease. Unsurprisingly, "See me, not my diagnosis," was a theme that ran through many of the stories shared by people with dementia, especially those shared by Betty, Sophie and Will. But, it is Rex's story that most aptly illustrates the difference sensitive, knowledgeable professionals can make when carers are left to cope alone. Rex and his wife Julia had many friends and a few close relatives before Julia became ill with early onset Alzheimer's disease. By the time she received her diagnosis, however, there were few friends and even fewer family members in evidence, especially in the months leading up to Julia's admission to hospital for cognitive

assessment and treatment. Alone and unsupported, Rex struggled with the effects of sleep deprivation among other stressful experiences.

Once the GP became aware of the family's situation, a referral was made to the CMHT and Leanne, Julia's memory nurse, became involved in the situation. Both the GP and Leanne treated Julia with the utmost respect. They also respected Rex's decision to continue to take care of Julia at home, intervening only when Rex wanted/needed them to do so. It was Leanne who was able to persuade Rex to allow Julia to be admitted for assessment and it was the GP who talked to Rex about the necessity of getting on with his life after Julia's admission into full-time care. The reason Leanne and the GP were able to support Rex both in relation to making difficult decisions about Julia's care and in relation to Rex developing new friendships in his life, was because they respected Julia and Rex as people first and foremost. They did not treat Julia as a 'patient' and Rex as a 'carer'. Rather, Leanne and the GP treated Rex and Julia as people of experience who were living with the effects of a terminal illness.

### 7.11.4. *They went the extra mile*

Stories of individuals who went the extra mile are peppered throughout the accounts of people with dementia and carers. These stories have a special place in the research narrative because they illustrate how we could make a difference in the lives of people with dementia by continuing to value them. They also illustrated the importance people with dementia

and carers attached to them. Practitioners and people who went the extra mile helped people with dementia and carers feel they mattered, that their lives meant something to someone, that they were not forgotten. Although there are too many examples to write about in full, stories about going the extra mile included: services in which appointments could be made at short notice, services that included a cup of tea and a friendly chat on arrival, staff who 'dropped everything' in response to an anxiety-filled call, staff who were 'never in a dash', consultant psychiatrists who preferred house visits over clinics, professionals who knew 'how to be a friend', neighbours who responded to crisis situations with tact and generosity, workers who were happy to challenge 'the system', PCT commissioners who went out of their way to ensure mental health services for older people were fairly resourced, CMHT staff and managers who never lost touch with the reality of living with dementia, and carers who, although they sometimes lost hope in the system, never lost hope in the person they cared for.

## 7.12. RQ3: What values, attitudes and practices among mental health practitioners and service-level managers facilitate the development of high-quality services and the effective involvement of people with dementia and carers?

> *The NHS…touches our lives at times of basic human need, when care and compassion are what matter most (Department of Health, 2013b).*

In this section I discuss narratives produced with staff from the CMHT and the MHSOP. Their narratives are discussed with a view to gaining a deeper understanding of how the values and practices of mental health

practitioners and the strategies adopted by service managers contributed to the delivery of dementia services that were highly valued by people with dementia and carers in this study. To assist in that exploration, narratives are discussed within the framework of collective leadership as espoused by the Center for Creative Leadership and The King's Fund (2014a). In the context of the NHS, collective leadership is an emergent form of leadership that argues partnership working with patients and carers and the development of a culture of responsive, imaginative leadership is the only way to challenge and change the prevailing (and often negative) culture of the NHS. Collective leadership shares much in common with transformational leadership where leaders, "…stimulate and inspire followers to both achieve extraordinary outcomes, and, in the process, develop their own leadership capacity" (Bass and Riggo, 2005, p3). Collectivist leaders embody the best of transformational leaders, but instead of inspiring followers into action, they develop followers into leaders. Collective leadership initiatives flow from the boardroom to every member of staff, influencing the way staff work with each other and the way care is provided to patients. See diagram 7-1 for how a collective leadership strategy works in practice.

**Diagram 7-1: A collective leadership organisational flowchart**

Taken from: Center for Creative Leadership and The King's Fund (2014, p14b) Delivering a collective leadership strategy for health care.

In pluralistic organisations such as the NHS where strategic leadership roles may be shared across multiple teams, where inter-departmental objectives may be conflicting and power structures unclear (Dixon-Woods *et al.*, 2013), implementing a collective leadership strategy is no easy

task. Denis *et al.* (2001) identified the fragile nature of such arrangements and argued that in order for a collective leadership strategy to work, there would need to be agreement between members of the leadership team, between members of the leadership team and their subordinate team members and between team members and the external environment, in the case of the NHS, patients, families and the public. However, despite the challenges of implementing it in practice, Gelfand *et al.* (2007) argue that collectivist approaches to leadership can meet organisational objectives while promoting the ability of team members to become less fearful of making mistakes, take initiative and support other team members.

Findings from the Francis Inquiry identified the criticality of developing a no-blame culture together with a culture of care and compassion capable of engaging ‘every single person’ in the development of high-quality, patient-focused care in the NHS (House of Commons, 2013a, para 41, p18). Taking the findings from the Francis Inquiry forward, the Berwick Report, an independent review into patient safety in the NHS by the Department of Health, argued strongly for service leaders to have the courage to undertake radical systemic change, develop a no-blame culture and reassert the primacy of working with patients and carers to achieve high-quality, compassionate care (National Advisory Group on the Safety of Patients in England, 2013). Taking these critical issues as their starting point, the Center for Creative Leadership and The King's Fund (2014a) argue that via the development of collective leadership,

these ideals can be integrated into the everyday work of the NHS. Although the MHSOP in this research still has, by its own admission, a long way to go, the wide-ranging service changes already implemented together with their treatment of change as an opportunity to move the service forward,[33] illustrate a style of leadership that embodies the core values of collective leadership.

### 7.12.1. *Developing a 'no-blame' culture*

The cornerstone of this new culture of 'compassionate care' (Department of Health, 2012c) is the adoption of a 'no-blame' culture that views mistakes as an opportunity to learn, not scapegoat. One of the most consistent messages to emerge from the findings in my research was the clear articulation of a no-blame culture that reverberated across the service. The consultant psychiatrist accredits the systemic integration of a no-blame culture with his particular style of leadership that infused a no-blame ethos into the everyday work of the service. The effects of this positive culture were evidenced in multiple ways. For example, during the caseload supervision meeting between the consultant psychiatrist and the two care home liaison nurses from Tadham. One of the nurses was anxious because, due to unforeseen circumstances, she had admitted a patient into the hospital assessment unit on a Friday afternoon,

[33] When I refer to the service I am discussing the wider mental health service for older people: the MHSOP. When I refer to the team I am referring to the CMHT, which also includes the memory service.

something the service tries hard to avoid as it can lead to long-term bed-blocking. The response from Craig was clear, consistent and empathetic: please don't worry about this, this is not your fault, these things happen, I will take care of it. The nurse understood the implications for the admission on the rest of the team, including the in-patient unit and was upset at the thought she had created extra work for other parts of the service. There was tacit acknowledgement that such decisions affected other parts of the service, consequently CMHT staff tried hard to ensure their actions did not impact negatively on others, hence the care home liaison nurses' apologetic attitude.

A positive approach to problem-solving characterised other interactions between the leadership team and other members of staff including between Lily, a specialist registrar, Craig, the consultant psychiatrist and Ben, the clinical services manager. During Lily's term as specialist registrar, the service had undergone radical changes across the board. These changes included moving from a psychiatrist-led model of service to a nurse-led one. Lily was outspoken in her criticisms of the changes, fearing that they would lead to lower levels of care for patients with complex presentations of dementia. Lily reported that Ben and Craig listened to her concerns and spent considerable time helping her to understand how the new system would improve patient care by shifting the responsibility of assessment from one over-burdened individual to the team. Lily eventually came to respect the changes and see the benefit for both patients and medical staff. Throughout the process, Lily reported

that her point of view was respected, she was given opportunities to talk through the issue at length and felt enabled to work effectively afterwards, processes that according to Center for Creative Leadership and The King's Fund (2014b, p16), exemplify the core values of collective leadership, “Senior leaders, individually and as a team, need to engage in real dialogue with each other and with staff throughout the organisation.”

### 7.12.2. *Developing a culture of support for staff*

This regard for how the work of one member of staff impacts upon another was also evidenced in the way staff behaved towards each other and in the everyday decisions they made, particularly in relation to how CPNs in the functional team[34] supported CPNs in the organic team[35] when referrals to the memory service became overwhelming. Despite the fact that a major feature of the service developments in the CMHT was the creation of two separate teams, and that staff continued to express concerns in relation to de-skilling,[36] they still had a ‘we are all in this together’ attitude and they worked together to ensure every referral to the memory service resulted in a first appointment within four weeks, something that can take up to three months in other parts of the UK

[34] Functional mental health team: support older people with depression, psychosis, etc.

[35] Organic mental health team: Support older people with dementia

[36] CPNs expressed concern that they would become de-skilled if they no longer worked with older people with dementia and that memory nurses would lose their counselling skills.

(House of Commons All-Party Parliamentary Group on Dementia, 2012). The Center for Creative Leadership and The King's Fund (2014b, p3) predicted that the outworking of collective leadership values in practice would result in increased collaborative working that would result in everyone in the organisation making:

> *...it a personal priority to ensure the success of the organisation as a whole, rather than focusing only on their individual or immediate team's success in isolation.*

Narratives produced by CMHT and MHSOP staff provided multiple examples of looking out for each other and supporting each other in making difficult decisions, thereby ensuring the overall success of the wide-ranging service changes.

### 7.12.3. *Getting back to putting patients and carers first*

> *"The words 'patient-centeredness' are verbal analgesics, but they mask real pain" (Berwick, 2009, p558).*

Patient-centred care has been a clarion call in human services for decades (Berwick, 2009), yet, findings from the Francis Inquiry and the Berwick Report indicate that its implementation in practice is far from universal. Reasserting the primacy of working with patients and carers in an environment that also values the unique contribution made by staff is the critical impulse that drives the MHSOP in its endeavours to remain flexible and responsive to patient need and service demands. The strategic adoption of the recommendations set out in *New Ways of Working* (Royal College of Psychiatrists and National Institute for Mental

Health, 2005) and the splitting of the CMHT into two separate but interlinked services[37] mean that CMHT staff are able to offer a person-focused response to every new referral. The importance of rapidly responding to every new referral is a key element of the service change as the team understand that initial visits to the GP by people with dementia and carers are usually precipitated by a crisis. Waiting weeks, or in some parts of the country months (House of Commons All-Party Parliamentary Group on Dementia, 2012), for a first appointment at a memory service adds stress to an already stressful time. The referral is, moreover, often the beginning of a long-term relationship with the service; knowing this, staff make every attempt to develop a strong and positive relationship with the person with dementia and with their families if they are involved.

CMHT staff worked hard to ensure patients were not kept waiting for appointments. Wherever possible people with dementia and/or carers were telephoned the same day the referral was allocated to a CMHT member and an appointment made at that point for the first visit. If an appointment was made to see the consultant psychiatrist at the clinic,[38]

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[37] One service for older people diagnosed with functional disorders, i.e. depression or psychosis and another for older people diagnosed an organic disorder, i.e. dementia.

[38] Dr Craig Adams prefers to make home visits. When Betty and Bill and Louisa and Nevin refer to their appointment with the consultant psychiatrist, they are referring to Craig's colleague Dr Anita Noble who left the MHSOP just before my research started.

people with dementia and carers reported that they were greeted by smiling, friendly reception staff and offered refreshments (Bill and Betty reported they were offered a cup of tea on arrival and nothing was too much trouble for the staff). Moreover, people with dementia and carers reported they: i) were given the information they needed quickly and with a genuine appreciation of the stress they were under, ii) were followed up regularly (some families - like Ewan and Liza - received a monthly visit), iii) knew who to contact for help and iv) when they made contact, someone from the team got back to them - usually the same day. People with dementia and carers noticed the lengths CMHT staff went to, to ensure their comfort and safety, making comments such as 'they are as good as gold', 'round pegs in round holes', 'we have become friends', 'never in a dash', 'nothing is too much trouble'. In this respect, CMHT staff exemplify the change that the National Advisory Group on the Safety of Patients in England (2013, p18) argued must happen if services are to put the patient back into patient-centred care:

> *Patients and their carers should be involved in specific actions to improve the safety of the healthcare system and help the NHS to move from asking, "What's the matter?" to, "What matters to you?"*

That CMHT staff set the needs of patients at the heart of the care planning process is evidenced in the narratives of multiple members of staff including Elena, a CPN support worker based in Wickham. Elena identified that in the rural community in which she works, older people are

very reluctant to take up services.[39] Their reluctance causes difficulties on a number of fronts, including carer/family stress, which if not addressed, can lead to family breakdown and early admission into long-term care for the individual with dementia. Elena described how she takes weeks, sometimes months, to prepare the individual with dementia to accept help and she supports them to make their own care planning decisions until it is no longer safe for them to live at home alone. The service goal is to enable people with dementia to live at home, with support, for as long as they have the mental and physical capacity. For people with dementia living in a rural setting such as Wickham, it is often not a lack of mental capacity that will deem a care home placement necessary, but lack of available facilities for food shopping, or health problems that need to be managed on a weekly basis in an area of poor public transport. The work Elena does prior to setting up a care package prepares the way for long-term involvement and her work undoubtedly contributes to delays in admission into long-term care. The long, slow introduction to the service is also of benefit to carers who Elena identified are sometimes overwhelmed with caring responsibilities, exhausted and close to breaking point as, over time, they get to know Elena well enough to confide in her. Elena's method of intervention is, therefore, beneficial on a number of levels, i.e. i) few people with dementia can resist her friendly

[39] The day care facility for older people in the area is housed in a building that was previously used as a 'poor house'. Older people have frequently said to Elena and her colleagues that have no intention of entering the poor house.

but persistent overtures for long and they usually end up accepting a service ii), it is likely that early assessment and intervention by CMHT staff results in fewer emergency calls to GPs and fewer admissions to hospital, iii) fewer crisis calls to the CMHT, iv) improved quality of life for the individual with dementia and v) support for the carer/family.

Further evidence that CMHT staff put the needs of people with dementia and carers at the heart of their practice can be found in Elena's account of how she and her colleague raise the finances and other necessary resources to keep the community-based support group they started in operation. For example, in order to recruit volunteer drivers, Elena contributes to other volunteer projects (in her own time). Without volunteer drivers people with dementia would be unable to attend Elena's group, so this activity is a critical one for group members who are no longer able to drive. Elena and her colleague will also sell a range of goods, the profits of which go towards funding trips away and meals out. Elena is always on the lookout for ways to resource the service, the only one of its kind for people with dementia in the area.

Findings from my research identified that CMHT staff were caring, compassionate, highly motivated and routinely set the needs of patients at the centre of their practice. However, despite the level of 'intelligent kindness' (Department of Health, 2012c, p13) they extended to patients, that same level of thoughtful care planning did not always appear to be extended to carers. For example, although carers are users of the memory service too, their needs were rarely addressed as a matter of

routine. This issue was brought sharply into focus when Ted, a memory nurse, identified that due to sheer volume of work, he is unable to take a full account of carers' needs. Ted identified that carers' assessments form a core component of the CMHT cognitive assessment process, yet carers are not routinely offered one. This is an issue that came up in advisory group meetings. Mary and Lewis were advisory group members and they also took part in the research as interviewees. In their interview they discussed the issue of support. Mary reported that their memory nurse did not seem to know what services were available for them to use locally. Lewis on the other hand reported that they had not been offered an opportunity to attend memory management clinics, something they had read about in the daily newspaper. Mary had not heard of carers' assessments until she joined the advisory group. Nor did she know she may be entitled to carers' allowance[40]. These issues were discussed at length during group meetings. Group members recommended that every carer who used the memory service should be offered a carers' assessment, during which they would be informed of their right to claim carer's allowance and informed of local services and support networks.

[40] With the support of another group member, Mary did successfully apply for carers' allowance.

The Berwick Report (National Advisory Group on the Safety of Patients in England, 2013, p18) makes it clear that in terms of service user and carer involvement:

> *The goal is not for patients and carers to be the passive recipients of increased engagement, but rather to achieve a pervasive culture that welcomes authentic patient partnership – in their own care and in the processes of designing and delivering care. This should include participation in decision-making, goal-setting, care design, quality improvement, and the measuring and monitoring of patient safety.*

What came through in the data was that although people with dementia and carers enjoy a warm and caring relationship with their named worker and they are very much involved in making decisions about the care they receive, the decisions they participate in are not based on a complete knowledge of what is available locally and people with dementia are not involved in any way, at any level in the day-to-day work of the memory service, the CMHT or the MHSOP. Involvement opportunities for carers of people with dementia were under-developed with only one example of carer involvement in a recent 'rapid process improvement workshop'.[41] Carers of people with dementia were, however, members of the service user and carer MHSOP involvement steering group.

[41] https://www.youtube.com/watch?v=qIFVeUNiZTg

### 7.12.4. *From inspiring followers to developing leaders*

According to the Center for Creative Leadership and The King's Fund (2014b, foreword) a key element of collective leadership is the ability of formal leaders to, "…embrace their organisation as a learning organisation in which the capabilities of individuals and teams are continually enhanced." A defining characteristic of the leadership style demonstrated by Ben, a clinical services manager, is that change, and ideas for change, are not the responsibility of 'the leader', but of every member of staff. Developing an environment in which CMHT staff could contribute to service change was not, however, entirely without challenge. CMHT staff, and Ben himself, acknowledged that Ben was 'an ideas man'. He understood how he wanted the service to look in six months' time, but did not always have a clear idea of how to get there. Rather than become overwhelmed by the scale of the changes he felt necessary for the modernisation of the service to take place, Ben decided that the teams (the functional and organic teams that made up the CMHT) should take responsibility for it. The Center for Creative Leadership and The King's Fund (2014b) identified that the adoption of a collective leadership style creates a curious paradox in that, in order to move the service on, leaders have to adopt a 'command and control' position to get the job done, a process which can be anxiety-provoking for staff and demands an empathic response from leaders. The progress of the CMHT in developing an environment of collective leadership provides a good example of this dilemma in practice.

Following Ben's announcement that the MHSOP and CMHT would be modernised, Ben and Craig set up development meetings during which Ben outlined his vision for the new service and the part CMHT staff would play in implementing it. This was experienced by staff, including Craig the consultant psychiatrist, as overwhelming on occasions. The process of working through the service changes provoked a lot of anxiety for CMHT staff who were more used to a 'command and control' style of leadership and who were unfamiliar with the processes of change management. However, Ben and Craig both believed that CMHT staff had the skills to take forward Ben's vision and make it a reality. Sometimes, however, CMHT staff demonstrated a reluctance to accept their new role as change managers, which threatened to stall the change process. When that happened, Ben would meet the team and just tell them they had to get on and do whatever needed to be done, otherwise they would be responsible for the service losing funding. In order to teach staff the importance of their decisions, he demonstrated what a loss of funding would mean in real terms, such as the loss of a member of staff. Thinking about the changes in these terms helped to focus staff attention on the task at hand. Craig referred to these 'team chats' from Ben as 'getting a gentle bollocking'.

The development of leadership capacity in CMHT staff was critical to the success of the service changes as they were implemented without the benefit of additional resources. Like other services for people with dementia, the MHSOP did not receive additional monies from the £150M

set aside in the original national dementia strategy implementation budget. Instead, existing services were reconfigured and any resources released by the change were used to develop new services. Every single penny in the service's budget was carefully and strategically put to work and every opportunity to optimise existing services seized. This meant, for example, that when a member of staff left the service, Ben took the team to one side and discussed whether that resource could be used more effectively elsewhere in the service. This ensured the service stayed sharp, innovative and focused and staff were highly engaged in the process of service development.

Using processes to work smarter and leaner was a particular hallmark of the way the service worked to stay abreast of the changes continually imposed from above. Ben understood only too well that unless they (as a service) were able to play the game and play it well, the biggest losers would be the people who use the service. Losing staff and other resources because the service had not grasped the importance of meeting targets was not an option for Ben. At face value, meeting targets may seem a long way from the issue of involving people with dementia and carers in the work of the service. In reality, meeting targets is critical for involvement to happen at all. A service that loses resources because it has not met its targets will eventually become chronically under-resourced and as a result will find it difficult, if not impossible, to focus on non-critical issues such as service user and carer involvement. By protecting scarce resources and beating national targets directly affecting

people with dementia, i.e. waiting times for first appointments, the service was creating an environment in which patient-centred care could inform service decisions and service user/carer inclusion could be fostered.

The Center for Creative Leadership and The King's Fund (2014b, p12) identify the important role drivers play in dictating, "…where trade-offs will be made between alternative investments of resources, time and energy." Although the CMHT and MHSOP are still in a state of flux, the primary objectives of the service changes have been reached and much has been achieved. This means that the time is right to identify new drivers for change based on the recommendations of the Berwick Report (National Advisory Group on the Safety of Patients in England, 2013) and the strategy for collective leadership devised by the Center for Creative Leadership and The King's Fund (2014b).

New drivers for the service should include generating ways to involve people with dementia and carers in the everyday work of the memory service, the CMHT and MHSOP. One way the involvement of people with dementia and carers could be effectively integrated into the everyday work of care planning, research and service development is via the employment of a social worker/development worker dedicated to the work of the memory service and whose role would include ensuring every carer had a carers' assessment, a welfare benefit assessment, information on and introduction to local networking and support services. Where these opportunities do not currently exist, the role of the new worker would be to develop them in partnership with people with dementia and carers and

local services. Additionally, the MHSOP should consider working with other local services to part fund a post of research and service development worker for dementia services. The primary function of this post would be the development of local networking opportunities and research and service development opportunities for people with dementia and carers. David Cameron has pledged millions of pounds in additional funding into research into dementia care (Department of Health, 2012a) and some of that money could be utilised to fund posts such as these, which hold the potential to contribute to radical and sustained improvements to dementia care and to the lives of people with dementia and carers.

## 7.13. Issues of reflection and reflexivity

> *We will not teach future professionals emotional distancing as a strategy for personal survival. We will teach them instead how to stay close to emotions that can generate energy for institutional change, which might help everyone survive (Palmer, 2007, Epub).*

In this study, I have used reflection and reflexivity as analytical tools to guide the process of knowledge production via the development of a methodology sensitive to, and capable of presenting the views of people typically excluded in the evaluation of dementia services and whose contribution to knowledge production is rarely acknowledged. I have, in particular, used reflexivity as a tool to understand and interpret the stories shared by people with dementia and carers. My interpretation of their stories is presented in the knowledge that I can never fully know their stories, that I do not have the right to appropriate their experience in any

way and that in re-telling their stories, people with dementia and carers are attempting to make sense of their experience of alienation, exclusion and marginalisation.

The stories people with dementia and carers shared affected me profoundly. Each and every time I read the interview transcripts I experienced a powerful, almost visceral response. Some stories made me chuckle and (really) laugh out loud. Others were read through eyes blurred with tears and others still made me angry. Because of this, the question I needed to address was how these responses might have affected my presentation and interpretation of the data. Law (2004) in his book about social mess and social science's attempt to capture it, talks about the value of experiencing the world with our senses, of feeling the world through pain, pleasure and even confusion. He refers to this as a form of embodied knowledge. As I 'felt' my way through the data, I began to understand what Law meant. Moreover, I was beginning to understand what Holloway (2010, p1) meant when he wrote of life-changing moments that begin with, "…an inarticulate mumble of discontent, tears of frustration, a scream of rage, a confident roar." Law and Holloway imply that not only is a personal response to emotive data acceptable for a researcher, it is also important to include aspects of that relationship in the discussion and interpretation of the data. This suggests furthermore, that an intellectual understanding of the issues being discussed is not always sufficient; that indeed *feeling something* is a legitimate response

to stories shared by people whose lives had been forever changed by (for example) a diagnosis of dementia.

Although I have refrained from writing myself into the research overtly, there can be no doubt that every thought I have had, every sentence I have crafted, was influenced by my own personal biography. Like Wallerstein and Duran (2006, p313), I write from my own perspective and position of, "…power, oppression, and privilege." I come to the research as a white, Irish/British, well-educated professional woman. During my growing up years, my family were poor. We experienced religious intolerance (forced to leave my country of birth under threat of death when I was twelve years old) and for many years experienced discrimination in our adopted country before finding a measure of peace. Although I understand something of what it is like to feel threatened, vulnerable or excluded, I make no claim to understand what it is like to receive a diagnosis of dementia and to experience being threatened, feeling vulnerable or excluded because of that. I can, though, claim to know something of the experience of being a daughter of someone diagnosed with the disease. But, even then, I can only tell of how my mother's diagnosis affects us as mother and daughter. I cannot claim to know how that diagnosis affects my mother or how it affects the relationship between my mother and my three sisters. Dementia may touch the whole family, but it affects each husband/wife, mother/son, mother/daughter dyad uniquely. I have worked with vulnerable groups as a professional since 1995. With training and experience came knowledge

and skills: and voice. I discovered language that told me everything I already knew about how it felt to be on the outside looking in: sometimes by choice, sometimes not. I suspect my desire to connect deeply with people with dementia and carers in the study was in some measure related to the fact that I was still experiencing the shock of my mother's diagnosis. Hearing their stories helped me to understand my own. Although deeply challenged by the stories shared during the research, this research was not about me. It was about people with dementia, carers and CMHT staff. Privileging their views was the central concern of the study. As Rose (2008, p449) argued, "Much as we may share experiences with our participants it is their voices, and they are heterogeneous, that we seek to enter into the arena of knowledge."

## 7.14. The role of critical gerontology in the study

Critical gerontology played an important role in the formation and development of my research. Reading the research narratives through a critical gerontology lens enabled me to understand the broader social and political context in which the narratives were situated. It also helped me to think deeply about the stories, heightening my sensitivity towards the unsaid, as much as to the said: both providing ample material for investigation. Viewing the narratives from a critical perspective also drew my attention to the fact that despite the high levels of service satisfaction expressed by people with dementia and carers on the service they received from the CMHT, they were not currently involved in the development or evaluation of the services they used. Nor, at the point the

study took place were any other people with dementia. Dannefer *et al.* (2008) argue that there is increasing recognition of the utility of critical social analysis for gerontology but that such an analysis represents just one possible facet of gerontology, i.e. the ability to discern and make known negative social structures and ideas. Dannefer *et al.* (2008) believe that given the potential of critical gerontology to bring about positive social change, the time has come to use the tools of critical social analysis to extend the theory-practice dialectic, using this process to transform care for older people. Although Dannefer *et al.* (2008) were writing within the context of institutional care, the principal of employing critical gerontology as a tool to improve our understanding of the experience of dementia as well as improving dementia services in the community also has potential.

Critical gerontology is interested, among other things, in issues of gender, identity, resilience and relationships and how these are affected by social structures, social policies and prevailing societal values and norms, an understanding of which could be valuable for CMHTs. Reading the stories shared in the research from these perspectives brings into the focus the drama of everyday life. Of how issues critical to our self-esteem, self-identity and sense of self are played out in the mundane and in the crisis, in front of an audience and when we are alone. Biggs (2008) argues that a key strength of critical gerontology is the identification of structural influences that would otherwise be hidden from scrutiny. Narrative gerontology provides a vehicle for bringing these hidden influences into

view, so that their stymying effect can be more widely understood and ultimately dismantled. Louisa and Nevin's story of how they received their diagnosis is a good case in point. In the two years it took for Nevin to receive a diagnosis of dementia, their knowledge of how dementia was affecting Nevin was discounted, their repeated attempts to bring the mounting evidence to clinicians were ignored and their cries for help were unanswered. To read the couple's story from the perspective of critical gerontology requires us to look beyond the individual actions of staff at the clinics they attended and to resist the urge to glibly recommend making services 'more sensitive' to the needs of patients and carers. Reading the story from the perspective of critical gerontology requires us to understand the value base from which the staff were acting and under which the service was delivered. Because it is only when we understand why Louisa and Nevin's explanation of what was happening was devalued, why the service chose not to train staff to recognise the symptoms of dementia and why, once a diagnosis of dementia was given, Louisa and Nevin were not informed and Nevin continued to be treated for epilepsy, that we can begin to understand the reach of ageist practices that pervade institutions such as the NHS. Only then will we be able to challenge the status quo and when we do, there will be no need to advocate for 'more sensitive' services, because sensitive services will be the norm, not the exception.

Moody (2008, p205) noted the tendency for academics to overlook the element of practice and to, "…look beyond, this domain of everydayness."

To do so, he argues, risks the entombment of critical gerontology in a self-delineated comfort zone of critical analysis and negativity which is at odds with the stories shared in my research which present a complex picture of life lived at the margins. Yes, there is misery, marginalisation, depression and bone-crushing disappointment, but there is also hope and resilience and solidarity. To present the first without recognising the ameliorating and life-sustaining effects of the second robs critical gerontologists of the opportunity to present glimmers of hope in an otherwise bleak landscape.

But, what do hope, resilience and solidarity look like? According to Dannefer *et al.* (2008) they look a lot like agency, examples of which permeate almost every story in my research. Dannefer *et al.* (2008, p102) contend that while critical analysis and negativism will remain constant companions of critical gerontology, critical gerontologists have to move beyond caustic critique in order to bring into view elements of hope, acknowledging that such inquiries, "…require more personal and existential engagement and critical self-reflection on the part of the theorist her/himself." They further argue that despite what is going on at the macro-level, it is at the level of the individual that agency is best understood.

In my research, Sophie's attempts to control her environment by presenting a version of herself that she thinks will be believed by others, perfectly captures this act of agency in action. Sophie understands she is 'putting on a show' but she also understands the necessity of doing so.

This is about Sophie retaining the identity she is most comfortable with and actively creating roles that she can fill, i.e. that of friendly and knowledgeable neighbour. Sophie draws on her not inconsiderable resources to keep the act going, fighting the action of dementia on her brain cells with multiple, small acts of defiance and compromise.

Betty also demonstrates the power of agency when she acknowledges the importance of replying to every invitation to go out. She understands that others will take their cue from her. And, if she starts saying ‘no’ the likelihood is that people will stop asking. Nor will Betty accept that because she has been diagnosed with Alzheimer’s disease she must therefore be helpless and need watching every minute she is awake. Betty is not about to play the role of Alzheimer’s patient, even though she knows the script.

Understanding that people with dementia and carers are engaging in multiple acts of defiance and compromise in order to combat the ravages of an unstoppable disease, is not only encouraging from the point of view of understanding humanity in all its frailty. It also provides us with vital clues as to what kind of support people with dementia and carers might find useful. While hope, resilience and solidarity are the intangible sequelae of a lifetime of experiences, it is nevertheless possible to teach people how to be resourceful, so that like Sophie, they can continue to present those aspects of themselves they want others to see and for others (carers perhaps) to understand and cooperate with their efforts. For this reason, critical gerontology is a useful tool for CMHTs to employ,

both to gain a better understanding of how dementia is constructed in policy and in society, and in involving people with dementia and carers in service development and evaluation. Given its roots in social reform and social justice, Dannefer *et al.* (2008) argue that critical theory is well placed to support practice, especially if the relationship between care-giver and care-receiver is viewed as bi-directional and reciprocal. In other words, people with dementia are viewed as capable of giving as well as receiving care. Taking a critical approach to care is about recognising the ability of people like Maria, Liza, Julia, Eva, Lesley, Sophie, Betty, Lyn, Michael, Lewis, Nevin, Jim, Harry and Will to participate in the act of constructing their own worlds, their identities and society.

Baars (1991, p220) reminds us that it is the identification (or bringing into view) of otherwise hidden social processes that enable those without dementia to improve the quality of life for those who live with the disease. Although he was arguing this mainly in relation to macro social processes, as Bill's story of how he consciously changed his pattern of communication with Betty powerfully illustrates, it holds true also for the myriad of micro social processes that constitute everyday life. More recently, Baars (2012) argued that the process of framing ageing within the minutiae of everyday lives of people who continue to live well, despite knowing they are old, is neglected, despite the important role it could play in mitigating the effects of less than optimal social conditions. Zeilig (2011), meanwhile, defends the role of narrative gerontology in relation to its role in influencing policy. And, while this is a necessary role to fill, like

Baars (2012) and Moody (2008), I argue that there is much to be achieved via the dissemination of stories of dementia and of old age that 'tell it like it is' but which nevertheless illustrate the possibilities as well as the challenges of living with a terminal illness. This rich, complex, tapestry of relationships and experiences that people in my study drew upon to make sense of their social world is succinctly captured here by Hendricks (2008, p113):

> *Social gerontologists need to take heed: human beings do not live life two variables at a time, but come as complex, oftentimes messy packages lodged in lifeworlds that have been years in the making. Try explaining that in a way that captures its richness.*

Critical gerontology is but one tool for unmasking the malevolent social structures and processes that render the needs of people with dementia and carers invisible, while pushing them to the margins of a largely ambivalent society. And, while it is not a perfect tool, it has played an important role in sensitising me to the social and political context in which the stories in my research were shared. Moreover, via exposure to the work of critical gerontologists such as Baars (2012), Dannefer *et al.* (2008) and Moody (2008), I am again persuaded of the importance of portraying the lives of people with dementia and carers as nuanced and complex and not simply in terms of tragedy or pathos. I am persuaded also of the need to take critical gerontology outside the academy and to use it as a tool to inform, challenge and ultimately change practice.

## 7.15. Chapter summary

In this chapter I discussed the research findings within the analytical framework devised by Willis *et al.* (2009). The chapter was divided into four sections. In the first section, I discussed the data that answered research question one (7.2). This explored data concerned with the first evaluation criteria: the initial experience of dementia (7.3). Within this section I discussed issues related to the 'un-dementia like' symptoms experienced by people with dementia and the difficulty that caused in recognising their problems might be linked to dementia, the support of family and friends after a diagnosis and that diminishing levels of support seemed to be linked to the view that dementia was fearful and unknowable. This was followed by a discussion of data that challenged this perception of dementia. I then discussed aspects of the data shared by carers on their experience of living with a spouse/partner with dementia and how medically-driven accounts of dementia failed to protect and care for people with dementia and carers. Next I discussed the importance of people without a diagnosis of dementia engaging personally with the lives of those who do and the work we need to do to ensure that happens. This was followed by a discussion acknowledging that engaging in research with people with dementia and carers is a learning process for everyone involved. In support of my argument that narratives by people with dementia and carers can play a critical role in knowledge production, this first section of the chapter was brought to a close with a discussion of the complex interactions between gender,

identity and relationships as revealed in the narratives of people with dementia and carers who took part in the research (7.4). In the second section of the chapter, I discussed data answering the second research question. Data in this section were discussed under the following headings: service experience (7.6), helpful interventions (7.7), normalising the catastrophic (7.8), communication (7.9) and gaps in services (7.10). This section was brought to a close with an interpretative account of the service evaluation criteria discussed by people with dementia and carers (7.11) which demonstrated how important it was for them to know they were i) listened to, ii) believed, iii) that professionals saw the person and not the diagnosis and iv) that professionals went the extra mile. In the third section of the chapter I discussed data answering the third research question which pertains to the manner in which the CMHT works to ensure that people with dementia and carers are supported (7.12). This involved a discussion of the leadership style adopted by the team. In the fourth and final section of the chapter I discussed issues of reflection and reflexivity as they related to my own role in the research process (7.13).

In the following and final chapter I provide a summary of the findings for each research question, identify the original contribution made by this research and provide a reflective account of the research methodology. This is followed by a number of recommendations for the development of future policy, research and practice.

# Chapter Eight: Conclusions and reflections

## 8.1. Introduction

In this chapter I provide a brief summary of the research findings (8.2), identify the original contribution to knowledge made by this thesis (8.3), reflect on the experience of undertaking the research (8.4) and make recommendations for a range of stakeholders and for future research (8.5) before bringing the thesis to a conclusion (8.6).

## 8.2. Summary of the research findings

The first research question focussed on the extent to which knowledges produced by people with dementia and carers can challenge negative stereotypes of dementia and demonstrate the benefits of involving people with dementia and carers in research about dementia and in service development. Although people with dementia and their carers reported frequent incidents of confidence-sapping treatment and disregard, they also generated strong accounts of their own experience, skills and knowledge to provide a powerful corrective to contemporary negative stereotypes of dementia. They demonstrated their unique perspectives based on knowledge and experience (expertise) of developing and living with dementia, their potential to use that expertise in contributing to the development of knowledge on dementia care and they also demonstrated that their contributions to processes of research and service development can inspire change in those willing to listen and learn. A key argument of the thesis is that narratives by people with dementia and carers could be

instrumental in generating knowledge about issues of importance to gerontology. This was demonstrated in the thesis via an exploration of issues of gender, identity and relationships as revealed in the stories shared by those who took part in my research.

The second research question explored the criteria used by people with dementia and carers to evaluate dementia services. A clear set of criteria emerged based on whether: i) staff take time to find out what matters to each individual ii) professionals attach importance to what they say, iii) services provided recognise their individual needs, iv) information is given at the right time in a format they can understand v) they are able to attend groups where they can meet other people with similar experiences and vi) they are able to share their knowledge and expertise with others.

The third research question examined the values, attitudes and practices of mental health practitioners and service-level managers who were key to the development of services recognised to be of high-quality, but less well developed in relation to service user and carer involvement. Data generated from CMHT and MHSOP staff demonstrated a sustained commitment to placing the best interests of patients at the heart of the service. This was associated with a style of leadership that encouraged continual learning to make the service more responsive and more patient-focused through the development of a culture of compassionate care that embraced not only patients but also staff. People with dementia and carers in the study confirmed that all members of the CMHT and MHSOP staff, from reception staff to consultants, often went ‘the extra mile’ to

ensure people with dementia and carers felt valued and to address their needs in a reassuring, friendly and professional manner.

## 8.3. Original contributions to knowledge

Memory clinics were identified in the National Dementia Strategy for England (Department of Health, 2009) as being an appropriate way for the twin processes of early diagnosis and intervention to occur nationally. But critics of memory clinics have questioned the ethics of early screening for dementia when evidence for the effectiveness of memory drugs is limited (Coombes, 2009). This view, however, fails to capture the wider qualitative benefits of memory services and their evaluation in building knowledge of what can improve quality of life, and minimise distress experienced by people with dementia and carers. My study has contributed to the knowledge base informing such qualitative benefits and to the development of a critical mass of qualitative studies that is required before a systematic review of qualitative research in this area is possible.

Specifically, the thesis makes an innovative contribution to understanding the possibilities of involving people with dementia as active participants and advisers in research. Smith and Cantley's (1985) study was among the first qualitative evaluations of mental health services for older people to include the views of carers, practitioners, managers and other professionals, it took over 20 years before Willis *et al.* (2009) included the views of people with dementia as well as carers and professional practitioners. This thesis has further extended methodological design by

including people with dementia not only as research participants but also as advisory group members involved in early dissemination of findings to public audiences.

Finally, the thesis adds to knowledge generated by Willis *et al.* (2009) (appendix 17) by identifying two additional criteria valued by people with dementia and carers in evaluating community-based dementia/memory services. These are: i) care and support for carers and ii) the availability of a research facilitator to promote, facilitate and support the involvement of people with dementia and carers in research and service development.

## 8.4. Reflections on the research: limitations and possibilities

### 8.4.1. *Generalisability*

Community-based memory services for people with dementia represent a new model of care that has only recently begun to be subjected to evaluation. While this study contributes new insights on the involvement of people with dementia and carers in service evaluation it is important to acknowledge a number of limitations that underline the importance of treating its findings as lending confidence to further developments in the involvement of people with dementia and carers, rather than demonstrating statistically significant findings. It will be important to replicate the study's methodology with other CMHTs. This replication will also assist with the production of comparative studies and with the completion of systematic review in the future.

### 8.4.2. *The sample*

The research design, based on a single memory service, meant that an important group of professionals, GPs, was omitted from the study. This decision was taken in the knowledge of the challenges of involving GPs in qualitative research (Parker and Hamill, 2011), but more importantly it was essential I used the resources available to me in the study to maintain energy and focus on the involvement of people with dementia and carers. However, I acknowledge that GPs clearly play an important role in referring people with dementia to memory services and in responding to health problems experienced by carers, and their inclusion in the research could have added a further dimension to the study.

### 8.4.3. *Interviews and interviewing*

In my desire to maximise the recruitment of people with dementia and carers to the study, I offered a choice of being interviewed together or separately. Arksey (1996) outlines the advantages and disadvantages of collecting data through joint interviews. More recently, Sakellariou *et al.* (2013, p1563) argued that, "…joint interviews can offer valuable information about how couples coconstruct meaning and share experiences." Additionally, Bjørnholt and Farstad (2014, p5) argue that interviewing couples is, "…a way of opening up new and interesting knowledge." Arksey and Knight (1999, p77), meanwhile, noted that it was 'regrettably uncommon' for researchers to develop theoretical insights by combining individual and joint interviews in a single study.

Despite the growing body of advice on interviewing people with dementia (see Beuscher and Grando, 2009) there is no direct guidance about interviewing people with dementia together with their spouses/partners. My own experience revealed a number of challenges: ensuring that both parties were able to contribute to the conversation equally, trying not to show surprise or shock when couples argued during the interview and regulating the pace of conversations to ensure people with dementia did not get 'left behind'. Interviewing couples together gave me an opportunity to watch them interact with each other as they constructed and re-constructed their dementia narrative, especially illuminating for me in the light of Gubrium and Holstein's (2009) criteria of what is a good story, who is a good storyteller and the narrative devices people use to ensure the correct version of the story is told.

In making a decision not to interrupt the speech of participants with dementia, even if they wandered off topic, I should have warned their partners of this decision in advance, avoiding the anxiety that some clearly showed. But I also learned that people with dementia were happy to acknowledge that they 'went off on bunny trails' and instructed me (light-heartedly) to stop them if they digressed too much. The lesson for future research is to include a short discussion of this issue in the preamble to interviews.

The stories produced through research interviews were extraordinarily rich and have the potential to extend the emotional, intellectual and political horizons of those who read them. They portray, without malice,

experiences of oppression faced by people with dementia and their carers in everyday life. They show the lengths to which people with dementia go to remain connected with their families, friends and communities. They demonstrate the insight of people with dementia into their condition and the way their diagnosis affected other people. They dispel the myth that people with dementia live a zombie-like existence, unable to understand their experience and/or contribute to decisions affecting their lives (Hill, 2008). They illustrate the potential of people with dementia to contribute to the day-to-work of services. And they exemplify the characteristics of services and people that help and hinder processes of inclusion.

### 8.4.4. *Ownership of data: reciprocity and validity*

As part of the study design I had always intended to return interview data to participants at the earliest possible opportunity and in an accessible format. Copying recorded interviews onto CD worked well but could have been even more effective if I had made a copy at the time of the interview and left it with the narrator/s before leaving. An important benefit of returning recorded data that I had not considered in advance was the opportunity to provide an audio recording of freely shared thoughts and feelings about their diagnosis of dementia and their lives before they lost the ability to share their thoughts with their families and friends.

In striving to ensure the accuracy of data and validity in the way I used it, my aspiration was to share findings of the research at an early stage with

participants. The intention was to continue the spirit of involvement, but also to receive critical feedback on my own interpretations of data. In reality this was an unrealistic aspiration as I underestimated the time required to complete the necessary work and to deliver it in an accessible way. The lesson for me has been a reminder that achieving high standards of integrity in research includes being realistic about what is possible within time and material resource constraints.

### 8.4.5. *Presentation of data*

The presentation of data in this thesis has been the subject of a steep learning curve. Before collecting data I imagined a much stronger role in shaping and interpreting the data to produce my argument as the author of the thesis. But in carrying out the research and working with people with dementia and their carers I quickly came to the realisation that to retain their power, individuals' stories had to be presented and interpreted in the same spirit in which they had been shared with me and not depending solely on my interpretation of what the stories 'really' meant. The voices of people with dementia have so rarely been included in the qualitative evaluation of dementia services, that I was keen to present their thoughts and insights with as little 'researcher noise' as possible. I was, however, mindful of arguments about the role and responsibility of the researcher in selecting and shaping the data in the direction of the intellectual puzzle embodied in the research questions (Mason, 2007) and have added my own thoughts, reactions and arguments to the central core of the data generated by research participants. These stories shared

by people with dementia and carers are able to give those without experience of dementia a rare glimpse into their daily lives. Moreover, such stories are useful as a 'heuristic for critiquing social policy' (Zeilig, 2011, p11) and, as gerontological narratives, are able to expose the exclusionary practices of daily life and how they are experienced by people with dementia and carers. As with other forms of discrimination, 'recognizing the problem' is a necessary step in addressing it.

### 8.4.6. *Reflections on the role of the advisory group*

I was inspired to create an advisory group after reading an article by Branfield and Beresford (2006) on the benefits offered by small networking groups, particularly in relation to promoting service user involvement. I was aware that, at that time, there was no involvement of people with dementia in the work of the memory service, CMHT or MHSOP I had approached. Although I was not able to create a user-controlled networking group as part of my PhD research, I saw the creation of an advisory group as a step in the right direction. I reasoned that if people who joined the advisory group enjoyed their experience, it may encourage them to explore what other options were available to them in terms of involvement in the day-to-day work of the memory service, CMHT or MHSOP.

Involving people with dementia and carers in the advisory group did add a considerable amount of practical work to the research, including recruitment, making necessary arrangements for each meeting -

transport, comfort and safety, expenses - and keeping in touch between meetings throughout the twelve months the group met. I was keen that advisory group members co-facilitated at least two information-sharing seminars during the twelve months we met as a group. Preparation for involvement at the seminars included co-writing content, and practising presentation skills. The seminars were presented to audiences of health and social care professionals and interested others, including students. The seminars were advertised through local networks and were well attended. Participant feedback suggested the presentations, involving Lewis who has Alzheimer's disease, Lewis' partner Mary, and Rose who had cared for her late husband, were the most inspiring and humbling they had attended. And they were inspired to go back to their workplaces and think of ways of involving people with dementia and carers in their work and/or research. In the case of one senior manager, this involved encouraging a whole department to re-think the way it involved mental health service users and carers.

Other benefits of the advisory group included the development of an information and support network. This led not only to increased social support, but also to learning about, and claiming, welfare entitlements and accessing available services. It also led to opening up of new opportunities, for example, an invitation to contribute to a research funding bid at the University.

While advisory group members said they enjoyed attending the group and taking part in all its activities they especially relished opportunities to

share what they had learned in terms of how to claim a particular welfare benefit, details of a ‘dementia-friendly’ café and other useful resources. They were also deeply appreciative of an opportunity to simply meet another person who had been, or still was in the same situation as themselves. The social aspects of the advisory group cannot be overestimated. As Rhodes *et al.* (2002, p406) discovered in working with an advisory group of service users, “At times, the group functioned more as a mutual support group than an advisory group. This was an important aspect of the group experience and necessary for group cohesion.”

These positive learning points made up, in part, for the externally imposed limits to the advisory group that could not be recruited until after ethical approval for the research had been granted. In summary, the advisory group was successful in developing aspects of what Branfield and Beresford (2006) felt were important components of involvement, local networking, knowledge generation and increased social and research capital.

While it is impossible to completely eradicate issues of power and how they play out in research and service development, involving people with dementia and carers in advisory groups is one way of developing research confidence, skills and local knowledge. People with dementia face challenges beyond those of mental health service users/survivors, and beyond those of disabled people, as their cognitive decline prevents them from taking part in long-term initiatives. It would be easy to use this as an excuse to ‘give up’ on involving people with dementia. But I argue

that it is the responsibility of researchers to seek out ways of involving people with dementia and their carers in research and service development opportunities. An evaluation of the advisory group by group members can be found in appendix 18.

### 8.4.7. *The use of research diaries*

I asked people with dementia and carers to consider keeping a research diary for one week. The purpose of this was to provide a detailed account of their day-to-day lives. Several participants were interested in the idea in the beginning, particularly when I explained that if they did not want to write, they could record their thoughts on a hand-held digital recorder. In the end, however, only one carer completed a paper diary that provided a detailed account of her day-to-day life with her husband who had early onset dementia. Ironically, the interview with this participant and her husband provided a similarly rich, detailed account of their experiences of dementia. With the benefit of hindsight I can see that the inclusion of research diaries in the research protocol was not only unnecessary in terms of generating sufficient data, but may have been unrealistically ambitious in terms of the daily demands already facing participants.

## 8.5. Recommendations

While data from small-scale qualitative studies cannot be generalised *ad hoc* to the wider population, when applied sensitively in local contexts, qualitative findings can be a useful starting point for service development and also for generating ideas for further research. In making the following

recommendations I draw not only on my findings that relate to three specific research questions about experiences and quality of memory services, but also on findings that draw attention to the continuing unmet needs of carers.

### 8.5.1. *Recommendations for memory services*

Although CMHT staff in this study were compassionate, caring and thoughtful, feedback from carers suggests that post-diagnosis support and advice remain an area for service development. The study also identified a need to devise a way to systematically involve people with dementia and carers in research on dementia and in service evaluation. This could be achieved via the development of a research facilitator role to ensure people with dementia and carers are systematically approached to take part in research about dementia and in service development in the future. The research facilitator role could be shared across a number of agencies ensuring the development of research and service development capacity locally. Therefore, in addition to the seven quality indicators generated by Willis *et al.* (2009), I propose two further indicators:

- Awareness that carers of people with dementia are also service users. Assessment of their needs should be an integral part of the overall assessment process and should be regularly re-assessed.
- The availability of a research facilitator to work in partnership with people with dementia, carers and other community agencies to

develop social networking opportunities and to generate participative research on dementia and service development.

### 8.5.2. *Recommendations for the memory service in this study*

Given the importance of drivers in shaping the direction of travel for services, it is suggested that new drivers for the service should take into account:

- The imperative to involve people with dementia and their carers in research about dementia and in service development, recognising that the knowledge, skills and expertise they bring to the table are critical elements in the production of high-quality services.
- The potential role of partner organisations, such as the Alzheimer's Society, in the production and dissemination of information, training and services for people with dementia and carers.

Additionally, the service should consider the development of:

- Targeted therapy groups for people with dementia to cover topics such as information about dementia, memory management and counselling.
- Targeted therapy groups for carers to cover topics such as information about dementia, caring for a person with dementia, strategies for supporting memory and counselling.
- Targeted therapy groups for people diagnosed with MCI.

### 8.5.3. *Recommendations for practice*

Complementing the recommendations made in the previous section, mental health practitioners should consider: i) developing greater awareness of the needs of carers, understanding that they cannot be divorced from the needs of people with dementia and ii) taking opportunities to develop skills through training to become research facilitators in their locality. In this way they would be able to contribute to the development of strategies that promote the involvement of people with dementia and carers in research about dementia and in service development and to influence the quality of their own working lives.

### 8.5.4. *Recommendations for future research*

During the conduct and writing up of this research project, a number of issues have come to light that underline the need for further research to illuminate the experiences of older male carers, older carers from BAME communities and older lesbian and gay carers, and an overarching recommendation arising directly from my study that relates to the potential gains of extending the involvement of people with dementia and their carers in service development and evaluation. I address each in turn.

The Office of National Statistics (2013) identified that in the future, older male carers will significantly outnumber older female carers, yet research stretching over a decade (Russell, 2001; Milligan and Morbey, 2013), points to a serious lack of research investigating the care-work older male

carers do and of their experiences of caring generally. It is, therefore, of great importance to carry out empirical research in this area, both for understanding more clearly the support needs of older male carers and for providing theoretical insights into the experience of caring for a spouse with dementia from the perspective of male carers. Such research could contribute towards the development of male 'scripts' (Goddard and Wierzbicka, 2004) that could help future generations of male carers feel less isolated and lonely and better able to support their spouse with dementia.

The ethnic homogeneity of the sample in my research did not allow for exploration of the research questions with carers from minority ethnic groups. But the very paucity of literature relating to carers of people with dementia from minority ethnic groups was conspicuous. A report by the All-Party Parliamentary Group on Dementia (2013) into the experiences of black, Asian and minority ethnic communities identified that despite the fact that the number of people with dementia in minority ethnic groups could rise seven-fold by 2051, awareness of their unique support needs is lacking, leaving society ill-prepared to address the consequences of this increase. People from BAME communities are under-represented in dementia services (less than 1% of people with dementia in the Trust that hosted my research were from a BAME community) and are frequently, "…diagnosed at a much later stage of their illness, or not at all" (All-Party Parliamentary Group on Dementia, 2013, p10). Of particular importance is that a lack of understanding of people's needs is associated with a

higher risk of abuse (Alzheimer's Society, 2004; Cooper *et al.*, 2009; Ash, 2014). It is, therefore, of critical importance that research is conducted into the unique support needs of people with dementia and their carers from BAME communities, so that, as a society, we are better equipped to meet their needs both now and in the future.

Similarly obscured in the literature is research on same sex carers of those living with dementia. As public acceptance for same sex couples grows following the introduction of civil partnerships and same sex marriage, it is likely that people with dementia and carers from the LGB community will feel more able to 'come out' when seeking support. However, as Alzheimer's Australia (2008), have argued, for older people with dementia who are gay or lesbian there are likely to be additional layers of complexity affecting their experience of dementia. And, as Price's study of 21 gay men and lesbian women with experience of caring for a person with dementia, showed, "…the stress of anticipated, perceived or actual negative responses from service providers compromised their ability to manage the demands that caring for someone with dementia placed upon them" (Price, 2010, p167). Understanding the support needs of LGB people with dementia and carers is, therefore, critical in raising awareness of their experiences to inform service provision. Such research would also have potential to offer further insights into the negotiation of shifting role boundaries associated with caring in later life that is currently dominated by heterosexist assumptions.

A final recommendation relates to the development of approaches to research that could helpfully underpin the first three recommendations. Despite the fact that Dannefer *et al.* (2008, p104) argue that, "A fundamental principle of critical theory is the importance of linking theory and practice," there is a dearth of research studies that have used critical theory as a tool for service improvement in dementia care. Because of this, Dannefer *et al.* (2008) argue that we have only just begun to understand the role critical theory could play in developing and evaluating services for older people. It has been acknowledged in this research that critical gerontology could have an important role to play in sensitising dementia services staff to the structural and political barriers people with dementia and carers are subjected to. And, that this knowledge could be used to devise meaningful ways to involve people with dementia and carers in service development and evaluation. However, the lack of empirical research in this area is a preventing a full exploration of the ways in which this particular theory-dialectic gap could be bridged. Future research in this area could investigate ways in which involving people with dementia and carers in research about service development and evaluation could be viewed as a form of care that values the involvement of those not normally involved, effectively re-positioning people with dementia and carers as expert problem-solvers.

## 8.6. Concluding comments

The Prime Minister's challenge on dementia: *Delivering Major Improvements in Dementia Care and Research by 2015* (Department of

Health, 2012a) was an ambitious document received with much excitement from statutory and non-statutory organisations alike. It: i) set out how additional funding would be used to improve the lives of people with dementia and their carers over the course of three years (pp6-7), ii) acknowledged the progress that had been made in terms of the number and quality of memory services and other supports available to people with dementia and their carers three years on from the launch of the National Dementia Strategy (p13) and iii) reminded us yet again of the need to re-focus on improving the lives of people with dementia and their carers by respecting their position as people of experience living with the symptoms of dementia (p19). While position documents such as these attempt to tackle issues of power and powerlessness from the top down, experience suggests it will not be enough. Issues of power and powerlessness also have to be tackled from the bottom up and that means there are opportunities for all of us to contribute to the change process. We may feel our sphere of influence is small but radical changes start with the thoughts of just one person. In protest at the way disabled people continue to be uncaringly treated in a society that seems largely unaware of their suffering, Oliver and Barnes (2012) wrote that it is time to re-politicise disability studies with our scholarship and with our research. In light of the stories shared in this research I wish to argue for a politicisation of dementia studies.

The most paralysing stage of any change is at the very start of the process. The fear of standing out, of saying something for which you will

be criticised, or of becoming an object of loathing all stop us from rocking the boat too violently and with good reason. Reprisals against those who speak out are a real danger. Moreover, the reality of how the system deals with those who try to 'swim upstream' (suspensions, exclusions, redundancies, etc.) can be a sobering reminder of just why (most of the time) we prefer to look the other way when our lives intersect with the lives of devalued people (Berger, 1970). Moreover, when we decide to stand up for devalued people, we increase the risk of becoming devalued ourselves. However, if we understood just how tenuous our hold on our 'valued' status really is, it is likely we would devote ourselves strenuously to the task of broadening society's view on who is valuable. Social divisions on the basis of class, race, gender, age, disability, sexual orientation, mental health status and more, lead to simple and complex forms of 'othering', often based on 'fear of the unknown', that leads to discrimination.

The stories shared by people with dementia and carers in this research are a rich source of data on lives that remain shrouded in mystery and fear. Their stories show us that something needs to change. But to understand anything about the nature of the world in which we live is to understand that real change is difficult to achieve, is reliant on multiple factors seemingly beyond our control and most importantly is risky. It is risky to be the one who stands up on a bus full of irritable passengers to say, 'Stop harassing this person, she needs our support and encouragement.' It is risky to be a nurse who argues to spend enough

time with a confused patient in hospital to ensure they finish their meal before the plates are cleared away. It is risky to be the one who blows the whistle on unethical and abusive behaviour, as it can lead to scapegoating. It is undoubtedly ‘safer’ to look the other way each and every time the lives of devalued people intersect with our own. But it is not safer for people with dementia and their families. Looking the other way propagates the myth that dementia is something that happens to other people. Dementia can affect anyone and any of us may, one day, be subjected to harassment in the supermarket, in the car park, on the bus or in the queue at the cinema.

As more and more people are diagnosed with dementia and fiscal purses are snapped shut in an effort to control the effects of a worldwide recession, there is a very real danger that people with dementia and carers will become increasingly marginalised and viewed as a burden to be shouldered by a financially squeezed nation. This is worrying, and not only because people with dementia do not choose to have the disease. We still do not know what triggers the initial changes in brain chemistry that cause otherwise life sustaining proteins to clump together between nerve cells (beta amyloid plaques) or inside nerve cells (neurofibrillary tangles) disrupting the ability of neurons to communicate with each other and which over time manifests as Alzheimer’s disease. Nor can we be sure why vascular disease commonly exists alongside the symptoms of Alzheimer’s disease and on its own as a separate sub-type of dementia. It is of course critical to continue research into possible cures. In the

meantime, people diagnosed with dementia now need the support of those without dementia to ensure they have what they need to live well with the disease. That support begins with the acknowledgement that people with dementia and carers have the capacity to be involved in decisions that affect their lives and in the day-to-day work of services. It is the responsibility of those who do not have the disease to make this happen. Stories shared by people with dementia, carers and CMHT and MHSOP staff in this research and in other published accounts (including autobiographical accounts of living with a diagnosis of dementia) show us where and how we can begin.

# List of appendices


| | |
|---|---|
| Appendix 1: | Autobiographical accounts of dementia |
| Appendix 2: | Participant information: advisory group members |
| Appendix 3: | Independent review of research protocol |
| Appendix 4: | NHS LREC approval |
| Appendix 5: | NHS Trust approval |
| Appendix 6: | Invitation to take part in the study: CMHT staff |
| Appendix 7: | Consent form: CMHT staff |
| Appendix 8: | Participant information: CMHT staff |
| Appendix 9: | Interview topic guide: people with dementia |
| Appendix 10: | Interview topic guide: carers |
| Appendix 11: | Interview schedule: CMHT staff |
| Appendix 12: | Interview transcript: Sophie, a person with dementia |
| Appendix 13: | Memos made in NVivo in relation to Sophie's interview transcript |
| Appendix: 14: | Invitation to take part in the study: people with dementia and carers |
| Appendix 15: | Consent forms: people with dementia and carers |
| Appendix 16: | Participant information: people with dementia and carers |
| Appendix 17: | Evaluation criteria: the Croydon memory service |
| Appendix 18: | Evaluation of advisory group by group members |

## Appendix 1: Autobiographical accounts of dementia

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Raushi, T. M. (2001) A view from within: Living with early onset Alzheimer's. New York: Northeastern New York Chapter, Alzheimer's Association.

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Skloot, F. (2005) A world of light. Lincoln, NE: University of Nebraska Press.

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Taylor, R. (2007) Alzheimer's from the inside out. Maryland: Health Professions Press.

Zabbia, K. H. (1998) Painted diaries: A mother and daughter's experience through Alzheimer's. Minneapolis: Fairview Press.

## Appendix 2: Participant information: advisory group members

## Title of the research: An evaluation of the memory services provided by a community mental health team for older people.

If you require information on any aspect of the study, please do not hesitate to contact me. I enclose my contact details below for your information. Please note that this study is being conducted as a piece of student research for the award of a PhD, through Durham University.


| | |
|---|---|
| Name: | Ethna Parker |
| Address: | University of Durham, Elvet Riverside 2, New Elvet, Durham. DH1 3JT |
| Email: | e.t.parker@durham.ac.uk |


**The purpose of the study**

The purpose of this research study is to talk to older people with memory problems, their families and carers and the staff team at [name of hospital], about their everyday lives and their experiences of the memory services provided by their local Community Mental Health Team (CMHT) for older people. It is hoped that information gathered during the research will help to improve services for older people with memory problems in the future.

**Why are you writing to me?**

I believe the best way to understand how the CMHT meets the needs of older people with memory problems is to talk to people who have experience and/or knowledge of how it works.

**Do I have to take part?**

No. It is up to you to decide whether or not to take part. If you do, you should keep these Information Sheets in a safe place so that you can refer to them throughout the study.

**What will happen to me if I take part?**

Advisory group members will be encouraged to contribute to the development of the study. For example, your views will be sought on the

best way to involve older people with memory problems in the study and what we (as the research team) can do to support their involvement.

Depending upon the level of involvement you would like in the study, you may be asked to:

1. Complete a research journal of your journey as an advisory group member.

2. Help to analyse (thinking deeply about) the information being gathered in the in-depth interviews that I will be conducting with older people with memory problems and their supporters.

3. Share the findings of the study with others locally and nationally.

**How the advisory group meetings will be conducted**

It is likely that advisory group meetings will be held every three months during the study. Each advisory group meeting will last for approximately two hours and will be audio-recorded using a small digital recorder. I will summarise the recordings from each meeting and copies of the summary will be sent to group members.

Initially, meetings will be held at [name of hospital]. All facilities – including toilet facilities - will be easily accessible to disabled people. However, once the meetings are set up if advisory group members would prefer to meet elsewhere, I will make the necessary arrangements.

**Expenses**

To ensure that you do not suffer financial loss by taking part in the study, I have made the following provisions:

- Stamped addressed envelopes will be provided for the return of any documents, for example: the signed consent form.

- Notebooks to write journal entries will be provided.

- Light refreshments will be provided at the advisory group meetings.

- Transport to and from the meetings can be arranged if required.

**What do I have to do?**

There is a number of research activities associated with the role of advisory group member. For example, over the course of several months you will be asked to:

1. Keep a research journal.

2. Attend an advisory group meeting every three months for approximately 12-18 months.

3. Contribute your thoughts and views on the best way to involve older people with memory problems in the study.

4. Contribute to the development of the study.

There will be a final advisory group meeting at the end of the study. The purpose of this meeting will be to evaluate how well the study has gone and to make recommendations for the inclusion of older people with memory problems and their supporters in research locally.

**What are the possible risks or disadvantages of taking part?**

In every kind of research there is a risk that people may be put at a disadvantage. The risks and disadvantages in studies such as this are minimal, however you should consider the following points:

- You may find it difficult to talk in front of other advisory group members.

- Issues may arise that you find uncomfortable, or other people may talk about issues that have caused you pain or loss in the past.

If during the advisory group meetings you become distressed by any of the issues that have been raised, please let me know and I will ensure you receive any support you need. This could include for example, leaving the room and chatting to me in private or talking over the issues raised with a member of the CMHT.

**What are the possible benefits of taking part in the study?**

The benefits of taking part in a study such as this tend to be on a personal development level, for example:

- You will have an opportunity share in the creation of a research study that will focus on issues that are important to people with memory problems and their supporters.

- You will have an opportunity to meet with other people who are interested in the same issues.

- You will have an opportunity to share the findings of the study with other people locally and possibly nationally.

- Through your contribution to the study, you will have an opportunity to become skilled in a number of research activities, i.e. keeping a research journal, data collection, data analysis and report editing.

**What will happen if I don't want to carry on with the study?**

You can withdraw from the study at any point. You have the right to decide if any of the information you have contributed will be retained in the study or destroyed. Even if you sign a consent form, you are still free to withdraw at any time and without giving a reason. If you are currently a patient using the memory services provided by the Trust, withdrawal from the study will not affect your medical treatment or care.

**What if I need to make a complaint?**

If you have a concern about any aspect of this study, you should speak to Ethna the principal researcher, who will do her best to answer your questions. However, if you remain unhappy and wish to complain formally, you can do this by contacting Ethna's research supervisor at the Durham University:

Research supervisor: Di Bailey

Tel no. 0191 33 41478

Email: di.bailey@durham.ac.uk

**What if I am harmed during the study?**

In studies such as this one, the risk of harm is very low. In this study, you will be asked to contribute to the development of a study that seeks to evaluate the memory services provided a CMHT. This study does **NOT** involve taking any drugs nor will any kind of clinical intervention will be offered. Furthermore, please be assured that I carry full indemnity insurance provided by Durham University.

**Will my taking part in this study be kept confidential?**

I will take every precaution to ensure that your contribution to this study remains confidential. Any contributions that you make to the study and which appear in a subsequent report will be properly anonymised using a system of coding. All data related to the study will be stored on a password protected remote server at Durham University. Your personal information will never be stored on my work or home computer.

With your permission, I will keep a list of contact details for each group member. These details will be used for the purpose of keeping you up to date with the progress of the research, or to arrange meeting dates, etc. In line with the Data Protection Act 1998, your contact details will never be given to anyone else.

If you are a patient currently using the memory services provided by the CMHT, your Healthcare Practitioner will be informed of the fact that you

are taking part in the research study. However, they will not have access to any of the information you personally contribute during the study.

**Please note**: I have a duty to report to the relevant authorities any information revealed during an advisory group meeting that I think puts you or someone else at risk from harm. Moreover, if during the conduct of the research issues are raised about unprofessional conduct/practice, I have a duty to report these issues to the Clinical Lead for the Trust.

**What will happen to the findings of the research study?**

The final report will be submitted to Durham University in September 2011. A summary of the report will be made available to the Local Research Ethics Committee, local carer support groups and other interested professional groups shortly after that. Findings from the study may be presented at local or national conferences and articles written for publication in professional journals and magazines.

**Who has reviewed this study?**

Senior staff at Durham University and the University of Birmingham reviewed the research proposal. This study was given a favourable ethical opinion for conduct in the NHS by [details have been removed].

**Audit procedures**.

Please note that data collected during the study may be audited by an independent organisation or by the Trust. This is to ensure that all research carried out within the NHS conforms to the ethical standards set out by NHS research ethics committees.

**Independent advice**

If you would like independent advice on how research should be conducted in the NHS, you can contact your local Research & Development office or the Patient Advice & Liaison Service on the contact details below [Details have been removed].

## Appendix 3: Independent review of research protocol

Dear Ethna,

**Independent review of PhD proposal – 'An evaluation of a community mental health team providing services to older people with dementia using participatory learning'**

Thank you for giving me the opportunity to review this PhD proposal. I found the proposal very interesting and think this will be a worthwhile and valuable study. In general it is strong proposal but there are some general and specific issues which I would like to comment upon.

**Timing**

I think this study is very timely on two counts. The Government's recent strategy on dementia calls for an understanding of what will improve services for older people with dementia. The strategy, and other government policy, also calls for the involvement of older people, including those diagnosed with dementia, in the evaluation and development of these services. This study addresses both of these issues directly.

**Definition of terms**

p.4 Although you describe Community Mental Health Teams (CMHTs) as the preferred model of service for adults of working age, you do not anywhere either define what a CMHT is or describe this specific CMHT (for example in terms of mix of staff, governance arrangements, location). If you do this, I think the understanding of the sampling process for the study will become clearer.

**Methodology**

The objectives of the study (p4) are very clear and the research questions you have posed should enable you to achieve your objectives. You have justified a case study approach as your chosen methodology.

As stated above, if you identify which staff work for the CMHT, I think you can be clearer about your sampling technique (p12). For example, you might want to include at least one person from each profession in your sample of staff to be interviewed.

Similarly, I think for the purposes of work load management, you need to have an indication of approximately how many interviews you intend to undertake with service providers and service users (pp12 and 13).

Is it only you who is planning to undertake the interviews and have you an enhanced CRB check?

**Recruitment procedure**

You first mention the advisory group on p 13 but it is not clear what the criteria for selection to this advisory group will be, nor its size. You are proposing that you will have one information session for the recruitment of advisory group members and interviewees but I was not clear who will be invited to this session. Will it include the older people with dementia who may become interviewees and if so, you may find that you cannot effectively communicate with the whole group together?

**Data analysis**

You talk about your interpretation of the data (p16) but you could give an indication of how you intend to analyse your findings, for example manually or using a particular computer software.

**Dissemination**

I was very pleased to see your plans for a local dissemination strategy and the involvement of the advisory group in devising this. I also hope that all participants will have the opportunity to have a shortened version of your findings written in an appropriate format.

**Ethical issues**

You rightly identify sensitive ethical issues when involving older people with dementia in research and you have addressed many of these well. You do not state whether or not this proposal has already received ethical approval from the University of Durham and where else you need to present it in order to receive approval before it goes ahead.

I suggest that you need more detail on how you will identify people for inclusion in the study, how the professional care team will judge their capacity and how this will affect the chosen sample. You could also address in more detail how you will get informed consent from the participants and what role their family members or carers may play in this.

**Literature**

You have already undertaken a thorough literature search and identified many relevant documents. Can I suggest you look at a few more?

- 'Duty to Involve' obligations of Local Authorities from April 1st 2009
- Dewing, J (2002) 'From ritual to relationship', *Dementia* 1 (2) pp 157 – 171
- 2 articles by Fiona Cowdell in *International Journal of Older People* – (2006) 1, pp85-94 and (2008) 3, pp29-34.

I hope you find the comments above helpful and look forward to hearing your response. [Contact details removed].

## Appendix 4: Ethical approval from NHS LREC

Mrs Ethna Parker

Elvet Riverside 2

New Elvet

Durham

DH1 3JT

Dear Mrs Parker

| | |
|---|---|
| **Study Title:** | **An evaluation of a community mental health team providing services to older people with dementia using participatory action learning** |
| **REC reference number:** | **[details removed]** |
| **Protocol number:** | **1** |

Thank you for your letter of 11 December 2009, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

**Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised subject to the conditions specified below.

**Ethical review of research sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

**Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk. *Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary. Sponsors are not required to notify the Committee of approvals from host organisations.*

**Other conditions specified by the REC**

**Consent Form for Participants**

This appears a little long winded and it may read better if similar statements were joined together. However, this is only a suggestion and is not a condition of approval.

The statement ''please initial the boxes if you understand and agree with the following statements'' should be placed at the top of the initial boxes.

Please delete the words ''things I need to know''.

**Consent Forms - Participants & Staff**

Please ensure the consent forms are printed as double sided documents to ensure that the signatures do not become detached from the statements.

Please submit hard copies of the following documents on appropriately headed notepaper:

Consent Form - Participants – please ensure a new version number and date is given

Consent Form - Staff – please ensure a new version number and date is given

Information Sheet - Participants

Information Sheet - Advisory Group Members

Letter of invitation - Participants

Letter of invitation - Staff

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

**Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

| *Document* | *Version* | *Date* | |
|---|---|---|---|
| Covering Letter | | 21 October 2009 | |
| REC application | IRAS 2.2 | 21 October 2009 | |
| Protocol | 1 | 19 October 2009 | |
| Investigator CV | | 10 July 2009 | |
| Referees or other scientific critique report | | 30 September 2009 | |
| Interview Schedules/Topic Guides | 1 | 16 September 2009 | |
| Participant Information Sheet: Advisory group members | 2 | 11 December 2009 | |
| Participant Information Sheet: Participants | 2 | 11 December 2009 | |
| Participant Consent Form: Staff | 2 | 22 December 2009 | |

| | | | |
|---|---|---|---|
| Participant Consent Form: Participants | 2 | 11 December 2009 | |
| Letter of invitation to participant | Participants V2 | 11 December 2009 | |
| Response to Request for Further Information | 1 | 11 December 2009 | |
| Letter of invitation to participant | Staff V2 | 11 December 2009 | |

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the

Standard Operating Procedures for Research Ethics Committees in the UK.

**After ethical review**

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email

referencegroup@nres.npsa.nhs.uk.

| | |
|---|---|
| **09/H0908/74** | **Please quote this number on all correspondence** |

Yours sincerely

**[details removed]**

**Chair**

## Appendix 5: Ethical approval from the Trust

Mrs Ethna Parker

Elvet Riverside 2

New Elvet

Durham

DH1 3JT

Dear Mrs Parker

**Title: An evaluation of a community mental health team providing services to older people with dementia using participatory action learning.**

**REC: [details removed]**

I am pleased to inform you that you have successfully gained research governance approval from the [details removed] Foundation Trust to conduct this study. All local checks are met and we have received a favourable ethical opinion. You may therefore commence this study in this Trust.

This research must be conducted in accordance with [details removed] NHS Foundation Trust policies and procedures, which are available to you on request. We require a report within three months of completion of the project outlining key findings for dissemination to clinicians, service users and carers as appropriate. We also encourage you to inform us of any publications which result from the project.

You must inform the R&D Office of any significant events or amendments in the course of the study, including:

- Change of Principal Investigator
- Early termination of the study, or continuation beyond the stated end date
- Significant adverse events
- Significant amendments to the study protocol

The Trust R&D Office conducts a yearly audit of research governance compliance, and you will be informed in advance if this study is due to be audited.

I would like to take this opportunity to wish you every success with your research. If there is any way that we can assist you in the future please contact us.

Yours sincerely

[Details removed]

## Appendix 6: Invitation to take part in the research: CMHT staff

University of Durham
Elvet Riverside 2
New Elvet
Durham
DH1 3JT

DATE

Email work: e.t.parker@durham.ac.uk

ADDRESS OF TRUST

Dear …,

**Re: Research project – Evaluation of the memory services provided by a Community Mental Health Team for older people**

I would like to invite staff working within the Community Mental Health Team (CMHT) at [name of hospital] to participate in a research study that will help to evaluate the memory services provided by the CMHT.

Data collection tools for the study will include in-depth interviews with older people with dementia, their families and caregivers and staff from the CMHT at [name of hospital]. People with dementia and their families will also be asked to keep a research diary for one week. In addition to this, all key stakeholders will be invited to participate in an advisory group. Members of the advisory group will play an important role in the on-going development and management of the study.

**What will participating in the study involve?**

You can participate in the study in two ways. Firstly, you can become a member of an advisory group. Advisory group members will offer advice

and oversight on the overall progress of the study and will contribute their expertise to any challenges I may face as a researcher. It is envisaged that advisory group members will meet every three months over a period of approximately 18 months.

Secondly, you can agree to be interviewed by me. During the interview I will suggest a number of topics for discussion, which you can choose to talk about in some depth. It is expected that individual in-depth interviews will last for approximately one hour. You can decide where you would like to be interviewed. You can be a member of the advisory group and also choose to be interviewed if you wish.

The *Economic and Social Research Council are funding me to complete the study as part of a PhD I am working towards with Durham University.*

**NHS R&D approval and Ethics approval**

This study was given a favourable ethical opinion for conduct in the NHS by [details have been removed].

Enclosed with this letter is a 'Participant Information Sheet'. Please read it through carefully before deciding if you would like to take part in the study. If after reading through all the information you would like to take part in the study, or you would like more information about the study, please return the reply slip in the stamped addressed envelope provided.

I look forward to hearing from you soon.

Best wishes,

Ethna Parker

## Appendix 7: Consent form – CMHT staff

Title of Project: Evaluation of the memory services provided by a Community Mental Health Team for Older People

Name of Researcher: Ethna Parker

Please initial the boxes if you understand and agree with the following statements.

| | |
|---|---|
| I confirm that I have read and understand the information sheet dated 11/12/09 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | ☐ |
| I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. | ☐ |
| I understand that data collected during the study, may be looked at by individuals from Durham University, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to data collected during the study. | ☐ |
| Advisory group meetings will be audio recorded and a summary typed up by Ethna. I will be given an opportunity to read the summary to check its accuracy. | ☐ |
| In-depth interviews will be audio recorded and typed up by Ethna. I will be given an opportunity to read the typed manuscript of my interview to check its accuracy. | ☐ |
| Information contained in the final research report will be anonymised using a system of coding. It will not be possible for anyone to identify my comments or written contributions. | ☐ |
| Ethna has a duty to pass on any issues raised in relation to unprofessional conduct to the Clinical Lead for the Trust. All issues of this nature will be handled via the Trust's usual organisational policy and procedures. | ☐ |
| Ethna will hold anonymised transcripts of the research interviews indefinitely. All original transcripts (i.e. those containing real names of interviewees) will be destroyed at the end of the study. | ☐ |

All study data will be stored on a password protected online storage facility provided by Durham University. ☐

The information I provide during the study can be used in the final research report. ☐

Matters discussed within advisory group meetings may be of a personal or confidential nature and as such, should not be discussed outside the group. This does not affect my right to make a complaint to the Research Supervisor Di Bailey. ☐

I agree to take part in the above study. ☐

Name of Participant Date
Signature

Name of Person taking consent Date Signature

When completed: 1 for participant; 1 for researcher site file

## Appendix 8: Participant information – CMHT staff

## Title of the research: An evaluation of the memory services provided by a Community Mental Health Team providing services to older people.

If you require information on any aspect of the study, please do not hesitate to contact me. I enclose my contact details below for your information. Please note that this study is being conducted as a piece of student research for the award of a PhD, through Durham University.


| | |
|---|---|
| Name: | Ethna Parker |
| Address: | University of Durham, Elvet Riverside 2, New Elvet, Durham. DH1 3JT |
| Email: | e.t.parker@durham.ac.uk |


**The purpose of the study**

The purpose of this research study is to talk to older people with memory problems and their families and carers together with staff from West Park Hospital, about their everyday lives and their experiences of the memory services provided by the local Community Mental Health Team (CMHT) for older people. It is hoped that information gathered during the research will help to improve services for older people with memory problems in the future.

**Why are you writing to me?**

I believe that the best way to understand how the CMHT meets the needs of older people with memory problems is to talk to people who have experience and/or knowledge of how it works.

**Do I have to take part?**

No. It is up to you to decide whether or not to take part. If you do, you should keep these Information Sheets in a safe place so that you can refer to them throughout the study.

**What will happen to me if I take part?**

You will be asked to participate in a research interview, during which I will ask you to share your thoughts and views on the memory services

provided by the CMHT together with your ideas on a range of related topics.

**How will the interviews be conducted?**

You will be asked to take part in one interview. The interview can take place in your own home, at your place of work or in any place of your choosing. It is expected that each interview will last for approximately one hour. With your permission, I will audio record our conversations and type them up at a later date. I will send you a copy of what I've written to make sure that I have captured what you have said accurately.

**Expenses**

To ensure you do not suffer financial loss by taking part in the research, I have put in place the following:

- If you choose not to be interviewed at home or your place of work, transport to and from the meetings can be arranged if required.

**What are the possible risks or disadvantages of taking part?**

In every kind of research there is a risk that people may be put at a disadvantage. The risks and disadvantages in studies such as this are minimal, however you should consider the following points.

- Issues may arise that you find uncomfortable.

If during the interview you become distressed by any of the issues that have been raised, please let me know and I will ensure you receive any support you need. This could include for example, stopping the interview or arranging for you to talk the issue through with your staff supervisor or the Trust counselling service.

**What are the possible benefits of taking part in the study?**

The benefits of taking part in a study such as this tend to be on a personal development level, for example:

- You will have an opportunity contribute to a research study that will focus on issues that are important to older people with memory problems and their supporters.

**What will happen if I don't want to carry on with the study?**

You have the right to withdraw from the study at any point without this affecting your medical treatment/care. You have the right to decide if any

of the information you have contributed will be retained in the study or destroyed. Even if you sign a consent form, you are still free to withdraw at any time and without giving a reason.

**What if I need to make a complaint?**

If you have a concern about any aspect of this study, please talk to Ethna about it first. However, if you remain unhappy and wish to complain formally, you can do this by contacting Ethna's research supervisor at Durham University:

Research supervisor: Ian Greener

Email: ian.greener@durham.ac.uk

**What if I am harmed during the study?**

In studies such as this one, the risk of harm is very low. In this study, you will be asked to describe how you feel about different aspects of the memory services provided by the CMHT for older people. Please be assured that I carry full indemnity insurance provided by Durham University.

**Will my taking part in this study be kept confidential?**

I will take every precaution to ensure that your contribution to this study remains confidential. Any contributions that you make to the study and which appear in a subsequent report will be properly anonymised using a system of coding. All data related to the study will be stored on a password protected remote server at Durham University. Your personal information will never be stored on my work or home computer.

With your permission, I will keep your contact details on file. These details will be used for the purpose of arranging interviews. In line with the Data Protection Act 1998, your contact details will never be given to anyone else.

**Please note**: I have a duty to report to the relevant authorities any information revealed during an in-depth interview or advisory group meeting that I think puts you or someone else at risk from harm. Moreover, if during the conduct of the research issues are raised about unprofessional conduct/practice, I have a duty to report these issues to the Clinical Lead for the Trust.

**What will happen to the findings of the research study?**

The final report will be submitted to Durham University in September 2011. A summary of the report will be made available to the Local Research Ethics Committee, local carer support groups and other interested professional groups shortly after that. Findings from the study

may be presented at local or national conferences and articles written for publication in professional journals and magazines.

**Who has reviewed this study?**

Senior staff at Durham University and the University of Birmingham reviewed the research proposal. This study was given a favourable ethical opinion for conduct in the NHS by [details have been removed].

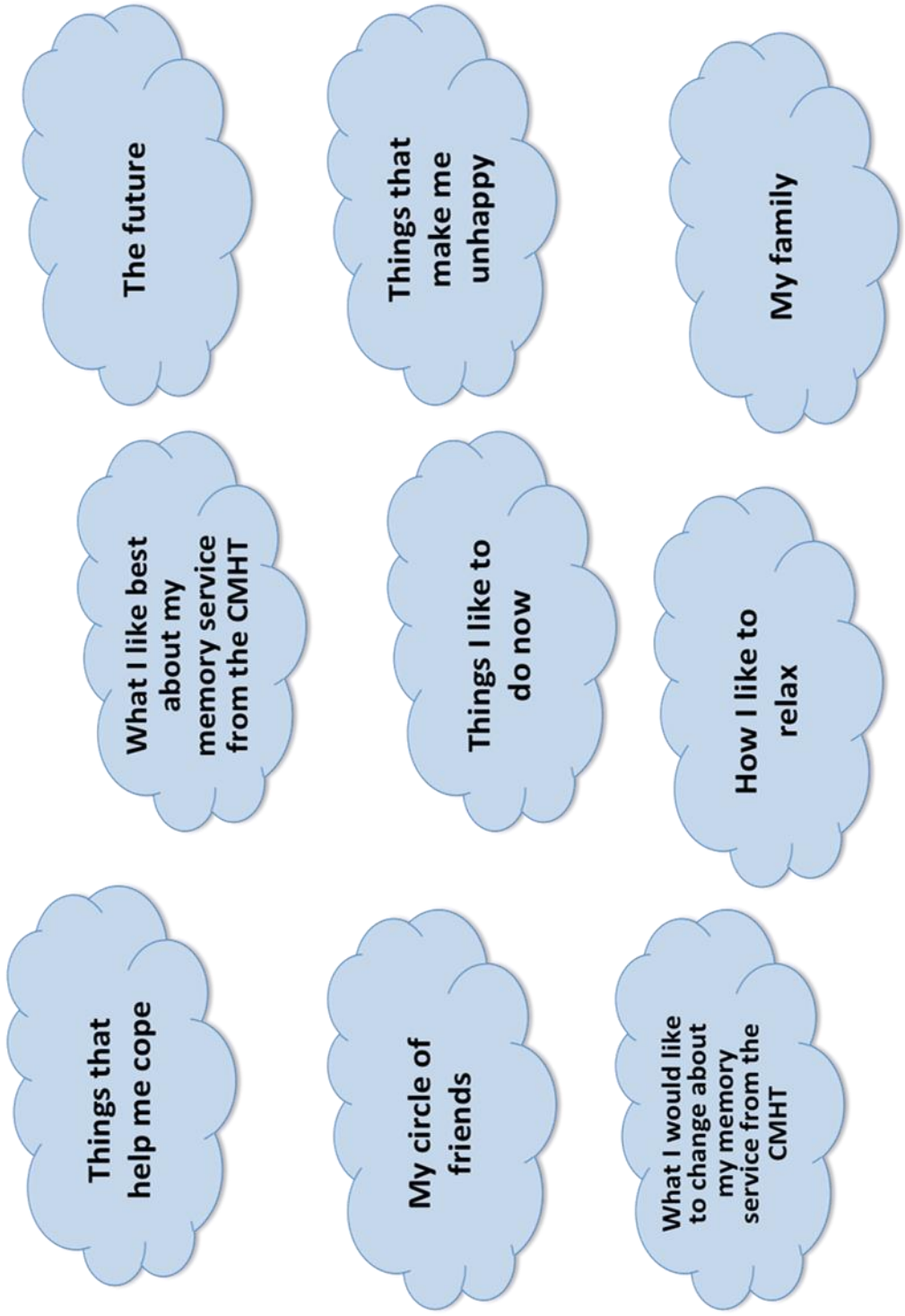
**Audit procedures**.

Please note that data collected during the study may be audited by an independent organisation or by the Trust. This is to ensure that all research carried out within the NHS conforms to the ethical standards set out by NHS research ethics committees.

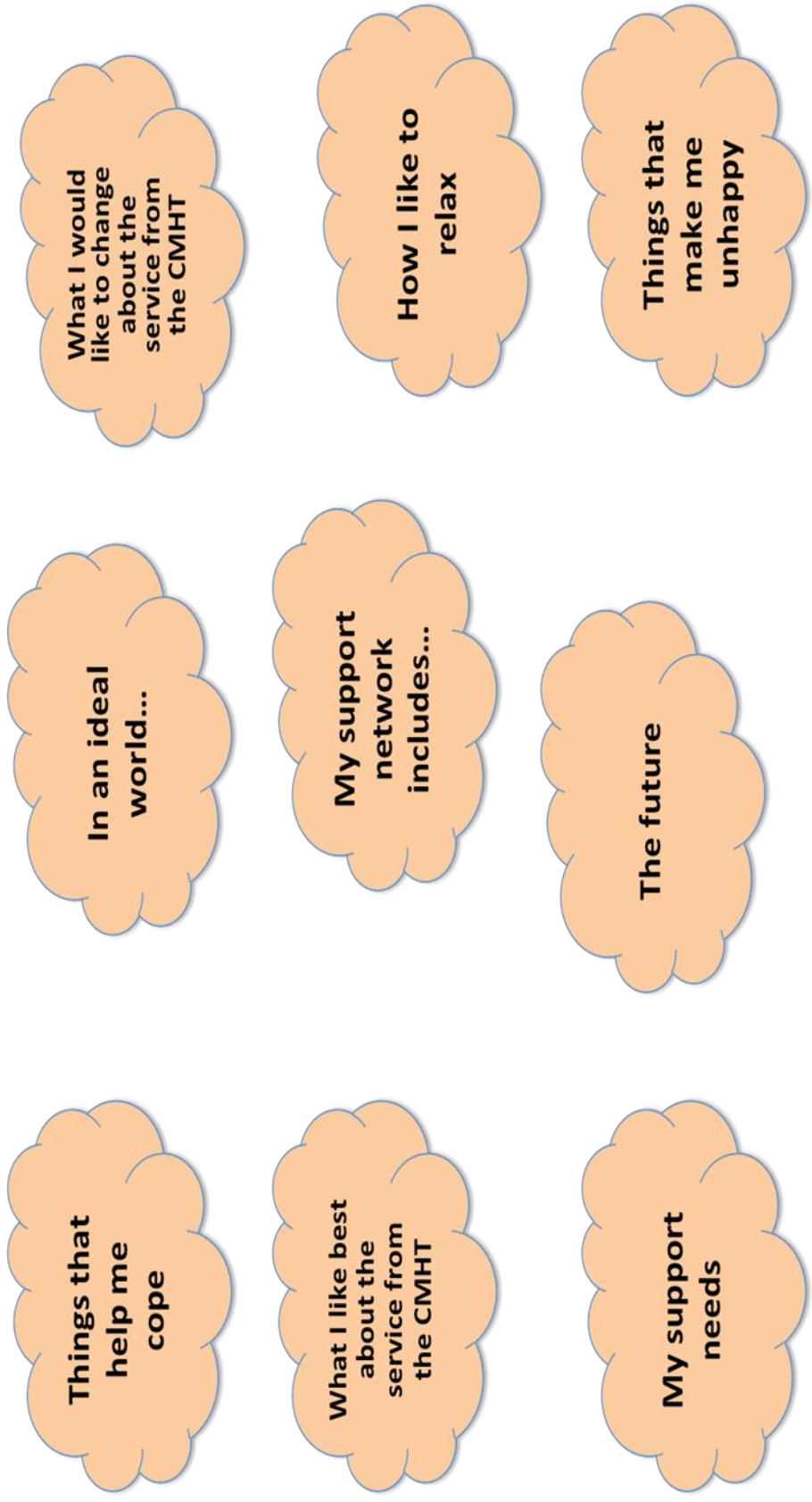
**Independent advice**

If you would like independent advice on how research should be conducted in the NHS, you can contact your local Research & Development office or the Patient Advice & Liaison Service on the contact details below:

## Appendix 9: Interview topic guide: people with dementia



## Appendix 10: Interview topic guide: carers



## Appendix 11: Interview schedule: CMHT staff

Own role in the organisation

- Length of time in post
- Previous skills and life experience
- Training for the role
- Most useful
- Least useful

The old system of service delivery

- Good points
- Bad points

The new system of service delivery

- Involvement with the development of the new service

Aim of the new memory services

- For people with dementia
- Their carers and/or family members
- For the Trust
- Local population

Aspects of a successful service for

- Older people with dementia
- Their carers and/or families
- Yourself
- The broader needs of the Trust
- The local population

Degree of success achieved

How is success measured?

Team working

- What works best?
- What works least?

In an ideal world…

- Areas for change
- Best practice
- Ideas for future development of the service

# Appendix 12: Sophie's interview transcript

### *Introduction*

I have included a copy of Sophie's interview transcript and the memos I wrote as I read (and listened) to it for a number of reasons. It is good, for example, to see the transcript in its entirety for reasons of transparency and also to demonstrate researcher integrity: have I used her words in a way she did not intend? It also illustrates how much of Sophie's interview I used in the thesis,[42] and in doing so, also provides a good illustration of how little was actually used and therefore, how much more could be analysed by me or other researchers in the future. I could have used much more, but I needed to include data from other participants as well, and everyone had lots of interesting things to share.

Presenting the entire transcript also provides an opportunity to see how I have linked Sophie's words together. Sometimes, Sophie's answer to a particular question spanned several paragraphs and/or pages, so I needed to piece the answer together. Some of Sophie's most insightful comments are tucked away in a muddle of words about something (that seemed to me) unrelated. The only way to make sense of what she said, was to read everything slowly, stop frequently and make lots of notes along the way. It was a long process, but an enjoyable one.

Ethna: Once it's recorded on there I am going to make a CD and give you a copy of the CD.

Sophie: [laughing] Oh that will be nice! Yeah. And here's me being silly or stupid.

Ethna: [also laughing] it will be wonderful.

Sophie: I know.

Ethna: The idea behind giving you the CD is so that you have got a total record of everything we have talked about.

Sophie: Oh yeah, that is fine love, thank you.

Ethna: So instead of me typing up a long manuscript and then you having to read through the long manuscript...

[42] To make it easier to find the quoted material, I have highlighted them in yellow in the interview transcript.

Sophie: That is a good idea.

Ethna: This is just dead easy to pop in a computer and it will...

Sophie: Yeah, that is right. And can I get a tissue?

Ethna: Yes. Absolutely!

Sophie: Thank you. That is better. It's just from having had that cold you sometimes you get a sniffle and it always comes at the moment you don't want it to do it.

Ethna: It does, so it is best to be prepared. So, these are the kinds of questions, or sort of areas that we are going to be talking about. Now, there might very well be other areas that you feel more interesting, or more pertinent and that is absolutely fine. This is just a guide to get us started if you like. Alright? So, tell me a about the service that you receive from the memory service?

Sophie: From which one?

Ethna: The memory service. That is where Dr Craig Adams works.

Sophie: Oh [smiling broadly, calls him an affectionate nickname]. Ok, well I get the girls, they come round and talk to me which is very interesting and, er, we have a laugh as well, and er...

Ethna: What kind of things do they talk to you about?

Sophie: Sorry?

Ethna: What type of things do they talk to you about?

Sophie: Well, just how am I doing and what, what has been happening, have I, do I feel good. And you know, I said to them, I do feel furious with myself sometimes when I cannot, because I used to be so, absolutely spot on for everything and I used to do a lot of horse doing thing, things here, erm, and it's...somewhere here. I would like to get on with doing things that I enjoy...

Ethna: Yeah?

Sophie: Some pictures of horses there.

Ethna: More drawings? [Sophie had shown me some drawings she had done before the interview started].

Sophie: Yeah. And I'm, my daughter is coming back from down south and she is going to bring me, erm a new computer, er, and I think she is also going to bring me, now what was the other thing? She said, 'Mum, I will bring you everything,' she said. And she's erm, what was the next thing? There were two things, I think, that she was going to bring me. She was going to bring me a, erm...

Ethna: Is it a programme to use on the computer?

Sophie: Yes, it is. It's her, she has got a spare one and so she said, she said, 'Mum I'll bring you that,' and she was also getting, to go and get me something else as well. Erm, I'm just trying to - oh God! Oh it is empty [looking into her bag]. So, erm, I think it is cos it has got, I forgot about that edge there. Er, so, erm...you know.

Ethna: So is that to help you with your memory problems then?

Sophie: What the…? Yes it is. It's to help me. And she is coming as well, and I am always… Oh I like books and things, as you can see, there is about 400 books in this house and I don't know how many other things. I love books and I love everything. I am very good on gardening and I think that is great and I used to do a lot of horse riding, as well. I had my own horses, and so, that was fantastic, I had a marvellous time. I have, so my life has got a bit, sort of, chaotic and not so enjoyable as I used to have. But, erm, I haven't got any problems really, I don't suppose, Tim, Tim looks after me really well. And I said to him, you I say to him, you know, he just keeps on top of me, he tells me off sometimes, 'No you can't, Sophie, you can't do that.' I know it is really good.

Ethna: Something that we need, we all need somebody like that don't we?

Sophie: Oh we do. And I was on my own for ages and ages and ages about 10 years and of course when you are on your own it gets worse and worse and I then found, he met me on a bus. I was coming home from, erm, [a local town], I think it was, Tim, where was I coming home from? When I met you? I was coming back from [a local town] wasn't it? In the bus?

Tim: [from the next room] you tell her all some story, go on, you tell the story.

Sophie: What did he say?

Ethna: You tell the story.

Sophie: I'll tell the story yes, anyway, I can tell a story. Anyway, I was coming back on the bus and things like that and I stopped the bus because I had to get because I could see I was getting near to home, so anyway, what happened was, er, I had got a little trolley, which is a really nice one, not big, smallish, and everything I was, I was, I was sitting, I came at the front, I was at the front of the place, in the, in the, erm...

Ethna: In the bus?

Sophie: Bus, yeah, thank you. In the bus so, I was at the front of the bus so I was going to get off at the next stop and what happened was, er, unfortunately I was on my knees and my trolley tripped up, right in front of the guy who was driving the bus. So I said to him, 'Oh my God I am really, really sorry, sorry.' Because, I mean, you know, it was all over the floor at the front there, so he said, he said, 'no, you just put everything back.' And then they started the people started, people at the back of the bus started saying 'hurry up! We want to get out of the bus. We want you out and we don't want you to be there, we've got shopping to do and we want to get out. Not your…' Because and then that turned me into tears because, I mean, I have never had anybody doing that for me and so, er… I was so upset about it, I was really crying buckets and er nobody seemed to be saying anything to me and the driver of the bus was very kind, he said to me, 'Don't worry love. Don't bother about them.' But I did because when you've got people shouting at you, 'hurry up and get off,' you know, 'we've got to go places,' it makes you really stres...really..

Ethna: Stressed?

Sophie: Yeah on edge. And so, anyway, I suddenly heard somebody say, a gentleman say behind me, he said, erm, he said, 'I think you need some help, don't you?' and I said, 'Yes, I think I do.' And he came up and it was Tim, and he came and he helped me get all the groceries back in. He said he knew because he'd seen me before on my own, with, sort of, going around, and so he said he would come back with me and he helped me get all the groceries, came back with me to the, the house and have quick, sort of surmise. I suppose, er, then he actually stayed and had a cup of tea with me and he said, 'I have seen you before,' he said, 'you have been walking around, wandering around,' and he said, he said, he said, 'It is nice speaking to you.' Because I gave him a cup of tea and thanked him. And he's, er, so, he went off. And I thought to myself, 'that's it, I

will never see him, that's it. And it will be back to the old story, on your own, Sophie'. And so, anyway, the next day, he knocked on the door again, and it was, he was there and he said, he said, he said 'I've come back.' Because he said, 'You didn't let me, er,' find, what I did find, which was a fact that I had, erm… Oh what was it now? What was he saying to me about it? Oh I said 'It was dangerous.' I had done a list of, I had er, a computer then and it is still upstairs and I am trying to get it sorted and fitted out, and er… So I've tried, tried to get someone to sort that for me, but my daughter, in the meantime, er, just to say that, she's bringing me a typewriter, when she comes up. But anyway, I went back and, er, and Tim said to me, he said, 'I saw something on the ground,' he said, 'and I think it is yours.' You see, I had been typing out labels for things and I had put my name and address on all of the labels, and if it was something I needed to give to somebody and they needed my address I was doing it, but it had fallen out of my bag, when I'd… Oh I was worried! But Tim said, he said, 'I thought that was going to be dangerous for you to leave that on the ground,' he said, 'because you might find some terrible person, turning up at your door and then you would be in a really bad way.' So I said, 'ok', I said, 'thank you very much indeed,' and then he said, 'I will stop and have a cup of tea with you today again.' So he did, and then it got to the fact that I think he came back again and he said to me and he said to me, 'Would you like to go on a boat?' Because he's got a boat. And I said, 'Oh I would love to go on a boat.' So that is how I ended up with Tim and he has got a family too, that he goes back to, so what we do is, er, I love him very much but I can't marry him or anything like that because I'm what? How many ages? I have about 95 ages, I think. But I laugh all the time. No, it is actually, I think, Tim, is it 75 or something? What?

Tim: 70

Sophie: 73?

Tim: When were you born?

Sophie: Seventy...yeah, I was born, yes, on the 9th of July nineteen thirty...oh God knows what, years and years ago.

Tim: What was birthday? When is your birthday?

Sophie: And I was, I was, I was, my parents had got me from, erm, erm, where do you call these paces? Where babies are thrown...are given to?

Ethna: An orphanage?

Sophie: Yes I was, I was actually a child, taken out of a hospital because I had no family. And so my mum and dad who are here somewhere here, aren't they, Tim? Somewhere? Ah, here it is. There. My mum and dad. They took me over and I was with them for donkey's years. They were wonderful people and I love them. They were really, really, fantastic. And, er, so, er, I had a fabulous time with them. Then the war came along and my mum and dad, she was a WAAF[43] and he was in the army, and he got caught by the Germans when he got into Germany and they took him in and he could not, er, get, get, see his wife again. That is Hilda...my mum was Hilda and my dad was Ernie. Ernest.

Ethna: Was he in the prisoner of war camp a long time?

Sophie: He was in it the whole of the war. He said the worst part that he would remember was that fact that the young guys who went into the fight, as well, they were stupid they tried to get away from the Germans and they tried to go away by putting German clothes on, and things like that but of course they were no good at all because, I mean,

Ethna: They probably spoke German?

Sophie: No. It was not. And so they were caught by the Germans and they had, oh a terrible time, but my dad, because he was a horticulturalist, thought, 'Right, I am going to stay here and I'm going to get through the war, the time I'm in, the time I'm in, that, erm, that German place.' And he said, 'I'm not going to try and escape,' But he helped the guys he could, as much as he could. But that's how, that was my mum and dad and so, erm, it was absolutely fantastic, they had a...what do you call it? Post Office. And, er, so they had a Post Office down in the south and that was where, in the end, after the war. My mum was in the WAAFs and she used to take me to London and I was only very, very young. Then I suppose I would have been about four. I could, she took me to Les Misérables. And I have been taking my children there because it has come on again and it is a wonderful, wonderful theatre. And I said to Helena, er, Kath can't come because she is in the States but she will come on another lot of it in the summer of this one, year. So she

[43] Women's Auxiliary Air Force

is going to come and come with me for that. So it will 3 times that I have seen Les Mesérables. But it is the most fabulous, if you can go there. Have you seen it?

Ethna: No.

Sophie: You want to go to London and that is the place to get a ticket, get it. And you see mum, because she was on her own all of the, the, erm, time I was with her, was, she used to, she was a theatre goer, and so she used to take me with her and so my first memory of going anywhere to be in the theatre was with Les Misérables. Les Misérables. But anyway, it is all coming back and I never lost the thoughts of that and mum used to take me there and she was with the WAAFs and as, as, I say, I had a lovely time, although my mum is, not my mum but it was absolutely fantastic so I can't say I have had any problems like that at all.

Ethna: Do you, do you find that since Tim's come into your life that your memory problem has got better?

Sophie: I have man in my life and that makes my life so much more better.

Ethna: Do you feel it helps you to manage the, the memory loss better?

Sophie: Oh yes. He does, he does and I am a lot, lot better. Because when I was, the first time I was, I, I, had to come to you [Sophie has obviously assumed I work for the memory service] is was because, I think I was getting to the point… I mean, I read books, I am terribly, terribly, erm, you know, wanting to, I do everything. And as I say, I do a lot of art, and I do, that I did. You see, if you turn to the side, you see those birds? The nuns taught me how to do that. And I did that. And they put that into a gold, er, little box there.

Ethna: [looking at a photo of a beautiful young woman] Is this you?

Sophie: That is my mum. That's her. You see, when she was young she was beautiful! And, er, you know, I am so lucky to get mum and dad. So, when I found that I was, like, a bit, you know, a bit like this, er, it was, I think, I think it came about because I was in a bad way. I had ended up on my own, my mum and dad had died, my children were, well, well away and things weren't so good with that. And, er, so it was very, very difficult, I have had quite a hell of a time in my life. But I have managed to get through each and every one of them, you know, I just won't give in. And I just keep on saying, 'come on' and just laugh about it because it is funny. You

know. If I miss a word or something like, ‘Oh! Bloody hell! It’s gone again!’

Ethna: When did you first start noticing that you were having problems with your memory?

Sophie: When I, just before I met Tim. Er, yes, it was, yes just before then, I was a bit, sort of, finding things were a bit difficult. And I think it was that spell, of it, I think it was about 10 years on my own and I’m a talkative person, as you can see. And I am also so very vain, aren’t I Tim?

Tim: Yep. Yep.

Sophie: I am very vain, aren’t I?

Tim: Yep, we are going to put it on your tombstone. ....

Sophie: But he manages to keep up with me. And, er, so, and I love dancing and theatre is my, oh I love it. I learnt, I've learnt, I came here, because I was working for Laura Ashley’s in the States, I have been all over the world. I have been everywhere.

Ethna: What were you doing for Laura Ashley in the States?

Sophie: I was one of her top girls.

Ethna: Were you a designer or…?

Sophie: No it wasn’t that. But I was her secretary. And so I had a wonderful time. I had no, I had no problems at all, at the, or anything at all at that time. And I had an absolutely marvellous life with her and I have got packets of Laura Ashley stuff upstairs, and, er… It was absolutely fantastic, so I have got no problems in that, but I think it was the fact that I ended up, so suddenly, because I had to come back from the States...I was in the States, I had been to South Africa. I've been to…, er, where was the other place I've been to? Tim, when I was young and I was at, with my mum and dad but I was with lots of places wasn’t I?

Tim: Think about where you’ve been. Go on.

Sophie: Yes, and I, I have been in so many countries, and er, New Zealand, I've lived in. I've lived in, er...

Ethna: How have you ended up in Wickham?

Sophie: Erm, when I got here, I think it was just I wanted somewhere to go that was nice for dogs. I love dogs, I am

passionate over them absolutely: Jeni and Sami. They are the best thing on earth so I am sorry you don't get the pleasure of them [Sophie knows I don't have a dog, she asked me before the interview began], but they are very good and so, I have had them for ages. And, er, I had 5 at one point.

Tim: Where did you, where did you live before you came here?

Sophie: Sorry? Can't hear!

Tim: Where did you live before you came here?

Sophie: What love?

Tim: Where was you living before you came here?

Sophie: I was in, er, what's it's name? I am forgetting the names of places, because I have been to so many places, you see. I get so confused. So at the end of the day, that was down in, er...

Tim: We catch the bus from […] and went into […]. And the little bus goes through the little lanes and it was, and it's...

Sophie: It was like, you know, it was further along than when we go to the stables, the stables in […], is that it?

Tim: No, no.

Sophie: I'll get it! Hang on. Erm, I will get it, it is, erm, er, at, it will come to me in a minute, erm… It is so annoying! I know so much and I can't always get it out, and so it's with the buses it will take two hours...ay?

Tim: This little 'shake rattle and roll' bus went through it and you always pointed out to me which house it was.

Sophie: [says triumphantly] Wickham!

Tim: No. this is Wickham.

Sophie: This is Wickham, yes.

Tim: What was the place called before you came to live here?

Sophie: Er, where I came to...?

Tim: Before you bought this house you lived in another village, what was the name of the village?

Sophie: Ok. So, this, this was, erm I was in, oh what was the name of it? That, because I don't, it is out of my memory because I haven't been there for so many donkey's years, you see.

Tim: Who was you with then?

Sophie: Sorry?

Tim: When you lived at […]

Sophie: Yes. That's it […] Thank you.

Tim: Who was you living with then?

Sophie: Sorry?

Tim: Who was you living with then?

Sophie: Er, that was with, erm, I think it was Ian, no it wasn't, it was… I have had three men in my life.

Tim: Ian was your husband.

Sophie: Yes, he was my husband.

Tim: But who, when you lived at […], who were you with?

Sophie: […]? I think I was with, erm, now who was it? It was, either, it wasn't Tom, because I never had a Tom. No...It was, er, you see, this is where I get stuck because it is to do with memory.

Tim: Now, it begins with B. The name begins with B

Sophie: Ay?

Tim: The name begins with B.

Sophie: I know it is not Peter, no, is it Philip?

Tim: No, B, B, B, B

Sophie: No its not.

Tim: B

Sophie: P?

Tim: Not P. B!

Sophie: Oh B! That's right. It was, oh it was, not Bob, it was, erm, b..b...er, God, it just goes in a bloody flash and it stays there

and it laughs at me out the window. And so, it will be, er, it was, erm, Bob? No. not Bob. Not bob. Bob...Er, Robert? No. not Robert because that I Bob.

Tim: Bar....Bar

Sophie: It will come in a minute.

Tim: Bra.

Sophie: Er, B...erm...Bi?

Tim: Bar...

Sophie: Bishop?

Tim: No.

Sophie: Bar? Bi? So I have got Bi...so...its er...

Tim: Barney.

Sophie: Barney. Yes. Yes. Barney. That's it.

Tim: Tell her about Barney then.

Sophie: Barney, yes. Erm, I, what about him?

Tim: Tell her about, go on, tell her about Barney.

Sophie: Barney, yes, well he was with me for quite a long time and, er… I don't think I was married to him...no I wasn't .I was, I was only married to Ian. And he was, absolutely, he was my husband. But then I had two men in my life afterward and one was Barney, they all died! I mean, it wasn't me who did it! Honest to God! I never did it! And, er, so, it is so difficult, so... I have got used to that [name of town] now. And that's up the road there.

Tim: Tell her the story about Barney!

Sophie: Barney, yes, well, Barney...

Tim: And how you come to live here.

Sophie: Oh he came no live here, yes...

Tim: No you.

Sophie: He, I think he was working here on the house or something, I think it was that. I am not sure, but he came with me down to have a look with a house with me and I said to him it

would be nice to live in the country and he said, 'Yes that would be smashing.' So, he said, 'Would it be alright, if I came and stayed with you?' So, yes, I think that was it, yeah. Wasn't it? I think? Is it? I think it?

Tim: I am not telling, I don't want to tell the story for you.

Sophie: No, I can't, I have got to think about it...er...you see it really, really makes me so furious when I can't get it when I need it and then it will come back again, when I don't need it and it is bloody annoying! So, anyway, Barney, er, he was in hospital. I think, he was ill, in hospital, he was very, very ill and so I was going backwards and forwards to the hospital with him and then he went into hospital and then sadly he died. And so, that was a very, very sad thing as well and I couldn't do anything about it. And because as I wasn't married to him, at all, the only one I ever was married to was Ian, my first husband, the Irishman. He was fine, except he had a [unknown word], I think is the word, er, you see, I can do all of these big words, [unknown word], and er, everything I have no problems with that, it is just the memory, the memory that has, if only I could get it back.

So, I could see some of the times what people have done for me, I would be so glad to have it. But anyway he died, so I lost him, which was a sad thing and he went back to his son before he died. Then, there was another one, came into my life and that was, erm, Barney. Am I right? Barney came into my life, he came here and stayed with me for about several years, and erm that was okay but he died too. He couldn't, I can't remember what that was, but he was in a terrible way, as well, and I didn't poison them! I didn't, I didn't, I didn't do anything. I had no problems at all at that stage because I was able to do every single thing. We used to go out dancing, there was a, er, a, erm a place, down in […] er, that had a village hall which was lovely and we used to go to that and that was very gorgeous. And that sort of thing and so I was, with him, and then he died as well. And I can't remember quite what happened to him but, he also died. Anyway and went with, back to his son and it was terrible sad because I saw him going, when he went, it was very sad. He had, there was something really wrong with and so he ended up going back to his son and, er, it was a very difficult thing. So, I ended up completely on my own and then for the next few years I was on own completely, and so I think it was the fact that it got to be so bad being on my own and all the stress, I'd had, and is there another one?

Tim: What else? Were you going, you had another problem, as well, you had a problem yourself?

Sophie: Yes.

Tim: What problem you had? You went through a lot of pain?

Sophie: Sorry love?

Tim: You went through a lot of pain. And you had a problem, you went through a lot of pain and you had to go to the doctors.

Sophie: Ah yes, that's it, yes, that's it, thank you for reminding me, I'd forgotten it. My hip here was terribly bad, and I was, I, in agony. And I, I was actually, I wouldn't let the dogs go and I wouldn't let them go at all, and I tried to take them for walks, and everything because I had five of them at the time and I had a little dog called Dougal. 'Where's Dougal?' [Sophie starts to look around for a photo of the dog] Dougal is looking at me from somewhere here. Can you see Dougal? Little Dougal. Little Dougal, is here somewhere, where are you? [Sophie starts to get upset about the missing photo].

Tim: Carry on talking. Carry on with the story.

Sophie: Yeah, I think it is here somewhere Dougal...er, little Dougal is, there! Isn't he? In there? On there somewhere, little Dougal. [Sophie stands up and starts to look for the photo].

Ethna: What is it about Dougal?

Sophie: It was, it was just here. I have got little Dougal and Dougal I adored. Oh there's little Dougal! [Sophie finds the photo]That was just before he was put to sleep. He was a little Chihuahua. He was gorgeous. And it makes me cry.

Ethna: Was it very difficult taking the dogs for walks?

Sophie: [smiling with relief] There he is again!

Ethna: He does look like a right cutie, doesn't he?

Sophie: He was lovely.

Ethna: Was it difficult taking the dogs for a walk with the, with your bad hip?

Sophie: Well, er, they sort of came, and the little ones went on their own with me and the big ones were, like, I had Tash, where is Tash? Anywhere? Ha, I don't know where Tash has gone to. Tash is beautiful he, is, he was a Labrador. He was,

about this height, and don't let anybody tell you that dogs are a mess or something. Beautiful. When I had to get this hip done, er, he was standing at the door, it was 12 o'clock when I had to go and he was there. And Rover, they were on the, on the, er, in the house when I went and left him. He was wonderful, he loved me to bits and when I came out of the hospital, with having to have this hip don't, because I had a terrible, I don't know what it was I got, but it was, er, it was, terrible. What? What?

Tim: It was your hip, they put a new hip joint. They put a new bit in.

Sophie: What?

Tim: They put a replacement part in.

Sophie: Yes, it was, it was a hip done. And I had been walking the dogs for ages, trying to keep them, all alright. It was a terrible stress, and it was, this hip, it's fine now, er, I'd, I'd, I'd walk on it, I deliberately do not use a stick. I will not use a stick and they've told me in the hospital that that is the best thing I ever did. 'If you pick a stick up', they said 'you'll never, ever keep that leg walking.' So, I go, right round the fells, yes, I go right round the fells, yes. I got this hip done. I take, erm, Tash, died, and that, that, that was terrible, and er, so, er, what? And I have lost me tissue. Where's that gone to? Oh it is on the floor, no wonder. But, erm, alright, I got, picked it up, thank you. And I had another dog, Sammy. I have given him to a friend of mine and he is only up the road still. He is still alive. And he is with a friend of mine up the road. Isn't he Tim? And this, that is him in the snow [showing me a photo] this year. I think it's this year isn't it? Yeah I think so.

Ethna: Looks well.

Sophie: [smiling with pride] Yeah, oh it is terrible when I see dogs I go barmy. To me, dogs are, er, top brand of human beings. They are absolutely… the night I went to get my hip done, night it was. They came to call for me and it was about 10 o'clock at night when they came to, the hospital came to collect me for this to be done, and he was looking at me from the door, and he was in tears himself. It was awful. So I ended up going in the hospital with this hip to be done and I came out and he was absolutely fantastic. When I came out he looked after me, did Tash. And, er, anyway, oh God. [Sophie starts to cry]

Ethna: Sophie, Sophie do you think we ought to stop the interview because you are getting really upset?

Sophie: No it is alright, I am used to it now.

Ethna: Are you sure? I don't want you getting all upset. Are you sure?

Sophie: [composed now] So what happened was, erm, I was alright after that, Tash was there for a while but he was getting old and he had to be put to sleep too. God that was terrible. So, it's been set of...and I loved the dogs.

Tim: And Sammy? Tell about her what happened to Sammy.

Sophie: Oh Sammy he is still here. He is fine and fit. I had to give him away. Because I thought he was going to have a lot happier life because, because, I , he was a very business-like dog. He wanted exercise. Yeah. And so, er, I had a friend up the way there, and so she took him, didn't she?

Tim: What is she called?

Sophie: D..D...er...I have to stop and think about it, I can think of dogs names Laddy and all these ones I've had...but humans.

Tim: We had a good walk with her over Christmas, didn't we?

Sophie: Sorry?

Tim: We had, she walks in (name of forest) doesn't she?

Sophie: Er…Alice?

Tim: No, Alice is your daughter.

Sophie: Alice is my daughter. And, what is the other one? It is, hang on, er, er, it I know because I have got on a piece of paper just there. and it's Janice and it is not...Jenice? Jan?

Tim: Are you thinking of your granddaughter?

Sophie: Pardon?

Tim: Are you thinking of your granddaughter?

Sophie: Which one?

Tim: Your granddaughter. Is that who you're?

Sophie: Might of, yes, yes.

Tim: What do you get at Christmas time with a lot of red berries?

Sophie: Erm, what?

Tim: What is the bush that you get? Well all…

Sophie: Oh yes. I know. Yes. It is, er, the, er, the, er, for Christmas...it is, erm, the, erm, God Almighty, red, er, and Janice, not Janice but…

Tim: Prickly bush with red berries.

Sophie: The red berries!

Tim: Prickly bush with red berries what do you call it?

Sophie: Yeah, I know, it is the, the snow, I have seen the snow, you see, and all that, and it is all gone now and, er, so...

Tim: What do you call the bush with prickly berries?

Sophie: Sorry?

Tim: What do you call the green bush with prickly...

Sophie: Holly! I've got it! I have got it finally! See? I mean, it is a hell of a bloody nonsense, this. I, I, I mean, I write books, I can paint, I can do anything like that, and er, I can be anything...

Tim: Tell her the story about the car.

Sophie: Sorry?

Tim: Tell her the story about the car.

Sophie: Oh the car, yes the car. I was furious my daughter, got, I had a car, well, I had a car, and then I was, it was before I met Tim, it was before I met Tim, wasn't it? I was using the car and anyway the car was getting a bit old and my daughter came over and she said to me, she said, or I said to her about my car and everything and I took her around in the car as well...

Tim: When you used to go out to […] how fast did you used to drive?

Sophie: Oh, yes I am a terrible driver, I hate this, one thing I must say is, I loathed this. I, I, would be far better if I had been in the times gone by, I do not like this world now, I do not like

it. It is too, ‘Mine! Mine! Mine!’ It has got no kindness, it doesn’t keep people, it doesn’t look, anybody I see who has got a problem. But people nowadays they just walk past problems, they do not give a damn and I do not like that line, I was in the, erm, I was in the...

Tim: You was, get back, back to driving the car, and buying the car.

Sophie: Well yes I was doing, I was doing that.

Tim: When you were driving 30 mile an hour and everybody was piping their horns...

Sophie: Yes, I was driving at 30 miles per hour because all the other bastards were going around about 70, I hate it! I think this world is littered by people who are just thinking of nothing but what they can buy, get and all that sort of stuff. They don’t try to help people, or dogs, or animals.

Tim: So, what happened to the car? Tell her...

Sophie: Ah yes, so my daughter came and she said she thought it wasn’t good enough to drive.

Tim: You took it to the garage to be repaired.

Sophie: I took it to the garage, and the bloke there, he was a sour old soul, and so he didn’t think I should be driving because, he said, he said, because you are too caring. He said, he said, and the things he said, is you aren’t being able to do what, you, er, in a car, which I would consider to be okay. So, he, er, he told me I should not have the car, didn’t he? I think? I was furious with him. I said it is not me who is the problem, I said, it is the bastards who keep running around on the bloody roads. And I hate people nowadays, people are so, cluttered, cluttered by their own pride and own things.

Tim: Now when I first met you, you kept going on about this car.

Sophie: Sorry?

Tim: You kept going on about your daughter

Sophie: Yes I did go on, didn’t I about it?

Tim: You were blaming your daughter, wasn’t you?

Sophie: I bet, I, I did, I blamed her, I said to her, ‘This is stupid’, I said, you know, I said, ‘it is the other ones who needs their

heads seeing to, not me.' I look out for the animals that cross the road, the humans that cross the road, and I don't, I will not, go at a speed that looks as though you couldn't stop, when you should do. And I just can't stand it. I hate it.

Tim: And they, I, and I asked you the question: had you gone out to […] on that day, in your car, where would you have been now? [meaning they wouldn't have met each other on the bus]

Sophie: Yes, I know, exactly. If I had been yes, yes, exactly, and so Tim, was, er, he was, he took me over, really more or less, don't you? And he came and talked to me and everything and I thought he was wonderful. And I still do.

Tim: Tell her where we've been to on our travels.

Sophie: Sorry love?

Tim: Tell her....tell her where we have been to on our travels, the different places we have seen.

Sophie: Oh God, I can't remember them all because you see, because there is only so much I can do. I mean, I have gone to place that I have never been to before, but, oh, my favourite is [name of local castle]. I love [name of local castle]. I want too, I want, I want to sing, I want too, don't I? I want too...and I love singing.

Tim: You are a very good singer.

Sophie: I am. And I love singing! I would have loved to have been on a stage show. I would have loved all of those things because I really am like, you know, sort of, good of those things. Art, singing, everything like that is my love in life. And I hate these, the fact that so many people are to just greedy and are, don't think about other people and things like that. I, I need to help, I'll help animals, I'll help everybody and I don't mind who help and I will go and help...but I just cannot go with this life now. I hate it, it is so horrible. You know, you ought to see the house here, I have got about 400/500 books and I have got, er, CDs by the back and they're beautiful ones, [looking at Tim] stick it on Tim. And, it is beautiful. It is big old fashioned one [showing me a radiogram], around the corner here. Now, my daughter said to me, 'why don't you just dump it?' 'I said you must be bloody joking.' And it is beautiful and, er, in the end when Tim came, I told him how I loved the, the piece here, that is for the D...er...all the lovely, erm, what I've got there, see all of them sitting there...

Ethna: Still there yeah.

Sophie: [becoming excited] Beautiful and there is an old fashioned thing there that people would say, get stuck, and don't have it, go and get something modern, I won't do it. Because all of these wonderful things are beautiful and they have lasted for donkeys years. And they are people squandering and throwing stuff away for cheap jack stuff that is going around nowadays and isn't worth its weight in gold. And so, I mean, those are beautiful, you should put that on Tim, just in the background because it is beautiful isn't it? Because it's snow. It's snow and it is Christmas. And then if you look at it, just come and look at it because this is why I get so furious with people, this is beautiful.

Ethna: Yeah.

Sophie: And this is marvellous and it is absolutely superb and if he puts it on, if Tim puts it on you can hear it. Because it is absolutely beautiful but I, I love the old books, I love the, er, everything that is old, I like it. I used to have a DVD, didn't I? I used to have one...

Tim: You still watch it!

Sophie: I still watch the television but, I but, when you came I was, I has another one didn't I?

Tim: Oh, the old television.

Sophie: I had an old television. I wouldn't let the old stuff go, I won't. Because if it is working.

Ethna: So, do you feel that, in the years leading up to when you became, it is possibly some of the stress that you experienced before, you become, before you started having a problem with your memory?

Sophie: Sorry love?

Ethna: Do you think that some of the stresses before you started having memory problems might off contributed to it?

Sophie: Yes, I think so. I was fine, when I was in the States I was fine. It only came back, it only started after I'd come back. And I think I would say it actually started really, when I was on my own for those years. And...

Ethna: So, thinking about the service that you get from the memory service. How, erm, Anita, is it Anita, that comes to visit you?

Sophie: Yes, she is, she is lovely.

Ethna: Is she? What kind of things does she do that is helpful?

Sophie: Sorry?

Ethna: What type of things does Anita to that you find helpful?

Sophie: She sits and talks to me. Because we chat about things. And things like that, and er, you know, and, er, sometimes I have to go… when like, I've, this I haven't had anything done to it since I have had it done, because it has been absolutely fine, but you know, but the stress with dogs and things like me, I mean I love them so much...

Ethna: But thinking about Anita...

Sophie: Anita, she is very, very good.

Ethna: What kind of things does she do that is helpful to you? What kind of things does she say that is helpful to you?

Sophie: Oh she just says, we just sit and have a chat and, er that sort of thing, and she says to me, how am I getting on and we talk about books and, er, you know, all of these sort of things and art and stuff like that and everything. I really do like, love everything like that, I, I'm probably in the century I think that is what it is because but I do hate the greed nowadays that goes around and how people junk stuff. If it, if it's working and it is a beautiful piece of art or piece of jewellery why on earth do they have this need of, incredible amount of always be buying and buying and dumping.

Ethna: Can I ask you about the drugs that you are taking?

Sophie: Sorry love?

Ethna: Can I ask you about the drugs that you are taking for your memory?

Sophie: Sorry I couldn't hear that.

Ethna: You know the drugs that you take for your memory.

Sophie: Oh yes! I do I have got them.

Ethna: Do you think they have been helpful to you?

Sophie: Oh yes, I think they're better, I think I am better, and I don't mind doing it at all it does my...

Ethna: In what way do you think, it is helping?

Sophie: Erm, I wouldn't, most of the time I am quite sober but I can't cope with dogs and things like that because I love the dogs so much, and then when I get, sort of, anything like that I get very stressed but, erm, and horses I had in my life too?

Ethna: How do you find the, the drugs that you take for your memory loss how do you feel they are helping you?

Sophie: I feel, I feel that I am better, and I take it quite happily and quite willingly but it goes in spasms doesn't Tim? Erm, I am sorry I have forgotten your name now...

Ethna: Ethna.

Sophie: E...

Ethna: Ethna

Sophie: Ethny? Ethny because, because that is an unusual name!

Ethna: It is.

Sophie: I was talking, you know, she was asking me, what I thought about the girls that come here to talk to me, you know, and they have been very good, all of them, yes. And they have looked after me and at one point in time there was a worse point, er, I had to have girls to give my, get my meals ready, er, but I got fed up with that because I thought they were taking me down a bit and I found that they were, I don't know, I wasn't happy with it, anyway, coming in and everything like that.

Tim: You thought they were taking stuff out of the house, didn't you?

Sophie: Sorry love?

Tim: You thought they were taking stuff out of the house.

Sophie: I did yes, my stuff and well, I there were just things missed, and I thought no, I am not starting, having that because they used to come and maybe they would do my meal for me and then after they'd gone I found a couple of things missing, you know. And I, I am not that stupid that I can't see that I have lost something, you know? And, er, it would be either a book or something like that, because I have got I don't know how many books, probably 500.

Tim: And you didn't like Dr. Craig Adams and you didn't like...

Sophie: I didn't like, when I first met him I didn't, we didn't get on first of all, because he was asking me questions and I said, 'I am fine thank you. I don't like anybody to worry about me. I am absolutely fine, don't let me get, you know, let me get on, I'm fine, and don't worry about it,' and er, he was a bit, he was saying to me: well, I want to find out that things and these things and that sort of thing. So, I mean...

Ethna: It is difficult when people ask you personal questions isn't it?

Sophie: No.

Ethna: It is yeah.

Sophie: No, sorry?

Ethna: It can be difficult when people ask you difficult questions...

Sophie: Oh it is difficult. It is. It is.

Tim: And it was the same with Dr. Craig Adams you didn't like him.

Sophie: Yes. That's right, what was it then, I can't remember?

Tim: You were the same again, when you met him, when you had to see him you didn't like him, did you?

Sophie: Oh I did, that's right, I said I didn't like him. Yes, that's right. Now I call him Craigy. Because I have got so, I say, 'Hi Craigy!' and I think he is really nice and everything. But just when you think you know everything and you think you are your own person, you think you are okay, and you don't realise that you are doing something maybe, that is [different] to what other people might have done.

Tim: Not long after meeting me, you had an appointment to see the doctor down at [a local] hospital.

Sophie: What was that?

Tim: Not long after you met me you had this appointment ...to see the doctor at the hospital.

Sophie: Yes, that's right, he was nice. Yes.

Tim: And you didn't want to go.

Sophie: I didn't want to go either. But you forced me down there. He forces me down.

Tim: Tell her the story about that…

Sophie: That is right, yes it is, because, you know, I have had such a varied life, I have lived in South Africa, New Zealand, wherever, Jamaica and I done everything, I think, in the world, my parents up, they were wealthy and they took me out and they were so good to me. And so, I've, I found it so difficult to, not have my parents and I lost them because they were so marvellous they had this shop, and they also had the Post Office down in, er, Peace Lake, which is a long way away from here and I often think I might like go and Peace Lake again to see what Peace Lakes like nowadays, er, I would love to do that, because they were so marvellous, but it was so great.

Ethna: Do you think that, help, that taking the drugs is helpful to you? Do you think it is making a difference?

Sophie: I think so, but as I, as I say, it came, I don't know. I don't know what would have happened if I stopped, because one day I did miss it and I didn't seem to be any different much on that particular day or the day after, but I thought I better get on with them. I have been told to take them, so I don't know, actually the only way to find out if I did, is to, is, er, stop taking them, I might find the difference then. But, er, you know, I just wonder what, what amount I could find back in the...because I am always asking Tim because things in my background. It is difficult, you know to find them up and get them up again, in your mind, and that's it you know.

And I, I was in a convent, a beautiful convent, when I was young, and when my mum and dad picked me up, I was probably about, I don't know what it was. I was picked up and then I went to the convent when it became the war because my mum was in the WAAFs and my dad was in Germany. He went off in the army then and he went. And I was with the nuns for over, oh so many years, the nuns, sister...when I remember from there, it's quite, in my mind is Sister Beatrice she was a marvellous nun and she was always telling me off and she used to say to me, 'Sophie?', she said, 'have you seen my hands?' and she had veined hands, very veined hands. And, er, in the hos...In the erm, er, it is not a hospital, it is just where the school, it was a beautiful school, and, erm, and absolutely marvellous. Cost a fortune but my mum and dad paid for my teaching and everything, beautiful and that is what has given me the feeling for singing, and art, I got, I was. Behind you is a picture I did when I was first with the nuns, yes, the nuns taught me how to do oil painting and everything like that.

Ethna: So thinking about how it would be possible for Dr. Adams to make the service better, are there any things that you think they could do to improve the service that they offer people like yourself?

Sophie: I've, I would just like to find out if I really have to do it with the tablets or whether there is some part of me that can actually come back again if I stop taking them, I don't know, it could just be that, er, all of what was, Dr. Adams says, and that will never go away again and maybe it was just because of the war and the fact that I was on my own, the nuns were fantastic! Absolutely, and as I say, our Sister Beatrice she was absolutely, always having a go at me. And she was saying, 'Sophie! You have got to do this, you cannot to that. God is watching you from above.' And I believe that too because I believe there is a God but I think we should all think more about God and I think we should all think that there is a God I think the whole world seems to think it is something that is going to be there forever and ever, it is not going to be, I don't think, in the end.

Ethna: Sophie, can I ask you, how often Anita and the other girls come out to visit you?

Sophie: Sorry love?

Ethna: Can I ask you how often the girls come out visit you? Anita and Elena?

Sophie: Er, it is quite a while, if, I suppose, I think it would be, Tim? How often do you think I have had the girls coming to see me?

Tim: Remember the last time they came.

Sophie: [looking puzzled] How many weeks, or months?

Tim: When was the last time, when was the last time they came?

Sophie: It's, it's, I think, it isn't, er, very much, it is not very much is it?

Tim: Have they been since I have been home, I have been back because we went to.

Sophie: You've come once, didn't you? Well did you see them? Yeah you have seen them once, or something?

Ethna: Do they come every six months?

Sophie: 6 months.

Tim: About every 6 months I would say.

Sophie: Yeah, 6 months.

Tim: Every 6 months yeah.

Sophie: Every 6 months I think, probably. I would say it is every 6 months. Because, and I am always pleased to see them, I always say hello and everything.

Tim: I have known Sophie now, for just over 12 months and just off the top of my head I think, I can make a calculate, guess they have probably been here about 4 times or something like that. I get a feeling yeah, and I have met them twice and I am away 6 month a year.

Sophie: Yes, and then you came round and now he comes and stays for, 4 day?

Tim: When do I come?

Sophie: Yes, yes, isn't it?

Tim: What day do I come?

Sophie: Sorry?

Tim: What day do I come?

Sophie: You come to me on, erm, hang on, I'll get it right because I know everybody is waiting.

Ethna: Don't worry, don't worry.

Sophie: And I… so I will get it right. I will get it right. What happens is, Tim, will be going back home tonight, to his home up the road and he will be there until Friday morning and he comes back, Friday morning to me?

Tim: Friday afternoon.

Sophie: Yes. At the end of the end of Friday morning, usually, half way through the day, anyway, and then he comes with me on Friday and he stay with me until today, so, he is with his own family for 4 days and with me with 4 days so we have both got the same amount between us, he is, going all through. He is a poor soul, he goes everywhere. And he comes and looks after me for the four days and, er, we have a lot of fun, and er, I he, he stays here and he sle...we sleep together.

Ethna: Oh you don't have to tell me. ....it is okay you don't have to tell me that!

Sophie: No, it is okay!

Ethna: That is well…private, like!

Sophie: Yes but one of the other ones did. And she said to me and she said about it, but no, I said to Dr Adams, I said, it is for, it has made a difference that fact that we do have a, have a, a bit of a, be so close, because otherwise if it was just, we weren't so close. I don't think it would be so good for me.

Ethna: I bet it makes such a big difference.

Sophie: It is much better to be together. Close. He, he cooks beautifully and, I do a lot of things, I do thing to, don't I? I mean, I am not lazy! I do all the house. And it's got 5 bedrooms upstairs and I have got them to clean and look after and I do and I look after anybody who will come to the door Tim says my problem, my worst part is that I am too good, aren't I sometimes? But that is it. If I see somebody and there is a problem I give them money or something like that, you know. I am very, very kind to people and I like people, you know?

Ethna: I can imagine that you are.

Sophie: You know, and so it is very, very difficult, but...

Ethna: So we know quite a lot about the things that make you unhappy because you have talked quite a lot about hat.

Sophie: Cruelty to animals. Personally.

Ethna: Yeah, I can see that you are very caring. So what do you do to relax now? Because before you used to take the dogs out. What do you do now?

Sophie: I used to do a lot of art, things like that.

Ethna: What kind of things do you do now?

Sophie: Er, what sort of things I do now. Er, when I can, I listen, well I do listen to the TV of course everybody does that and I like the really good programmes on the television. I don't like junk, at all, I don't like junk at all. But I do like good food...and things that the television is.

Tim: What did we watch last night that you liked?

Sophie: Er, what was it now? You see I have forgotten that now, what was it? It was...give me a start.

Tim: It is a series that has been on before.

Sophie: Sorry?

Tim: It is a series that has been on before and it has come back on again.

Sophie: Oh my favourite, yes, I have remembered that now, it is, Clarke, Lark Rise to..to..er..what is the other bit of it? Lark Rise to..can...can...candleson, or something. Isn't it?

Tim: Nearly, Candleford.

Sophie: Yes, Lark Rise to candles...something.

Ethna: That is quite had to remember isn't it?

Sophie: I know yes. Clark rise...I love the old stuff and this is all old stuff I love, I love, you know, I am not interested in junk.

Tim: And then later on we watched, we watched the one about the Catholic Church.

Sophie: Oh the Catholic Church.

Tim: What was that called?

Sophie: Oh that was, that was funny, funny. Funny. Funny. Oh God, you can say that, you are brilliant on that. Er, it's about, oh, I, I , want to get, I was brought up in a ...

Tim: What is that programme called?

Sophie: Sorry?

Tim: What is it called? The programme?

Sophie: What?

Tim: The programme, what is it called?

Sophie: What's it called, it, er, Ted, isn't it?

Ethna: Father Ted?

Sophie: Father Ted. Oh, it is funny! It is hilarious but I have been all my life in a convent with my mum and dad when they were in the army and everything and the WAAFs and er, and that was a long period of time that was. And the nuns, never

stopped looking after us children in the worst of war, of the, of the war. At night time the nuns went, we were in down, the children that were in the convent, we were in, er, put down, this, er, it was a magnificent convent, massive. And it had, of course, cellars and the nuns had us in the cellars in beautiful, beautiful, they looked after us. They used to go, around at night with erm, praying, as the bombs were going on, down, in er, where I was? And, er, it was er, Peace Lake. Peace Lake, I remember that now, so Peace Lake I was in and it was down south and it was, er, I was there for ages, and the nuns were going and when the bombs were going and everything was going hell outside the nuns would be praying and saying God and they would go by with candles and everything and I was a terror, I really was.

Tim: What's the other programs you like watching on the telly?

Sophie: Sorry?

Tim: What's the other ones?

Sophie: Yes. What?

Tim: Last of the..?

Sophie: Er, what, which?

Tim: The three old guys, the three guys, last of the...?

Sophie: Let me think...

Tim: What is that called?

Sophie: Has to be...

Tim: Last of the...

Sophie: Oh, last of the, last of the, erm, I am, that one is coming back.

Tim: What do you pour into a glass and drink?

Sophie: Less than, last of the...er...

Tim: And you pour it into a glass and drink it.

Sophie: Yeah. Drink. It is not last of the drink is it? Last of the drink? Last of the...er…

Tim: Summer?

Sophie: [smiling proudly] summer wine! Last of the summer wine! That is another one I like.

Tim: And what is that little fellow you like? The little fellow?

Sophie: Sorry?

Tim: You know, the little fellow who knocked all the chimneys down.

Sophie: Oh yeah. Yes, yes, that's…

Tim: What is he called?

Sophie: Sorry?

Tim: What is he called?

Sophie: Who?

Tim: Him who knocked all the chimneys down.

Sophie: Oh! Dibley, Dibley, Dibley? He is famous. We've got books on him.

Tim: What is his first name?

Sophie: Er, er, er, Fred.

Tim: Ay.

Sophie: [smiling broadly] ah you see, I can do something! Straight away, some things come at me 'woo' like that.

Tim: You went to see his statue, haven't you, in Bolton?

Sophie: I have, there is picture of me, with me on the...isn't it here?

Tim: Yeah we sent it to Helena and Kath.

Sophie: Yes, but I have got it here though, still.

Tim: No you sent it to Helena and Kath.

Sophie: Who did?

Tim: Us.

Sophie: We did?

Tim: It might still be here, I don't know, I forgot.

Sophie: It is here somewhere as well.

Tim: Anyway, what else do you like?

Ethna: So, just to, I have got to be finishing off soon....

Sophie: [looking worried] Oh, you have had such a hell of a going over, poor soul!

Ethna: I said I would keep you for an hour, so I have got about 5 minutes left, right?

Sophie: Oh you poor soul.

Ethna: So, there is just one last thing that I would like to ask you. And thank you so much I have really appreciated talking to you, it has been much fun. But things that help you cope? Memory problems are so difficult, what kind of, what helps you to cope, day by day, what strategies have you got to help you cope with...?

Sophie: Mostly Tim. Mostly Tim. Mostly Tim. But things will come back to me sometimes and I will say to myself, some days it is absolutely clear as anything and I can do ok, but I do get so furious because, you know, because, I was always, my mind was always so clear, and it was so good, and when I was young, I er, didn't have to, sort of, you know. And my art is good. And, erm, I can do paintings.

Ethna: So when Tim is not here what kind of things do you do to help cope day, to remember, to remember thing?

Sophie: Well, I do have this big house anyway that is a good start because it takes me a long time because of 5 bedrooms and I have got the children coming up as well, they are coming up soon aren't they? [Looking towards Tim] As soon as the weather is better, they are going to come up and see me for about two weeks. Er, to come and stay because they love coming because they have got a space here and it is so nice and, er, so they thoroughly enjoy it don't they? I like doing er, the garden, when it is good weather. I do, do that. My dad was a horticulturalist and so I take after him, so that is good, that is part of my life. And I love singing and sometimes when I am watching the television and it's there and will be dancing and going, [Sophie is singing]. I love dancing, I really do. And, er, I love everything like that. It is really, really good and I think it's, it's a nice thing to do, is to be like that. And I like when people are nice and very helpful and things like that, which is nice.

And nobody knows that I have got this problem mostly, because when I am out and I am talking, just plainly out in the street and not picking up all the things all the things that have happened to me than nobody would know that I have got a problem. Because I can talk to them and say, 'Hi, how are you doing,' and, 'Isn't a lovely day today' and 'How are you getting on with your garden?' and I have no problems when I am talking to somebody outside. Er, but, sometimes I do, stutter a bit, but it is, mostly just when I can't… One thing if it stops me and I can't remember it then that makes me, er, er, upset. It makes me upset because I would love to remember all the things. I remember the name Peace Lake because that was where my mum and dad had their shop and everything and that was where my life started. So that was the beginning of my life, but you know, it is just so sad that I cannot remember some of the parts in, I know I have been in the States. I remember when I went to there. I have been to several parts from them. I have got some family in the States who I do ring and talk to. Sal is a love of mine she is one of my friends in the States and she is a family friend. And, er, so, I do like to ring them and try and keep in touch with them and things like that, and, so, but I am, I just, I just wish that the world would stop and be a bit more better for people.

Tim: Your biggest problem, really, when I am not here is relating to time, erm, it's...

Sophie: I am very, I don't worry about time much. I don't worry about time.

Tim: I will come here on a Friday afternoon, and she is just making her breakfast, that is because there is no...

Sophie: I know that he is coming yes. Because Tim comes on a Sat, Fri, er, Friday. And then I'm home alone. I am on my own for 4 days of the week, which is going to be today, tomorrow, really, and that´s, one, two, three, four days, yes four days.

Tim: And that is the only time you get a bit upset isn't it?

Sophie: I do yes, it is sad because I would have liked to have married him, but he's, he's, er, it is, it is not possible.

Tim: I told you I had no intention of getting married

Sophie: He has no intention of...

Tim: It would spoil it.

Sophie: Yes.

Tim: She would get fed up of me.

Ethna: She would. Keeps it very romantic and fresh.

Sophie: It does, it does and I, I you know, I miss him when he is always and… I get through it ok because it is not like it is a problem. I go out with Rover, but at the moment it is not very good and it is icy. And I don't think I will be going out much in that. But when it gets into better weather then I take Rover for long walks. And things like that. And I alright, I am better, but, when is like this, erm, it is not so good, and I miss Boomer too [Tim's dog who is in the garage for the duration of the interview], when he goes with you, Boomer goes with, him, Tim, because that is his dog, he is sitting there [pointing to the living room] isn't he?

Tim: No he is in the garage.

Sophie: Oh his is in the garage I forgot they were going in to the garage. But, er, you know, I am not unable to do anything really. I can do everything. I used to make cakes and do cakes, but er, I don't do that much now because you can buy cakes quickly. And it, it is not really, er, you know, I have had to get all of the stuff out and do it and that sort of thing. But I can still cook quite well, and I can get myself a meal and things. I haven't got a problem like that. And one of my favourites, is, the, er, er, you know, this, er, having the, er, this brown bread and I like some things that are [Sophie pronounces some words I don't recognise] home-istic? Home-isitic? Is that it? Home-istic?

Ethna: Home economics?

Sophie: Yeah, it is. It's, it's, to me it means doing, trying, to keep things to the home, you know, like sort of, making different things, like that.

Ethna: Home-making?

Sophie: Home-istic. Yes. So, you see sometimes I come out, I come out with these words because I have had a wonderful education and I had a fantastic life I have had, isn't it? And I am just so furious about the way the world is going now. Where money is the most important thing to everybody, and they are just featuring on it all the time and that's it and I think it is so bad.

Ethna: Sophie, I am going to...

Sophie: [looking sad] You are going to end!

Ethna: I am going to end the interview now. I shall just turn this off.

Sophie: And you can tell Dr Adams I am still as mad as I was.

Ethna: So, thank you so much, I have really, really enjoyed talking to you, and I have learnt a lot. So...

Sophie: Well I hope you… You are probably thinking I am completely barmy. But still, I am not really. But, I like, I like to be very, very precise and I mean I am going to take the kids to see that theatre and I am looking forward to it because I loved it when mum...

Ethna: Yeah I hope you really enjoy it [the upcoming visit from her daughters].

Sophie: And I'm going to!

## Appendix 13: Example of memo made in NVivo: Sophie

**Created: 23/03/2011**

Very good relationship with the memory nurse and support staff. Sophie finds the illness to be very frustrating. It stops her from doing the things she loves, i.e. horse riding, painting and more.

Sophie met a wonderful man and they have a great relationship. Sophie feels safer when he is around, but he can't be around all the time as he has other family commitments. But, he makes sure she has everything she needs when he's not there. Not the only person to meet someone after they have been diagnosed with dementia. Love and romance are still important in the life of someone with dementia.

Sophie's story of spilling her groceries on the bus was a good example of a lack of concern for older people and a lack of awareness of dementia. People presumed she was stupid and treated her accordingly. Britain is an ageist society. This was an extremely stressful situation for Sophie, who even though she was 'crying buckets' still got no sympathy from the other passengers. Only the driver showed her any compassion. It was on the bus that she met Tim, who helped her pick up her groceries. Having a man in her life is important to Sophie, Tim brings, friendship, romance, love, a wider network of friends and activities such as going out on his boat that she wouldn't normally get access to. He also brings stability and predictability to her 'chaotic' life.

Sophie wonders if her past life has had an influence on her diagnosis of dementia. She was adopted as a baby - an issue that came up several times during the interview, i.e. how grateful she felt to have been adopted, the great life that her adoptive parents gave her. There have been difficulties with the relationship she has with her own daughters, still tense but since her diagnosis there is a relationship of sorts. Her first husband and another long-time partner died from ill-health, she makes a joke of this, 'I didn't kill them you know'. She was very lonely for 10 years and found this to be a very difficult time in her life. She wonders if there is a link between the stressful life she has lived and the diagnosis of dementia. This is interesting because the Alzheimer’s Society is currently funding a study investigating a possible link between stress and dementia.

Sophie has decided to take a pragmatic approach to the illness, laughing at the language gaffs and trying to take it in her stride. But she still feels the frustration of not being able to draw upon the memory she needs to complete a story or line of thought. Tim carefully draws her back to where she needs to be by providing contextual clues. He does not just tell her wants she wants, he patiently guides her back via a series of audit trails

'where were you when that happened, etc. until she remembers and in the process she remembers the detail of the memory.

The utter frustration of losing the driving licence. Especially of feeling duped by her daughter and the garage mechanic.

The importance of keeping your personal belongings around you. In a way, the objects represent who you are. The choices you made, your philosophy/outlook on life. Sophie is happy in a slower world of days gone by and didn't like, hated even, the fast paced life she is forced to enter. She hates that people are self-orientated and don't seem to care about others. Certainly, she didn't receive a sympathetic hearing when she got into difficulties on the bus.

**Created: 20/04/2011**

Sophie used to have carers come into the house to prepare meals, but she suspected them of stealing. So, she stopped that. People with dementia are extremely vulnerable to that kind of abuse. I remember staying over at a relative's house once who had dementia. The staff called at 8.00 supposedly to give the lady breakfast and have a chat. When I opened the door to her, I noticed that a car had dropped her off and was driving up the road slightly to turn around and park outside the house again. The driver did not switch of the car engine and the 'carer' left a few minutes later. She signed the book as not needing help that day as there was a guest in the house. I wondered how many times the 'carer' popped in and signed the book and left within a few minutes, instead of taking the opportunity to ensure drugs had been taken, breakfast prepared and eaten and how the person was that day. All the training in the world will not change the fact that low pay sometimes attracts people with very little interest in the needs of devalued people. It is just a job to be completed in the minimum amount of time with the least interaction with the person.

Sophie thinks about the first time she has her memory assessed with the MMSE. The first interviews/assessments are so difficult, because you don't think there is a problem. You don't want to answer the questions, in case your answers betray you. So, you get prickly and defensive. You realise somehow that other people see things that you don't. And that you need help.

It's hard to know if the drugs work or not. The only way to tell is to stop taking them and even then you couldn't be sure because you may be more confused than you realised without them. Sophie feels she would like to see if she could recover some parts of her memory without the pills, but doesn't want to take the chance.

Sophie enjoys watching 'good' programmes on the TV 'well, everyone does, don't they', good food, good conversation with friends, being active,

going on the boat, going dancing, getting dressed up, painting, keeping house, seeing family,

Keeping up appearances was very important to Sophie. She was proud that few people would know she had a problem because she could ask and respond to everyday conversation. She seems to go to great lengths to ensure no one guesses her secret: her diagnosis of dementia.

Keeping things as normal as possible, but not attempting things that are too complicated, like cake baking - why bake when you can buy one Sophie points out.

Sophie is an animal lover and really misses having her dogs around. She took a lot of pleasure in their company and felt loved by them in return. She is a gentle, free spirit.

**Created: 29/07/2014**

It feels odd to be reading Sophie's interview manuscript at this point in my PhD journey. Sophie's interview was one of the most challenging for me in terms of conducting it and analysing the narrative produced. Between Sophie and Tim, it was hard for me to get a word in during the interview, but still I managed somehow. The sheer volume of words made the interview transcript challenging to analyse. Yet, it was the way the words tumbled simply and joyfully out that made the interview so very enjoyable.

One of the things I learned quickly about Sophie's interview transcript was that if I wanted to really listen to what she had to say, then I needed to put aside a couple of hours and just work my way slowly through the mass of words. If I rushed the process, I suspected I would miss the wonderful things Sophie had shared with me. From the tumble of words Sophie had shared I needed to tease out those things that were relevant to the research question. What I found was, everything Sophie shared was relevant to the research question. It might be jumbled, for example, it is not unusual to find answers to a question scattered over two or three pages of narrative. Sophie's role in the research was to tell her story. It was my role to help her do that and to put it all together at the end. Re-assembling the constituent parts of any given answer was a time-consuming process and a humbling one.

Despite the painful experiences of being abandoned as a baby, being left in a convent during the war, the death of her adored parents and husband and the subsequent death of her partner of many years, the difficult relationship between herself and her daughters and the loss of her beloved dogs, Sophie was a joyful person. She loved life. She loved experiencing life. She loved sharing her life.

Coming to the narrative again I see something that escaped my notice before. The incident of Sophie on the bus was a terrible one for her. She was humiliated by strangers who, despite the fact she was 'crying

buckets' showed her no mercy, no compassion. And yet, it was because of that incident that she met Tim. Tim's influence in Sophie's life is a positive one. His presence brings joy, comfort, intimacy, love, new experiences, an extended social network and stability. But still, although I understood all that, I hadn't understood properly how the site of Sophie's humiliation was also the site of her salvation. The double-edged sword. How often life seems to work that way.

Reading through the interview transcript I experience vicariously Sophie's natural exuberance for life and the deep sadness she feels at the memory problems she experiences. I listened to the audio file again. It made me cry. Sophie feels robbed. I understand why.

## Appendix 14: Invitation to take part in the research: people with dementia and carers

University of Durham

Elvet Riverside 2

New Elvet

Durham

DH1 3JT

DATE

Email work: e.t.parker@durham.ac.uk

ADDRESS OF OLDER PERSON WITH DEMENTIA/FAMILY MEMBER OR CAREGIVER

Dear …,

**Re: Research project – Evaluation of a Community Mental Health Team for older people**

**Background to the study**

I would like to invite you to participate in a research study that will help to evaluate the work of your local community mental health team for older people (CMHT). The aim of the study is to talk to older people with dementia and their carers about their everyday lives and their experiences of the services they receive from their local CMHT. It is hoped that information gathered during the research will help to improve services for older people with dementia in the future.

I have chosen to evaluate your local CMHT because it is going through a period of change in the way it delivers services. This study therefore offers a rare and exciting opportunity to capture the work of the CMHT *as*

*it is changing* and to explore what it means to the people affected by the change.

**What will participating in the study involve?**

You can participate in the study in two ways. Firstly, you can become a member of an advisory group. Advisory group members will offer advice and oversight on the overall progress of the study and will contribute their expertise to any challenges I may face as a researcher. It is envisaged that advisory group members will meet every three months over a period of approximately 18 months. To ensure that advisory group members have an opportunity to share their skills and knowledge about the research, I will facilitate a series of meetings called extended Action Learning Sets. Action Learning Sets are a useful way of enabling everyone to share their experiences, developing skills and provisional findings from the research and ask for ideas on the best way to take particular issues forward.

Secondly, you can agree to be interviewed by me. You will normally be asked to participate in two interviews three months apart. During the interviews you will be encouraged to talk about your life experiences and the service you receive from the CMHT. It is expected that interviews will last for approximately one hour. You can decide where you would like to be interviewed. You can be a member of the advisory group and also choose to be interviewed if you wish.

**How the data will be gathered**

Data collection tools for the study include in-depth interviews with older people with dementia, their families and caregivers and staff from the Trust. People with dementia and their families will also be asked to keep a research diary for one week.

**Funding for the study**

The *Economic and Social Research Council are funding me to complete the study as part of a PhD I am working towards with Durham University.*

***My background***

I have been involved with the development and management of health and social care services for many years. In terms of research experience, I was recently the principal researcher in a study in which I worked with older carers gathering data on:

- The lived experience of being a carer later in life
- The process of involving older carers in research.

**NHS R&D approval and Ethics approval**

Senior staff at Durham University and the University of Birmingham reviewed the research proposal. This study was given a favourable ethical opinion for conduct in the NHS by [details have been removed].

Enclosed with this letter is a ‘Participant Information Sheet’. Please read it through carefully before deciding if you would like to take part in the study. If after reading through all the information you would like to take part in the study either by joining the advisory group or by agreeing to be interviewed, please contact me so that we can arrange a convenient time to meet.

I look forward to hearing from you soon.

Best wishes,

Ethna Parker

Principal Researcher

## Appendix 15: Consent form for people with dementia, carers and advisory group members

## Title of Project: An evaluation of the memory services provided by a Community Mental Health Team for older people.

Name of Researcher: Ethna Parker

I don't have to take part in the study. My participation is voluntary. If I wish to leave the study, I can do so, at any time and without giving a reason. ☐

Advisory group meetings will be audio recorded and a summary typed up by Ethna. I will be given an opportunity to read the summary to check its accuracy. ☐

In-depth interviews will be audio recorded and typed up by Ethna. I will be given an opportunity to read the typed manuscript to check its accuracy. ☐

Audio recordings of the advisory group meetings and/or in-depth interviews will be destroyed at the end of the study. ☐

Information gathered from research diaries and issues discussed within advisory group meetings may be used in the final research report. ☐

Ethna will write a detailed report of the study, which will become a PhD thesis. ☐

Information contained in the final research report will be anonymised using a system of coding. It will not be possible for anyone to identify my comments or written contributions. ☐

The information I provide during the study can be used in the research report.

☐

Matters discussed within advisory group meetings may be of a personal or confidential nature and as such, should not be discussed outside the group. This does not affect my right to make a complaint to the Research Supervisor Di Bailey.

☐

Ethna may use some or all of the anonymised information gathered during the study in future research studies.

☐

If I am a patient and currently using the memory services provided by the Trust, my Healthcare Practitioner will be informed about my participation in the study, however, he/she will not have access to any of the information I give.

☐

Ethna has a duty to pass on any issues raised in relation to unprofessional conduct to the Clinical Lead for the Trust. All issues of this nature will be handled via the Trust's usual organisational policy and procedures.

☐

Ethna will hold anonymised transcripts of the research interviews indefinitely. All original transcripts (i.e. those containing real names of interviewees) will be destroyed at the end of the study.

☐

All study data will be stored on a password protected online storage facility provided by Durham University.

☐

All data collected during the study may be subject to audit by NHS research ethics or governance organisations.

☐

I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these questions answered satisfactorily.

| | | |
|---|---|---|
| Name of participant | Date | Signature |

Ethna Parker

| | | |
|---|---|---|
| Name of researcher | Date | Signature |

When completed: 1 copy for participant; 1 copy for researcher site file; 1(original) to be kept in Trust medical records

## Appendix 16: Participant information: people with dementia and carers

## Title of the research: An evaluation of a community mental health team providing services to older people with dementia.

If you require information on any aspect of the study, please do not hesitate to contact me. I enclose my contact details below for your information. Please note that this study is being conducted as a piece of student research for the award of a PhD, through Durham University.


| | |
|---|---|
| Name: | Ethna Parker |
| Address: | University of Durham, Elvet Riverside 2, New Elvet, Durham. DH1 3JT |
| Email: | e.t.parker@durham.ac.uk |


**The purpose of the study**

The purpose of this research study is to talk to older people with dementia and their carers about their everyday lives and their experiences of the services they receive from their local Community Mental Health Team (CMHT) for older people. It is hoped that information gathered during the research will help to improve services for older people with dementia in the future.

**Why are you writing to me?**

The Department of Health has noted that there is very little published on the work of CMHTs providing services to older people with dementia. I believe therefore that the best way to understand how the CMHT meets the needs of older people with dementia is to talk to people who have experience and/or knowledge of how it works.

**Do I have to take part?**

No. It is up to you to decide whether or not to take part. If you do, you should keep these Information Sheets in a safe place so that you can refer to them throughout the study.

**What will happen to me if I take part?**

You will be asked to participate in a research interview, during which I will ask you to share your thoughts and views on the service you receive from

the CMHT together with your ideas on a range of related topics. You will also be asked to keep a diary every day for one week. Diary entries will be used to identify the real challenges you face on a daily basis and identify whether the support you receive makes a difference to your quality of life. You can choose whether to participate in the interview or the diary keeping activity, you can also choose to participate in both research activities.

**How will the interviews be conducted?**

You will be asked to take part in two interviews, three months apart. The interviews can take place in your own home or in any place of your choosing. You may like to be interviewed on your own with me, or you may prefer to have a family member or close friend with you. It is expected that each interview will last for approximately one hour. With your permission, I will audio record our conversations and type them up at a later date. I will send you a copy of what I've written to make sure that I have captured what you have said accurately.

Each time I type up an interview, instead of inserting your name, I will insert a code. Only I will know the codes. All identifying information will be destroyed at the end of the study. It will not be possible for anyone outside of the study to link quotations with individual interviewees.

If you have extra communication needs, and require support to take part in an interview (for example, if you are deaf and need someone to sign our conversations), please let me know.

**Expenses**

To ensure you do not suffer financial loss by taking part in the research, I have put in place the following:

- If you choose not to be interviewed at home, transport to and from the meetings can be arranged if required.

- If you choose to keep a research diary, I will provide the diary and writing materials. If you choose to record your diary using an audio device, I will provide the necessary equipment.

**What are the possible risks or disadvantages of taking part?**

In every kind of research there is a risk that people may be put at a disadvantage. The risks and disadvantages in studies such as this are minimal, however you should consider the following points:

- Issues may arise that may make you feel uncomfortable.

- It may be difficult to weigh the pros and cons of committing to an interview against your own busy schedules.

**What are the possible benefits of taking part in the study?**

The benefits of taking part in a study such as this tend to be on a personal development level, for example:

- You will have an opportunity contribute to a research study that will focus on issues that are important to older people with dementia and their supporters.

**What will happen if I don't want to carry on with the study?**

You can withdraw from the study at any point. You have the right to decide if any of the information you have contributed will be retained in the study or destroyed. Even if you sign a consent form, you are still free to withdraw at any time and without giving a reason.

**What if I need to make a complaint?**

If you have a concern about any aspect of this study, please talk to me about it first. However, if you remain unhappy and wish to complain formally, you can do this by contacting my research supervisor at Durham University:

Research supervisor: Di Bailey

Tel no. 0191 33 41478

Email: di.bailey@durham.ac.uk

**What if I am harmed during the study?**

In studies such as this one, the risk of harm is very low. In this study, you will be asked to describe how you feel about different aspects of your life together with aspects of the service you receive from the CMHT. You will also be asked to complete a daily diary for seven days. This study does **NOT** involve taking any drugs nor will any kind of clinical intervention will be offered. Furthermore, please be assured that I carry full indemnity insurance provided by Durham University.

**Will my taking part in this study be kept confidential?**

I will take every precaution to ensure that your contribution to this study remains confidential. Any contributions that you make to the study and which appear in a subsequent report will be properly anonymised using a system of coding. All data related to the study will be stored on a password protected remote server at Durham University. Your personal information will never be stored on my work or home computer.

With your permission, I will keep your contact details on file. These details will be used for the purpose of arranging interviews. In line with the Data Protection Act 1998, your contact details will never be given to anyone else.

As this study is taking place through your local CMHT, your Healthcare Practitioner will be informed of the fact that you are taking part in the research study. However, they will not have access to any of the information you personally contribute during the study.

**Please note**: I have a duty to report to the relevant authorities any information revealed during an in-depth interview or advisory group meeting that I think puts you or someone else at risk from harm.

**What will happen to the findings of the research study?**

The final report will be submitted to Durham University in September 2011. A summary of the report will be made available to the Local Research Ethics Committee, local carer support groups and other interested professional groups shortly after that. Findings from the study may be presented at local or national conferences and articles written for publication in professional journals and magazines.

**Who has reviewed this study?**

Senior staff at Durham University and the University of Birmingham reviewed the research proposal. This study was given a favourable ethical opinion for conduct in the NHS by [details have been removed].

## Appendix 17: Evaluation criteria: the Croydon memory service

1. Provision of broad-based care and treatment as well as assessment.
2. Clear communication given to people with dementia and their family carers about their diagnosis and the care to be provided.
3. Provision or facilitation of structured continuing peer support groups when time limited psychological assessments or interventions are completed.
4. Easy availability of staff to carers and clients to answer questions and address issues when they arise.
5. Considerate, professional staff behaviour.
6. Where dementia services are provided across the age range, they should construct themselves to be acceptable and to meet the needs of people with young-onset dementia and their carers as well as those with dementia in old age. Specific groups may need to be convened for these people.
7. Services that are designed to treat people with dementia need to develop strategies to manage those with subjective memory impairment but no objective deficits.

## Appendix 18: Evaluation of the advisory group by group members

Thank you for taking part in the advisory group supporting my PhD research. If you have time, I would very much appreciate it, if you could complete the following evaluation of your experience of being a member of the group.

**1) Why did you join the advisory group?**

Because I am passionate about improving services for people with dementia and felt that my background experience may have made a useful contribution to the group.

When Ethna asked for people to help with her research, I said yes because I wanted to give something back for the help I'd received in the past. My husband Marcus had vascular dementia for 13 years. Ethna came across as a very warm, kind and caring person. As time went on, I also found she understood about dementia, and did indeed care about people with dementia and their carers, which bore out my first impressions of Ethna.

I thought it would be interesting to meet other people in the same situation as me. I thought also that I might pick up helpful information on caring for my wife and to share what I had learned with others. I also thought it would be interesting to help Ethna with her research.

Because I value the contribution research can make to dementia and I wanted to learn what I could from others. And to contribute my experiences.

**2) Did you feel that your contributions to the group were valued and respected?**

Yes, at all times.

As a group, we all felt that in the group discussions our contributions were listened to, not only with respect, but were acted upon.

Very much so. I think everyone appreciated my contributions and I really felt listened to.

Yes, very much so. Even though I thought my experiences was limited at the beginning of the group, everything I said was valued. The same was also true for my husband Lewis who has Alzheimer's disease. Eighteen months on, my experience of living with dementia is much greater. I feel I could possibly contribute a lot more now on many different levels.

**3) What did you like most about being a group member?**

Meeting regularly with group members, hearing their perspectives on topics discussed and the peer support evident within in the group.

We all understood each other extremely well because we had similar experiences, and it was very therapeutic for all the group. Good friends and friendships were made and formed.

Being able to learn about other people's experiences. And to be able to add my knowledge to the general body of knowledge on dementia. It was a good social gathering. We enjoyed each other's company very much.

I appreciated the input of others and the interest of others in my life and in my husband's life. Being a member of the group meant that I shared my knowledge of dementia with groups of professionals. I quite likely expressed views that they may not have heard otherwise. The feedback we got from those meetings showed how much of an impression our talks had on them.

**4) What did you like least being a group member?**

Nothing.

In a word, nothing!

No, there wasn't anything I didn't like. Except, that I would have liked to have been more involved and to have been kept in touch more afterwards.

There was nothing I disliked about the group. Although, I found it incredible that the money I got from the Trust as an honorarium was taxed.

**5) Are there things that you think could have been done differently?**

The only thing I can think of is to rotate the meeting venue to lessen the travel for some group members who had to travel quite a distance.

Definitely not. Everybody was very pleased with the way things were done, and the finished outcome.

No, I don't think so. Everything was carried out quite well. But, I would have liked to have met more frequently. I would have liked to have met every week, certainly in the beginning.

It might have been nice to get a newsletter on the months we did not meet, just to keep up to date with progress. Also, it would have been better to get the agenda for each meeting in advance of the meetings and not at the beginning of the meetings.

**6) Is there anything else you would like to add?**

The group also helped me to reflect on my own practice when supporting people with dementia and their carers.

No, just to say that it was a great experience, and one I would certainly do again if the occasion arose.

In hindsight, it would have been good to have my wife, who has Alzheimer's disease, involved with the group. But, at the time, I didn't think of it. I think her insights would have added to the group's knowledge of dementia.

I really valued being a member. Eighteen months on from the beginning of the meetings and my husband Lewis is no longer aware of his contribution to the meetings. But, I would like to say on his behalf, that he got a lot out of them in the early days and was very pleased to be a part of the group.

## Thank you for taking the time to complete the evaluation.

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