

The transition from cognitive impairment to dementia: older people's experiences

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Contributions of authors

Jill Manthorpe was Chief Investigator and is the guarantor of this study. She assisted in writing and editing the report, developed the proposal, budgetary and data management, contributed to the literature review and data abstraction tool, supervised research associate in London site, participated in team meetings, coordinated the National Advisory Group and attended Local Advisory Group meetings.

Kritika Samsi, Sarah Campbell and Clare Abley undertook field work in the local sites, contributed to the data analysis, liaised with the Local Advisory Groups, attended the National Advisory Groups and wrote sections of the report.

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Louise Robinson, grantholder, undertook the literature review and contributed to data analysis and interpretation and writing of the final report.

Alan Gemski contributed to the literature review through data abstraction, analysis and writing up.

James Warner, grantholder, developed the proposal, assisted with acquisition of data and the interpretation of findings from professional and service standpoints.

Claire Goodman, grantholder, developed the proposal, assisted with ethical concerns, commented on the report and its findings from professional perspectives.

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Executive Summary

Background

Greater awareness of Alzheimer's disease and other dementias in the media is being accompanied by high profile campaigns to raise the awareness of dementia among the public by Alzheimer's Societies around the world. Nonetheless, the increasing testing of cognition among older people is associated with fears about cognitive impairment and anxieties about obtaining a diagnosis of dementia. Two key documents depict this increasing interest from a UK perspective. The first is an authoritative investigation of the social and economic costs of the increases in the numbers of older people with cognitive impairment and dementia. The second is in the *National Dementia Strategy* in England, which has already led to public awareness campaigns to increase early recognition of memory problems or other symptoms suggestive of dementia, calls for increased skills in a broad range of professions, and the introduction of pilot developments, such as Dementia Advisors with liaison roles to help people with dementia to navigate through health and social care. As the *Strategy* notes, society needs to be prepared for this additional demand, not simply by being able to manage numbers, but by providing the information and advice people need prior to, during and after the diagnostic process. It is here, at this process of transition, the individual concerned will be acquiring the identity of a 'person with dementia' both in their own minds and in the views of others. Little is known about the experiences of people with memory problems accessing memory clinics in England or those of their family members. Previous research on this subject took place at a time when 'anti-dementia medication' was not available and public awareness of the possibility of dementia was less widespread.

Aims

The aim of this study was to understand the experiences, expectations and service needs of the person who is becoming the person with dementia, from the perspectives of the older person and their supporter or carer. Our specific objectives were to describe the process, experiences of assessments and encounters with health and other professionals of older people with a recent diagnosis of dementia, and to describe the process from the perspective of people supporting them (carers). We further explored how older people with dementia and their carers understand, access and use services following assessment and diagnosis and how this is affected by treatment decisions and contact with different sources of advice and information. Our final objective was to develop a model of care for older people newly diagnosed with dementia and their carers that promotes integrated and cross agency working and strategies to support self-management during a time of transition.

Methods

The objective of the systematic literature review was to update a review on the topic of disclosure of the diagnosis of dementia to inform the study fieldwork. Initially, in order to identify any existing reviews published since 2004, preliminary pilot searches of key databases and the Cochrane Database of Systematic Reviews (CDSR) were carried out. The main review directly replicated the methods employed by the earlier review. Key electronic databases were searched for relevant sources including OVID Medline, CINAHL, Web of Science, EMBASE, and Sociological Abstracts; which cover medical, nursing, social science and psychological literature. The results of this search were supplemented by hand searching reference lists of the articles retrieved, and by sending an initial bibliography to experts in the field to identify any missing articles. A date limit was imposed according to the previous literature review on this topic carried out, and papers published after 2003 were included.

The exploratory aim of this study necessitated a qualitative research approach. Separate interviews were carried out with 27 people with memory problems as well as 26 key supporters and carers, regarding their perceptions of expectations, experiences and perceptions of the process of assessment and diagnosis. As the research questions of this study were challenging, ethical considerations were central to the study and care was taken to respect confidentiality and anonymity of all participants. Interviews were transcribed and the approach to formal analysis borrowed from the principles of the constant comparative method, as well as using reflective field notes of the researchers. Themes and codes were generated by the researcher at each site independently, and analysis meetings were held regularly to develop these. Thematic tables were drawn up and iteratively revised as the coding developed. Findings were written up in relation to the overarching themes generated and conclusions and implications developed from the findings.

Results

Few people interviewed in this study experienced the system of memory assessment as patient-centred. They felt that they were kept waiting for long periods of time without knowing what was going on, they sometimes experienced tests and assessments as distressing in settings that could be alarming. It is important to note that such experiences are not unique to dementia services but the early recognition of dementia is a key policy goal of the *National Dementia Strategy*. People with other long-term conditions also enter the healthcare systems with unclear problems and symptoms and may experience their assessment and consultations as confused and prolonged. The issues arising for people with possible dementia may be similar but they may also be experienced to a greater degree in the context of people's declining cognitive abilities, the stigma of dementia and possible ageism. These confounding effects may need to be investigated so that healthcare practices can be better tailored to support people, encourage self-management and to develop person-centred models of care.

This study identified five transitions in the experiences of participants: 'Internalising dialogue': the self awareness that something may be wrong; 'Confirming positions': the seeking of confirmation from those closest to the person with memory problems that help is needed; 'Seeking expert advice': disclosing position to professionals (usually GP); 'Being tested': undergoing diagnostic investigations and receiving results; and 'Seeking understanding': from professionals and other sources. Our findings exploring peoples' expectations and hopes revealed that information provision and communication could be improved and that practitioners often, but not always, helped people to make sense of these uncertain times. This study suggests that there may be different needs among those presenting to memory services with early suspicions that something is wrong and those presenting later when memory problems are evident. Services did not always appear to be equipped with person-centred responses to individuals' varying needs and circumstances.

The limitations of this study are that it is confined to four areas which may not be generalisable and that data was provided by participants with memory problems who may have provided incomplete recollections or may have been distressed. This study attempted to minimize the limits of this approach by setting the data in the context of a systematic literature review and exploring generalisability of the findings with National and Local Advisory Groups.

Conclusions

The key challenges identified in the qualitative literature review conducted for this study related to undergoing the transition from a person with memory problems to one living with dementia. These were seen as coming to terms with losses on multiple levels; psychologically, socially and functionally. We found that those authors who pointed to the need for timely identification of people experiencing emotional distress and struggling to cope reported that early specialist help might be beneficial. However, the literature refers to a shortage of specialist services in many countries and notes that psychological therapies may not be easily accessed. There is increasing call for alternative sources of support to be made available via peer support groups or a stepped care model of psychological interventions. Unfortunately, the literature reveals few validated stepped care models of delivering psychological therapies especially in dementia. This study provides new evidence about the experiences of people through the process of transition to a 'person with dementia'. It concludes that the process is sometimes characterised by uncertainty and waiting. These findings suggest that transition is not a linear process. We conclude that professionals are able to provide tailored support to individuals and their carers at this uncertain time if they are better informed of the 'journey' from the insights of those who have undertaken it.

1 Transitions in cognitive impairment

World wide populations are ageing (1) and life expectancy continues to increase at the rate of approximately two years per decade (2). The so-called oldest-old (people aged 85 years or over) constitute the fastest growing age-group within the population (3). Ill-health and morbidity increase markedly with age (4) and few of the oldest-old are living without disease (5-6). The prevalence of cognitive impairment and probable dementia also increases with age (7-8) and about a quarter of people aged 65 or over and about two-thirds of people aged 90 years of age will die with dementia. It is hard to ignore the almost inevitability of cognitive impairment in later life.

Greater awareness of Alzheimer's disease and other dementias in the media is being accompanied by high profile campaigns to raise the awareness of dementia among the public by Alzheimer's Societies around the world (9). Nonetheless, the increasing testing of cognition among older people is associated with fears about cognitive impairment (10-13) and anxieties about obtaining a diagnosis of dementia (14). Two key documents depict this increasing interest from a UK perspective. The first is an authoritative investigation of the social and economic costs of the increases in the numbers of older people with cognitive impairment and dementia (15). The second is in the *National Dementia Strategy* in England (16), which has already led to public awareness campaigns to increase early recognition of memory problems or other symptoms suggestive of dementia, calls for increased skills in a broad range of professions, and the introduction of pilot developments, such as Dementia Advisors with liaison roles to help people with dementia to navigate through health and social care. As the *Strategy* notes, society needs to be prepared for this additional demand, not simply by being able to manage numbers, but by providing the information and advice people need prior to, during and after the diagnostic process. It is here, at this process of transition, the individual concerned will be acquiring the identity of a 'person with dementia' both in their own minds and in the views of others.

The receiving of a diagnosis and becoming a person with dementia is only one of a number of transitions along the 'dementia pathway' from the first recognition of cognitive impairment to the end of life. Transitions in cognitive status may be viewed in different ways by the various stakeholders: biomedical scientists, health professionals, policy makers and politicians, the media and other opinion leaders, the general public, family carers and people with dementia. Their different perspectives are influenced by the meaning that each stakeholder gives to the signs and symptoms of the condition or the disease labels applied to the various levels of cognitive impairment. Experiences and expectations of people undergoing assessment and their carers have long pointed to equivocal views about the adequacy of information and service response (17), a finding also observed in a recent study from the Netherlands (18).

From a biomedical perspective transitions along the pathway are most often defined in clinical terms using the array of information available to the clinician from diagnostic tests such as brain scans, psychological tests and traditional semi-structured interviewing of the 'patient'. To aid the classification of cognitive impairment in later life, diagnosis and prognosis, and the development and trialling of interventions, biomedicine has categorised different stages along the dementia pathway. Such formal taxonomies suggest a linear pathway from a 'normal' cognitive status to severe cognitive impairment. For example, one early rather simplistic classification system describes seven stages from no cognitive decline to very severe cognitive decline using the analogy of the process of cognitive development in children and associated behaviours in reverse (19). Rather like the stereotypical account of the seven ages of man portrayed in William Shakespeare's *As You Like It* the language used to describe the different stages of the dementia pathway infantilises older people and people with cognitive impairment and dementia. A less simplistic and widely used tool in the UK which has been used to describe the different stages along the dementia pathway is the Clinical Dementia Rating (CDR) (20), although the prime use of the 'scale' is to monitor changes in a person's clinical status rather than simply describing the stages in the condition.

It is important to acknowledge the clinical value of such thoughtful classification systems, but also recognise that the labels used in such systems are frequently applied to people with cognitive impairment or dementia with negative consequences for the individual, e.g. stigmatisation and loss of social control (21-22). Inevitably, such classifications systems also imply clear cut boundaries separating stages and distinctive clinical transitions, but in reality boundary issues arise (23-24) that create clinical uncertainty in individual cases for clinicians and patients alike (25-26). However, the dominance of the biomedical model (27) has probably influenced other stakeholders - policy makers and politicians, the media and other opinion leaders and advocates of people with dementia - to think in terms of specific transitions along the dementia pathway. For people with cognitive impairment and their carers, the patient and carer's journey may feel very different.

The aim of this study was to understand the experiences, expectations and service needs of the person who is becoming the person with dementia, from the perspectives of the older person and their supporter or carer. Our specific objectives were to describe the process, experiences of assessments and encounters with health and other professionals of older people with a recent diagnosis of dementia, and to describe the process from the perspective of people supporting them (carers). We further explored how older people with dementia and their carers understand, access and use services following assessment and diagnosis and how this is affected by treatment decisions and contact with different sources of advice and information. Our final objective was to develop a model of care for older people newly diagnosed with dementia and their carers that promotes integrated and cross agency working and strategies to support self-management during a time of transition.

2 Methods of research

The focus of this study was on the views and experiences of people with dementia and their carers about the process of diagnosis, information provided during the assessment or diagnostic processes and the use of cholinesterase inhibitor medication. We undertook qualitative research interviews with both people with dementia and nominated carers. As Chapter 3 reports, the background to the study included a systematic review of research papers on the disclosure of a diagnosis of dementia, updating the review published by (28) to complement the primary research. We have actively involved people with dementia and their carers from local dementia support groups in a collaborative role in the research, through Local Advisory Groups and a National Advisory Group.

2.1 Systematic review

The scope of this review was to update a review on the topic of disclosure of the diagnosis of dementia (28) to inform the study fieldwork. Initially, in order to identify any existing reviews published since 2004, preliminary pilot searches of key databases and the Cochrane Database of Systematic Reviews (CDSR) were carried out. The main review directly replicated the methods employed by the earlier review. Key electronic databases were searched for relevant sources including OVID Medline, CINAHL, Web of Science, EMBASE, and Sociological Abstracts; which cover medical, nursing, social science and psychological literature. The search strategy employed is described in Table 1. The results of this search were supplemented by hand searching reference lists of the articles retrieved, and by sending an initial bibliography to experts in the field to identify any missing articles. The literature search for the previous review was conducted in September 2003 using an identical search strategy; consequently a date limit was imposed and papers published in 2003 which had been included by Bamford *et al.* (28) were excluded.

Table 1. Search strategy for systematic review and inclusion criteria

- 1) diagnos* (all fields)
- 2) dement* OR alzheimer* OR "MCI" OR "mild cognitive impairment" (all fields)
- 3) disclos* OR tell* OR told OR shared OR sharing OR inform* OR communicat* (all fields)
- 4) 1 AND 2 AND 3
- 5) LIMIT 4 to year of publication: 2003 – current

Inclusion criteria

- 1) Original, empirical data

2) Addressing disclosure of a diagnosis of dementia or Mild Cognitive Impairment

3) Paper in English language

Abstracts identified by this search were assessed against predefined inclusion criteria as listed (see Table 1). Abstracts were scrutinised by two independent reviewers (Gemski, Robinson), with disagreements resolved through discussion or via a third reviewer (Abley), with a presumption of inclusion in cases of doubt. Full text copies of the papers included were then assessed by the two reviewers (Gemski, Robinson) against the inclusion criteria, with disagreements resolved as described for the assessment of abstracts.

Data abstraction from included papers initially followed the principles of the original review. However, after carrying out data abstraction from the first five papers, the data abstraction form was refined, following discussion between the two reviewers, to include additional quality assessment criteria for included papers (29). Information was thus extracted on: bibliographic details; description of the study; setting and study population; sampling criteria; study methodologies and limitations; participant numbers and response rates; data analysis; outcome measures; key themes/results; main conclusions; implications for policy and practice and suggested future research. A copy of the data abstraction form is provided in Appendix 1. It is based on the template used in the review of subjective experiences undertaken for the NICE/SCIE dementia guidelines (as outlined by (30)).

2.1.1 Data analysis

A wide range of methods for synthesising and integrating qualitative research into a systematic review has been described with a recommendation that the chosen method be determined by the purpose and focus of the review (31). Thematic synthesis (32) has been used successfully in reviews where the aim was to understand the health issue in question from the perspectives of relevant groups of people (33-34), thus the basic principles of thematic synthesis were selected for this review.

The papers selected for inclusion in the review were read at least twice or more by the two main reviewers (Gemski and Robinson). Line to line coding of the data from the primary studies was carried out independently in order to identify similarities and differences in the coding and determine key descriptive themes. A draft narrative summary of the findings across the studies, organised by the descriptive themes was produced by the reviewers and this draft was then reviewed by other members of the project team covering a range of different professions and disciplines (Abley and Keady [nursing]; Bond, Campbell and Samsi [social and behavioural science; and Manthorpe [social work]]. A final version of the narrative was agreed and reviewed by the first author of the original review (Bamford).

2.2 Qualitative study

The qualitative study had both retrospective and prospective elements. Retrospectively we recruited participants for whom a dementia diagnosis had already been disclosed and interviewed them and/or their carer about their experiences around the diagnostic process. Prospectively we recruited participants who had not yet received a diagnosis of dementia and interviewed them and/or their carer about their experiences before and after the diagnostic process.

2.2.1 Research ethics and governance

Ethical approval for the study was obtained from Newcastle & North Tyneside REC 1. Research governance approval was provided by each of the participating NHS Trusts. There are particular ethical issues to consider when conducting research with people with deteriorating mental capacity, especially with regards to them giving informed consent to participate in a research study. Depending on severity of cognitive impairment, people with dementia may not have capacity to consent to a research interview, and may be unable to express their wishes. However, people with dementia have a right to be heard, a 'right to voice' (35) and discounting their participation on the basis of presumed inability to consent would be taking away this right (36). Excluding people with dementia in research goes against the principle of 'equality' (37) and assuming that they inevitably lack capacity can be seen as disregarding their autonomy, a related form of stigma and labelling (22). It is also now part of the legal framework surrounding decision-making for adults (under the Mental Capacity Act 2005) in England and Wales that one must assume capacity when working or supporting with people with dementia unless otherwise established (38). For this reason, and in keeping with the Mental Capacity Act 2005, people with dementia who were able to consent to participate in the research for themselves were included in this study of the subjective experiences of the transition to dementia.

2.2.2 Participants

Participants were recruited from four memory clinics in London (1), Greater Manchester (1) and North East England (2). Memory clinics were chosen as a recruitment source, as these early assessment centres may be the most efficient way to access people at a relatively early point of the transition to dementia (39). As later described in Chapter 4, all four of the clinics operated in different ways but have some overlapping features. The three study areas were selected on the basis that together they covered a range of diverse populations, specifically in terms of different socioeconomic and ethnic groups.

2.2.3 Recruitment

The principle of theoretical or purposeful sampling (40-41) guided the selection and recruitment of participants but the process was constrained by

the practicalities of recruiting in clinics that support a range of research activities. The three researchers (Abley, Campbell and Samsi) responsible for data collection in each area were introduced to key members of staff at each of the clinics. They attended team meetings in order to meet the rest of the team and discussed the best way to stay in regular contact according to the organisation of the clinical work of the team and recruit participants to the study. A recruitment template was produced to clarify this (Appendix 7 and 8). In some areas, the researcher was required to undergo the induction processes of the NHS Trust running the clinic before recruitment of study participants could begin. There was variation between each of the clinics with regards to the level to which each researcher was embedded within the work of the Trust. In one site, for example, the researcher was given office space at the clinic and her presence, therefore, appeared to be more prominent. In all other clinics, the researchers attended weekly meetings, but had little other regular contact with staff. In turn, this may have impacted on the rate of referral to the study, which varied between sites and clinics. In one site, the researcher dealt with a single key contact, which was effective in identifying potential participants.

At each site, the researchers remained aware that the over-riding priority was for the research to work alongside clinical work and not to disrupt it. A slightly different way of recruiting participants was adopted at each site, in order to ensure minimum disruption to working practice at the memory clinics. As a result of this, recruitment approaches at each of the clinics varied (See Appendix 7 and 8).

2.2.4 Data collection

The breakdown of language and memory in dementia may result in some individuals with dementia, as the syndrome proceeds, being able to provide only a partial view of the illness narrative (42). In most cases in this study, where possible, the person with dementia and their carer were included in interviews so that a joint illness narrative could be obtained. Where it was not possible to interview both members of the dyad (person with dementia and carer), interviews were conducted with the individual willing to be interviewed. This was done in order to encourage participation of people with dementia who may not have a carer, as well as to hear the views of carers whose relative with dementia may be reluctant to participate, as they would add diversity to the sample.

A shared interview topic guide was developed (Appendix 9 to 12). The interview topic guide was largely dictated by the original research questions of the study. These research questions in turn were primarily based on questions that had been raised in previous work completed by the main grant-holders. These primarily included exploring the process of the neuropsychological assessment process (13), the process of diagnosis disclosure (43), the experiences of being prescribed medication to help with symptoms of dementia (44-45) and the unpacking of what appear to be 'contested territories' in dementia relationships, namely the issues of risk and decision-making (46). The lack of evidence about the experiences of

people with dementia was also observed in the evidence underpinning the NICE/SCIE dementia guidelines (47).

Each site undertook data collection independently for purposes of convenience and efficiency, in order to optimize the individual relationships researchers had with the clinics and for purposes of research governance. Monthly meetings involving the three researchers and other members of the project team (Bond, Keady, Manthorpe, Robinson, Watts) discussed the interview process in order to explore the different interpretations of questions, and revisions were made jointly with the research team. Throughout data collection, perspectives across each of the sites were regularly shared in teleconferences between the three researchers and at the monthly meetings. These have been documented in minutes of the meetings. Emergent ideas and concepts were also captured at these meetings.

It is important to consider the different background of each of the researchers and their experience of the participant groups that they brought with them. All were female. One researcher was currently working as a nurse consultant, another was a social scientist with experience with research with people with dementia and carers, and the third was also a carer for a family member with dementia. The interview style and data collected at each site were, therefore, influenced by each researcher's personal and professional background and experiences.

Interviews were arranged for a day and time that suited participants' convenience, and all of them took place in participants' own homes. The researcher began by introducing themselves and explaining the purpose of the research study. They stressed that although participants had been recruited through the memory clinic, the research study was completely independent of the clinic and that participation was entirely voluntary. The researchers asked if interviews might be conducted separately, in a private room, and the order of who was interviewed first was left to the participants' preference; in cases where neither the person with dementia nor the carer had a preference, the person with dementia was interviewed first. In five cases, the person with dementia and their relative asked to be interviewed together.

The interview topic guide directed much of the conversation, although the approach the researchers adopted was less question-answer style and as informal as possible. All interviews were digitally recorded. At the end of the interview, both the person with dementia and the carer were thanked for their time. The researcher once again explained the proposed outcome of the research study, and names and contact details were left if they required any further information. All digital recordings were transcribed by a trained and experienced transcriber, which were then anonymised, an identifiable number was inserted for each participant and details were stored securely. Personal, identifiable information was kept separately from transcripts, in order that the two could not be associated. Anonymised transcripts were routinely collated and shared with the rest of the research team for purposes of data coding and analysis.

At the end of each interview, the researchers wrote summaries covering the salient issues discussed which were sent to each participant to corroborate and/or comment on. Researchers also wrote regular reflexive diaries that served as field notes and recorded their impressions of the interview, focusing on body language, tone of the respondent and characteristics of interview setting; as well as their own ideas of emergent themes and concepts. The reflexive diaries were a way of capturing the development of researchers' ideas around the topic and a space in which they could reflect on the progress of the research study and developing concepts. Both interview summaries and reflective diaries were used as data for analysis. The regular discussions around the issues of data collection and data analysis were minuted and these also form data for analysis.

2.2.5 Data analysis

Four pieces of data were analysed for this study; first, the transcripts from participants, which remained original data; second, summaries written up by researchers that summarized the key points discussed at the interview; three, reflexive diaries that captured researchers' impressions, interpretations and concept-development; and four, minutes of the thematic discussions and meetings held.

The data were subject to constant comparative analysis (41), most familiar in grounded theory work but common to most qualitative methodologies. Although other qualitative methodologies were considered, they were disregarded for the following reasons. The stringency of the research question encouraged exploration around the issue but not around concepts of self in much detail. Interpretative Phenomenological Analysis (48) was therefore discounted, as it would have required greater idiographic participant accounts for an adequate level of depth of analysis to take place. *A priori* research questions of this kind which may have policy implications could have been analysed by framework analysis (49) but the research team was keen that the findings should emerge from the data rather than be dictated by the research questions; framework analysis was, therefore, discounted as a method of analysis. Grounded theory itself was not formally used as it would have been challenging to justify lack of awareness of existing research in this area (50). Members of the research team have considerable familiarity with research in dementia and this experience generated the research questions as well as enriched the analytical process.

In keeping with the 'constant comparative' method, as the study progressed, data were purposively collected from groups that were at risk of being under-represented in the sample. Regular team meetings helped identify these groups and further sampling included greater numbers of women, greater numbers of people living in urban and rural situations (as opposed to suburban) and more variation in socioeconomic status. At one stage, it was decided to concentrate on recruiting people with dementia who had been diagnosed relatively early, because a growing proportion of the sample had been diagnosed with MCI. In order to balance these numbers,

more people were recruited and interviewed who had received a diagnosis of dementia.

Data analysis procedures incorporated a number of iterative steps; first, transcripts were shared between the various research sites and members of the analysis team (Abley, Bond, Campbell, Keady and Samsi) were encouraged to read all transcripts. At this stage, early impressions were noted. Second, transcripts were coded by smaller groups consisting of two members each, in order that individual perspectives were obtained and incorporated. This involved assigning a label or name that adequately captured sections of the text. Manifest codes as well as latent codes were identified. All the codes taken together were used in the development of the thematic table (version 1). The thematic table has since undergone considerable number of revisions and is currently on version 5 (Appendix 13). Next, using the thematic table, each researcher began coding transcripts from their site. For purposes of cross-coding, transcripts were shared between sites and each site has had a proportion of its transcripts cross-coded by another member of the team. Regular analysis clinics were conducted to generate thematic discussions and to consider emergent issues and themes. These emergent over-arching themes were noted and reflected upon. The thematic framework was also regularly updated at these meetings. Researchers' reflexive diaries were used to add to the thematic discussions to the emergent themes, specifically, to consider whether they corroborated what the researcher had recorded in their post-interview field notes. NVivo (Version 8), a form of data analysis software, was used to manage data analysis so that retrieval at the time of pulling together concepts for model-building would be more straightforward.

In preparing the results for this report a number of 'propositions' were constructed and thematic memos were produced by different members of the team using the combined data set before the results sections for the qualitative analysis were drafted.

2.3 Patient and public engagement

Historically, carers were perceived as the 'hidden victim' in the disease course (51), as a result of which they became the primary goal of dementia care services (52). Research incorporating the subjective views of people with dementia, however, has been on the increase (53) and a significant body of literature now attests to the fact that it is no longer acceptable for people with dementia to have a 'silent presence' in research, with their views represented through others (54). Quality of life literature indicates that, despite cognitive impairment, many people with dementia are able to state consistent preferences, make self-assessments about their health status and describe their feelings and concerns (55). Engaging with people with dementia to gain their perspectives on their unique situation also provides fresh insights (56). Although early studies focused primarily on people with early dementia (57), this is changing, as greater numbers of people with moderate to severe dementia are being encouraged to lend their voice to research (58) with some able to report coherent responses to

structured questionnaires (59-60). People with dementia documenting their own experience are also increasingly encountered in public and professional circles (61-63).

People with dementia, carers and professionals were engaged in collaboration at each stage of the research study. A National Advisory Group was set up during the early stages of the study and members assisted with development of key ideas, research questions and early drafts of the interview topic guides. At the second meeting, the National Advisory Group assisted with coding the transcripts, in order that a more holistic perspective than that of the research team was obtained. Local Advisory Groups were set up at each of the three sites; this was to facilitate obtaining useful local context views from people with dementia and carers. The group in London, for example, provided useful information with regards to the development of the interview topic guide. These included the suggestion of the following topics: (1) encouraging carers to describe how they negotiated tricky issues like driving while still maintaining their relative's independence and well-being; (2) asking participants to consider the use of any alternative treatments in their daily lives, such as ayurveda, ginkgo, reiki and modification of their diet; (3) asking participants to reflect on their attitudes to being ineligible for medications as it was increasingly common for people to enquire about purchasing anti-dementia medications privately; and (4) exploring with people with memory problems any caregiving responsibilities they had and whether these continued after a diagnosis as it was common for people to have child minding duties with grandchildren. The group also said that, apart from wondering whether the condition was hereditary, participants were less likely to be concerned about the cause of the condition, but more driven towards a solution. They therefore advised us to exclude the question exploring participants' understanding of the cause of the condition.

In terms of services, the Local Advisory Group in London also indicated that the use of diagnostic indicators like 'mild cognitive impairment' or 'MCI' varied between services and were likely not to be familiar concepts to all participants. They also identified a differentiation between 'memory clinics' and 'memory services'; the former being more diagnostic driven, while the latter adopted a more holistic approach to care. Finally, the Group also advised about impending changes to Alzheimer's Society local branches and the impact these changes may have to the study and to the diagnostic process as professionals would have one less source of support to refer patients on to. The Local Advisory Groups in North East England and Greater Manchester advised on methods by which to disseminate findings once the study had been completed. Regular emails and letters also apprised the Local and National Groups of the progress the study was making. In North East, the group commented specifically on the acceptability of local materials (handbook given out at group sessions). At the end of this study, findings will be fed back to the Local and National Advisory Groups, as well as to staff in the participating memory services.

3 The transition to becoming a person with dementia

Individual and carer experiences of receiving a diagnosis of dementia are the focus of this study and this chapter outlines what was known prior to our research. As Chapter 2 explains, our study included a systematic review of the literature to investigate the existing evidence base and to enable use to set our findings and approach in context. This background is synthesized here and the full systematic review is being developed for publication (for details, please contact the authors).

Although wide variations exist internationally, there is evidence that dementia is probably under-diagnosed and under treated, with an estimated half of people aged over 65 not diagnosed by their primary care physicians (64). Research from the United Kingdom (UK) found that from the initial presentation of patient symptoms and/or family concerns, confirmation of a diagnosis of dementia may take between 18-30 months, and sometimes up to four years (65); this is reported to be twice the time to formal diagnosis in some other European countries (66-67). Currently there is international consensus favouring earlier or more timely diagnosis of dementia (68) although concern exists that both benefits and risks need to be better appreciated (69). While some people may find being diagnosed with dementia distressing, reported advantages include a better understanding of the situation, an end to uncertainty, the ability to plan ahead and undertake care planning discussions, access to practical and emotional support and the chance to develop positive coping strategies (28).

An earlier review, focused on the process of disclosure of a diagnosis of dementia, revealed wide variability in reported practice (28), and theoretical 'guidelines' that do not reflect practice (70). Disclosure was rated by primary care physicians as one of the most difficult areas in the management of people with dementia, with this group of clinicians less likely to use the correct terminology than psychiatrists (28). In addition, family members were more likely to be told the diagnosis than people with dementia, with euphemistic terms used more commonly with people with dementia than with their relatives (28). The review concluded that research which seeks to better understand the individual's perspective of becoming a person with dementia has been considerably neglected (28) and it was this recommendation that informed our search and analysis.

However, people's experiences have not been entirely overlooked. Research is emerging which describes the views, experiences and coping strategies of people with dementia upon receiving their diagnosis. A range of responses is reported from positive reactions through to depression, grief and active denial (71-73). A more recent review summarised current knowledge on living with dementia from the individual's perspective and covered all aspects of dementia including the transition from independent living to nursing home care; it concluded that the process of disclosure was a "more

subtle picture than the assumptions made by the general public". The review, although comprehensive in including non-English language papers, was limited in the number of databases searched (74).

This systematic review undertaken for the present study builds upon the work referred to above (28), but sharpened its focus on the diagnostic process, synthesising existing evidence on the transition of a person with cognitive difficulties to one receiving a diagnosis of dementia, from the perspectives of both the person and close family members or carers.

3.1 Choice of review material

We outline in Chapter 2 the methods of this literature review, including the process of analysis. One early task was to assess the quality of the 32 included papers. The majority had employed qualitative data collection methods (see Table 2) but the methodological quality of the included papers was variable (29, 75).

Table 2. Details of methodology

Methodology	People with dementia	Caregivers/family	People with dementia/carer dyads	Total
Postal questionnaire	0	3	0	3
Self-completion questionnaire	0	1	0	1
Structured interview	2	0	0	2
Semi-structured interview	4	5	7	16
Qualitative interview	1	0	0	1
Focus group	0	2	1	3
Other/mixed methods	2	4	3	9
Totals	9	14	11	35

Of the studies examining the views of people with dementia, the overall median sample size was 30, with a range of 1-149. Studies of family members or carers had a slightly larger overall median sample size of 43, range 1 - 1214. Only nine studies reported response or participation rates, these ranged from 38.4% (76) to 96.2% (77). Of the studies which presented qualitative data, the median sample size was 18 (range 1-149) for people with dementia, and 23 (range 1-71) for carers or family

members. Qualitative studies had undertaken purposive sampling techniques in nine studies, convenience or consecutive samples in seven studies, whilst the remainder did not clearly describe the sampling techniques used. Most of the studies accessed participants from specialist dementia services. Several of the remainder employed samples from pre-existing research registers of people with dementia. Of particular note, no study included a sample drawn solely from a primary care population. Many of the studies gave very limited descriptions of the methodology employed (29). Of the studies which undertook structured or semi-structured interviews, 12 gave details of the questions or interview schedule used (77-88), and eight gave a detailed description of how the interview schedule was developed (71, 77-78, 83-84, 89-91).

In terms of data analysis, eleven studies stated use of elements of grounded theory analysis (71, 75, 78-79, 83, 89, 91-95), four used the method of interpretive phenomenological analysis (IPA) (86, 90, 96-97) and the remainder used other methods or gave little detail of methods. Only six studies explicitly stated that data saturation was achieved (78, 84, 87, 89, 91-92). Eleven studies reported independent analysis of data by two or more researchers (82-84, 86-87, 89, 91, 96-99).

Of the questionnaire based studies, four gave details of the questions which were included (76, 100-102) and two described in detail how the questionnaire was developed (102-103). One study used validated symptom measurement tools to assess the psychological effects of disclosure (Geriatric Depression Inventory and State/Trait Anxiety Inventory) (104).

3.2 The review findings

Six reviews published since the earlier review in 2004 (28) were identified (70, 74, 105-108). A detailed summary of the key findings and methodological limitations of these reviews is provided in Appendix 2 and Appendix 3 and the review was published early 2011 (109).

Overall these literature reviews concluded that empirical research in this area is sparse, with the views of people with dementia and their carers around the process of diagnostic disclosure of dementia largely neglected to date. One review was particularly inclusive, addressing the spectrum of living with dementia and including non-English language papers (74). Although several reviews were focused purely on the process of diagnostic disclosure in dementia (70, 106, 108), they had searched a limited number of databases (70) or did not report systematic methods of review (105, 108).

The search strategy yielded 941 articles of which 62 papers met the inclusion criteria (see Figure 1). Of these 62 papers, 35 reported the views/experiences of people with dementia and their family members (usually described as carers or carergivers); 24, the views/experiences of health and social care professionals and 3, the views of the general public. Table 2 summarises the 35 papers describing empirical research involving people with dementia and their family carers included in the review.

Eighteen studies reported research carried out in Europe and 16 from the United States (US) and Canada. The majority of studies included carers only (14), whilst 11 studies included both people with dementia and their carers. Six studies focused solely on the person with memory problems/dementia; only one specifically included people with dementia under 65 (see Table 2).

The majority of included studies used individual interviews and focus groups to collect data (22 studies), four employed questionnaires, eight studies used mixed methods and one paper employed narrative analysis of written life stories (Table 2). Only one study (71) included empirical evidence of the actual disclosure meeting or encounter (achieved through audio-recording) and only one study used validated outcome measures to assess impact of disclosure on the person with dementia's health (70).

3.2.1 Attitudes towards disclosure of a diagnosis of dementia

Few studies have examined the views of people with dementia regarding the disclosure or the telling of the diagnosis. In common with the previous review (28), studies continue to report that the majority of people with dementia are in favour of being told what is their diagnosis, with up to 92% preferring to be told the cause of their symptoms than having it withheld (85, 88, 98), compared to 98% wanting to be informed of a hypothetical diagnosis of cancer (88). A wish to be informed of the diagnosis may be associated with pre-existing knowledge of the prognosis of dementia or with previous family experiences of someone with the condition (87). However, in some studies, fewer people (69%) expressed a desire to be told of a specific diagnosis, e.g. "Alzheimer's disease", compared with more generic explanations of memory problems and a small minority expressed a firm wish not to be told the diagnosis at all (85-86). People with dementia appear to believe that they should have a choice about being told, but that information should be available if it is desired (96).

From the perspectives of family members or carers, most studies report that the majority of family members favour being told the diagnosis but to a lesser degree than patients (39 – 97% of carers) (88, 103, 109-110). As reported earlier (28), there exists some discrepancy between what family members think their relative with (suspected) dementia should be told and what they would wish to be told if they were to develop dementia. Over 90% of carers reported a wish to be informed of a dementia diagnosis for themselves (88, 109, 111) but only between 43% (111) and 76% (109) favoured disclosure to the person with dementia. Examination of socio-demographic and caring characteristics in relation to views on disclosure has yielded mixed results. One study found no associations (109), whereas in other samples higher education was associated with greater reluctance to tell a relative of a diagnosis of dementia (103). Carers of people with moderate to severe dementia, with psychotic or depressive symptoms, or who were the same age as the them, were more likely to wish or think it best to withhold the diagnosis (111).

There appears to be considerable variation cross-nationally, with up to 97% of caregivers in a Finnish sample (102, 109) and 76% of a Taiwanese group

(109) favouring full disclosure, whilst a Belgian study reported that only 43% of relatives supported disclosure (111). A study conducted in Brazil (103) found that 58% of carers of people with dementia believed that the diagnosis should be disclosed to patients, as opposed to 88% of controls who were not carers ($p=0.0007$).

With the increased emphasis in many countries on early detection and diagnosis of dementia some researchers have examined the likelihood of a predictive test being used if it were available. In one study, the majority of people with dementia (88%), and also their carers (75-86%) said they would make use of such a test for Alzheimer's Disease (88, 111).

3.2.2 Benefits and disadvantages to receiving a diagnosis

There was little difference from the findings of the earlier review (28) in reported benefits to disclosing a diagnosis of dementia (82-85, 88, 98, 109). These included: the right to know; confirmation of suspicions and better understanding, allowing opportunities for future care planning; facilitating a focus on the person with dementia's abilities rather than their disabilities; positive adaptations within family and spouse relationships; access to early treatments, both pharmacological and psychological, and participation in research studies. Reasons given for not wanting disclosure included: the potential for giving rise to emotional upset, prior distressing experience, rejection by family and friends, social stigma and embarrassment, no effective medical treatment available, may cause suicide ideation and not wishing to create a burden on family (82-85, 88, 109).

3.2.3 Experiences of receiving a diagnosis of dementia

These studies are varied in terms of whether a person has been assessed or had received a diagnosis. We turn now to the kernel of the review, that is, people's experiences of receiving a diagnosis of dementia and the transitions around this process, since this is not likely to be a single event. By the time people arrive at the point of being told their diagnosis, some studies reveal that they may have been through an often lengthy and confusing process of assessment and investigation (79, 97, 99). Despite the possible complications of anosognosia, or denial of any problem, it appears that some people at least are expecting to be told that they have dementia before the diagnosis is "officially" disclosed and do not perceive the diagnosis as a shock (71, 83-84, 91). However, for those who have less insight into their symptoms, the experience of being informed of a diagnosis of dementia is commonly associated with negative emotions such as shock, fear and sorrow (71, 91, 98, 102, 104). In one study (99), half of the family carers/family members reported adverse experiences in the pathway to receiving a diagnosis and complained of discrimination and uncaring attitudes from professionals; in addition they felt that diagnostic pathways were fragmented or might end without a diagnosis being given ('dead-end' pathways). These forms of transition were of particular interest in the present study.

The term "Alzheimer's Disease" has been reported as more likely to be associated with an initial negative emotional response than other terms or causes of memory loss and dementia. Both people with dementia and carers voice concerns about stigmatisation associated with the term 'Alzheimer's' (71, 84, 86). Where a diagnosis of vascular dementia was given, this tended to be explained in lay terms, for example, using the term "strokes" (71) to describe what happened. In studies of people informed of a diagnosis of Mild Cognitive Impairment (MCI), participants commonly expressed relief that they had not been given a diagnosis of Alzheimer's, though some expressed a fear that it could lead to Alzheimer's Disease (89, 112). Most people with MCI were not aware of a specific name for their diagnosis (112).

Only two studies were identified which attempted to capture data on the diagnostic disclosure process as it occurred (71, 98). Aminzadeh et al. (2007) found that the majority of people given a diagnosis of dementia showed obvious signs of shock and distress as a result, which were expressed both verbally and through body language. They observed that this immediate emotional reaction to the diagnosis could be so powerful as to impede cognitive intake of any other information delivered. A smaller proportion responded to the revelation of the diagnosis more positively, with relief at the confirmation of their expectations. Some family members reported that their relative was more distressed in the days following the disclosure than at the time (71). Byszewski et al. (2007) found that although people with dementia often could not recall their diagnostic 'label', other information given at the time of diagnosis, such as advice on driving, medication, and onward referral, was more frequently retained.

Little empirical research has been undertaken exploring the process by which a diagnosis of dementia is shared and explained. In a study of younger people with dementia, participants reported feeling unprepared to hear the diagnosis (79). This was also reported by Byszewski et al. (2007), with both people with dementia and carers expressing a preference for 'progressive' disclosure, with a degree of initial forewarning (98). It has been suggested that physicians should explore both patient and carer views and experiences of dementia prior to disclosure in order to determine how best to communicate the diagnosis to the individuals concerned (82). From a carer's perspective a range of preferences exist; some favour a direct approach whilst others wish to be "eased into the results" (82). There does appear to be 'professional' consensus amongst the included papers that the disclosure of a diagnosis of dementia should be an ongoing process, with an emphasis on positive aspects of a person's life, provision of information and ongoing support tailored to an individual's needs (85-86, 90, 94, 98).

In terms of who should break the news of the diagnosis, Keady et al (2005) reported that both people with dementia and carers placed more emphasis on the importance of a positive relationship with the professional sharing the diagnosis, rather than an expectation that this person should be a medical practitioner (94). In addition, key family members should be present at the discussion if possible (88), with other professionals, for

example nurses, acknowledged for their potentially empathic relationship (98). The environment in which the diagnosis is disclosed, the way in which choice is offered, especially where cognitive testing occurs, and the existence of a “reliable, close and trusting relationship” appear to be influential in the disclosure process (94, 98). One survey of carers reported that the diagnosis was disclosed by a specialist practitioner in 73% of cases, versus 19% of diagnoses given by primary care practitioners (113).

In terms of post diagnostic support, studies have confirmed that people with dementia and their carers feel let down by the lack of follow-up (97-98, 114). In one study where the majority (80%) of carers were present when the diagnosis was shared with the people with dementia most were happy with the amount of information given to them at diagnosis but only half were satisfied with the follow-up arrangements (114).

3.2.4 Information provision

The amount of information provided about dementia also influenced the disclosure process. Only one of the included studies explored what people with dementia felt about the type and nature of information they should be given, with participants stating that they required more information in general and that it should be provided in a variety of different forms (98). Some people with dementia may experience a dilemma between wanting to find out more about their illness and a wish to avoid thinking about the future as a way of coping with the diagnosis (96).

Several of the included studies found that carers wished to be given as much information as possible and were generally satisfied with the amount provided during the disclosure process (77, 100, 102). However, in a US study comparing the experiences of family carers and the primary care physicians involved in the diagnostic process, carers felt they had received too little information and expressed a sense of urgency and frustration in their attempts to seek a diagnosis (82). This contradicted the clinicians' views, who reported feeling pressurised to make a diagnosis by family carers and considered that they provided sufficient support and information (82). Findings from a large international postal survey of 1,181 carers of people with dementia found that almost half (46%) were fairly or very happy with the information they were given, although 19% reported receiving no information at the point of diagnosis, half (50%) had received no information on dementia as a disease and 48% no information on drug treatments. The most commonly desired information was about disease progression and availability of services. The most commonly desired information was about disease progression and availability of services (101). A telephone survey of carers reported that 78% had received information about treatments at the time the diagnosis was given; most commonly this was medication but other therapies and services such as cognitive stimulation, psychotherapy, day care and support groups, were also mentioned (113).

Only one study explored in detail the nature and type of information that was considered useful during the process of becoming a person with

dementia and the appropriate time to provide this in primary care settings; however only carers were included in the sample (77). During the diagnostic period, carers felt they needed to know what dementia is; information about medication, and the behavioural and psycho-social problems that could arise in the illness. At the first follow-up meeting, they wished to have more detail about the range of social care services available, the course of the disease and what to do should a crisis occur. Later on, information about financial and legal issues became more relevant (77).

3.2.5 Factors affecting disclosure and recall

The information that people with dementia and carers retain following the diagnostic disclosure varies, but it appears that frequently little is retained (80, 100). Between one fifth and one third of people with dementia can recall their diagnostic label accurately (80, 85, 88, 98), though many more are able to recall some elements of the process of disclosure (98). Not surprisingly, recall of the diagnosis is associated with a higher Mini Mental State Examination (MMSE) score, as well as younger age and higher levels of education, and poorer self reported health status (80). In one study, 70% of people with dementia were unable to correctly report their diagnosis within only a few minutes of this being disclosed to them, compared to only 12-16% of carers who were not able to do so.

Recall of the diagnosis can be equally limited among people with Alzheimer Disease and MCI; in a study comparing both groups, both expressed uncertainty about what they had been told and had difficulty reporting their diagnosis (112). With respect to MCI, one small study revealed that only 1 out of 12 people with MCI were accurately aware of their "diagnosis", although most understood and were aware of the changes occurring. Factors influencing how the 'diagnosis' was processed included participants' prior experience of dementia, their current health and their expectations of normal ageing (89). Pre-diagnostic views of older people attending a memory clinic associated the diagnosis of dementia with "malignant societal attitudes" (87). Factors influencing their desire to know the diagnosis were chiefly related to their previous personal and family experience of people with dementia (87). In addition, people with mild dementia were concerned others might think them "demented" and mad (86).

Cultural factors may be influential in shaping carers' views towards diagnostic disclosure. In one very small qualitative study with African-American carers of people with dementia, a cultural tradition of respecting elders' autonomy and independence appeared to delay presentation, as carers perceived their role to be to protect their loved ones and respect their dignity (81). A study from Taiwan revealed that family carers might favour disclosure of a diagnosis of dementia but prefer to use of a "softer term" like memory loss rather than the actual word dementia, as some Chinese terms for dementia have had pejorative connotations (109). A study comparing pathways to diagnosis across different cultural groups within the US found that Chinese-Americans were more likely to have

cognitive impairment recognised by professionals than for such health seeking behaviour to be initiated by their families (99).

3.2.6 Coping with a diagnosis: people with dementia's perspectives

Following the diagnosis, people with dementia exhibit a variety of coping mechanisms from positive responses, through feeling empowered, to difficulty in accepting the diagnosis and active denial (71, 78, 86, 91, 97). An oscillating process has been described, with a slow realisation of their difficulties balanced against a gradual adjustment to their losses (97). Disclosure of the diagnosis can lead to positive strategies, such as seeking opportunities for future care planning and sharing the diagnosis with the outside world (71, 78, 86, 91, 97). For some, receiving the diagnosis appears to offer an opportunity to reconsider their priorities and make positive changes, such as spending more time with family and focusing on things which bring enjoyment (92).

People with MCI also exhibit the same variability in coping strategies (positive, negative and neutral) as people with dementia (89). They appear to have insight and awareness of their difficulties and employ emotional and cognitive strategies to deal with these (89-90); such insight is gradually, though invariably, lost in those who progress to dementia (112). Factors that influence coping strategies include people's perceptions of normal ageing and their prior experience of people with dementia (86, 89). As observed, some people find the term Alzheimer's disease more difficult to cope with than dementia or memory loss (86, 89).

From the person with dementia's perspective, the greatest difficulty they appear to have to deal with is the prospect of losses, both contemporary and prospective. Such losses may include loss of self-esteem, loss of social status and roles, and loss of function and activities of daily living, particularly driving (71, 78, 83-84, 86, 91-92, 97, 112). In addition, people with dementia describe a feeling of stigmatization or "social demotion" as a result of their diagnosis (92, 96), however for some this may be counterbalanced by reinforcement of a shared group identity, such as via access to support groups (92).

People with dementia highlight the dilemma between balancing their private world (the 'self') and their public world (how others view them) (78, 86, 91). A desire to be treated "as normal" helps maintain this balance (86, 97), with some people making active attempts to manage their reaction to being diagnosed and undergoing changes in their social identity (92). However, they are aware of the burden (real or prospective) their illness places on their families (112); this awareness being more acute in people in the early stages of the illness (89-90, 112).

3.2.7 Coping with a diagnosis: carers' perspectives

Similarly family members of people with dementia are also undergoing a gradual transition, to the social status of carers, experiencing a variety of losses and emotions and employing a range of coping strategies (71, 75-76,

83-84, 91, 112, 115). Those that progress gradually into a care-giving role appear to continue to provide practical care or instrumental support for their relatives for longer (76). Whilst their relatives are coming to terms with personal 'loss', carers of people with dementia are principally faced with increased responsibilities with a focus on decision-making and dealing with the practicalities of life (75, 83-84, 91, 97).

In addition, they feel required to take on the role of "emotional cheer leader" (75). This comprises attempting to come to terms with changes in their relationship with the person with dementia (possible loss of closest confidante and loss of intimacy) and also managing the emotional interface between personal and public worlds (115), despite often feeling considerably upset and distressed themselves (75, 83-84, 115). However by focusing on the positive abilities of the person with dementia, rather than their disabilities, couples (a major group of carers included in the studies considered in this review) can be assisted to make positive joint constructions to enable them to make sense of the illness (83-84, 97). Positive adjustments to the illness appear to facilitate future care planning for both people with dementia and their carers (75, 83-84, 91, 97).

3.2.8 Long term consequences of disclosure of dementia

Only five studies (83, 88, 91, 98, 104) have explored participants' views over a period of time, with two attempting to define the longer term impact on a person with dementia's health (88, 104).

Carpenter et al (2008) measured anxiety and depression levels using validated outcome measures, including the Geriatric Depression Scale, three months after a disclosure of a diagnosis of dementia, with a sample of 90 patient/carers dyads. The study found that in general symptoms of anxiety and depression remained stable and the majority of participants did not experience adverse psychological reaction following disclosure; factors such as age, sex, levels of education and severity of dementia did not affect this outcome. In addition, individuals who were experiencing high levels of anxiety before disclosure appeared to exhibit relief afterwards. Interestingly participants who had received 'informal' feedback about the possible diagnosis prior to actual disclosure were less anxious. Further supporting evidence that disclosure of a diagnosis of dementia does not precipitate a catastrophic psychological reaction comes from a small study by Pinner and Bouman (2003). They reviewed the case notes of 50 patients with dementia, one year after diagnostic disclosure; only 6% had been diagnosed and treated for depression but there were no recorded catastrophic reactions or suicides.

None of the included studies directly measured the long-term impact on carers' health and wellbeing after disclosure, although several reported the increased responsibilities and day-to-day tasks that they were having to take on (75, 84, 91). In one large survey (n=1214) of care-givers of people with dementia (mean age 78; 63% female), around half developed 'depressive symptoms' following communication of the diagnosis (102).

Two studies explored whether carers or family members had completed any formal advance care planning documents in their own right. In a large survey (n=1214) only 4% of older spouse carers had made a living will or advance decision about care and treatment (102), whilst in a much smaller study of siblings of younger people with dementia (n=25), 11 (45%) had completed living wills and 3 (12%) had taken up genetic testing (95).

3.3 Discussion

One of the key messages of an earlier systematic review of this area (28) was that recommendations around the process of disclosure of a diagnosis of dementia were not informed by a detailed observation of practice or grounded in the personal 'lived experiences' of people with dementia. Our review aimed to address this deficiency through identifying and evaluating evidence focused solely on the experiences of people with dementia and their relatives in the transition from having memory problems to receiving a diagnosis of dementia and the period thereafter. We found that although the views of people with dementia are still largely under explored, research is slowly emerging to allow their voices to be heard. The experiences documented in the included papers reveal that the vast majority of people with dementia wish to know their diagnosis, although the majority (taken broadly) can not accurately recall their diagnosis afterwards. However, there was consensus that the breaking the news of a diagnosis of dementia should be an ongoing process with an emphasis on the positive aspects of a person's life and the provision of continued support and information tailored to individual needs. The use of the term 'Alzheimer's disease' would appear to have more negative connotations than the word 'dementia'; in some countries non-specific terms like memory loss are preferred by relatives.

Despite recommendations from the earlier review (28) for detailed scrutiny of the process of diagnostic disclosure in dementia, only two of the 35 included papers attempted to do this (71, 98) and only two to evaluate the effects on the person with dementia's health (88, 104). How a diagnosis is disclosed appears to be often as a single event and not a managed process, where the possibility of dementia is raised and discussed before the actual confirmatory diagnosis (69) and follow up ensues. The results of the studies reviewed would suggest that although there may be short-term distress, generally the majority of people with dementia do not experience long term negative effects on their psychological health, with low levels of depression recorded (104). This may contradict the findings of previous research which suggested that many family carers did not support breaking the news to their relatives for fear that it would provoke significant emotional distress (28). For family carers, becoming the main decision-maker and adjusting to increased levels of responsibility appeared to be a common concern. Carers also reported trying to maintain emotional *status quo* (75) and cope with changes in the nature of their relationship with the person with dementia, despite often experiencing negative and distressing emotions themselves.

The review included a wide variety of studies and methods with researchers still mainly concentrating on elucidating the views and experiences of carers

rather than those of people with dementia themselves. This may reflect a number of perceived barriers to including people with dementia in research, such as concerns regarding ethical approval and informed consent to participate, difficulties with communication and possible negative effects on the person with dementia (116). In addition, the quality of the included studies was variable and their generalisability limited, with generally small sample sizes and limited information on data analysis methods. No study recruited people from primary care settings, with most set in memory clinics or similar specialist services, which may not be accessed by some groups of people, such as those living in care homes. The restricted sampling frames in most studies led to some uncertainty in generalising data to all people with dementia and their carers, rather than just those who were already accessing a specialist dementia service. Recall bias was also a possibility in some studies as data collection often took place several months following disclosure of the diagnosis, but sometimes as long as two years (97).

There are several limitations to this review that should be acknowledged and were taken into account in this study. Due to funding and time constraints, included papers were limited to those full papers written in the English language. Thus studies which could have provided valuable data on difference cultural perspectives to the disclosure of a diagnosis of dementia may have been excluded. In addition, the review attempted to provide a quality assessment of the included papers, the majority of which used qualitative methods. Unfortunately, consensus on the criteria by which to assess the quality of qualitative studies in a systematic review has not yet been reached and a range of approaches are available (117).

The findings of this review certainly had implications for out study processes and thinking and they may have implications for practice. Before talking about a diagnosis of dementia, professionals should explore the concerns of both the individual and their family or social supporters as to what they think the cause of their cognitive difficulties may be and identify any particular individual concerns around diagnosis. The consensus from the papers included in this review is that the process of disclosure should be just that, a process, with protected time for follow-up and to ensure exploration of subsequent concerns and coping strategies adopted. Ideally, the diagnosis should be communicated by a professional who will have an ongoing relationship with the person with dementia and their carers. Health professionals involved in this task should have a thorough knowledge of key subjects, including the ability to discuss planning for the future (currently few studies have addressed this newly emerging topic (114, 118). Surprisingly, there is little research exploring the views of people with dementia on the type and nature of information they would wish to receive around the time of and after diagnostic disclosure. In England, the introduction of the new dementia advisor role, as one of the recommendations of the *National Dementia Strategy*, may be one means of providing post diagnosis support and information (16). However, our review has revealed an urgent need for research which explores the needs of different cultural groups in receiving a diagnosis of dementia since

transitions may be different or better access to support may need to be improved.

The key issue for people experiencing the transition from a person with memory problems to one living with dementia was coming to terms with losses on multiple levels; psychologically, socially and functionally. Timely identification of people who are experiencing significant emotional distress and struggling to develop positive coping strategies to adapt to this may allow referral at an early stage for specialist psychological or community based support (119-120) or opportunities to gain the benefits of peer or other trusted support. Due to a shortage of such specialist services in some countries, psychological therapies may not be easily accessible or available to all people needing them in the early stages of dementia (120).

Alternative sources of support may be accessible via peer support groups or a stepped care model of psychological interventions. In the latter, interventions of different intensities are delivered across primary and secondary care, and may be a more cost effective way of delivering psychological therapies to those who most need them (121). Unfortunately, as yet there are few validated stepped care models of delivering psychological therapies especially in dementia; further research in this area is needed in the light of the key findings highlighted in this review.

The background to this study assisted in the development of the research team's thinking and development of the analytical framework. Undertaking a systematic review further confirmed the value of exploring the propositions we have developed for the following accounts of the findings and our interpretation of their meanings and relevance to policy and practice.

4 Memory services and participants

This study was conducted in four sites, situated in three regions of England: London, Greater Manchester and North East England (an urban and rural site). This chapter presents details of the study sites and of participants to set the context of the research. We also provide details of the operation, location and service context of the four memory services. The term 'patients' was not used in all services but in order to maintain anonymity, it is used here.

4.1 *Study contexts and memory services*

4.1.1 London site

The London site is set within an inner London borough. The area covers approximately 12 square miles, is predominantly urban and the most recent Office for National Statistics (ONS) figures put the population at approximately 175,000 in 2007. Like all inner London boroughs, this is a densely populated borough with a diverse population: around half of residents are white British, over a quarter is from 'white other' ethnic groups and over a fifth belongs to a black or minority ethnic group. Over 100 languages are spoken in the borough; up to half of the population was born in countries other than the UK, and many residents do not have English as their first language. House prices and average earnings are among the highest in England, with unemployment rates lower than the London average. Like other London boroughs, it includes some wealthy neighbourhoods; however, some parts of the borough face problems of low incomes, unemployment and poor health. Islam, after Christianity, has the largest proportion of followers. The population is relatively young, with the average age around 40 years. Those over 65 years of age comprise around 11 percent of the population (number = 19,415).

4.1.2 North East England sites (urban and rural)

The urban North East site, on the other hand, has a population of approximately 270,000. Previous heavy industry has suffered a gradual decline, but substantial redevelopment in recent years. The city has a diverse population as regards social class, but a relatively low proportion of people from black and minority ethnic groups. In 2008, just over 60 people in the area had young onset dementia and just over 3,000 had late onset dementia.

The rural North East site has a population of nearly 200,000 and like many rural areas of England, includes several towns and suburban settings as well as rural communities. Extrapolation of national figures suggests that in 2008, just over 50 people in this site had young onset dementia and approximately 2,500 people had late onset dementia.

4.1.3 Greater Manchester

The study sites lies within the Greater Manchester conurbation. The area is predominantly urban, with a small suburban 'fringe'. As with the North East sites, traditional manufacturing industries in the area have declined and levels of unemployment are high. There has been some redevelopment. In terms of Indices of Multiple Deprivation, this study site is one of the most deprived in England. High levels of poor health and risk factors for dementia contribute to a higher than national frequency for vascular dementia compared to other parts of England. The population is just over 200,000, of which, around 20% are over the age of 65 years. As a whole, this area of Greater Manchester has significantly worse health than the national average on 24 out of 32 key indicators, including some of the highest rates for alcohol misuse, smoking, heart disease, stroke, and for over 65s 'not in good health'.

4.2 Memory assessment services

4.2.1 London

In the London site, the memory service is located at an old hospital site and provides treatment and support to people over the age of 65 with symptoms or signs of dementia. It also has a service for people with young onset dementia. The team is multi-disciplinary and assumes a holistic approach providing a range of therapies. In terms of other dementia services in the borough, the site does not have a local Alzheimer's Society although the branch a nearby branch serves the population. The borough has a local Age Concern branch which incorporates a dementia service, is free to access and does not require people to have a diagnosis to receive its service. Within this service, Outreach Workers are employed to visit people in their own homes, encourage stimulating activities, arrange group activities and pass on queries where relevant. The memory service building is very easily accessible as it caters to hospital patients and is convenient as it houses a number of other services. New patients are seen within the first month of referral by a member of the multi-disciplinary team. A thorough neuropsychiatric test is undertaken, along with obtaining background history of past health problems, family history and so on. Scans and blood tests are conducted where appropriate. Patients are then referred to the day hospital for a period of 3 months, where they receive therapeutic support in the form of reminiscence groups and art therapy. In some cases, lunch is provided. A diagnosis is made within the 3 months according to a result of the scans and tests. Patients are given a diagnosis in a multi-disciplinary team setting. Those with a dementia eligible for medication are prescribed the relevant medication. People prescribed medication are followed up by members of the multidisciplinary team and administration is managed where necessary. Additional information regarding other sources of support, Alzheimer's Society and other relevant legal issues is given at this time.

4.2.2 North East England

In the urban North East site, potential participants were referred into the study by one of two old age psychiatry consultants based at the General Hospital in the Memory Clinic. The clinic is situated at the back of the hospital site, in a modern building along with other old age psychiatry services i.e. wards and day units, alongside a research unit. The memory clinic was established in 1996 and moved to its current site at the hospital in 1998/9. Patients are referred to a consultant, seen in the clinic, have physical examination, cognitive testing and scans and then given a diagnosis if appropriate. Those with mild cognitive impairment are followed up annually. All who have memory problems are given the opportunity of attending a 'memory strategy group' which runs for 7 weeks. There can be a waiting list to attend, however. In the rural North East site, the Memory Clinic has one consultant. It is situated in a 1960s single storey building, which it shares with the Day Hospital. The building is easily accessible, being on a community site, adjacent to a GP Practice, Pharmacy and Ambulance Service base. The nurse led Memory Clinic was set up approximately seven years ago and has had dedicated input from a consultant old age psychiatrist for the last five years.

At both sites in the North East, assessment follows roughly the same procedures. Patients are seen by a member of the team who carries out a memory and neuropsychiatric assessment; relatives are interviewed separately. All patients are also subjected to routine tests, including scans and usually take place in approximately four weeks' time. Patients with abnormal blood results are referred back to their GP for follow up. This takes place within the hospitals; in the London site, this initial visit may take place in the patient's home or at the day hospital.

In the North East site, patients are reviewed by the consultant at their second visit – in approximately 6-7 weeks time. The memory clinic nurse sits in on this consultation. According to the results available, patients are given a diagnosis and/or referred on e.g. to a neurosurgeon, cardiologist, or psychologist. Those with significant cognitive impairment, who are diagnosed with Alzheimer's disease, are offered an anti-dementia drug (donepezil, galantamine) and are visited at home by the memory clinic nurse who delivers the medication, providing information. The nurse then carries out regular reviews of the medication. Those diagnosed with Alzheimer's disease who are below the threshold for prescription of the anti-dementia drugs are either reviewed at a later date or discharged from the service altogether, depending on their preference. Those with vascular dementia are discharged from the memory clinic. Some are referred on to a Social Services run day centre, according to need.

In the rural site, the memory clinic runs a 'memory strategy group' which is available for all patients with memory problems and carers. This runs for seven weeks providing support, help and the opportunity to meet others with memory problems. All patients with memory problems are offered this. The service also runs a carers' group twice a year, usually for a seven-week period, one evening per week. Speakers include: a consultant (who talks

about dementia), the Alzheimer's Society, a solicitor, Social Services, and Age Concern. For carers who do not have anyone to be with their relative, if necessary, the service offers a sitting service, during the carers' group session, within the same building.

4.2.3 Greater Manchester area

The memory service team includes three Community Nursing staff, including the current Team Leader, a Support Time & Recovery worker, two part time Occupational Therapists, part time Clinical and Assistant Psychologists, a part time Consultant Psychiatrist and two administrative staff. A majority of referrals are made by local GPs, with smaller numbers from neurology, geriatric medicine and other mental health teams. Referrals are forwarded to the NHS Mental Health Trust and then allocated for investigation and diagnosis of possible mild to moderate dementias without challenging behaviours to the memory service. The team attempts to respond to escalating demand through continual review of practice. It has moved from a traditional consultant-led model to a fully multidisciplinary approach; with nursing and occupational therapy leading initial assessment and monitoring. Part time psychiatry and psychology staffs contribute mainly through multidisciplinary consultation and targeted involvement at appropriate stages of assessment and treatment on the basis of agreed pathways. Due to the size of the caseload and available resources, the team has moved from a home-based assessment and treatment model to a predominantly clinic-based approach. Permanent provision of a team base has represented a significant problem for the service. Currently, the team is in the process of re-location to a former day centre, based on the same site as the local dementia in-patient wards. There is good parking and easy physical access to a relatively modern building in quiet wooded surroundings.

The referral rate at the memory service has shown some signs of stabilising since a peak from when it started to about 400 new referrals accepted by the team each year. Clinical impressions are that more people are now referred in the earlier stages of dementia, though this has yet to be fully analysed. Currently, the service is supporting approximately 530 people and their families/carers at any one time. The service is unable to provide long term follow up after diagnosis, although it does offer information provision, clinical advice and basic work on adjustment for all people with dementia and their families. Individuals who receive acetyl cholinesterase inhibitors (anti-dementia drugs) are monitored, and only discharged when no longer eligible for this treatment. A majority of people with mild to moderate vascular dementia are discharged by the team, though they are directed to other voluntary sector support and mental health services, where appropriate.

The following section illustrates what happens to an individual with memory problems. Similar descriptions were compiled for the other three sites. This section is therefore provided to set the participants' experiences in the context of the service perspective of their transition.

Initial assessment involves a semi-structured interview (undertaken jointly with the person with possible dementia and a relative(s) where possible), followed by separate standardised assessments with the person and family. The standardised interview includes: items to help clarify the referred person's understanding of the reason for referral, their capacity and consent to participate; a detailed medical history; history of cognitive changes; current functioning; and social issues. Assessments include: the Mini Mental State Examination (MMSE) and Demtect (where the person with possible dementia scores above 26 on the MMSE). Mood measures may also be undertaken at this stage. The Bristol Activities of Daily Living Scale is completed with the relative and carer stress and psychological well-being will also be considered at this stage. On the basis of these initial assessment results, memory service staff follows local protocols/decision trees to refer people with dementia for neuroradiology (brain scans) and ECGs or to clinical psychology for neuropsychological testing and/or investigation of complex psychological factors which may be affecting cognitive presentation.

Where diagnosis of dementia is very clear and the person has requested to be told this, the assessment staff may provide the basic diagnosis of an unspecified dementia at this stage, and support the family with initial information around benefit claims and other issues. A proportion of patients request that they be investigated, but ask not to receive any formal diagnostic information. Both initial assessment and detailed investigations are discussed at a weekly multi-disciplinary team meeting, at which part time psychology and psychiatry staff provide consultancy around the assessment and initial management process. Need for management of mood and anxiety disorders is also considered. When a formal diagnosis has been confirmed, a follow up appointment is booked at which a member of nursing staff and the consultant are present to discuss findings with the person and their family and to begin the process of providing relevant information. Additional leaflets relevant to the individuals in question may also be supplied at this stage. An individualised letter summarising the information from the meeting is sent to the person and/or their carer (dependent upon the person with dementia's consent) and copied to the referrer and/or GP. Where appropriate, arrangements to commence medication are also made.

Subject to available resources, people with dementia diagnoses may be offered the option to take part in a facilitated peer support group around adjustment to diagnosis. For people with vascular dementias the team has limited resources to address diagnosis, adjustment and support for people with mild and uncomplicated conditions, who are likely to be referred on or discharged, unless specific needs have been identified (such as occupation therapy interventions around aids, adaptations and strategies to manage memory or other daily living problems). Patients commencing on medication are followed up by members of the nursing team to ensure that medication is increased at an appropriate rate, administration aids are introduced where necessary, and side effects are managed. Additional information about legal issues, such as power of attorney, future planning etc will be

introduced or repeated with the person and their family as part of this process, based on clinical assessment of readiness to address these issues and/or expressed choices.

This section has described the context of the memory service in the four study sites. They varied considerably in terms of staffing, resources, work patterns and location. The next section describes participants' characteristics.

4.3 Participant characteristics

Participants in the study included people with memory problems and their supporters or carers (the term carers is generally used, although people were not providing significant care as yet). Fifty-three participants were included in the final study: 27 people with memory problems and 26 carers; 20 were matched pairs. There was a relatively equal split between the numbers of men and women with memory problems (13 men compared to 14 women), while amongst the carers, there was a greater proportion of females (20 women compared to 6 men). Over half of all carers were spouses; the rest were mostly adult children. Two carers were part of the extended family of their relative with memory problems. Eight people with memory problems had no immediate carer and lived alone; one of these was living in sheltered accommodation.

A majority of the people with memory problems lived with only their spouse (14), seven lived alone and six lived with other family members, one of whom included the spouse. Almost the entire sample was retired; 25 of the people with memory problems and 20 of the carers. Two people with memory problems were still working part-time, and seven of the carers were in full-time employment. One of the carers was unemployed. All participants were community-dwelling; that is, they lived in their own homes.

In terms of ethnic groups, the sample for this study was entirely white British except for one South Asian matched case (person with memory problems + carer). A likely reason for this was that the inability to converse in English was one of the exclusion criteria and hence participants referred to the study were all English speakers. However, it is worth noting that none of the rest of the sample who were English speakers described themselves as being from any other ethnic groups.

Eighteen people with memory problems and 12 carers were aged between 65 and 79 years old. Five people with memory problems and one carer were over 80; the rest (three people with memory problems and 12 carers) were all under 65 years of age. Seventeen people with memory problems left school at the minimum school leaving age (varied between 15 and 17 years), while 10 people with memory problems had pursued higher education beyond school.

There was a mixture of the type of diagnosis people had received, ranging from Alzheimer's disease, vascular dementia and, in some cases, MCI

(according to the Petersen criteria). Out of the 27 people with memory problems, eight interviews were conducted with people who already had a dementia diagnosis at the time of the first interview. Thirteen subsequently received a diagnosis by the time of the second interview. The rest were still waiting to receive a diagnosis from the memory service. Those who had received a diagnosis of MCI were expecting to be followed up in 12 months' time.

5 Transitions in uncertainty

Modern life has become increasingly complex and is characterised by both risk and uncertainty (122). Despite the increasing use of sophisticated technologies in contemporary medicine, clinical uncertainty remains in the treatment and management of dementia. As highlighted in Chapter 1 transitions along the 'dementia pathway', as with most long-term or chronic illness are not straightforward; they are rarely linear and the boundaries between different phases of the pathway are often uncertain and frequently contested (25). At an international level too, exploring pathways to diagnosis is becoming an increasingly important area of enquiry (124). For biomedicine, significant transitions along the 'dementia pathway' are captured in diagnostic assessment; between normal age-related cognitive impairment (normal cognitive ageing) to MCI to a formal diagnosis of dementia (with possible sub-types, such as Alzheimer's disease, vascular dementia, Lewy-Body dementia, mixed dementia). Although this linear clinical pathway would appear to be quite straightforward there still remains considerable clinical uncertainty around many of the processes used in diagnostic assessment. Once a diagnosis has been achieved there remains further uncertainty about how the condition will develop in terms of the symptoms and behaviours which different individuals will experience and how individuals may respond to pharmacological treatments and psycho-social interventions.

The focus of this study is on participants' lived experiences of the early stages of the 'dementia pathway' using retrospective accounts of participants with memory problems (hereafter referred to as people with memory problems) and participants who were the significant others of the person with the memory problem (hereafter referred to as carers¹) from the time when it was first noticed that something was wrong through the processes of diagnostic assessment. In addition to the traditional clinical transitions implied by the dementia taxonomies (e.g. Clinical Dementia Rating (CDR), a number of different 'transitions' experienced by people with memory problems emerged through the analysis of the interview transcripts (see Table 3).

¹ Significant others were most often spouses, children, siblings or friends (see Chapter 4). Few described themselves as carers of the person with memory problems although in due course it is likely that they will take on that role further along the 'dementia pathway'.

Table 3. Transitions in uncertainty

<p>'Internalising dialogue': self awareness that something may be wrong.</p> <p>'Confirming positions': seeking confirmation from those closest to the person with memory problems that help is needed.</p> <p>'Seeking expert advice': disclosing position to professionals (usually GP).</p> <p>'Being tested': undergoing diagnostic investigations and receiving results.</p> <p>'Seeking understanding': from professionals and other sources.</p>
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5.1 Internalising dialogue

Recognising that something seems wrong can be difficult for most people who experience a chronic condition. This reflects individual awareness of what might be normal for your stage in the life course and what might be abnormal. This is a particular challenge as we age and recognise changes in our cognitive functioning, such as difficulties with word finding or remembering why we have gone to the fridge! Among people with memory problems participating in this study, awareness that something was wrong was heightened by their past experience or exposure to others with dementia and changes in their life course experience.

The time before help is sought is a time when the family and the person with memory problems begin to acknowledge there is a problem, although such awareness may not be a joint act or undertaken openly and in agreement. For example, the carer may wish to push the person with the memory problems to seek help, and to have their own worries and concerns validated. Before this happens, however, the process has often already begun with an internal dialogue within the person with memory problems. The person is living their life and all that it entails in terms of their family context, becoming a retired person, dealing with bereavement, health issues and for some, work and 'hands-on' parenting is still part of their life course.

In all of our interviews, participants were asked to tell us something about themselves, their previous occupations, educational histories, families, locations and their health. Memory problems are not isolated phenomenon and they are part of a lived experience; all participants responded to their problems in an individual way within the context of their life.

One participant described the impact retirement had had on her at 65. After having left a busy career earlier than planned due to the ill-health of her husband, this participant's memory difficulties were embedded within this experience:

"I felt as though I should be at home and that's why I retired. And I suppose in a way when you've always worked like that and then you're at home, I suppose you can go into freefall a little bit can't you because although we keep busy don't we G, we're either in the garden or

doing in the house but it's a different ... it's an entirely different thing than leaving the house at seven in the morning to go to your daily job and what have you. I am glad I am at home, don't misunderstand me but I don't think it's very good being at home really because I've not got that same train of thought for things because I am just toddling around now and doing what I want to do when I want to do. That might have to deal with the fact that my memory isn't good. My memory isn't such that things are blanked out, what happens with me is I tend to ask the same question two or three times."

(Person with memory problems)

This participant clearly described the loss of work and the impact of her husband's health, which she later reveals is a great worry for them both, especially when he was first diagnosed with a serious illness.

The journey described by the person with memory problems can also be very different to that of the carer, and later the professionals that become involved. For some the internal dialogue may have been going on for many years. One person describes the traumatic loss of her husband 15 years previous and the devastating impact this had on her life:

"it's a big thing when you've been with somebody over 50 years, you know, it's, um, very distraught, distraught you know but it's the way he went so quick, unexpected. We didn't think he was really that ill but he was very quiet that day, sent for the doctor and they put him in hospital so he only had one evening in, one night in hospital and I come out of work the next day and there he is dead for no reason, they couldn't say any particular illness ... I don't know, I think, um, more or less when your dad died wasn't it that I couldn't be bothered going out now because A was always here, we were always together and we had a car and he'd take me here, there and everywhere, you know, but now he's gone – he's been gone 15 years now hasn't he – so it was very unexpected and, um, it was a great shock really..."

(Person with memory problems)

People live complex lives within family networks; evident in participant narratives describing the importance of the relationships in their lives. In this study, participants had experienced the loss of partners, children and siblings. Although there were strong extended family networks, others had children living abroad, and one family had a disabled child with many complex needs to support. These challenges contributed to the process through which people reconciled themselves to acknowledging memory problems and the part these played in their everyday life.

To some extent many participants, who eventually sought help because of pressure from other family members, perceived themselves as managing without any real difficulties. They did not have a strong urge to find out about their memory problem; they did not see it as affecting their lives in a negative way, including their relationships. Although this could be due to lack of insight as a result of the dementia that they may be diagnosed with, it should also be seen within the context of the life lived. The woman (see above), who had lost her husband 15 years ago, also lost her son after a serious car accident that had left him 'brain damaged' for many years. She was apparently offered no bereavement counselling or support after these traumatic and damaging life events. Her desire to stay in her room and watch TV, *"just so long as I've got me telly and me coffee and me fags I'm alright"* may not be satisfactory for her daughter or for the health of their

relationship. Her daughter conveyed that she was terrified of a further loss, of her mother; a loss that she felt certain was going to happen.

Another participant who described her life as shrinking also provided a picture of the many things that she continued to do and the rich history of her life experience within the context of not remembering, not managing the housework, and the pressure from her daughter that she is not coping as well as she used to. She described a car accident in which she felt that the other driver was at fault, although she thought her daughter did not believe her:

“... she won't allow me to buy a car, because she doesn't want me to have an accident ... Well, the last car I had I didn't have the accident, I was parked and I was going to move forward and I had a look in my mirror and there was a car coming, but it was, it was, it had come round the corner, and I moved off and it hit me ... And it hit me; I was moving forward like that, and it hit me there ... So he was going far too fast and there was a van behind him, and they were two ... And (daughter), I don't think, believes what I said. She thinks it was my fault.”

(Person with memory problems)

Our study indicated that dementia is not something that suddenly happens to you; that you are suddenly a different person in need of help. It is a complicated and slow process of internal recognition and acknowledgement, external acknowledgement within families and relationships and finally a slow journey through health services, and this continues as a process beyond any given diagnosis. For many participants it was the weighing up between 'normal' ageing, and something being wrong, enforced when other families members were vocal about the 'problems'. For the following participant her family were the ones rationalising and emphasising that it was likely a problem of age. Yet she felt that something else was happening and they were becoming concerned:

“About how I felt, like, and of course they've put it down to age as well, don't they, but ... [Interviewer: And is that what you feel, it's just part of the aging process, or ...?] Well, I feel as though it's part of it, but apart from that I don't really know, just seems to be getting worse, doesn't it ... with different things, I seem to forget, be forgetting of those.”

(Person with memory problems)

This participant's husband had died over a decade years ago and she seemed to have a good relationship with all her daughters who lived locally and were actively involved in her life. She lived very close to one daughter who participated in the interview. She had worked all her life, been a mother, was now a great-great grandmother and grandmother to many; she had friends, a social life, a well-kept home. Her life was full. But for her the missing something that kept presenting itself, the lapses in her mind, were worrying for her to the extent that she sought family consensus and support to seek help.

For other participants, perhaps due to their heightened awareness through being younger and more aware, and with previous experience of dementia, the diagnostic quest was something sought by themselves. This was to either discount the worst, the 'dreaded fear' of Alzheimer's or to catch it early and ensure that they could make plans and receive any available

treatment. One participant, who was aged under 60 and lived alone, was highly alert to their memory changes due to her father's past dementia and the genetic risk of developing the same kind of dementia. She had been prompted to seek help for herself having worked with a younger person with dementia and felt strongly that if it was anything like this she should get it 'checked out' sooner rather than later. This heightened awareness appeared to exert a powerful impact on the internal dialogue that an individual may have with themselves; however it does still require consensus of some sort within the family context. For the person above, despite her partner having reservations about the problems she acknowledged, he was still supportive and attended appointments with her:

"Yeah, if he's home, he's good that way ... if I need any support in any way, I mean he thinks it's a bit of a joke but you know if I need him he'll always try and come to the hospital with me or wherever I have to go, he will always try and come with me."

(Person with memory problems)

The internal (me), the external (others), meanings and assimilation of these meanings can establish an agreed awareness. In other interviews there were areas where there was disagreement and people did not come to the memory service together. It seemed that it was only because of forced family pressure that help sometimes was eventually sought and the denial of problems was externalised by the memory services.

5.2 Confirming positions

Once a person with memory problems developed awareness that something was seriously wrong with their memory they moved into a second transition during which they sought to confirm from those closest to them that they needed to seek formal help. Confirmations of people's suspicions were embedded within family, social and cultural contexts. These were identity driven, rationalising the experiences, leading to multiple meanings of events and interpretations.

Within a family or a relationship, the period of external acknowledgement may take time and the length of journey will depend on many complex circumstances. How are problems within the family usually discussed and articulated? Who usually takes responsibility for problems? Is health prioritised or acknowledged? What is the history of the family or relationship?

These factors may contribute to the huge step that needs to be made before help outside of the family is sought. First, a problem inside the family must be acknowledged, and this is not a linear journey. It does not change overnight; the internal dialogue of the person with memory problems will continue with the individual struggling with what is 'normal' and what is 'abnormal'. The internal dialogue may well be different to the family account. Eventually the growing lists of worries or concerns, the particular event that has become the climatic family story of the problem, are jointly acknowledged. Previous knowledge of dementia may influence the family to act. A number of participants in this study had previous exposure to

dementia through work experience, other family members or friends being diagnosed, or through the media. There was no doubt that this various knowledge had an impact on the family dialogue as this person indicated:

"It weren't bad, but like you say, we've got no answer yet or anything like that, so like everybody says it's just his age coming up or he's just, I don't know. I work with a lot of people, that's who I work with dementia and Alzheimer's and stuff like that, every day ..."

(Carer)

The overlap between 'internal dialogue' and 'confirming positions' was illustrated by a person with memory problems whose account showed the complicated internal process that they were in the midst of. Despite seeking help she was still battling with her own rationalisation of the problems:

"erm, because I don't think my memory really is any worse than friends. All our friends tend to be round ... well, close friends tend to be round about our age and we're all complaining about the same things, you know, you ask questions like have you seen my keys, do you know where my purse is ... and, you know, that sort of memory ... and I think that is mostly lack of concentration ..."

The participant went on to say:

"No, I go with the flow, I mean if you put your hand ... yourself into the hands of somebody who is going to help, or think they can help, erm, hope they can help, I have been aware that my brain is not as sharp as it has been, but then you're 72 and you think it's aging, it's erm, but erm, I've been curious about the bangs on the head...and thought could it be some brain damage with it... when I fell in the park".

(Person with memory problems)

The participant indicated how to make it right within herself that she was seeking help, and there may be reasons for the changes that were occurring, such as a fall which incurred a serious head injury. The person she lived with described the detail of the problems that were occurring and the circumstances in which they went to seek help:

"And then there were all the bills, so she knows what's coming in and what's going out and projects what we're going to need, and things like that, but she weeps over them now because she can't get the figures right ... Because she transposes the figures or she gets ... she just writes the number down wrong ... And it was really distressing her and one or two other things. So I suggested that she went for a check up, you know, like an M.O.T."

(Carer)

The experience of another family, illustrated in the following interview extract with a mother and daughter, the complexity of such family debate leading up to some kind of consensus in the journey to seek professional help is apparent. The daughter in this family worked with people with dementia and for her the signs were clear. Her mother acknowledged deterioration in her memory but considered it normal with ageing and felt that it was not a problem for her. Her daughter had knowledge and experiences that led her to believe that early diagnosis was vitally important in the support of a person with dementia:

Mother: "Um, just getting forgetful, you know. I don't think it's that bad for me age, you know. I mean I can still converse with people but, um ... Eh, well, I can, I can talk to anybody, even talk to strangers, um, so ... but, er, it doesn't bother me. I mean, I accept it as part of your

growing older isn't it?...Just old age, everybody's different you know ... I don't think it is dementia, it's only me age."

Daughter: "No, dementia and Alzheimer's are completely different."

Mother: "No, I don't think so. It's just that I accept everything as it comes ... Age to me ... it's different in everybody isn't it, everybody's not the same. I mean, um, but I can live without, you know, whatever, um, it ... who needs to know what happened yesterday, eh, who needs to know what happened, I don't need to know what's happened yesterday, it's gone."

In some circumstances the person themselves had taken responsibility for their own health and the internal dialogue was not challenged within the family context. This person saw their GP regularly due to other health concerns and so this may have made it easier to act upon their difficulties:

"Oh yes". [Interviewer: "And in your memory, have you noticed changes there?"] "As I say, it was always my pride knew that. But I would say, I'll not pin it down to months, this last year I've noticed it all the time, and I couldn't make it out. I never gave it a thought that it was my memory." [Interviewer: "What kind of things had you noticed?"] "Anything really, I just couldn't remember. I just wasn't remembering, and I thought this is peculiar this. Anyhow, I went to see my doctor up the road there, and a very nice fellow, and he talked, said, 'no, I've got to get in touch with somebody.' So it came through him, to go and see them."

(Person with memory problems)

Another participant who lived alone and had a family background of dementia with a genetic risk factor had an obviously heightened awareness of the disease:

"Two occasions where I went to get money out of the bank and walked away without the money. Left it in the machine, you know, the ATM machine. Then one day, I was coming back from my sons and I sort of got lost and it's a journey I make fairly frequently, you know, and that was scary because I didn't know where I was and the other thing which I found alarming was something I've done from being a child is always saying my prayers every night and I'm forgetting, I'm forgetting the words, now that...because it's something I've always done, that really, really alarmed me and that's why I went to see the doctor about it."

(Person with memory problems)

Despite not having the dialogue within a family, the internal dialogue between 'it's a mistake everyone can make' and 'there may be something wrong' will interplay within the person's thought processes until they reach a transcending moment where they recognise the need to seek advice or help. One person was tenacious in his need to seek information and help for his problems. He had been in control all his working life in a high-powered career and the lack of control that his health problems were presenting brought great challenges for him. Within his family dynamic, he felt the need to convince his wife that there was something wrong, although this was not an isolated case. The carer in this situation may have been in denial possibly due to her own fears of the future if her partner had a dementia:

"He's been, he went to his GP – he kept me out of it quite a bit at first – he was just trying to make enquiries himself and really he was non-stop reading about it and going on the internet and things like that which I used to get annoyed about, I have to say, because I felt he was talking himself into this problem. I said "why don't you just leave it and see how you go" but no, he wants to know what's to be expected and this type of thing ... I felt he was being paranoid, I suppose, at the time and I just felt he was reading too much about these problems and talking himself into this condition. Maybe I should have been a bit more sympathetic at the time, I don't know, or maybe it was just a case of not wanting to face up to it really."

(Carer)

The study therefore identified a threefold contribution to what may be referred to as a 'transition' in taking the 'problem' to professionals. There may be *a dialogue*, characterized by events that form the transition from internal dialogue to discussion with the family. There may be *a threshold*, in situations when consensus for seeking help differs within families in its degrees of seriousness. Most commonly, however, is *a collection*, when the realization is crystallized that memory problems are not lapses in isolation but are examples of more consistent changes in a person. These were often different for the carer and person with memory problems, though both may have been struggling with the admission that there was something wrong.

Where it was a child caring for an ageing parent, or a caring relationship that had a clear generational difference, there was a pattern of deterioration, of losing independence and increasing reliance on the extended family. Within spouse or same generational relationships this transition was more complex:

"you know, like you would with your mum, and it's just pointless because she's no idea what's going on in the world or anything, you know to me she can't take it in ... I mean whatever you might start a conversation about then she'll join in, but she goes straight back to 70 years ago."

(Carer)

For others it is possible no consensus is sought, and it is only externalised because the carer seeks help without the person's consent, and only once a referral from the GP has come through does the person at least acquiesce to talking with services or professionals. Sometimes the debate about the acknowledgement continued in the interview context when participants were interviewed jointly:

Father: "I mean this morning put some toast under, looked it was all right one minute, I thought, I was dashing a bit so I thought I'll go clean my teeth and I came down and toast was burnt, but I should have known."

Daughter: "But the thing is you shouldn't go upstairs to clean your teeth if you've got toast under. But you were trying to dash out, that's the problem, get it over in two minutes."

Father: "I was running a bit late, I had a few other things to do, I thought, well toast will just be done, a quick fly on my teeth, the toast was for work, to take with me at work, cold toast while I was at work, I'd had a bowl of cereal for breakfast."

A perfectly rational discussion about problems that can occur in any household, but in these interviews, the list of people's errors were related to something much more serious, they were from a catalogue of unusual behaviours, disconnection or forgetfulness as cited by family members. The father in the above quotation did acknowledge a couple of quite serious incidents regarding memory loss where he had two periods completely 'blacked out', one relating to a period of a few days and another relating to a serious health problem of one of his children. He conceded that he would seek help; however on a day-to-day basis he argued that he wasn't any worse than many people his age, and that he had never been good with names and dates. On the one hand he acknowledged having no memory of conversations, while countering this with trivializing the problem.

The 'outing' of memory problems is a process that begins with a person's own internal dialogue and will continue further on than diagnosis. This daughter described her mother after the first appointment with the memory team:

"Very nice to the chap, don't get me wrong, she was very nice and she answered his questions, the ones she could do, but it was 'What am I doing here? There's nothing wrong with me' you know, and all this business and then on the way home we had a terrible do, didn't we, she was crying and screaming and shouting 'I don't want to go in a home' and I says 'No one's putting you in a home mum, this is nothing to do with that, we just had to see that gentleman and that's where his office was.' It took me ages, quite a few days to calm her down from that, she didn't like it at all, she really got scared ..."

(Carer)

It is clear that even once acknowledged within a family or relationship, for people with memory problems, a complex range of emotions followed. One participant described how their life was shrinking, how they no longer did all the things that they used to and how they were becoming more localised by the ageing process. They also describe their daughter becoming more protective over them as the realisation that everything is not as it was:

"Just the, well, I'm grinding down, you know ... I'm just thinking that's not on, it should be ... and I was thinking oh, but then I think my memory for back there, I mean, that's normal, isn't it...The memory from back there is better than the memory of what the hell I did yesterday."

(Person with memory problems).

Another couple discussed the emotional burden of acknowledging the problem:

Husband: "I do tend to think that if I put one word out of place you snap a bit quick, or her mood can change a bit quicker than it used to shall we say."

Wife: "That is because I am feeling vulnerable isn't it, so if somebody is getting at me about something, something I might not have."

Husband: "It takes you a while to come out of it."

Wife: "I am going to sort of snap back and to be honest with you I would hate it if I couldn't do that because then I'd be like a little frightened puppy. I don't want to get to that stage, you've got to be. I know it's not nice if somebody is having heated words or what have you but I have to deal with that in my own way so that I don't feel too crushed."

5.3 Seeking expert advice

The boundary between family consensus and seeking expert advice was not always clear cut. For many people with memory problems the moment that they externalised their difficulties through the consensus to seek help, they appeared to become passive in this process. In some cases, they were even excluded in the first steps to seek help, already deemed too vulnerable and in need of protection.

The perceived timeline for the carer or the person with memory problems about how long memory problems had been evident emerged through the list of difficulties and incidents relayed to the professional first contacted:

“Really a good year ago really and at first you laugh at it and you say it’s old age and that but then it started getting a little bit serious when he was doing things that weren’t normal, like putting his clothes on the wrong way round and he’d suddenly have a think about time and then if he goes anywhere strange he gets confused and doesn’t know where to go. It was that kind of a process really.”

(Carer)

Another carer related:

“But it was just little things that I noticed I had to keep repeating them and telling him and I kept saying to him, you know, you’re forgetting. ‘No, no I’m not, no I remember’ (he says). And I can tell when he cannot remember, you know, things like that. And that was it. And of course I had the doctor’s (an appointment) that day and I said he’s getting a bit forgetful. And it started from then.”

(Carer)

The majority of people in this study first sought help for their own or family member’s memory problems through their general practitioner (GP). In a small number of cases people were involved with other professionals who they chose to talk to first, but were then directed to their GP for further advice. There are cases where another health professional or tertiary health service had been involved with the person with memory problems but did not refer to the memory service despite what relatives describe as obvious cognitive impairment. There is no evidence in the study of professionals crossing professional specialist boundaries to seek advice regarding a client.

For example, one participant was being treated for epilepsy and their memory problem was linked to the epilepsy medication that they were using and no action was apparently taken to have the person assessed for memory problems. In another example a carer described her mother’s experience of memory loss and confusion after a stay in hospital, but there was no follow up or particular concern about her memory, despite her daughter describing obvious and deteriorating changes in her abilities over the previous 12 months.

A few individuals sought help for themselves through their GP. They were motivated by either their own heightened awareness of dementia or because they were particularly independent in their health responsibilities. One younger participant whose father had had a diagnosis of frontal lobe dementia had been told they had a ‘1 in 4’ genetic chance of having this disease passed on to them. As soon as they began to notice some changes in their memory, such as forgetting prayers they had been reciting since childhood, along with getting lost in an area they knew well, they went to see their GP.

Another younger person who sought help worked as a care worker with a person with young onset dementia. They were concerned that their own memory difficulties and disorientation in conversations might be a sign of this too; they had been proactive in seeking advice through their GP who had been reassuring but who had also asserted the need to do something sooner rather than later.

In contrast, another person described frequent visits to their GP in recent years for a range of health difficulties, all of which had been diagnosed, except what they considered to be clear cognitive deterioration. They felt that they had to push for a referral to the memory service:

“Yes, reluctantly, right, so when I kept saying, ‘I’m having memory problems’, it went on over a year I would say, it was February before I was referred anyway, and it wasn’t his fault, he’s an excellent doctor, I could see he was getting slightly annoyed with me but unfortunately my approach is, I have no intention of giving up when I want something done and I’m very polite ...”.

(Person with memory problems)

In contrast to these few examples, the majority of participants with memory problems either first went to their GP in response to pressure from the family or a member of the family went to see the GP alone to raise concerns and arranged for the GP to see the person with memory problems. For example, one carer described talking to the GP and arranging with the GP that they would bring their mother in under the guise of a ‘medication review’ so that the GP could do a memory test. The consensus sought by carers to get to the point of seeking help was not without conscience. One carer described their guilt in pushing for the person they cared for to confront the issue. Carers who sought help for the person with memory problems in their absence, tended to be adult children in this study, though not always, as sometimes spouses felt the need to discuss with their GPs their worries and concerns:

“I was feeling quite low and I went to see the doctor on ... I suppose it was a pretext of something that I wanted to talk to her about but really I was so wound up about J’s change and so many things and I said to her, you know, that his personality seemed to have changed. Oh to ... did she say bring ... I’ll make an appointment to see him. And so we made an appointment.”

(Carer)

In other situations the carer instigated the visit to the GP and then accompanied the person with memory problems. However, sometimes carers themselves would cite pressure from other family members; one spouse said:

“The family kept saying there’s something wrong with dad and the pressure from them a little bit and then in my own mind I thought I’d rather nip anything in the bud not knowing what it could be.”

(Carer)

Significant numbers of participants had some previous experience of dementia, either through a family member or through their working experience: two carers were care workers with people with dementia, another was a nurse, and another had worked on a ‘geriatric’ ward. For others it was a family event or crisis that led to the seeking of help for memory problems:

“He (dad) went into hospital and it was then because mum was on her own that we realised ... We thought at first mum was obviously stressed and upset about dad being in hospital because they were always together. Dad had retired and she was ringing me up at two

o'clock in the morning, four o'clock in the morning, and again we put it down to the stress of worrying about dad."

(Carer)

5.4 Being tested

As reported in Chapter 4 the four memory services through which participants were recruited had different processes and models in place. Three of the four services were clinic based but one service at the beginning of the study used home visits for the initial assessment. Later on during the study people were asked to attend clinic for the first brief initial assessment before having a full assessment at home. By the end of data collection, however, all assessments and subsequent follow-up contacts were taking place in a hospital venue.

For most people it was after first seeking help through their GP that they were referred to memory services. However, a lack of clarity with the process appeared to begin at this point as often people were unclear who referred them there, or even what the service was:

"so it said, we've got... you know we've been asked to make an appointment for you, but we're not what you need ... We think you need the memory clinic." [Interviewer: "So you'd initially been referred somewhere else?"] ... "Yeah" ... [Interviewer: "and they then referred you onto the memory clinic?"] ... "Yeah, yeah."

(Person with memory problems)

Another person had no knowledge of how their GP knew that they were unwell or in need of help:

"Yes, my GP, because I couldn't understand what. I think he guessed because he must have referred me to the hospital because he came to see me and he had never come to see me before in my life you know what I mean. And I thought 'how does he know about me?' I didn't like to be rude and ask him."

(Person with memory problems)

For many, it appeared to be a long and difficult process to reach the point of being referred to a memory service. People were then thrust from a social process into a medical process. They were no longer active agents in their lives but became disconnected from themselves as their status, identity and biographical history were overtaken by their problem once they were part of the medical system:

[Interviewer: "Was there anything that you wish you'd had the chance to talk about with the consultants at the hospital that you didn't have chance to talk about?"] "No because I hadn't a clue what this was all about until it was referred by Dr C so really it was a little step into a system which I took on and did what I thought was right in accordance with what they were saying."

(Person with memory problems)

In some cases, this appeared to be in contrast to the carer's feelings that now 'something is being done':

"I think the fact that you know you're going to get some professional advice calms the situation, you don't get too frantic and I try very hard with M because sometimes he can get a

bit emotional about things and I do try and just calm things down, I'm one of these people, I don't like confrontational situations."

(Carer)

Once in the system, the difficulties experienced by the person with memory problems became catalogued by professionals, and they were tested, questioned and scanned. Some carers commented on the difficulties of talking about the person with memory problems in front of them, for fear of upsetting them with a list of all the things that they were doing:

"But as I say, when you go to the hospital, don't get me wrong, I think it's a smashing hospital and I think they're doing great with him ... you're not really getting a chance to tell him his problems because he's there with you. And I mean, no way do I want to embarrass F. I mean, he admits he's getting forgetful, but you don't want to embarrass him by saying he couldn't tie his shoe laces..."

(Carer)

Another person said:

[Interviewer: "And do you feel that you've had the opportunity to ask all the questions you would want to ask at those appointments or?]" "Not really because my mum's normally there ... So that means that to some degree, if they ask me the questions and I answer it, I'm calling her a liar because I'm saying that what she's told them is a load of rubbish."

(Carer)

When describing the process of assessment for memory problems, a large proportion of people remembered being tested and scored. Many of the participants referred to scores given in memory tests and the way this made them feel. It was good if they did well, that could be a hopeful sign:

"Well, when the ladies came originally, the assessment team and asked me questions, and I probably fluffed ... no, I didn't fluff them all, we went up there, didn't we, and they asked me questions. And my score was something like, was it 13 out of 18, I think. It wasn't a bad score."

(Person with memory problems)

But the testing process also led to participants feeling stressed and unprepared:

"Which made me think when, you know, this thing started to roll, this memory clinic, why am I going to a memory clinic, you know, I can ... if somebody said, you know, who was King in 1936 and things like that, it's ... I mean I must, I must admit when they said count backwards in sevens from 100 ... I panicked, but that test that they did that day was not really fair to me."

(Person with memory problems)

One carer described it as a realisation of how bad things actually were:

"The gentleman that she saw there, she had a test, they asked her about 30 questions and I think that was what I found that bit upsetting ... and it was a case of just sat there and just kept quiet and mum ... I mean some of the thing is... [Interviewer: "And why was it upsetting... because?"] ... "I suppose it was because it's reality."

(Carer)

In contrast, another carer described the process and found it difficult to come to terms with the person they were describing:

“Oh really, what I felt were silly questions, but I suppose they were relevant at the time – is he able to dress himself, was he just as careful about his appearance, that type of thing, how was his driving, had he had any particular crashes and no, he’s fine with his driving, he just doesn’t like driving at night because the lights affect his eyes but he’s no problems with his driving so that type of thing really, his behaviour and that sort of thing.”

(Carer)

There was little understanding about the diagnostic process and it is not clear if people were told what was going to happen and why. Few people had an understanding of the medical process that they were experiencing or the complexity and uncertainty involved in making a diagnosis of dementia. Often people were told verbally, but the lack of written information made it difficult for participants to retain information given in a consultation so highly charged with emotion.

Due to the current policy interest in dementia (16) on early diagnosis, this study has been timely in exploring the impact of these messages on people accessing services. Participants suggested that they were attempting to get to a diagnosis because they believed that there would be treatment or that something might be done if caught early. The fact that there is professional uncertainty in diagnosis and in knowing what the future holds was not discussed in this early stage of the assessment process.

Despite the lack of clarity with the assessment process, the importance of the relationship between professionals was indicated through the recounting of professional qualities:

“Yes she was brilliant, and I was glad of the time because I was upset that K couldn’t dress himself properly and little things like that. And then I forget her name, and she said it’s normal... and I was frightened of leaving him on his own because he can’t cook a meal or anything, he will leave the oven on and gas on and things like that. I’ve always been an outgoing person really socially and everything, I’ve had to stop a lot of that really. But she said to me you mustn’t stop everything because you need that break as well really and that, and other things that you can’t quite remember I had them all written down. She was a real help to me really.”

(Carer)

Words such as ‘faultless’, ‘reassuring’, ‘supportive’, ‘kind’, ‘helpful’, ‘doing a good job’ were used to describe the encounters with professionals and professionals themselves. The lack of clarity continued however, though participants referred to individuals and their interactions with them. Overall, there was a general lack of knowledge about individual professional roles and continuity of care:

“Well I think if we’d have had contact with somebody because we had two nurses come, well one was a nurse and I think one was a social worker, and this was quite early on.”

(Carer)

“You know, so I just thought that this was the route it had to take, you know, you had to go through, you know, the path that we were on was the path you took and then I presumed that like when we went, when we would have gone tomorrow and saw this doctor and this other

gentleman who I think must be a nurse clinician or something, that they were then going to probably tell us a little bit more about what was wrong with M and what was available if, you know, or what care or what advice or what everything but ... but it's not happened yet so and I don't know."

(Carer)

In terms of the service pathway little was understood about what would happen next or how long the process would take, despite the urge for seeking help being to 'catch it early'. Memory services were said to have offered little information about the assessment process. Apart from being tested, little else appeared to have been retained from the appointments.

Other than appointment letters, there was no contact from the memory service between appointments and some participants described waiting two or more months for their follow-up or diagnostic appointment. This waiting time was a time of great uncertainty and worry for people. There was little feeling of people being held in the system and cared for. Participants experienced little feeling of support at this stage and it seemed expectation moved to the belief that questions and support would be there at the end of the process. Participants in one service were told that they could always call:

"Because they can't until they're a hundred percent certain on ... 'cause I mean, it's like every ... everything else. You goes to the doctors and until you've had some form of examination you can't tell you exactly what's wrong with you ... Yeah ... So, you know, I mean, we accept that and ... we've got the phone number and they've said, like, you know, 'Anything you want, phone us up.'

(Two carers)

At appointments there was often time for questions, however mostly people did not know what questions to ask or what information they might need:

[Interviewer: "And would you say all the appointments with the different professionals that you've seen, the doctor and the people at the memory service that you've had enough time to ask questions or discuss things?" ... "But I don't know what questions to ask."

(Carer)

In terms of process some of the important elements remembered and described by the people in the research were practical and physical rather than about the medical process. For some, the venue for assessment was difficult to find, for others it reminded them of previous family members who had been unwell in the same hospital. These kinds of situations may be unavoidable, however it is important that they are recognised and people are supported with what may be an even more distressing encounter. Other participants referred to the way the seating was arranged with problems encountered when the doctor directed the talking to the person with memory problems, and it was felt they didn't understand, but equally there were difficulties described when the person with memory problems was not fully included.

For many participants this notion of catching something whilst in its early stages sets the context in which help is sought:

“To me the earlier you catch something, the better chance you’ve got of slowing it down. It’s no good in, like, six months’ time when it’s got a grip, there’s no slowing it down then, it’s too late.”

(Carer)

Some participants described the process as moving along without much delay, and one participant was able to compare it to a previous diagnostic experience for their other parent which took far longer. They saw great improvements in the service and declared it ‘faultless’. For many others the waiting between appointments for results and explanations was a heavy burden in the process:

“I have no idea how long the process will take ... because we don’t know, what the waiting times for these things ... so I don’t know, we just wait ... that’s why they call us patients isn’t it?”

(Carer)

“very distressing ... you get disillusioned. It’s like I said to my friend, you can be in a room full of people but you’re still on your own.”

(Carer)

“We’re still waiting for something to happen. Because they reckon early diagnosis don’t they and then they can do something and try and hold it if that is the case. Give you something to slow it up a bit. But we’re still waiting.”

(Carer)

Each memory service has clear protocols for the diagnostic pathway. Although services are very busy, it was not clear if this information was given to participants or not. Sometimes people were waiting after they attending their scan and they were uncertain who their next appointment would be with – the GP or the memory service? It is also possible for assumptions to be made during the waiting time, one carer said *“no news is good news”*. There was no sense of people being ‘held’ by the memory service on this difficult journey. Not everyone will go on to receive a diagnosis, and for some the journey will be longer because there is a more complex assessment required for diagnosis or because of other health conditions.

In addition, information about the complexity of a diagnosis was not known to the people in the assessment process and the focus during interviews was on the experience of waiting. It seemed there was no preparedness for the waiting or any sense that they were being cared for by a service whilst they waited. Yet people waited because of the diagnostic quest, because they wanted to find out what the matter was or to be reassured that it was not anything to worry about:

“It’s just the not knowing if it is something that’s wrong with you, or if it is just forgetfulness.”

(Person with memory problems)

5.5 Seeking understanding

One would assume that participants who received a diagnosis of dementia were likely to have a better understanding and more knowledge of

'dementia', 'memory problems' and so on, and feel more confident about discussing this knowledge, asking appropriate questions and accessing the right sources of information. Participants, however, did not feel adequate information had been provided (see Chapter 7) and felt less reassured by the opportunity to ask questions. Some said they were unsure what more could be asked at different stages of the diagnostic process as they were unsure what was coming next (see above 'Being tested').

For most participants, carers assumed the more proactive role in the dyad. This role extended to them identifying change in their relatives, recognising the significance of it and reporting it to services in order to seek help. This was also reflected in carers' responses that demonstrated their tendency to seek further information about the condition, devising and using a variety of coping techniques in order to help their relative manage the condition on a day-to-day basis and particularly with medication, in terms of administering it regularly and ensuring the quality of the drug prescribed:

"My next question is when I actually go on the 18th (day of month), because I don't actually know much about the drug, somebody said, oh you want to be careful because some drugs are experimental and blah and blah, so I want to make sure, I don't want any experiment ... I know it might sound awful but I don't want any experimental drugs. I want a drug that's sort of been tested and proven, I don't want any, you know ... because she's got enough problems without adding to them.

(Carer)

5.5.1 Sources of knowledge

Information from services was not the only way participants gained knowledge. Participants described a variety of subtle, mostly unintentional, messages picked up at times of encounter with services which enabled them to develop their knowledge of the condition further. For instance, one carer reported on their experience of receiving a diagnosis of dementia at the same clinic which also housed a day-centre for people with fairly advanced dementia. The appointment was delayed for five minutes, during which time this carer and her relative waited and watched all the day-centre clients leaving. It was clear they incorporated the level of impairment they witnessed as knowledge of what deteriorating dementia would be like, and receiving the diagnosis five minutes later had a profound impact on them:

"I think it is a pity that you do meet the poor ladies and men who are taken care of daily at the hospital. I mean obviously that's what the hospital is for. But perhaps a different suite. I don't know. It was hard. That was awful. We watched them crossing ... and bless their cotton socks, they are beautifully cared for, and the ones that are slightly aware seem to be happy, but some of them ... my mother used to look at people like that and say, 'you can live too long', and I used to jump down her throat, but she was right. She was right. They are no good to themselves, never mind anybody else. But the rules of society being what they are we live with it. But that's it though. There is no joy in their life. Don't care what anybody says, there is no joy. And we sat and watched all of that and then five minutes later, bang" [referring to receiving the diagnosis].

(Carer)

Another source of knowledge came from past experiences of someone they knew with dementia or previous experiences of caring for a relative with it.

These experiences appeared to be a double-edged sword as, in some cases, they highlighted to participants the necessity of contacting services for support but also emphasised increased care needs at the end of life of the person with dementia:

“And of course our experience with my friend was very fast, we’d been to see her a few weeks ago and she didn’t know where she was, she was almost in a ... not in a padded cell but it was terrible, totally out of this world, but she didn’t know. She’s totally at peace; she doesn’t know where she is or anything else”

(Person with memory problems)

Ingrained public perceptions also influenced general knowledge of dementia that participants demonstrated. Once again, public knowledge appeared to be a double-edged sword, as it resulted in triggers for help-seeking in some cases, but also resulted in negative perceptions of the condition:

“You see my mother had Alzheimer’s and it was horrible, she had the best brain ever my mother. She could have her shopping in her basket, reckoned up before it even went through the checkout, phone numbers straight there, she had a fantastic brain my mother she was dead brainy and she got this blooming Alzheimer’s and it was horrible”

(Carer)

Some carers, however, discussed the objectivity that was required when watching or reading any public health messages and trying not to get too influenced by the inherent negative messages:

“The downside is having seen docu-dramas where people have it and it gives you the really awful side where they go wandering off in the middle of the night and don’t know how to get dressed and get lost and dah dee dah and so that’s the scenario that I want to not really know about at the moment. We’ll cross that bridge if and when it comes to it.”

(Carer)

5.5.2 Understandings of dementia

Different understandings of dementia and Alzheimer’s disease were revealed by people with memory problems and carers. Some reported a medical understanding, primarily focusing on the degeneration of the brain and that things would get worse, gleaned from discussions from medical professionals as well as their own readings. Despite the focus on the medical model, participants talked in terms of it being their bad luck to get the disease, highlighting perhaps their inability to identify any predisposing factors of the condition:

“Well I think it is a degeneration of the brain isn’t it, and it just gradually gets worse and worse, I think, is that right?”

(Person with memory problems)

Participants also reported being confused by the number of messages from the media about the condition and the different use of terminology. They found it challenging to identify and understand the differences between words used and, in some cases, this confusion may also reflect the lack of clarity provided by professionals during the diagnostic process:

“It’s just that, you know, there are so many people are saying that it sounds like short term and then others think it’s Alzheimer’s and I don’t know what the difference is.”

(Carer)

A large proportion of participants perceived dementia and Alzheimer’s in terms of extreme scenarios. Their descriptions of the condition included what they felt was unfathomable behaviour. Most of their responses reflected reports of their friends or family who had also had dementia and included words with high emotional content such as ‘bizarre’, ‘horrible’ and ‘faded away’:

“And whilst he was off work for six months he started with dementia. And probably because he’d always worked hard, long hours and what have you and he didn’t live very long, because he just got it really, really bad, and just faded away. It’s horrible isn’t it when you think about it. It’s bad enough to die anyway but when you’ve been a clever person like he was and then he didn’t even know his name. But I know quite a few people like that that are retired from work and started with dementia and one of my friends, her father, he was a company director and he started losing the plot a little bit, and I think he was taken into [name of care home] at one point. He was a very, very kind gentle man and when he got into [name of care home] he (injured badly) a member of staff. Because he’d got very aggressive. Before it got to that stage though I remember her saying to me, ‘I don’t know what’s with my father but he keeps hiding pens, all the, just biro pens, hiding them down the back of the settee’ and silly things like that. It was really, really sad.”

(Person with memory problems)

What was most apparent in the way participants talked of their understanding of dementia was the level of strain it would place on carers. Carers discussed this in terms of their future fears, while people with dementia talked about it more neutral, abstract terms and not always in relation to themselves. When people with dementia equated the scenarios to their own condition, they were more likely to cloak their conversation in positive terms and adopt psychological coping styles to come to terms with the condition:

“I think the people that I have known with brain damage of whatever kind; I know I’ve only known two, possibly three, have been quite serene. It’s not them that’s been affected, it’s been the family that’s been distressed, which must be awful, especially in the last stages I would imagine. I don’t know about the end, I imagine it’s different for everybody. But I don’t know. I mean what do you do about it? Why think about it? Apart from taking the medicine and doing that you’re told, there’s nothing that you can do about it; what will be, will be.”

(Person with memory problems)

The future role of the carer was also seen in terms of the battle with services that they were likely to face in order to receive good care for their relative. Once again this was based on past experiences of caregiving, but perhaps reflects an underlying assumption that services cannot be trusted to support people with dementia well and that carer involvement is vital in order to ensure that support happens effectively. In the extract below, the participant is discussing a friend (X) who cared for her husband in a care home (Y):

“And X said this will not do, and she searched, she went to endless residential homes finding the right place and the hospital ... because I went with her on the day that they were testing Y once, at that same hospital... it was the physiotherapist that were trying to make him stand up, which he couldn’t do, he was a very heavy man, and he couldn’t stand up out of his

wheelchair, and I knew at the outset that he wouldn't manage to stand up on his wheelchair, the way they were doing it, and they said to X, 'he will never walk, he will never manage a wheelchair on his own' and he did, because X got him in the place where he needed to be"

(Person with memory problems)

5.6 Outcomes of information

5.6.1 Perception of support or the lack thereof

Participants in this study described receiving support and information from services. Most participants reported on verbal information that was given to them at the time of assessment and diagnosis, with time at the end to ask their own questions. Some appreciated this and felt reassured that the doctors were there to speak to anytime they wanted:

[Interviewer: "And did you feel you were able to ask as many questions as you liked?"] "Yes, she said, she said 'if you want to ask me anything, ask me' she said, 'I am in the office upstairs so come drop in anytime you like', oh yes she did, she is very good."

(Person with memory problems)

There was a mix of participants who had been seen in their own homes and those who had been asked to visit clinics for appointments. Being assessed and provided information in one's home appeared to result in more positive outcomes as participants described feeling relaxed and more reassured with the doctors' presence in their "own territory". This is likely to have resulted in better information processing, greater confidence, more reassurance and a generally positive outlook about memory problems and caregiving:

"Because you feel more relaxed when you have got a doctor in your home when you go to these other places, offices and that, you – it is a bit hard, but when Dr X comes here, and he is a young fellow as well, and he is quite you know, he came by bike actually the first time [laughs] keeps you fit, and the second time by car."

(Carer)

All participants appreciated face-to-face contact that originated from services. People expressed diffidence with initiating contact and ringing up doctors for questions and help. Most said that they would have appreciated services contacting them regularly just to ensure that things were stable:

"I think it would be a good thing to have someone visit on a monthly basis or something just to keep an eye, yes. Because it is difficult to always reach out because you have so much to do."

(Carer)

Perceived support also appeared invaluable to participants. This included professionals who had left a telephone number and asked participants to call with any queries. Although most participants said that they had never done this, the fact that the doctor had seemed approachable during service encounter reassured them of the support they could access:

[Interviewer: "During these appointments with the doctor did you feel you had enough time to discuss things?"] "Oh yes, yes. When he came the second time he didn't stay for long, but he did give us a diagnosis what had happened and what it was and who he was going to get in touch with, and that was all we wanted to know really he couldn't do anything himself, but he

did say that any problems at all you want to know get in touch with me, I will you know, if you want to get in touch with me.” [Interviewer: “So you felt like you could always call him up?”] “Yes, yes. He seemed busy but very kind, I could just ring him now if wanted any help or information.”

(Carer)

5.6.2 Limited knowledge generation

All information does not necessarily assimilate into knowledge and a prominent distinction emerged between the information that professionals gave to participants and the knowledge acquired from it. It appeared that following encounters with services, participants were given information, usually in the form of reading material, leaflets and websites that could be accessed. Some participants appreciated this support and developed it further. The majority, however, found other barriers that prevented them from using this information in a constructive way to develop their understanding or to make their own plans. The information given was described as generic and relevant to every situation, making it challenging to choose between options and identify which suited them and their situation best.

Carers described a range of other personal problems, not always related to their relative’s memory problems and they felt stretched with everything they had to take care of. One carer complained of not having the time to read all the information sheets given to her and struggling to make a choice between all the available options. She said more specific information would have been beneficial, as would have someone to briefly talk with through the various choices:

[Interviewer: “Have you been given any advice about how the future might be and what plans you might need to make?”] “No. No. The thing is I was told that I should get some sort of papers signed, erm, but as I said, somebody said go to the website and download it, I haven’t really done that, I mean I e-mailed her back, the lady who told me to do this in the first place, you know from what’s it place, and just said “What exactly do you want me to do? Which form?” you know, and I haven’t had access to it since then”

(Carer)

Some carers were appreciative of the support services had given them in the form of information, but felt that it was challenging to involve their relative in the recommended readings. One carer, for example, found the information folder supplied by the memory service very interesting and enjoyed reading it with her husband. However, his sense of contentment, which may have reflected a form of avoidance on his part, proved to be a barrier for any further education or knowledge generation:

“And well everything was in there, you know, it’s quite a good folder that. It was very helpful I found. Because I used to sit beside him and they went through it word for word and I read it then, you know. But it was like more for him, and I’d say, you know, “you should read”. “No, no, I’m quite happy with the way things went.” I don’t think they could have done much more. I found they were very good.”

(Carer)

5.6.3 Greater fear

Limited knowledge generation was reflected in more negative attitudes to the deterioration of dementia and the demands this could place on future caregiving:

“I mean will my memory go altogether and I go funny in the head if you know what I mean? I don’t want to go rambling around and getting lost and things like that”

(Person with memory problems)

Although most participants preferred face-to-face contact when receiving information, some expressed how crucial it was that professionals got the timing of this information right. One carer had the experience of receiving too much information about deterioration at the time of her relative being diagnosed and she did not feel that this had been appropriate. She felt that this reflected the ‘tick-box’ approach that services might sometimes take when giving information in an effort to provide transparent communication. The poor timing, however, resulted in poor knowledge generation for this participant:

“Yes, we were invited to express concerns and satisfy curiosity, but it’s a blow. You are absolutely punch drunk. You don’t think straight. We made a lot of jokes, but then that’s what you do when you’re nervous. Maybe that was misread by the professionals. Maybe they thought oh, they’re alright these two, we’ll let them have the rest of it: make your will, put your affairs in order, arrange a power of attorney, don’t save your money, spend it now, if you’re going abroad do it now. You don’t want to know all that. I think it was good advice to do it now. But I think it was impractical. Well, it was insensitive to do it when it was done, but they’ve got a job to do: right, that’s another box ticked, we’ve done that bit, in the nicest possible way.”

(Carer)

Similarly, the consequences of receiving too much information too soon were identified by one participant who following a visit to the day care centre had been left to consider that may be their fate, evoking fear and anxiety about what the future might hold:

“I think the down side of going to the X [day centre] is seeing all of these very old ... probably the same age as me ... because I am old ... but seeing these disabled people and think ‘oh God is that, you know, going to be the future?’ It’s a bit sort of ... bringing reality up a little bit close, I think.”

(Carer)

In this chapter we have described the experience of participants within five transitions: ‘Internalising dialogue’: the self awareness that something may be wrong; ‘Confirming positions’: the seeking of confirmation from those closest to the person with memory problems that help is needed; ‘Seeking expert advice’: disclosing position to professionals (usually GP); ‘Being tested’: undergoing diagnostic investigations and receiving results; and ‘Seeking understanding’: from professionals and other sources. In the next two chapters we explore in greater detail the expectations and hopes that participants had about the future illness pathway and satisfaction with the services received to the point of diagnosis (Chapter 6). In Chapter 7 we focus on communication between participants and the professionals with whom they had contact.

6 Expectations and experiences of memory services

In Chapter 5 we focused on a number of transitions for the person with memory problems during the early stages or recognition of dementia. A range of experiences of people with memory problems and their carers was explored and in this chapter we focus further on expectations and user views of memory services.

6.1 Expectations and hopes from services

People with memory problems and their carers approached services with a number of expectations of the support that services would provide. Expectations of support from services appeared to impact on reported levels of satisfaction with services, long-term management of the condition and attitude towards the future, which are discussed below.

6.1.1 'Early intervention', specifically medication

The most prominent reason given by some participants for accessing services for their memory problems was awareness of the need for early diagnosis. Media and public health messages seemed to influence public perceptions and most appeared to expect a speedy referral and assessment process, followed by 'early intervention'. The possibility that this may be a longer process than anticipated had not been discussed by the memory service or recalled and, alongside disappointment, participants regularly worried that their memory was getting worse while waiting for appointments:

"We're still waiting for something to happen. Because they reckon early diagnosis don't they and then they can do something and try and hold it if that is the case. Give you something to slow it up a bit. But we're still waiting."

(Carer)

Furthermore, there was the added expectation expressed by most participants that, following a confirmed diagnosis, some form of medication or treatment to control or stabilize the condition would be offered. Those who accessed services early appeared not to consider the possibility of not receiving any support or treatment. Participants did not describe the concept of eligibility being discussed by professionals and they appeared confident that, if there was a medication for the condition, they would receive it:

"All we want is a diagnosis and either they say 'yay or nay' with some sort of a tablet or medicine. If it is Alzheimer's they do have things to slow it up don't they, slow the progress".

(Carer)

Those who accessed services early also had higher expectations of medications; in some cases, carers appeared to be more proactive recommending the treatment to their relative, even if the latter expressed reluctance to take the tablets:

“The downside of the medication was perhaps heart problems but they would monitor it, erm, ‘did he want to go ahead with the medication?’ and I said to the doctor ‘if it was your dad what would you say?’ He said ‘well I can’t say, you know, it’s ... you’ve got to make the decision’. So [person with dementia] said ‘oh I don’t like taking medication’, so I said ‘X, you’ve got two choices, either get worse or take the medication’. So I said to the doctor that I really think that X needs to go ahead with the medication. [He said:] ‘Actually I think you’ve made the right decision’.”

(Carer)

Those who accessed services rather later, on the other hand, appeared to be more nonchalant about receiving medication, although they also tended to be the group that were more likely to receive a prescription. This reluctance may have been because of their limited awareness of the condition and medications available, as well as a consequence of the likelihood that they may have been coping for longer with the condition without support. In some cases, they were less aware of available support and hence had lower expectations:

[Interviewer: “So at the moment do you know whether she [wife with memory problems] is going to get any treatment or not?”] “No, we don’t know that, not at the moment, no.”
[Interviewer: “Do you have any opinion about that, whether you hope she will get it or not?”] “I haven’t, he (doctor) asked about that, he said, “Would you like to have treatment?” I said “yes, if there is treatment going we should try it, if it does help at all?”.”

(Carer)

6.1.2 Expect accurate, timely diagnosis

All participants appeared to have limited understanding of the complexity of the diagnostic process. Interviews at Time 1 highlighted the level of anticipation with which participants waited for results from scans, hoping these would be definitive and that a confirmed diagnosis would be given. A large proportion of these expectations were expressed by carers. A tentative emotional expression inherent within these narratives was the expectation that a confirmed diagnosis would bring relief as the ‘limbo-land’ or liminal phase would have ended:

“So I suppose when the scan’s done it ... because if there’s nothing there, like, then it is ... at least you can say, well, it’s like, you know, it’s nothing.”

(Carer)

Some of those who accessed formal services earlier appeared to be seeking reassurance that their memory problems were not serious enough to require a diagnosis of dementia or Alzheimer’s disease; the search for a diagnosis was, therefore, triggered by a need for their anxiety to be quelled. Often these participants had greater knowledge of dementia and Alzheimer’s disease and the consequences of a diagnosis. Therefore, they described expecting services to be best placed to make an accurate

diagnosis of the presence or absence of dementia and for them to be reassured:

“I just want a name. I just want an answer, I just want to know why these things are happening to him and hopefully it’s not anything like Alzheimer’s and stuff. I just don’t know because he’s not pretending. I know that he’s not putting anything on. I mean he’s not that sort, you know?”

(Carer)

Participants seeking reassurance were looking to be ‘held’ by services and believed that a confirmed diagnosis and having a name for it would help ease the confusion and enable them to deal with the consequences. For instance, one carer was prepared to look into the possibility of buying her own medication to help with the consequences of a diagnosis of Alzheimer’s disease. Their experience of obtaining these medicines had always been met by the response that they needed the diagnosis first and hence expected that a simple diagnosis would ease current anxieties:

“At that point, we said look, we want a diagnosis for my mum, because we knew that the drugs were ... were better, there was a better application of drugs with an early diagnosis of Alzheimer’s. Now ... and because my sister, she’s married to a millionaire so, erm, she said, ‘Look, I’ll buy the drugs myself and we’ll give my mum the drugs.’ So we sort of like ... we said ‘look’, to the GP, ‘look, we need a diagnosis so we can get these drugs for her’.”

(Carer)

Those who accessed services later appeared less diagnosis-focused and more concerned about the type of help that could be offered. In a few cases, they had already accessed other sources of support, for example, speaking to the bank manager about finances:

“The only thing we – everything is in both our names – so all the banks (accounts) are in both names, every other thing that we had to deal with; lately it’s the rent, this place is rented, direct debit, insurance is on direct debit, council tax on direct debit, so everything goes, what we have to pay regularly, it is on direct debit anyway – so that is all sorted – but I have done that on purpose for myself really– because if I go first ...”

(Carer)

6.1.3 Expecting ‘closure’

It also appeared that participants expected the anxiety and the waiting to reach a ‘conclusion’ at the end of the assessment process. They discussed the context of the diagnosis as being an end to the process and speculated on the relief they expected the conclusion would bring. This expectation was much more apparent amongst those who accessed services early, compared to those who came to services later:

“But I also think it’s hard and stressful for mum sometimes because I think she’s concentrating really hard on trying to not be forgetful as well. Which is a lot of stress to be under which I think then can make it worse because you know yourself if you’re under stress then quite - it’s easy to forget.” [Turning to her mother] “You’ll be glad when this is over won’t you? I think she will, the scans are finished and here’s tablets or two tablets you’ll feel happier then won’t you?” [Mother with memory problems: “Yes I will.”] “That you don’t have to keep going to the hospital.” [Mother: “I mean if they come up with a diagnosis for it, I’m not going to be back crying again like I was.”... Carer: “No no”. Mother: “Because I’ll just be

relieved. They've found something and there's a possibility they can put me on a different road sort of thing."

(Carer and person with memory problems)

6.1.4 Efficient, person-centred service

Perhaps not surprisingly, all people with memory problems and carers approached services with the expectation of being seen relatively swiftly and expected an efficient service, involving person-centred care principles. Expectations of efficiency included limited waiting time, good communication between services, high-quality assessment and diagnostic processes, and being assessed by the senior-most people in the service:

"I mean he's on ... he's on Metazepine for panic attacks. He's not had panic attacks. I've told them all the time, them seizures weren't panic attacks and he's still on them. And I says to her 'well now that this Lewy Bodies has been mentioned', I says, 'does he still have to take these Metazepine?' 'Oh well I think so, just for now.' I'm thinking, well if it is Lewy Bodies and there's a man who's the top one, why has he not interviewed my husband and seen if it is Lewy Bodies, you know? It just seems like limbo again.

(Carer)

Waiting for services to respond was heavily criticized as participants expected to receive information and letters sent at regular and appropriate times (see Chapter 7). Some described this period of waiting as a continuation of being in limbo as participants felt unable to move forward without some of this information:

"But we need to be able to talk to somebody, and all we can do now is wait for Doctor X to shift themselves to write this letter. Now, I don't know what the problem is. I don't know why it's taking so long."

(Carer)

Throughout this process, descriptions by participants reflected a relatively passive role within services and a lack of awareness of patient's rights. This lack of empowerment was exacerbated by limited clarity of the assessment and diagnostic process, rendering participants unable to know what to expect and unable to state their needs and requirements:

"No because I hadn't a clue what this was all about until it was referred by Dr Q so really it was a little step into a system which I took on and did what I thought was right in accordance with what they were saying."

(Person with memory problems)

Others described expecting services to provide them with information, support and reassurance from the time of first encounter and often found the process long, confusing, unclear, non-confirmatory and not providing the reassurance they hoped to get. Services provided no information about what the likely outcomes may be, nor did they provide any information about how long the process of diagnosis may take. Alongside growing anxiety, this tended to result in a building up of expectations of the outcome of the diagnostic process and consequently greater frustration:

"When Dr X [consultant] said, 'we will send the prescription to your doctor, to your GP', we said, 'well, that's alright because I have got an appointment with my GP next Monday'. Which

I had made expecting them to have forwarded the report from the scan people to the GP by that time. Well it's taken a lot of chasing about to try and get that, and I still don't know what the result of that was. I was reduced in the end to phoning the hospital and speaking to the radiotherapy unit, and spoke to the man who operates the machine. And he said that the report from their department was sent to Dr X at the memory service on the [date in November]. And it's now the [date in February], and I'm still no wiser."

(Person with memory problems)

Participants described feeling confused about the diagnostic process, health outcomes from likely diagnoses and the options for support. As a result of having to manage daily life, they felt that this information should be more forthcoming from services itself and that it was the responsibility of services to reach out to clients:

"Because you're so busy dealing with life with it, with the problem, with the family and everything that you tend to forget that you've said that, you've done that and I do like that ... I think they should give us something back really. Because I've not heard from the memory service place at all, in fact the GP receptionist said, 'you should phone them up for the results of the brain scan', but I don't feel as though I should be doing this really."

(Carer)

6.2 Expectations and hopes from future

6.2.1 Expectation of condition

Although those who accessed formal services early appeared to have greater awareness of their condition, after the assessment and diagnostic process, most were unclear about the disease trajectory and when things would start getting worse. Alongside expecting early diagnosis, intervention and treatment, this group hoped that services, adequate support and appropriate treatment would allay some of the anxiety and lack of clarity experienced during the assessment process. Participants wanted greater understanding of the disease process, specifically about when it would start getting worse. Most of the anxiety about deterioration was expressed by people with a diagnosis of dementia and there appeared to be a degree of watchfulness inherent within their narratives:

"And I think that's one of the problems, is, when does it start and what at what stage does it get worse?"

(Person with memory problems)

Some participants expressed concern that it would be challenging for them to identify signs that their condition was getting worse and that it would require an external source, such as family, to help identify any change in their memory. A state of equilibrium also seemed to precipitate worry as services seemed unable to respond to queries about deterioration:

"I worry a lot really, I'm afraid and I don't know whether will get worse. Do you know? Yeah, I worry about it."

(Person with memory problems)

Carers expressed greater concern about increasing care needs and the impact this would have on their lives and they had higher hopes from

medications. Proactive carers, keen to seek information for themselves, felt held back by services not providing adequate information about the name of the condition. This made them more anxious as they were unable to access what they felt was adequate and appropriate support. As a result of this, they felt let-down, confused and consequently anxious about the future.

6.2.2 Expectation from medication

Participants had high expectations of what the medication would do to the deteriorating condition. In some cases, these expectations were developed in conjunction with the memory service and participants appeared aware of potential side-effects. Mostly, they reported that they expected medication would stabilise the condition, which also reflected their awareness that medication will eventually be withdrawn:

“Erm ... [consultant] indicated that, well Dr X [consultant] and Y [nurse] indicated that the tablets would have a two year span, that’s right, of holding it in abeyance and then after that, as Dr X said, nature takes over. Erm ... so from that point of view, they explained that.”

(Carer)

Despite knowing the short-term efficacy of medication, carers of participants who accessed formal services earlier were keener to try the drug than those who accessed the service later. One participant reported that they were willing to pay for it themselves if they were ineligible for it from the NHS:

“And certainly, I know, which I have since ... somebody at some stage, if there’s medication, like, Aricept, I think it is, is it something that, that you would take at a certain stage? I would willingly pay for that irrespective of the cost. Even if it only kept one in that situation for, say, a couple of years.”

(Person with memory problems)

Perhaps as a consequence of the hopefulness about the impact of medication, those who accessed formal services early were very much aware of the potentiality of things getting ‘worse’ in the future. One participant demonstrated avoidance of knowing too much more about the severity of her condition. This participant also wished to know ‘what happens next’ in terms of the support she and her husband were eligible for, and she repeated this wish frequently during the interview:

[Interviewer: “How do you find your memory problems affect your life on a daily basis?”] “No it doesn’t affect me just now because I am taking Aricept so it doesn’t affect me.” [Interviewer: “Did she [consultant] tell you what might happen next?”.] “No she didn’t.” [Interviewer: “Would you have like that?”] “Well, I don’t want to know if I am getting worse.”

(Person with memory problems)

Those who accessed services later, and who were taking medications without side-effects, were mostly content being on medication and felt reassured that it was stabilizing their condition. However, if they experienced any side-effects to the medication, this group was more nonchalant about giving it up and managing the condition for themselves:

“As I said they offered the tablets and we said ‘yes, we would like to try them’. And in the beginning it seemed fine, but then my father, he started to have other problems, so he couldn’t

handle it, we decided to speak to the doctor and said 'no'. It just didn't agree with him, that's the thing, he just said he didn't feel the same anymore so he didn't want to take them. And anyway his memory wasn't so bad so it doesn't seem like it was doing him any good, if you see what I mean."

(Carer)

6.2.3 Expectation of emotions being contained

A proportion of people with memory problems demonstrated that receiving a diagnosis of dementia did not in itself ease any anxiety as the person with the diagnosis seemed to be, once again, thrust into confusing and worrisome territory in terms of deterioration and when they might get 'worse':

"It's just all happened at the wrong time so I don't know where I am. It is a bit ... I read that [letter confirming diagnosis] and it's a bit depressing because I knew I was going to get worse, they've been telling me, but not so much worse that everybody says, you know, I'm going daft or whatever but it's certainly much sooner than I expected and when you're worried you're not yourself. You don't, you know what I mean?" [Interviewer: "Do you feel worse?"] "No. Of course no! Not a bit!"

(Person with memory problems)

Carers appeared to cope better emotionally when they knew the diagnosis and felt more confident about envisioning future caregiving responsibilities and taking these on. For some help-seeking may be care-driven in order that future deterioration may be managed better. Some carers faced the future with a 'cross that bridge when we come to it' attitude and felt that speculating and worrying now would be unnecessary. They took the approach of 'a day or a week at a time' and dealt with current issues and challenges. This enabled them to live in the moment, cope on a daily basis, alongside ensuring their relative's daily needs, well-being and care were addressed:

"It's ... it's made me realise, I suppose, that the tables have turned, it's me looking after my mum now, and not that I'd have it any other way because I wouldn't, you know, and as long as ... I mean, [husband] and I have talked about it; what will happen if mum gets any worse and she can't look after herself; and we both said, 'well obviously we'll cross that bridge when we come to it', but we'd like to be able ... she's very... she's safe in her own environment now because the big thing with it is mum won't go out, so that in itself is great. She goes out in the back to feed the birds, so we make sure we've got buckets of bird seed and everything for her and she's happy with that, but that's as far as she goes. So we know in that ... at the moment we know everything is taken week by week or whatever."

(Carer)

6.2.4 Expectation of being able to rely on shared social network for practical as well as emotional help

A proportion of participants demonstrated their independence through the social interaction and social roles they maintained. Most said that they had shared their diagnosis with their friends and wider family, although a few participants indicated that, following diagnosis, they had gone into a process of withdrawal for a while. Some participants were accessing their local Alzheimer's Society and strongly appreciated their support in giving

them face-to-face time, being approachable, social contact with others in the same boat, as well as being given the emotional space to express themselves. Both carers and people with memory problems said they benefited from the social contact:

“Yes, and it was a get together, there were different people in the position as we are, and they have tea and a chat with one another and it was nice, very nice in there. ..they have done it all up and it is quite smart inside now, nice and bright and cheerful.”

(Carer)

Participants with extended families appeared to benefit from considerably more support than those who lived alone. They could rely on them for local chores, help with advice, and the perception of support from other family members enabled both people with memory problems and carers to feel positive about caregiving. However, some participants betrayed feelings of reluctance to call on extended family, like adult children, as they had busy lives to lead:

“Like I say the kids are good, I mean they’ll say we are here but they’re not they’re working, you know my daughter works at [name of hospital] and my son’s at [name of firm] and X’s just started a job and she’s at college, Q’s across there so you don’t want to have them bothered you know they had time off work when I was bad, I felt awful, you know they were helping me everyday, staying off work and you know they gave them compassionate time and I says to them, ‘look just go back to work and I’ll persevere’.”

(Carer)

Participants in shared spousal relationships were more likely to manage change by continuing with life as normal. Some demonstrated a protective role towards their spouse by mitigating, as much as possible, the daily impact of the condition, as well as the societal impact of the diagnosis:

“I mean if it is Lewy Bodies we’ll all deal with it, the whole family will deal with it. And we’ll cushion X [husband] as much as we can, you know, from it. We’ll just take it as ... as he is that day, which we’ve always done. I mean we’ve always been there for him and you know he would never be put anywhere so ... it’s just like I’ve said all the time I just need people to listen and believe.”

(Carer)

There was a greater sense of shared togetherness in accounts of dyads where the participant with dementia appeared to be aware of the strains of caregiving and showed gratitude for the support they received. This shared understanding of the situation appeared to have positive outcomes as both shared the frustrations and tried to attain stability together:

“I’m quite alright with that because when you ... when you’re talking to your family, yes, they’re there all the time for you and you know we just act as though nothing’s happened.”
[Interviewer: “Have they made any comments or have they said anything to you?”] *“No. I mean my wife has, because, well she gets the brunt of it. If her ... if somebody says, er, phones up and I’ll say nobody’s phoned up, and then she goes on and redials.”*

(Person with memory problems)

6.3 Long-term management of condition

In order to cope with longer-term worry, participants appeared to adopt a number of coping techniques to manage everyday life.

6.3.1 Practical coping strategies

Those people with memory problems who accessed formal services later tended to have developed their own strategies and techniques to manage the impact of the condition on daily life. Within this group, people who lived alone were still more likely to have devised their own strategies, as well as demonstrating a high level of confidence in these strategies. One participant described her technique of throwing her keys on the floor of her flat so she could always see them. It is telling that, while other participants discussed keeping their keys in the same place every time, this strategy appeared to have more positive consequences as it was visually striking. Similarly, her diary method of writing down appointments was one she had full confidence in and when an ambulance came unexpectedly to pick her up, she was certain they had got the wrong day rather than doubting her ability to remember and record accurately:

“It [keys] is on a big bunch and when I go in I throw them on the floor so they are bright green I can’t miss them, they are always there, but if I hang them on a hook, put them in a drawer, on the dresser, in a coat pocket, I panic that I am going to be stuck all day, I can’t go out because I have lost them. But since I throw them there I am all right. Ever since I got locked out, not locked out, left my keys in there. A few people I know are doing that themselves now; they say, ‘we are always losing our keys’, they buy a band and throw it in the middle of the room [laughs]. I do write things down before I go out, I have a big diary, hospital appointments, like a couple of weeks ago an ambulance turned up, and the driver came up to the flat, and he said my name, I said, ‘no I don’t have an appointment’, he said, ‘well I have got you down’, anyway he went and I went to the big diary and I looked at the date, no appointment, because when I have an appointment I write it in the big diary and I slide the letter in that day and there was nothing there, so I wrote to the hospital and said I didn’t have an appointment and I know I didn’t because there was no letter and it is not in my diary, so they gave me an appointment three months later.”

(Person with memory problems)

At one of the study sites, participants described attending classes that addressed the issue of coping with memory problems. Practical strategies were discussed at this course and participants described using them when they returned home. These included establishing routine, writing things down on a board that was visible to the family, keeping an up-to-date diary and encouraging large signs around the house with instructions. However, participants demonstrated less confidence in the application of these strategies and greater scepticism in the relevance they may have to their personal situation, citing such statements as *“well it’s worked for so and so, it might work for me”* (Person with memory problems). This could be because these strategies had not been adopted naturally by them. Establishing these strategies, therefore, potentially required practice and was not always straightforward:

“I should write it down but the trouble is you can’t write everything down as you’re ... as you’re sitting and talking and walking around. It seems to be nearly the answer to what was

said ... But I'm trying to do, it's not easy really when you're haven't done a lot of reading, but I'm trying these things out naturally because I did know at the time that you will be coming back again, you know but that's ... that the thing I'm looking forward to, improving that way by trying to do something like ... like when my legs were weak I did these exercises knowing that these exercises did strengthen legs but nobody told me what to do I just I did them every morning for a good twelve month."

(Person with memory problems)

The downside to some of this emphasis on memory retraining may have been that some participants felt the need to remain constantly vigilant about their memory problems. For one participant, this extended to having a plan during spontaneous social interactions as well:

"I've got a plan, I don't like to be caught unawares in conversations, you know, if you're conversing with different people. So I've got to think ... because there's nothing worse than half way through a sentence, you say "oh my god, what's that, I don't know what's happening." [Interviewer: "So when you say you have a plan for conversations, can you say a bit more about that?"] "Not a plan as such, when I'm there, I've got to be very careful on the subject we're talking about. If it's a subject that I haven't got a readymade answer for, I've got to pull back off that and unless somebody will say 'what do you think?' Eh, I've got to take a chance then, you know." [Interviewer: "So you've got your own little strategies in a way?"] "I suppose so, yeah. I don't get caught very much."

(Person with memory problems)

Another participant, however, cautioned against being too vigilant and 'on-alert' all the time, highlighting the unpredictable nature of the condition and the value of accepting it and the memory loss and the difficulty of relying on any one specific strategy. He felt that he was likely to have taken things more in his stride previously but the diagnosis had made him cautious and watchful, which was not always helpful:

"And when we went to [abroad] we were delayed for a day and a half, that would have made a major difference to me before, now it doesn't, so I still would tend to worry about plans being made to make sure that ... I would want to take all safeguards, like going to [abroad] and those to make sure it went smoothly, whereas four or five years ago I'd make the arrangements, if it went wrong so what? So it's a tendency to be over cautious."

(Person with memory problems)

While written cues like diaries and calendars are typically seen as a source of support to people with dementia, some carers discussed these helping them as well. They reflected on the dependency on such a diary for official things, like medical appointments, as well as social events such as family birthdays:

"My diary, there, that's my lifeline. If I lost that I would be in dead ... dead trouble."

(Carer)

6.3.2 Emotional coping styles

People with memory problems were likely to adopt coping styles that managed the emotional content in their lives, such as their changing sense of self. Seeking contentment was the primary motivator for these sorts of coping strategies and most people with memory problems were keen to see the positives in their situation and thereby accept their condition. They

sought the assistance of their carer in most of these strategies, but some appeared to be conducted in isolation. Some emotional coping styles were conducted alongside other more practical strategies for daily life. Some participants focused on the positives and accepted their condition by looking at their lives as a whole and not merely on the present, resulting in a more positive outlook and perceiving greater contentment:

“Memory is ... I can’t help the way it is because there’s no use just thinking, thinking, thinking all the time, I don’t like that, erm, I haven’t actually missed anything, nothing at all so. Its going on and on just like that and my life is going on as well.”

(Person with memory problems)

Although the use of emotional coping strategies was more prevalent amongst those who accessed formal services later, perhaps as they had to manage with the condition without services for longer, those who accessed formal services early also made use of some emotional coping strategies. The positivity demonstrated by some participants, however, appeared to be tied to the hope that medication would keep deterioration at bay for as long as possible:

“It’s funny, X said to me last week, ‘you don’t seem any different to me, you know’ and I said, ‘well I don’t seem any different to myself’, I know, memory problems, forget little things, but I can remember my childhood, I can remember what I did at work, people I knew there but you know I understand it will deteriorate, just keep it at bay for as long as I can.”

(Person with memory problems)

Acceptance was a key feature in emotional coping strategies and people with dementia struggled with having to give up hobbies and activities they enjoyed in the past. However, motivated by the desire to remain positive, they focused on other aspects of their lives that gave them joy:

“I have to accept it don’t I, I would rather get on with life and enjoy what I can and if there is anything I can help anybody with, I mean it is a bit annoying not to be able to take responsibility for helping them, I mean when you are in your thirties or forties you – well for good causes – you could do a bit of voluntary stuff you know whatever that might be, but you are not much use in that way. No, no. I am very lucky to have such a happy life, and you know I sleep well.”

(Person with memory problems)

Acceptance was also derived from a sense of shared togetherness between the person with memory problems and their carer (most often their spouse). Being with their loved one gave people with memory problems a sense of security, a sense of confidence, faith in their preserved abilities, a more positive attitude to life and an ability to accept their memory problems and their condition:

“Well nothing happens next in as much as if there’s anything important, of course, I always have something to say about it, or we talk about it. And in turn I might not remember certain dates, as I said, in the future, for things happening. I can still remember our anniversary, and still remember X’s birthday. So I don’t get wounded for that, don’t get any troubles. And, other than that, I mean everything goes along very well.”

(Person with memory problems)

A sense of trust in professional services also impacted on the level of acceptance people with dementia demonstrated. This generally meant that participants felt they were in safe hands, well looked after and gave them a greater sense of confidence in themselves and an ability to accept their condition in a more positive manner:

“No, I go with the flow, I mean if you put your hand... yourself into the hands of somebody who is going to help, or think they can help, erm, hope they can help, I have been aware that my brain is not as sharp as it has been, but then you’re 72 and you think it’s ageing.”

(Person with memory problems)

6.3.3 Carrying on as normal and maintaining personhood

Carrying on as normal was highly valued by carers as a means of supporting their partner or relative with memory problems. Carers felt that in the context of limited amount being done to change the course of the deterioration, taking each day as it comes and carrying on as normal was invaluable. This was more commonly reported by spouse carers, perhaps as a result of their life being more intertwined with that of their spouse. Adult children carers, on the other hand, reported more severe disruptions in their lives, including visiting their parent more frequently, changing expectations of the future, and formalising plans such as a will and lasting power of attorney sooner than they had anticipated. Adult-child carers were more likely to take these disruptions in their stride by emphasizing that getting on with it, compensating for their relative, and looking at the bright side were necessary:

“I think the thing is though that you’ve got to remain really positive about a lot of this because even though it’s obviously horrendous for mum because it’s happening to her, she has got a supportive family. And there’s no way on God’s earth that me or dad would ever give my mum anything other than absolute top notch care, do you know what I mean? We’ll always be there to support her and help her with things.”

(Carer)

In the context of carrying on as normal, maintaining the personhood of their partner or relative with dementia was also embedded in narratives. Some carers felt this was a positive step towards minimizing the impact of the diagnosis and to maintaining well-being on a daily basis. Other aspects of maintaining individual personhood encompassed preserving the continuity of their relative by focusing on preserved characteristics and loving them for the person they had always been:

“I don’t think we said very much and when we came out I said to [husband], ‘look you are the same person now as you were when you went in so let’s live now not what might be, what can be etc., etc.’ And that was our general attitude; it still is our attitude isn’t it? We try to be positive about it.”

(Carer)

6.4 Role of carers

6.4.1 Maintaining independence

Maintaining one's independence despite memory loss was described by most participants as a guiding principle in their daily lives. People with memory problems were keen to retain their autonomy and carers were instrumental in supporting this in several ways. Some carers reported a reversal of roles (e.g. husband managing the meals instead of the wife) in order to prevent accidents, but manipulated the situation to preserve their relative's independence:

[Interviewer: "How independent is [your wife] at the moment?"] "Making teas, or coffees, quite happy, she gets the breakfast, we don't have a cooked breakfast, it is cereal and coffee and toast, she does that every morning and I will leave that to her, because I think she should do things like that as much as possible until, if she does anything unseen, then I will step in. I don't cook, we buy the ready cooked stuff from Marks or Waitrose and I deal with that in the evenings because she can't cope with time and the cooker and different temperatures."

(Carer)

Other carers tried to provide assistance without taking over a task but were watchful:

"But, no, I say to him, 'you write that cheque, fill that cheque in'. Because, 'for me eyes', you know, I make that excuse. So he'll fill the cheque in which very ... very seldom filled the cheque in, even before he retired it was a case for me, you know, and that. And I get him to ring through on the phone for his car tax and all of that. So that he's got to use the numbers and do all that, and he does it. That's no problem, you know. So at least he's not sort of forgetting that."

(Carer)

Ensuring the safety of their relative or partner appeared to be the guiding principle as carers negotiated tricky situations of their relative or partner being a threat to themselves. In some cases, despite the fact that these strategies appeared to take away individual autonomy of the person with dementia, carers felt adoption of these strategies was the only way they could cope and ensure their family member's safety:

"She was having the bread in the bread bin, and I don't know what she was doing but it kept going mouldy so I said I'll just bring a couple of slices a day, because she really only has it for toast in the morning, and we'd make sure ... and we'd got a toaster so that if she felt she could do it, she could use a toaster, but we'd make sure that everything's cleaned away, so that we know everything's alright, and we still find that she can ... we feel that she's doing her toast at night under the grill ... But it's so hard I mean I do most things for her, you know, and I sort out the bills because she's just no idea what they're all about."

(Carer)

Those who accessed services later appeared more likely to manage independently, especially those who lived by themselves. Some had other support systems in place, such as family nearby or were living in sheltered accommodation which appeared to give them a sense of security and confidence to be able to continue with their daily independent life as normal:

[Interviewer: "So how do you manage most of your affairs?"] "I do my own cooking, I have a bread machine but I haven't used it lately, and I do my own pastries, and now and again I cheat and I get frozen meals but at Christmas I won't cheat, oh no, I will have the real thing! [Interviewer: "Do you, are you hoping to be able to look after yourself in future?"] "Yes I don't think it should be too difficult, we have got a pull (alarm) cord anyway."

(Person with memory problems)

Some participants drew solace about their own abilities when they reflected on things they were still able to do. One participant with memory problems was quick to point out that her condition was probably mild as she was still allowed to drive her nieces in the car. She confessed to being extra careful in other areas of her life, but attributed this vigilance to ageing:

"I take comfort from the fact that if it was doubtful, they would not let me drive a motorcar with the little girls in. And that's not happened yet." [laughs]. "And when that does happen, I don't know, I'll surrender my license. But things like that, I don't think are a problem. As I say, I'm very careful crossing the road these days, but that's because the traffic goes so fast, but perhaps it doesn't go any faster than it did when I was just 60."

(Person with memory problems)

Few specific attributes could be identified in relation to participants whose narratives reflected fear of their relationship with the caregiver deteriorating in the future. People with dementia who discussed this were more likely to describe poor past relationships, particularly marital discord. They were sceptical of the consistency of the affection and worried about growing dependency on their partner and the potential of moving to a care home. One participant, in particular, described her relationship with her husband in a formal way: she referred to both as tenants in their current house and was anxious that she should not be 'bossed around' when the time came for her to move to a care home. She also hoped that her daughter would stand by her side, reflecting perhaps her scepticism of her husband doing the same:

"Rather want to be independent as long as I can so I suppose there will be a certain amount of friction when I really have to hand myself over partly because we have always been joint tenants in common here and I sort of feel that he is going to boss me around, and I shan't take awfully kindly to that, but I suppose that is just a human relationship risk which is very common and people manage somehow to keep going. And I think, I hope, our daughter is alive to that and knows the sort of ... she is a very wise young woman and I have tried pretty hard, how can I put it, she was an only child you see and so not to try and play off the triangle thing ... in some ways she is much more like her father than she is like me."

(Person with memory problems)

6.4.2 Practical proactive approach and information seekers

In cases where carers felt they had not received enough information from services, they took a more proactive role with seeking information out through other sources, such as the internet. For instance, following the prescription of medication, more than one carer then followed this up by seeking information for themselves, commonly via the internet, regarding its tolerability, effects and side-effects. In some cases, this reflected participants' wish to be better informed and empowered in future consultations with the service:

“Well it was mentioned in the letter that she was being put on 5mg and the most you can go up to is 10mg and that’s...and I know that that’s for a mild and moderate...mild up to moderate Alzheimer’s and it was mentioned in the letter that mum’s was moderate. And I know that there are drugs over, for if it’s more than moderate, but that’s purely what I’ve read on the internet anyway. So really it’s like...it’s...I’m making myself aware of what’s available and I can ask the questions and I know that they would help and X [nurse at service] said to me, ‘If you’ve got any problems at all just ring,’ you know, so I know that I can, I can do that.”

(Carer)

Carers appeared to be managing change on a daily basis as well, mostly with regards to the impact of their relative’s memory problems but also with growing into the caregiving role as they accumulated responsibilities and described the necessity of having to remain vigilant. They adopted a more practical attitude to manage and support the daily life of their relative with memory problems. They sought predictability, routine and stability in their daily lives and described this affecting the well-being of their relative with dementia:

“Well there has been a change, I can’t deny. I have to look out for her whenever we go out, and we worry, she worries a lot and I try not to worry too much but it does happen. I do all the meals now but it’s not too bad as I get ready meals, so yes our lives haven’t changed all that much really, we’re still together and still happy.”

(Carer)

As noted, differences emerged in the level of support people with memory problems received from carers who were spouses compared to those who were adult children. Spouses tended to consider aspects of future care and dependency more as they worried about both getting older. In some cases, this had resulted in a trigger for people with memory problems accessing services in the first place as the couple had worried about consequences. Carers also reported a reversal of roles which they struggled to come to terms with. This was more common with carers who were adult children for their parents with memory problems who discussed having to take on the responsibility of caregiving for their parent now and found this difficult to come to terms with. Some spouse carers, however, also appeared to struggle to accept their partner’s memory problems and divulged their hopes that they would go back to being like they were. This was perhaps a greater reflection of their tendency to see their partner in terms that defined how changed they thought they had become and their own sense of loss.

6.4.3 Shared togetherness

Some spouse carers also demonstrated a degree of ‘shared togetherness’ when they discussed their partner’s memory problems in the context of managing it. For some, this was demonstrated by doing things together and undertaking activities they had both previously enjoyed; for others, it was exhibiting a united front to deal head-on with the challenges and problems of dementia and was presented more as an ethos for life. This was particularly true in the case of people who had accessed memory services later as it may be likely that they had been dealing with their problems for longer:

“Quite worried to start with but as I say we have always been together and helped one another so it doesn’t come as a – I mean she still does the cooking and that, you know, I give her help with the potatoes now and again, and I do a bit of housework, mainly because she is tired, but that is the only reason, yes and we go out every day and to the shops and that.”

(Carer)

Carers often talked of their role in terms of the emotional support that they provided their partner, including humour, gentle dissuasion and reassurance. In some cases, carers talked of having to negotiate the fine balance between reassuring their partner or relative with memory problems while not trivializing the significance of the condition on their mood and sense of self. In some cases, however, it seemed like the caregiving role was an extension of the relationship dynamic, albeit with greater intensity of emotions. A sense of shared togetherness was also apparent in these situations, when carers specifically sought out positive activities and keeping up a strong positive front. However, in some cases, it appeared that some carers seemed to struggle to maintain this positivity all the time; these feelings may be a front that carers felt obliged to keep up for the well-being of their spouse:

“I mean we’re not miserable people. It might sound like we are but we’re not, you know we always have a good laugh at things, we laugh at comedies, we watch the quiz shows and sometimes he comes out with answers and I think where’s that come from, do you know what I mean? You know we do try and get out, you know we’ll get the train down to X and have our dinner or we go to Q. Sometimes we just get the bus and not know where we’re going to go or we’ll have a ride to W or somewhere it’s just to get out for a couple of hours, you know, but sometimes I just sit there and I just ... oh I don’t know ...” [tears well up].

(Carer)

6.4.4 Perception of the future

Perhaps as a result of the practical approach that carers took to manage and integrate dementia into their daily lives, they appeared more aware and sensitive to future difficulties and changes. Carers appeared to have a more negative image of the future, the dependency of their relative and the level of care that they may be required to provide. Most of these discussions reflected carers’ worries that they would be unable to cope with caregiving responsibilities:

“I wonder how long I’ll have to cope and how I’ll cope and how bad it will get for me to cope with ... uhm ... which is a selfish attitude but I can’t change who I am and saying I want to put the down side, you know, put it away until it happens ... because I worry about him every minute of the day, but I always have.”

(Carer)

Some carers’ narratives reflected sceptical views of caregiving in the future. Their responses reflected a mixture of feelings of their caregiving role, their wish to provide best quality care to their loved one and despair for the future:

“Depressed. Trapped. At 73 I’m going to be looking after an old lady. Doesn’t please me. I love her to death but ... and obviously she will be looked after. I will do my level best for her. But I am concerned about the future. Concerned. Very concerned. Mainly for her peace of mind, because it must be...I think I’d go and jump in the (river), frankly, if somebody told me that I

had Alzheimer's, because they can say what they like, they don't really know what to do about it. Although I do believe the drug she's on is quite good. The GP had a look at it, oh, she said, this is good."

(Carer)

6.5 Reported levels of satisfaction

There were mixed reports of satisfaction of services from participants, as they struggled to justify the reasons for poor response from services. Overall, those participants who accessed memory services early appeared to be less satisfied with memory services compared with participants who accessed services later. This may have been a result of having lower expectations but in the context of long-term management of the condition this is worth noting.

6.5.1 Disappointed expectations

In order to identify the implications of un-managed high expectations amongst people with memory problems and carers who approached services, the emotional content of participant narratives was delineated and analysed. A notable finding was that those participants who accessed memory services early were more likely to express a higher proportion of negative emotions such as disappointment, frustration and anxiety, while those participants who accessed memory services later were more likely to be shocked about their diagnosis. The presence of negative emotions appeared to have implications for long-term management of the condition as well as consequences for caregiving, and will be explored in this section. Carers were more likely to express disappointment with services, such as the lack of support received; while people with memory problems were more likely to express disappointment and dissatisfaction with the outcome of the assessment process, such as not receiving a confirmed diagnosis.

In some cases, high expectations exacerbated feelings of disappointment when the diagnosis disclosed was not a confirmed 'yes' or 'no' regarding a diagnosis of dementia but one that suggested the presence of cognitive impairment but not enough to confirm diagnosis, support or treatment:

"It was a disappointment to wait so long, 13 weeks. I just thought, especially when I'm not used to tablets and what have you, I didn't expect to wait so long. That was a disappointment to us ... Because I was expecting like a short term thing where I'd go in and the doctor sees me, the doctor gives us a remedy and I get rid of A, B or C type of thing."

(Person with memory problems)

Disappointment, frustration and anger were embedded in accounts where participants felt let down by the lack of response from services. The waiting and poor communication were strongly criticised and the lack of understanding of the clarity of the assessment process appeared to exacerbate this. The extract from a carer interview below illustrates the frustration she felt regarding the lack of support from services and her feelings of guilt about the strain caregiving was having on her husband:

“I mean, you know, you’re the closest thing to him 24 hours a day, seven days a week, and 52 weeks to the year. You know the difference and the changes and we’ve never, ever changed the symptoms or whatever’s gone on and I just thought, well there’s a year and half to two years wasted where he could have been seeing somebody if that’s what it was sort of and I was angry about it and so was the family, because I mean it’s me that it falls back on and I wasn’t fit anyway because I broke my arm and I just wasn’t in my, you know it wouldn’t have bothered us if I hadn’t have been so ... like disabled with my arm anyway. Do you know what I mean? It just come at a bad time.”

(Carer)

A further point to note was the disappointment expressed by those participants who accessed memory services early on the lack of support post-diagnosis when they had been deemed ineligible for medication and had been discharged with no further input. These participants described feelings of surprise, abandonment and once again being unsure about whom to turn to next for support. As most help-seeking had been initiated by carers, it appeared that carers were particularly disappointed with services:

“It feels strange, really. Yes, I thought there would be some follow-up, but obviously she [relative with dementia] is under the day care. She goes to day care, so there is people there that would follow us up if there was a problem that I need.” [Interviewer: “You understood that there wasn’t nothing ...”] “Nothing more they could do ... that side of it. It’s going to be the GP or people from – we had an outreach nurse at the day centre. She can keep an eye on things like that. As I say it’s just time and suddenly you’re finished with them and there’s that sort of ‘yes, you’ve got the day centre’ but I think sometimes it’s good to go back to the clinic and just make sure as to where you are really.” [Interviewer: “Did they talk about whether there was any deterioration you would need to go back to the clinic or ...?”] “No, no.” [Interviewer: “So nothing like that? So you felt a kind of over?”] “Yes that’s it.”

(Carer)

Those participants who accessed memory services later, on the other hand, appeared to take discharge from services with no further support more in their stride and exhibited a greater sense of confidence of being able to carry on. This perhaps could reflect the fact that they had been managing for longer without formal support:

[Interviewer: “Do you know what happens after you stop coming here, will you be able to speak to these people again will they be coming to see you?”] “No they don’t need to, because all that was being done here was the memory thing and then going to the drawing painting with [name of nurse] and the memory thing well it isn’t going to go any different I will either forget or remember but I am not worried.” [Interviewer: “Did it help you to come here?”] “Oh yes, it has given me more confidence, yes.”

(Person with memory problems)

6.5.2 Reaction to diagnosis

Those who had received a diagnosis revealed feelings of fear of the consequences in a future of potential deterioration and care dependency:

“Well I do worry a bit about Alzheimer’s, I do worry, but because I am frightened in case I am left without anybody to care for me, because my husband won’t last forever, he’s 80 soon, so, you know but then I have my daughter who lives near so she will come and help me out, yes.”

(Person with memory problems)

Those participants who accessed memory services later appeared to be more shocked about their diagnosis, as most had not explicitly sought help for their memory problems. Furthermore, participants in this group appeared to have little indication that the GP had referred them to specialist memory services and they appeared to be more confused and unsure of the assessment process:

“I got a bit of a shock really, it upset me, because I didn’t feel that there was anything wrong with me, no, and I was shocked to think of this dementia thing, because like I say no one in my family had it, so.” [Interviewer: “Do you think anything could have prepared you better for it?”] “I think they told me something earlier I might be more prepared, yes, I’m having to accept it now. I know it is a shock when you are not expecting it, when you think everything is right, it is an awful shock so I will have to put up with it and see this doctor.”

(Person with memory problems)

Those participants who accessed memory services early and who had initially sought reassurance from services also described feeling shocked about the diagnosis, despite having some awareness of what might be the matter. Being informed about deterioration when they had hoped for having no diagnosis was, therefore, unexpected:

“Dr X says, ‘But the only thing I can tell you with certainty is that it won’t go better’. You know, so we came out of there feeling, well, you know. You do know but you try to pretend someone’s going to tell you differently, you know what I mean. You, sort of, think, well perhaps it’s not quite that or they can give her this or, you know, it’s when it’s actually said and you think, oh God no. And we thought that was the only problem we had, you know, and then, how do you say, it wasn’t.”

(Carer)

Any form of relief identified in participants’ narrative accounts was only amongst those who had not received a confirmed diagnosis of dementia; this included participants who had expected relief during Time 1 interview:

[Interviewer: “And did you feel at any of these appointments that you’ve been able to raise any concerns that you have, or ask any questions?”] “It made me feel more relieved than anything.” [Interviewer: “After going to [memory service] the last time?”] “Well I feel alright in myself, I’m quite happy.”

(Person with memory problems)

6.5.3 Other criticisms

Other criticisms of the service primarily related to the trouble described by some carers around negotiating the shared narrative of memory problems with the doctor in joint interviews. A number of carers described the challenge of discussing this in the presence of their relative with dementia, feeling unable to ask relevant questions or give a detailed account of their perception of daily life. They appeared particularly disappointed with the lack of support from services to negotiate this problem:

[Interviewer: “And do you feel that you’ve had the opportunity to ask all the questions you would want to ask at those appointments or ...?”] “Not really because my mum’s normally there. So that means that to some degree, if they ask me the questions and I answer it, I’m calling her a liar because I’m saying that what she’s told them is a load of rubbish. Because I know that it is, because she’s going back years in her mind and not what happens now, if you

know what I mean. So ... and the one time that the lady was asking me questions, on my own in my mum's house, my mum didn't like it ... because I was taken in another room.

[Interviewer: "So that makes it very difficult to try to find out more, there may be questions then that you would liked to have asked were there?"] "You can't really do it; do you know what I mean? And then as I say if you go round and ... and they'll say what do you find that she can't do this that and the other, and as soon as you say something she jumps on you doesn't she? 'I can ... I did this and I did that ... ' so it's ... you know, I've found when my mother was saying things I was just sort of doing this ..."

(Carer)

Some also criticised services for being more task-focused than person-centred. They described services as not addressing personal needs and preferences were not addressed but taking a more mechanical approach. For instance, carers talked about being given too much information about the diagnosis at the first disclosure meeting itself, and not being prepared. Similarly, the extract below highlights this person's need to understand greater detail about the brain in Alzheimer's disease; this information was, however, not forthcoming:

"But we were told that the possibility of brain damage from the falls, possible Alzheimer's, just wear and tear and getting old. But there were no details given. And then she talked about the possible need to look at your will, setting up a power of attorney should be considered. And she will have to report this to the DVLA about my driving, which would be a terrible blow, because I've driven all around the shopping precinct this morning with a friend, and parked it and done a greater job than I did than I arrived just now. But that is my criticism of what's happened so far, the fact that you don't get to know. And I know everybody's pulling the stops out about dementia and Alzheimer's now, this is getting to be like when you took your child to the doctor and it was tonsils, take the tonsils out. If you were a woman you went to the doctor, you had a hysterectomy, it seems to be they've just caught on the need I think, and I think they probably don't know which way to turn because there's so many."

(Person with memory problems)

6.5.4 Satisfaction with services

There was a variety of reports of things that had gone well during service encounters. This usually was more praise for individual professionals and individual manner rather than the assessment process itself. People with memory problems and carers were often very grateful for support they received and the perception of support for themselves made them feel more confident and positive; carers were more likely to report on satisfaction with services:

[Interviewer: "Is there anything that you would have liked to have discussed with the doctor that you didn't get the chance to?"] "No they were both excellent. They really were, much better than I had expected because I had, I've been blessed with good health so I haven't been to see consultants, only maybe twice in my life and I've always had an impression of them bustling in and [makes a noise] and out, both X and Z; you think we were the only patients there. I was very much impressed."

(Carer)

An informal, friendly atmosphere, with the time to ask questions, was appreciated by participants as they felt they had time to reflect on the information given to them, consider the options and then raise queries:

“It was a relaxed atmosphere which was nice, it wasn’t like ... wasn’t very formal, it was just nice for obviously [nurse] who I’ve met before ... from my point of view, and my brother being there as well and mum, bless her, she didn’t understand any of it, you know, it was way over her head but it was a nice atmosphere, it was. You know, I wouldn’t have any complaints and I could ask any questions I wanted, you know, and my brother as well, there was no problem with that.”

(Carer)

Although waiting time for initial appointments and scans was strongly criticised, a few participants appreciated that this was beyond the control of the memory service. They also felt that once things were established, they moved quicker than they had anticipated and were grateful for support offered:

“I don’t think so, no. I mean I think they were quite, you know, they were quite good, they were on the ball. You know, once things were in motion, you know, we didn’t have to wait long for appointments and that type of thing, you know, they were certainly very forthcoming with things like that, so it wasn’t a long drawn out experience, I thought it was quite well handled to be perfectly honest.

(Carer)

The memory retraining groups offered by some memory services were seen as being especially helpful as participants enjoyed the social contact, the practical strategies discussed, and felt they benefited from the experience:

“We did actually go for a very helpful set of sessions that were run by the memory clinic with C and various other ladies, very supportive and people with memory problems went with their partner, with a carer, sometimes it was their grown up daughter or a friend even. One gentleman was there with a friend because he hasn’t got any close family and they were talking about ways of dealing with memory loss and being very constructive and helpful on that. We found that very helpful didn’t we?”

(Carer)

Support at the end of a telephone was highly valued by participants as they described the relief at being able to ring up their key worker and share a problem or obtain advice or be signposted elsewhere. This support appeared to be stronger in more longer established relationships with the key worker:

“Like trying to sort – I can ring her up and just say we’ve got this problem. Like the phone bill; I rang up about that and she – I should get in touch with somebody who then told me to get in touch with somebody else, sort of thing. Any problems with, like, the Care Service, I will ring her up and she’ll sort that out.”

(Carer)

6.5.5 Consequences for caregiving

High but unfulfilled expectations from services also seemed to have consequences for caregiving as carers described feeling frustrated with their relative’s memory problems, unsupported by services regarding how to deal with these, fearful of the future and feeling like they were letting their relative down:

“The thing is, we feel almost that we’ve not done my mum full justice by getting her some medication and things like that, and it’s frustrating, but I don’t know.”

(Carer)

Consequences for caregiving were also reflected in accounts where carers displayed sorrow regarding their relative’s deteriorating condition, highlighting potential carer burden, and escalating depression and frustration amongst the carers:

“We’ve always helped anybody that wants it, we’ve never ever asked anybody for anything, never, you know we don’t owe anybody anything or, but we are there for other people and this is, I mean jobs that ... Decorating, that would be no problem, garden we used to have the best garden in the street back and front. He can’t do it now. You know like he’ll go in the kitchen and he’ll not remember what he’s gone in for, he would, you would say, ‘X’, you know, ‘if you’re upstairs can you get me such and such?’ and you can hear him ratcheting around because he’s forgot what he’s looking for and then you have to remind him and it’s just awful, it’s just awful.”

(Carer)

Building on the accounts of transitions reported in Chapter 5, this chapter has described the expectations and experiences of people with memory problems and their carers across these transitions. A key emerging finding is the difference in expectations and experiences of those participants who accessed memory services early compared with those participants who accessed memory services later. This contrast is influenced by clinical factors as well as social factors, such as social networks and participants’ personal biographies. Nevertheless, an emerging finding is that although many expectations and experiences are shared by both groups those participants who accessed memory services early often have higher expectations for support and treatment, particularly in relation to receiving a diagnosis and reassurance, and are more likely to be disappointed by their experiences of the early transitions along the dementia pathway. Participants in both groups lacked an understanding of the clinical uncertainties surrounding a diagnosis of dementia and were frustrated by not getting a clear answer or prognosis. A lack of information about the process of diagnosis has resulted in unmanaged expectations. In Chapter 7 we explore in greater detail the information needs of participants and how the quality of information influenced communication between participants and health professionals.

7 Communication and information along the dementia pathway

In Chapter 5 we introduced the idea of transitions in uncertainty highlighting five: 'internalising dialogue', 'confirming positions', 'seeking expert advice', 'being tested' and 'seeking understanding'. The transitions described were not conceived as temporally distinct but in the case of the first four reflected different phases early in the dementia journey, while 'seeking understanding' reflects the whole participant experience of the early dementia journey for people with memory problems and their family. General practitioners (GPs) and staff working within the memory services became a critical source of knowledge for participants about cognitive impairment once participants contacted services. This chapter focuses on the ways that information was communicated to participants from the time that participants first contacted primary care, memory services and other health services about memory problems.

Communication is an essential part of all professional practice in health care and dementia care is no different. Nevertheless, due to clinical uncertainty, professional attitudes and training and every-day resource pressures, communication between health professionals and patients and their family members is rarely as clear and transparent as users of health services may want. Dementia care is likely to be no different. In this chapter we explore three areas that participants highlighted as being particularly important: being kept informed about what is happening; knowing and understanding what is wrong, and practical advice on how to handle the experience of memory problems and dementia.

7.1 *Knowing what is happening*

This theme focuses on what people are told about the process of assessment and follow up (and where relevant, treatment) and how people are kept informed throughout the process.

Our analysis suggests that participants were given very little information about the process of assessment and follow up and therefore did not know what to expect. One couple was asked whether they had been told what would happen next. The carer replied: *"They didn't really mention it, said he will get hold of the doctor to send a review through"*. The couple had not heard anything and did not know how long this might take. Another carer had been told simply that the results of a scan would be sent to the GP. A person with memory problems had been told she would be *'sent for'*, but had heard nothing. Following assessment, one person was told that their condition was *'pretty stable'* and that they would be *'sent for in a year'* and another was told: *"We'll just keep following things up you know, and we'll see what happens"*.

Several participants could not remember what they had been told. When asked what the doctor had said one person with memory problems said simply *“I haven’t a clue sorry, you know, it was all new to me and it was just that I have been waiting a long time.”* Another carer remarked about her husband: *“When we ask him, what did they say, when he comes back, he can’t remember what they’ve said”*, adding that this was why she attended appointments with him.

Although the diagnosis of dementia is often a lengthy process and one which varies considerably from person to person, it would seem that little information was given to participants about the assessment process as a whole and what would happen next as they go through the process. As highlighted in Chapter 6, there was a huge variation in participants’ expectations and understandings of what the process involves.

Despite the lack of information about the process and what to expect, participants did recall appointment letters. Many kept these in a safe place and referred to them during the interview, either to remind themselves about when they had to attend an appointment or to ensure that they gave the researcher accurate information. This suggests that when written information was provided it was used and appreciated by people with memory problems.

There were no examples of people being given information at their first appointment about the assessment process and what to expect, apart from being told how long they might have to wait for a scan. Written information about what will happen with approximate time scales would have been particularly helpful for people with memory problems, so that this could have been referred to after the actual appointment. One participant expected the whole process to be over in a couple of weeks:

“He (GP) referred me to the memory loss clinic, when they were taking tests and what have you. Then it went on from there and I thought I’d go in and do a couple of weeks and then I’ll go, but it wasn’t like that. It took a long time.”

(Person with memory problems)

As Chapter 4 reported, the memory services included in the study operated in different ways and therefore specific information about these services and the way that they would communicate with users would have been helpful to participants. One participant explained how her mother had had difficulty understanding what she was being asked when professionals had asked her if she wanted her daughter to be sent copies of letters:

“He asked mum would she like anybody else to have a copy of the letter and ... it was really, did they want me to have a letter and mum couldn’t quite grasp that, so he had a try a couple of times, and mum will actually say, A [daughter] does everything for me, you know but she couldn’t quite work it out, what he was trying to say to her, but I mean she did say “yes” in the end, you know, we got there eventually.”

(Carer)

This suggests that agreeing with patients that copies of letters will be sent to carers may not be as easy as expected. It is clear, however, that carers appreciate receiving copies of letters, if not resident with the person with

memory problems. Another carer felt it necessary to receive copies of letters so he could remind his father to attend the appointment and a third carer said letters would get lost if just sent to the person with memory problems. This highlights the important role of carers in supporting the process of assessment and how being copied into written information, such as appointment details, can enable this.

Following attendance at clinics or home visits by professionals, people with memory problems were often not sure what this was for, what it achieved and what would happen next. When speaking about what happened at the end of a week of daily attendance at a hospital one participant said:

“Nobody said anything. They just came and collected me ... I would have, probably the doctor said something, but I don’t remember it.”

(Person with memory problems)

The same participant had been visited at home by an occupational therapist (OT). When asked what the OT had done when she visited, she said:

“Nothing. They just came and said a few words and I told them what I told you when you first came and I never heard anymore.”

(Person with memory problems)

Because of her memory problems it is possible that she simply could not remember what had been said and was therefore unable to expand on it when interviewed. In any event, people with memory problems need to be told and kept informed about what is going on at every stage of assessment and intervention and this verbal information needs to be backed up with clear written information, which confirms what has been said. It may seem obvious that people with memory problems will forget what is said to them. Despite this there appeared to be a lack of mechanisms to enable participants to remain informed about the situation.

Being told and kept informed about what is happening are clearly important. Good professional practice, however, suggests that this should be done sensitively. One participant described receiving a copy of a letter from the old age psychiatrist to her GP. This had been sent initially to her daughter and passed on to her. Reading it had caused considerable distress and it did not, according to the person, provide an accurate reflection of how she was, some of it being based on information provided by her daughter when she was not present. It also contained medical terms that she could not understand:

“You had better see this letter which I don’t like at all! The doctors would pass them to each other. That’s what I am supposed to be like at the moment, but some of those things are what D (daughter) told them and they’re not quite accurate ... My elder daughter, she mostly told them things like I’d been dizzy twice, dizzy, but it’s not what I would call dizzy, but she said it was. If you stand on top of a mountain and look down you feel dizzy, but the sort of dizzy I would get comes from inside ... You better read the letter ... It makes me feel much worse that I thought I was ... I didn’t think I was as bad as that ... They didn’t tell me anyway and I was thinking things were just normal ... Apparently I am half mad, half forgotten myself. I haven’t really. I do lose my words, but I always have done ... I’ve been sort of reading it a few times, ‘cause I can’t believe some of these things. She (daughter) had a long talk with the doctor and the doctor said do I do this and do I do that and do I do the other and she , I suppose, I just

wish I'd been there, but I suppose it wouldn't have been the same ... the chap (old age psychiatrist) was surprised I could talk to him sensibly! Doesn't it say in there, I was actually looking at him!? ... 'Euthymic in mood', I don't know what it means. 'I'm concerned that I may get lost' (reading from letter). Now where on earth did D (daughter) get that one from? And I can't find dyspraxia in the dictionary. I've got a medical book and also an encyclopaedia ..."

(Person with memory problems)

Other people with memory problems and their carers spoke about receiving copies of letters from other professionals to GPs, so it would appear that the above is not an isolated case. The fact that the issue was raised at the interview may have been because the person had recently received the letter and because of the upset it had caused. Despite this, the illustration highlights several potential areas for improvement.

Participants did not report any examples of direct communication between memory services and the person with memory problems or their carers in which letters were written in a style that might be easily understood by a lay person. Instead of copying letters written to the GP to study participants, secondary care professionals could have written letters to the person with memory problems and copied this letter to both the carer (with permission) and their GP. These letters could have been written with the patient in mind and not contain complex medical terms without explanation. This would have resulted in more person-centred information giving.

Participants also did not report receiving written information that confirmed or backed up information already given during a face-to-face consultation, which would have ensured that whatever information participants received in writing, they had first been told during a face-to-face consultation. This would have given people with memory problems the chance to think again about what they had been told, thus facilitating memory and recall and hopefully subsequent understanding and coping.

An important issue emerging from the data concerns the differing perceptions of people with memory problems and their carers about the person's problems and how professionals communicate with all those concerned to elicit and then use this information. In the example above the old age psychiatrist had spoken to the daughter whilst her mother had been elsewhere in the department. This example suggests that professionals involved may have missed an important opportunity to facilitate communication between the person with memory problems and their carer. Encouraging both the person with memory problems and the carer to voice their opinions in a joint consultation may have facilitated this communication, although triadic consultations may not be without problems. Another way to have improved communication in this example might have been to acknowledge the divergence of views and not to have privileged either view. The information provided by the daughter seemed to the person with memory problems as having been viewed as more important than her own.

As well as for themselves, people also need information about what is going on, so they can pass it on to other professionals, if required, thus taking

ownership of their health problems. One participant wanted written information to pass to her social worker:

“Not got it in writing, which is annoying, because when the social officer came, the only information I had was the interview (with researcher), so she was taking my word ... and I thought why isn't there a letter to show her? So that is bad, I think.”

(Carer)

7.2 People want to know and understand what is wrong

The focus of the following analysis is on communication between professionals and people with memory problems and carers during the assessment process. Following an initial assessment, a number of people with memory problems were informed that they did *not* have Alzheimer's disease. In the absence of any further help or advice, this was not generally helpful. For some participants it left them in a situation in which they still had problems but had no explanation for these. Other participants experienced particular problems associated with their poor memory and desired professional help. One participant had been told how he had done well in the memory tests but added that knowing this did not help him. He still had memory problems and wanted help to deal with them.

In contrast, other participants came away from appointments with the impression that 'everything is OK' and responded positively to this information:

“... He (doctor) took me in and said things are pretty stable and we'll send for you in a year. He said it wasn't a worry about Alzheimer's or anything at the moment you know. He wasn't worried about that which obviously I was; otherwise I wouldn't have went in the first place would I? ... When he turned round and said everything's OK, that's great, you're over the moon when he said it was OK. You know that's the best answer he could give you”.

(Carer)

This participant was clearly pleased to be told that his wife did not have Alzheimer's disease. One cannot speculate as to what might happen in the future here, however if the person were to go on and develop Alzheimer's disease. Would this carer feel cheated; that he had been misled into believing his wife was 'OK'? We have insufficient data about the experience of participants who were told they do not have Alzheimer's disease or dementia, but then go on to develop it. The detail of what people are told, however, is clearly important here, as is the impression people with memory problems and their carers glean from the information conveyed by professionals.

Scans, blood tests and memory tests form an important part of the assessment process for people with memory problems. Some participants felt that the results of scans were well explained, whereas others did not receive results, waited a long time for them or even had to contact various people to obtain results that appeared to have been lost as described in Chapter 6. One participant with a positive experience said:

“I think the doctor in the hospital shown me the scan, and he said this is interesting. He said the right side of your brain has got a blockage and the blood is not going through. Do you understand that and it’s affecting the left side?”

(Person with memory problems)

One participant explained how the doctor had asked him to see her at the hospital. The doctor had explained that he had a burst blood vessel in his brain and that this was the cause of his problems with short-term memory loss. The carer had appreciated this explanation for her husband’s problems, saying *‘at least we knew what it was’*.

Another participant spoke favourably about what the doctor had said when explaining the results of a scan, giving specific details:

“He could see on the x-rays that he bought up on the computer. He says, like that bit is the Alzheimer’s, because the brain is shrinking ... and then this bit here is the vascular bit ... where clots are formed, was it clots or something. The blood wasn’t hitting the right place and so that was causing ... two problems in a way, because don’t they react differently?”

(Carer)

On the other hand, below is an illustration of results not apparently being communicated clearly. One participant had been frustrated and angry by being told different things by different people in relation to receiving her mother’s blood test results:

“When mum had the blood tests I asked the doctor, I said ‘what will happen about the tests?’, so she said, ‘would you like me to ring you?’ and I said ‘yes please’, and I gave her my number and never got the call. So this was one thing I found very infuriating. I rang the doctors and explained to her and she said ‘oh no, I can’t give you that information. You’ve got to ring your mum’. I said ‘but my mum won’t be able to understand, I am the carer, my mum’s carer, you’ve got my details there. The doctor’s got my number’. ‘No sorry, we can’t give them to you’.”

(Carer)

As well as the results of scans and blood tests, participants also wanted to know what is wrong with them. As a diagnosis is not based solely on the result of a scan (seemingly something that many people do not realise, although this was not considered specifically as part of this study), communication of *‘what is wrong’* is not just about feeding back the results of a scan. A number of participants simply did not know what was wrong. When asked what one person had been told about her memory problems, she said that *‘nobody had said anything in particular’*. Later on she added: *“Nobody’s talked about it yet. I was expecting to see a ... somebody a bit higher up, to tell me whatever.”* Another participant said:

“We thought we were going to get more information than we did, you know, we thought we were going to get information about the scan ... to know what was going on, but we didn’t”.

(Carer)

One participant spoke in depth about wanting to know what she was *‘up against’*. She had been told about what might be the cause of her memory problems, namely Alzheimer’s disease, brain damage as a result of falls or *“just wear and tear and getting old”*, but not what was actually wrong:

“What I need is advice. I need to talk to somebody to see what the outcome could possibly be. I want to know what I am up against. When they put me forward for this they said: if we find anything, do you want to know, and I said yes and they said yes, of course you do, you are an intelligent lady, but whether they changed their mind about that I do not know. Not knowing what you are in for is one of the things I would criticise.”

(Person with memory problems)

When asked how she felt about being told the various possibilities, she added:

“... Quite disturbed, because I can't find anything more about it. I don't know whether there's an ulterior motive, the fact that you can't find anymore about I ... I said I needed to speak to somebody, can you advise me where to go and she said well you are coming on the 17th, but that was two possibly three weeks ago, so I don't know. I'm probably asking for the moon. I know everyone's very busy. I know there are people at worst stages than I am, but it does take a long time ... I need to know how bad it is, the state of my brain!”

(Person with memory problems)

One carer whose husband had been experiencing, what doctors had so far described as panic attacks (shaking), as well as memory problems, for a couple of years, was particularly frustrated and upset by not having a diagnosis for her husband's problems. This was exacerbated by the fact that the scan results were normal:

“It's just not having a name! I just want a name you know what I mean? He's had two heart operations. If he was to have a heart attack, I would know what to do. If he had a broken arm or leg you can see it ... You know that it's going to get better at some time, but this you just can't, you can't!” ... I just want to know why these things are happening to him and hopefully it's not anything like Alzheimer's and stuff. I just know, because he's not pretending. I know he's not putting anything on. I mean he's not that sort, you know.”

(Carer)

It is likely that the level of emotional upset experienced by this carer in relation to not knowing *“what was wrong”* with her husband was exacerbated by the considerable length of time that had elapsed between her husband being seen in the memory clinic and the present time (over a year), the fact that she felt that she and her husband were not being listened to and their previous negative experiences of the health care system. It is also possible that fearing her husband had Alzheimer's disease, as alluded to in the excerpt above, increased her emotional upset.

Although it is evident that this carer wanted to know what was wrong with her husband, it is possible that at the time of the interview professionals did not know what was wrong and therefore this information could not have been given. One can conclude however that communication about what is wrong needs to be timely. Failing to provide a diagnosis when a person or their carer wants one, may be justified, but only when this is due to the uncertainty of the disease progression and not due to service delays (probably relevant in this case).

Communicating with people with memory problems and their carers about *“what is wrong”* needs to be done in a sensitive and planned way. One participant described a positive experience:

“Well they did explain when we went to ... [name of the memory clinic]. She explained everything to us. She put everything the way it should be put, so that we understood, you know.”

(Carer)

Where multidisciplinary teams are involved, communication about what is wrong needs to be coordinated and agreed by the team. In the main this relates to disclosing a diagnosis of dementia. This had been particularly traumatic for one carer and, to some extent, her husband, who had memory problems, who had been receiving regular visits from a psychologist. When the psychologist was moving to a different clinical placement, she wrote to the consultant providing a summary, which included the statement that in her impression the man had Lewy-Body Dementia. The couple had been sent a copy of this letter without being told the possible diagnosis at a face-to-face appointment.

The issue of copying letters to patients and carers, when these letters are written primarily for another professional, has already been raised. As was suggested above, an alternative approach would be to write to patients and send copies to other professionals. The timing of the letter is also an issue here. Had the psychologist spoken to the old age psychiatrist and discussed her clinical impression? Had the team agreed what would be communicated, when, how and by whom?

Teams could ensure that there is a process of agreeing what will be communicated, by whom and when, and ensuring that whatever information is given during a face to face appointment is then confirmed in writing. As well as communication being sensitive, planned and timely, the amount of information given must be individually tailored to the needs of the person with memory problems and their carer. One carer said she had received '*tons and tons of written information*' which had been a problem. She explained that it was '*too much to read and understand*' and that she had not had the time to read it.

The difficulty of individually tailoring the amount of information given was illustrated in an interview with a participant who had found the whole process of being told a diagnosis somewhat overwhelming. She acknowledged that the '*signals*' she and her husband had given may have been contrary to their real feelings at the time and that their shock may not have been evident. In this instance, time pressures may have contributed to information being 'given' but not necessarily 'communicated appropriately'. For some people, disclosure and the other communication associated with it, such as providing emotional support, giving practical advice and simply repeating things in a way that can be understood, might be better done over several consultations or home visits, at relatively close intervals. This would relieve pressure on professionals to 'get over' certain information in a single consultation.

There was no evidence of this 'staggered approach' to disclosure and information giving in this study. The only exception to this was when people were given a diagnosis of Alzheimer's disease and then started on anti-dementia medication which was reviewed by a nurse, who visited the

person at home, relatively quickly after the diagnosis was disclosed. Here, though, the prime aim of the visits was to start, review and monitor the effects of anti-dementia medication. Other communication, such as providing emotional support or practical advice, as well as reinforcing disclosure of a diagnosis, was secondary to this. Had anti-dementia medications not been prescribed, these opportunities for communication would not have been provided.

So what other important conclusions can be gleaned from the study about disclosure or communicating a diagnosis of dementia? One participant said the following:

“When he (old age psychiatrist) came the second time, he didn’t stay for long, but he did give us a diagnosis, what had happened and what it was and who he was going to get in touch with, and that was all we wanted to know really. He couldn’t do anything himself, but he did say that any problems at all you want to know, get in touch with me. I will, you know (be there)...”

(Carer)

This is probably a good example of disclosing a diagnosis from a carer’s perspective. The diagnosis was given during a home visit (being given a diagnosis whilst at home was felt to be beneficial by other participants too) and it appears that an explanation was given (‘what had happened and what it was’). The couple were told clearly what the doctor would do next and they were encouraged to get in touch with the doctor with any queries or problems. The latter was perceived as helpful as the carer stated that she would get in touch with the doctor if she wanted to.

The enormity of being told you have dementia and some of the associated emotions were illustrated succinctly by a person with memory problems and also by a carer:

“I didn’t realise until suddenly he said ‘I think you have early dementia’ ... just like that ... I got a shock really. I felt terrible, because you don’t expect it you know!”

(Person with memory problems).

“Absolutely devastating! For a week after that neither of us said very much of anything at all. You eventually get things back into perspective as much as you can, but it is not a good way to do it. It really isn’t. If you are examining the process of this then it needs looking at.”

(Carer)

It is clear that there is a need to prepare people for receiving a diagnosis. However, further work would be required to identify ways in which this might be done. For people with memory problems and carers, the opportunity to ask questions of professionals is an important part of understanding what is wrong. Participants provided numerous value examples of being given the opportunity to ask questions. Despite this, others explained how they did not necessarily know what questions to ask, especially immediately after being given a diagnosis:

“It was quite a blow, it was, even though you keep the conversation lighter, there’s wheels whizzing at the back of my head, thinking I know what happens with Alzheimer’s ... and you don’t know what to ask.”

(Person with memory problems)

A carer also said simply that she did not know what questions to ask while another explained how she could not think of questions at the time, but thought of things to ask later:

“They did ask if we’d got any questions, but it is not then you have the questions is it? It’s when you come home and you sit and you think and then you question, that’s when you have your questions.”

(Carer)

Evidently opportunities to ask questions need to be ongoing. Professionals also need to be aware that some people will simply not know what to ask. Asking people if they would like to know more about something or other might be more constructive, especially for those who do not have questions to ask. Having been given a diagnosis of dementia some people liked to have factual information about what was wrong, to aid understanding about the disease, and what it will mean for them in the future. One person with memory problems explained how she wanted to know the difference between Alzheimer’s disease and dementia. Another participant said:

“If they would have given me a book on Lewy-Body Disease, I would have read it and I’d have been more knowledgeable.”

(Carer)

This carer also pointed out that a standard leaflet, like the ones in GP surgeries would not be suitable as it would be likely to contain information that you already knew. In relation to the detail of the information required, another carer added that the only information that is relevant is that which is *“relevant to your circumstances now, because you can’t see what the future is and you don’t know at that moment in time, what you are going to need.”*

Also in relation to Lewy-Body Dementia, another carer spoke about contacting the Lewy-Body Society to get information about the disease. She and her husband had received no information from professionals and so she felt it necessary to seek it out herself. Most participants had not been given any factual written information about the diagnosis they had received, but some had received information booklets produced by the Alzheimer’s Society. Those that had received information produced by the Alzheimer’s Society were satisfied with it. The majority of examples of people wanting more written information came from the carers of people with Lewy-Body Dementia, which suggests that there is a dearth of patient and carer information on this subject.

Other participants were quite happy with not receiving written information, illustrated by this participant, who when asked if he and his wife had received any written information, explained:

“We’ve seen the specialist and I’m happy with seeing the specialist. If someone’s going to help you, it’s going to be them.”

(Carer)

These findings suggest that written information about the different types of dementia, at a variety of levels, should be available for people should they

want it. The main benefit of knowing what is wrong, from their perspective, was the chance to plan for the future:

“Yes – I would like to know, definitely knowing everything is better than not knowing. It has helped us to plan and be aware of things that may happen.”

(Carer)

“I would like to know if it’s going to get worse suddenly, or in a long time, because I know it is not getting better, but I don’t feel it’s getting worse.”

(Person with memory problems)

What participants were told was not only important for those given a diagnosis of dementia, but also for those with memory problems who did not receive a diagnosis. Some participants were told that they have cognitive impairment. Although seemingly accurate from a professional perspective, on its own and without explanation, this seemed meaningless and therefore was not considered helpful. One participant reported:

“They’ve just said that they think if they’d seen my mum a few years ago, they might have been able to do something.”

(Carer)

Here the overriding message is one of ‘hopelessness’. Again it was not helpful to the recipient. It is possible that other information was given, but this is clearly what was remembered and what was seen as significant. So if the above are unhelpful, what would be of benefit to people in this situation, where there is no definitive diagnosis of dementia? The study elicited considerable evidence about what people find helpful. Much of this relates to practical strategies about how to deal with memory problems on a day to day basis. This is covered in the next section.

7.3 People benefit from pertinent advice

In terms of advice, some participants wanted to know what they could do to help themselves, one participant said:

“Well I would like to, yeah I would, as long as the information was going to develop something or put me on a course or something like that you know. It might be up to myself to do more reading and that might develop into remembering what I’ve read ... I am trying to do ... It’s not easy when you haven’t done a lot of reading ... That’s the thing I am looking forward to, improving that way by trying to do something ... I don’t know whether it’s something you can do, repetition each day, like reading, reading and reading, whether that’s a way of improving your mind, memory, you know, if at the end of the day you say well what did I read and you can memorise it?”

(Person with memory problems)

Group sessions run by memory services, often referred to as memory retraining classes or memory strategy groups, had positive outcomes for people with memory problems and carers. Several participants from one of the study sites had attended these sessions, which were held on a weekly basis. People with memory problems generally attended with their carer:

“We did actually go for a very helpful set of sessions that were run by the memory clinic ... very supportive and people with memory problems went with their partner or carer, sometimes

it was their grown up daughter or a friend even. One gentleman was there with a friend because he hasn't got any close family and they were talking about ways of dealing with memory loss and being very constructive and helpful on that. We found that very helpful, didn't we? ... Just to talk things through with somebody else is good ... They were talking about little things you can use in your home to help you remember things."

(Carer)

Those who attended the sessions were given a file containing the handouts from each session. One participant explained how the written materials had been referred to and used at the sessions:

"Well everything's there (in the file) really. It's quite a good folder that. It was very helpful I found. Because I used to sit beside him and they went through it word for word and I read it then you know. I found it very good because it's a decent size print ... I found it very helpful."

(Carer)

One person stated how since attending the sessions, he had started writing things down to prompt his memory. This he saw as the greatest benefit of attending the sessions. He also spoke about how the sessions had '*got everyone talking*' and how '*everyone was in the same boat*'. For another person with memory problems the benefits were also in being able to talk to others in the same situation:

"The last session ... we were just talking among ourselves, which was quite nice, getting used to ... The memory clinic (group sessions) was helpful in that I realised so many other people doing just the same, I mean, has the same problem. That's always a help, knowing you are not quite so odd! ... I've learnt I'm not particularly forgetful more than a whole load of other people, that's always encouraging. It's sort of mental things".

(Person with memory problems)

Therefore, as well as an opportunity to give advice about dealing with memory problems on a day-to-day basis, group sessions run by professionals also provide an opportunity for people with memory problems to talk to others in a similar situation, this being perceived by participants as beneficial.

In terms of advice, participants also appreciated being put in touch with local voluntary services which may be of help. For this study the Alzheimer's Society and Age Concern (now Age UK) were the most relevant. Both organisations have an important role in providing advice and support for people with memory problems and carers:

"The doctor from the hospital was quite good because he said there is an Alzheimer's Society ... he wasn't sure where it was but I got the address from the civic centre."

(Carer)

One participant had already been to the Alzheimer's Society and been given advice about financial help that might be available in the future. She stated simply:

"It's good we have the Alzheimer's people helping us because they know what to do is best."

(Carer)

For others, however, the experience was less positive in terms of outcome. One carer explained how the doctor had said he would put them in touch

with Age Concern, but she had then not received any information. There was some question as to whether information had in fact been sent to the person with memory problems, who had then mislaid it. This would suggest that it is best to give out written information at the time of the consultation rather than sending information in the post at a later date and also that information should be sent to carers as well as to the person with memory problems if they are not co-resident.

Additionally, in places where the voluntary sector provides a key role in information giving and advice, professionals should explain this to people, so they do not miss out on this vital resource. One carer said she had received '*bits of information*' from the '*carers place*' and '*some from talking to people down at the Alzheimer's Society*', but nothing '*officially from anyone in any sort of position*'. It is possible that she did not realise the key role played by the Alzheimer's Society or the scope of the carers' centre. Advice pertinent to people with memory problems is not necessarily all that is required by carers. One carer spoke about receiving leaflets specifically for carers, detailing peer support or a '*buddy scheme*' that was available and also a befriending service. The latter was described as '*so busy*' however and so the carer was doubtful about when or even whether it would contact her. It was not clear to her who ran the befriending service and, in particular, whether it was based in the local authority or a voluntary sector.

Another carer had gained benefit from reading the Alzheimer's Society magazine:

"I have read and I get the magazine, the Alzheimer's magazine, so I know what to expect".

(Carer)

Practical advice about dealing with personal finances, often from social workers, was also welcomed, as was advice on other aspects of personal affairs:

"The social worker's been quite good ... like trying to sort out ... the phone bill. I rang up about that and she said I should get in touch with somebody."

(Carer)

One carer explained how following the doctor's advice, the couple had been to see a solicitor to sort out their will and also to apply for Lasting Power of Attorney. Another couple had been given advice about Power of Attorney from the doctor. For another participant the advice to sort out such arrangements had come from a nurse:

"The nurses said you need to get your affairs in order ... so we went to the bank and I explained like my mum's in the early stages of Alzheimer's and they advised me which way to go. There's two ways we can do it and they advised me which one they thought was the best".

(Carer)

The timing of practical advice is also important. One participant made the following suggestion:

“Perhaps the advice on the practical aspects could come later on when you’ve had time to calm down and realise that it’s not all going to happen overnight. It’s bad enough it’s going to happen.”

(Carer)

In this chapter we have focused on issues for participants about communication with health professionals and the information they provided. From this analysis a number of low-cost practical suggestions about how to improve practice in relation to information giving and communication can be made and these are brought together with other recommendations in Chapter 8.

8 Conclusion: limitations, implications and recommendations

Few people interviewed in this study experienced the system of memory assessment as patient-centred. They felt that they were kept waiting for long periods of time without knowing what was going on, they sometimes experienced tests and assessments as distressing in settings that could be alarming. It is important to note that such experiences are not unique to dementia services but the early recognition of dementia is a key policy goal of the *National Dementia Strategy* (16). People with other long-term conditions also enter the healthcare systems with unclear problems and symptoms and may experience their assessment and consultations as confused and prolonged. The issues arising for people with possible dementia may be similar (87) but they may also be experienced to a greater degree in the context of people's declining cognitive abilities, the stigma of dementia and possible ageism. These confounding effects may need to be investigated so that healthcare practices can be better tailored to support people, encourage self-management and to develop person-centred models of care.

Limited information about the diagnostic process and the meaning of the diagnosis once it is made compounded these feelings of powerlessness as indicated in the literature review. Some participants understood that reaching a diagnosis could be a lengthy and complex task, although in such circumstances it was not generally the waiting that caused distress but the lack of information about why that was occurring. This understating may have been influenced by professional communication or it may reflect social conversations or media presentations of the recognition of dementia (123). There may be room to explore the impact of public discourse about dementia recognition in future studies. Some expected that the diagnosis would be revealed more quickly than it was and were disappointed when the process was lengthy and entailed much waiting. There were impressions that technology was more precisely diagnostic than it actually is. While many professionals were valued for making sense of the system, and in providing a person-centred approach, there was a perception that some staff found it difficult to talk about diagnostic processes and that team work (communication between professionals) could be better. In this context the following recommendations are made for consideration by three key stakeholder groups. These findings support other studies identified in the literature review, although our identified themes of 'waiting' as central to the experience of transition has not been so commonly reported [see Cahill *et al.* 2008; (124)].

Analysis of the data revealed a number of overarching themes which we have used to construct a set of recommendations for three key audiences; policy makers, practitioners and researchers. While there is some overlap in some of the points made, they are a unique set of recommendations coming

from the experiences of people undergoing assessment for a possible dementia, of those who have received a diagnosis, and of those who accompanied them on this journey as family members or carers. This chapter first acknowledges some of the limitations of the study.

8.1 Limitations of this study

This study has limits in three main areas. First, there is the risk of bias in that the study sites may be atypical and reflect practice and organisation that are not commonly found in England. We sought to minimise this risk by selecting three very different sites and including, within one of them, a rural area. We describe the sites so that readers may consider whether they relate to their own area, while respecting anonymity. We also debated the sites' characteristics with our National Advisory Group to see if they could identify any key characteristics that might render our sites highly atypical. This limit gives rise to the risk that our findings are not generalisable and that our observations are context-specific. We again sought to explore this with our National Advisory Group and debated this within the research team, members of which had experiences of other areas.

Our study is, of course, limited in further ways, outlined in our proposal. We sought to investigate the experiences of people living at home but we are conscious that care home populations are also assessed for dementia or memory problems. We highlight the need for greater understanding of this in our recommendations for research. Similarly, our study design meant that we were unlikely to obtain participants who lived alone without family or friends as supporters. Again, the position of isolated older people may need to be explored further (125-126). Furthermore, our study design, while including people with a wide range of socio-demographic characteristics, did not in the event lead to participants volunteering who had learning disabilities or who did not speak English. These omissions should be noted.

A further limitation, but indeed the strength, of this study is that it rests on the lived experience of individuals and not on professional perspectives. We have not sought to triangulate experiences or to assess the truth of recall or impressions; but there may be scope for further studies to adopt a dyadic or triadic perspective. Our reliance on participants' recall clearly has its limits, as too does the inevitable risk that those who volunteer to participate in the research may have strong views or be atypical in some respects. We sought to consider this in our discussions with members of the study's three Local Advisory Groups and the National Advisory Group.

8.2 Recommendations

This study took place in the first years of the *National Dementia Strategy* (16). This is a unique document in England in its focus on dementia and some of the early implementation processes of the *Strategy* touch upon the study objectives, such as the establishment of demonstrator sites for

Dementia Advisors and of peer support. Our recommendations for policy are high level and may fit with further reworking of the *Strategy*.

8.2.1 National Issues

1. Further investigation of the model of memory clinics or memory services should be undertaken over the longer term, establishing, for example, whether their presence in secondary services is cost-effective and provides a quality service. The experiences of people attending memory services is sometimes characterised by long and unexplained waiting and this system does not always seem to them to be person-centred or therapeutic.
2. Home visits for early or initial assessment and discussion following diagnosis may be cost-effective and need to be explored. They were the choice of some people in this study who indicated that they found them less stressful and reported that they felt better engaged with the process.
3. Policy initiatives stress the value of advance planning; however, these do not always fit with people's wish to live 'in the present' as expressed during this study. Ways of exploring the fit between these aspirations might usefully be reflected in policy guidance and professional guidelines about the Mental Capacity Act 2005 in particular.
4. Policy aspirations to increase the numbers of people with advance care plans and similar might be better realised if there is greater publicity about such options among those in mid life and older people generally. Discussion about future planning was not easy for some people in this study who were facing the emotional impact of the diagnosis of dementia for themselves or a relative.

8.2.2 Issues for Commissioners and practitioners

This area of recommendations is wide-ranging as the study was practice and service focused. There have been few opportunities to develop recommendations from people with recent experiences of assessment and diagnosis. Implications and recommendations of this study covered a number of areas, specifically assessment, information needs and the management of uncertainty. The latter seemed particularly characteristic of the transition process in receiving a diagnosis of dementia.

8.2.2.1 Assessment

1. Local commissioners should clarify local pathways around assessment and support for people with a suspected dementia and information about these should be easily available. Services should develop information about what might happen, the next steps and so on (pathways of care) and ensure that these are made available to people using their memory service and any supporters. As with other public information, the involvement of older people and lay readers looks likely to improve the relevance, person-

centeredness and accessibility of such information. Few of the participants in this study were happy with the coherence and quality of the information they received.

2. The process of testing or assessment is not always well-received by people with memory problems or similar. Other means of introducing and delivering testing might be usefully explored. Some valid tests themselves are more or less acceptable to people with a possible diagnosis and consideration should be given to using acceptability to recipients as a factor in choosing tests for the diagnostic pathway (see research recommendation number 4).
3. Separate consultation may be helpful but in terms of the diagnostic meeting there seemed value in talking to individuals and their carers together. Overall opportunities for later separate consultations were welcomed by carer participants and a minority of people with memory problems in this study.
4. Scans were seen by some people in this study as interventions that would immediately identify what was wrong and their experiences of scans in respect of memory services were therefore not so positive since these rarely exposed problems so rapidly. Discussion of the nature and purpose of scans might be helpfully part of the clinical conversation and written materials.
5. While practitioners may have little say in the physical location of the memory service, there were problems for some of this study's participants in some of the memory services' locations, arising from proximity to services for people with very severe disabilities that suggested immediately that rapid decline was inevitable. In contrast, some participants appreciated the quality of some memory services' settings.

8.2.2.2 Information needs

1. Participants who had been waiting for assessments or whose diagnoses were unclear were a group in this study who particularly raised the need for information about what was going on. There appeared to them to be information for people with a diagnosis but little for people in their position, which could last a long time. For those who were told they had mild cognitive impairment or similar there seemed to be little specific material outlining what they might expect or could do.
2. Feedback about patient and carer experience of local assessment and treatment pathways should be collected on a routine basis and utilised in reviewing the pathway and skills set of memory service staff. Interviews about experiences may be more productive than questionnaires and surveys among people whose recall is not always good. Our interviews with people in their own homes seemed to be encouraging of discussion and facilitated recall in some instances. Such information confirms that people using services are not simply passive recipients of information but possess unique insight into the workings of memory services.

3. While appreciating pressures on professional time, effective sharing of information needs to take account of well-established research evidence into the limited amount of information people can absorb during an inevitably stressful diagnostic discussion. Multiple sessions may be needed to share information, supported by individually tailored written notes. This can help avoid overload as described by some participants in this study. Not all information is person-centred – study participants described it as often offering a range of confusing options and failing to explain the system from the perspective of the individual.
4. Information, both verbal and written, needs to be tailored to the person with dementia and/or their family/carers and applicable to the current level of needs, rather than generic information covering a range of circumstances and levels of need. Participants said they would find this useful at all stages of the process and in all parts of the system.
5. Study participants highly valued those practitioners who offered them the opportunity to ask questions and to get back to them with further queries, confirming Cahill *et al.*'s study of people with dementia attending their first appointment in a Dublin-based memory clinic (124). The participants often remembered these staff well and saw them as modifying a system that appeared difficult to fathom.
6. Professionals might usefully share experiences on how to work with people attending memory services who do not feel 'that they should be there' but whose relatives are concerned. Carers found this difficult, with published information not evidently applicable. They described varied reactions from primary care and memory services to their concerns, many of which were long-standing or accumulating, and about which they had deliberated and had taken time in bringing to the NHS.
7. Information communication takes part in a context and practitioners should be mindful of the impact of family dynamics on the receipt and understanding of information. Family conflict or history of difficult relationships appears to be rarely addressed in material that presents carer relationships as positive and supportive. This may fail to recognise the biography of the relationship and lead to failure to adapt communication to what may be ambivalent or tense relationships. Some participants in this study felt that the background to their family relationships had not been explored and did not seem of interest to professionals, despite the effects this might have on caregiving.
8. The type of dementia is currently often being told or indicated to individuals and carers on diagnosis. While only a small number of participants commented on this, a diagnosis of Lewy-Body Dementia elicited high degree of concern when people were given information about this or sought their own. Practitioners might alert people to this and be ready with information that is high quality and supportive.
9. This study did not include people who had attended on their own for assessment and communication of the diagnosis; however, in light of the experiences of people who were supported by carers that information was

patchy, particular care needs to be taken with people who attend on their own about ensuring that information is provided in other formats and that support is offered and sustained. Other studies have pointed to the vulnerability of this group (125-126).

10. Participants in this study valued the supply of memory tips and hints and these should be available in a variety of formats. Not everyone is able or wants to attend courses or support groups and relatives or friends may also find such information helpful.
11. Practitioners may wish to develop their knowledge of local voluntary support services beyond the dementia specific sector, particularly carers groups and older people's networks. This was valued by some participants in this study.
12. Copying letters to the person with suspected dementia and after a diagnosis is confirmed was greatly valued by participants in this study, particularly if the letter was addressed to them and copied to other professionals. They saw this as person-centred, as a way of avoiding jargon or inexplicable terminology, some of which could be alarming e.g. 'dyspraxia', 'euthymic', and so on. Such correspondence facilitated recall and could be used for a variety of purposes. They felt able to share such letters with other professionals when details of their condition were not so easily recalled. This practice might be more widespread and form an indicator of good practice for dementia services more widely.
13. While it may seem obvious, copying letters to family members or other supporters about appointments and so on was valued by relatives or carers who were involved in ensuring that appointments were kept. Some participants suggested that services should bear in mind that people with memory problems were likely to forget things and should have an explicit strategy for addressing this. Carers who were denied this information were, not surprisingly, distressed.
14. While this study did not explore team working or professional practice, the experiences of people with suspected dementia and their carers suggest that there might be value in team approaches to agreeing communication with patients and carers, outlining who is responsible for communication, and so on. This might reduce the risk of people being told their diagnosis by letter or apparent confusion about who has been told what, such experiences being recounted by a minority of participants in this study. In a sense there may be merit in thinking about people with memory problems and carers being more the navigator of their own care and participating in assessments more proactively. The interviews conveyed a very strong sense that they were the experts on what the problems were, the impact they had and their priorities over time. Such experiences chime well with current emphases on self-management (127).

8.2.2.3 Management of uncertainty

1. Memory services and health professionals, e.g. GPs, psychologists or nurses, could start the dialogue about a possible dementia earlier when an

individual presents with symptoms that lead to a referral to a memory clinic or service. This seemed to be welcomed by participants in this study when it had occurred. This suggests a role for GPs to prepare people about the diagnostic process and what it entails – this might include providing an information sheet at the point of referral and explaining the process.

2. People might be encouraged to take a more proactive part in their investigation and treatment if professionals encouraged them to think about their needs prior to clinical encounters, e.g. writing down questions, formulating concerns. This might be relevant in consultations in primary care or later after referral and diagnosis. Some people might benefit from assistance in thinking about the questions that they would want to ask and this might be a role for peer group members, carers' workers, voluntary and community groups/individuals or primary health practitioners. This point was raised by both people with dementia, those undergoing assessment and family members. It may usefully be placed in the growing debates about the potential for self-management of long-term conditions, including dementia (127).
3. Due to the complexity and variability of dementia conditions, uncertainty – about diagnosis and prognosis of the condition – will be a feature of their contact with memory services for many people with possible dementia and their families. Not all practitioners are skilled in conversations with many patients or clients around issues of uncertainty. Sharing good practice and skills in teams may be important parts of continuing professional developments. Participants in this study suggested that some professionals were better than others at this task.
4. Responses to diagnosis, both within an individual and a family group, may be complex. Practitioners need sophisticated skills to understand and work with such complex responses, and make explicit options for emotional support. They also need to recognise, as many of them reportedly did in this study, that the needs of people with memory problems and their carers may diverge. Both people with memory problems and carers undergo the transition to a diagnosis of dementia. Participants were sometimes themselves aware of the ways in which their initial reactions might have seemed to close doors on further discussion.
5. The ability to build or sustain confidence among people receiving and then living with a diagnosis of dementia is a valuable skill and its development should be promoted and fostered among teams and the wider network of support. Some participants indicated that this skill was appreciated and lightened their load. There are implications for providing continuity of support across healthcare services in terms of team formation and notions of key working.
6. Managing expectations is another valuable skill and examples of how to provide this in a realistic way should be shared. People may benefit from factual information but also from guidance in managing different expectations, such as those related to medication effects, the trajectory of the syndrome, and levels and extent of professional contact. Along with

waiting, managing expectations was an important way in which individual professionals buffered the 'system'. There may be scope for individual key workers to hold such roles, as with the new Dementia Advisors being piloted in demonstrator sites in England (16).

7. Carers may seek feedback from practitioners about their handling of difficult situations and may wish for validation of their approaches. Some carers in this study described seeking such consultation. Practitioners should be prepared for such questions and acknowledge that meeting these needs for support enhances carers' abilities and addresses their concerns.
8. Individuals and their families may hold different views of the meanings of terms such as '*dementia*' and '*Alzheimer's*', with some fearing one more than the other or seeing them in different lights. Our study revealed that there were various views or opinions, some influenced by people's earlier experiences of dementia among family and friends. While some people may hold views that are in line with current practice terminology, the importance of exploring with individuals and families their understandings should be better and more consistently undertaken.

8.3 Research questions

In this section we outline some of the emerging questions arising from this study. Each of the areas concludes with a possible research question or debate.

1. There are opportunities for people with dementia and/or carers or other public involvement groups to explore adequacy of local information sheets and to alert services to areas or topics that they feel might usefully be included (128). User-led research or studies with high levels of user and carer involvement would be one way of ensuring this addressed information science and appropriateness criteria for an impact study. *What information meets the needs of people being assessed for memory problems and of their carers? How localised should this be?*
2. Because care home populations were not included in this study, information and other needs might usefully be addressed for this population and those supporting them. For them too, there will be information requirements and needs to manage uncertainty. This might be set within skills developments around person-centred care. *How do people living in a care home experience seeking help with a memory problem and what might help support care home staff?*
3. Because most of the study participants were living with family members or had strong support, further research investigating the pathways to diagnosis among people living alone or who are isolated might lead to better insight into the needs of this population and greater confidence that services are able to meet their requirements for support [as called upon by earlier studies from the USA and Australia (125-126)]. *What would be the*

best pathway and practice for a person living alone and with little social support in seeking support with memory problems?

4. Development of more patient-acceptable screening and neuropsychological assessment tests should be explored. Study participants had various experiences but felt that testing was largely a passive process. What tests are effective which also do not contribute to ill being among them taking them? There is room for development and evaluation of learning packages to support skills development in communicating the diagnosis and managing information sharing with people with dementia and their families/carers. The managing of uncertainty is a skill that may be needed in the context of greater efforts to encourage people to seek early advice about memory problems [see e.g. NHS Choices 2010; (129)]. *What skills sets are needed to communicate well, especially when there is no clear indication of a definite diagnosis?*
5. There may be merit in exploring the ways in which other services in the NHS with which older people are often engaged are able to suggest that people talk to their GP about emerging memory problems or other difficulties. In this study some participants had had long encounters with other parts of the NHS but did not appear to have had it suggested that they raise their memory or similar concerns with their GP. *What might be the protocols for linking up other parts of assessment and treatment in the NHS with memory services?*
6. Memory tips and hints are variously suggested and appreciated. A stronger evidence base for these might be developed so that those that are effective are more widely promoted. *What are the relative merits and benefits of different resources and supports for people wishing to sustain their abilities and memory?*
7. The literature review highlighted the continuing absence of validated stepped care models of delivering psychological therapies relevant to people with dementia and concluded that further research in this area is needed. This recommendation was reinforced by the empirical data from this study. Which models of stepped care work well and how do they work in combination with other models applicable to individuals who may have other long-term conditions?

8.4 Conclusion

The key challenges identified in the qualitative literature review conducted for this study related to undergoing the transition from a person with memory problems to one living with dementia. These were seen as coming to terms with losses on multiple levels; psychologically, socially and functionally. We found that those authors who pointed to the need for timely identification of people experiencing emotional distress and struggling to cope reported that early specialist help might be beneficial. However, the literature refers to a shortage of specialist services in many countries and notes that psychological therapies may not be easily accessed (120). There is increasing call for alternative sources of support to be made

available via peer support groups or a stepped care model of psychological interventions. Unfortunately, the literature reveals few validated stepped care models of delivering psychological therapies especially in dementia.

Chapter 5 describes the experiences of participants that we have conceptualized as encompassing five transitions: 'Internalising dialogue': the self awareness that something may be wrong; 'Confirming positions': the seeking of confirmation from those closest to the person with memory problems that help is needed; 'Seeking expert advice': disclosing position to professionals (usually GP); 'Being tested': undergoing diagnostic investigations and receiving results; and 'Seeking understanding': from professionals and other sources. Building on the accounts of these transitions, Chapter 6 describes the expectations and experiences of people with memory problems and their carers, observing the frequent reports of waiting and feeling to be in a limbo-like state (87). A key emerging finding is the difference in expectations and experiences of those participants who accessed memory services early compared with those participants who accessed memory services later. This contrast appears to be influenced by clinical factors as well as social factors, such as social networks and participants' personal biographies. Nevertheless, our interpretation is that although many expectations and experiences are shared by both groups, those participants who accessed memory services early often have higher expectations for support and treatment, particularly in relation to receiving a diagnosis and reassurance, and are more likely to be disappointed by their experiences of the early transitions along the dementia pathway. Participants in both groups lacked an understanding of the clinical uncertainties surrounding a diagnosis of dementia and were frustrated by not getting a clear answer or prognosis. A lack of information about the process of diagnosis appears to result, for some, in unmanaged expectations. Chapter 7 explores in greater detail the information needs of participants and how the quality of information influenced communication between participants and health professionals.

This study provides new evidence about the experiences of people through the process of transition to a 'person with dementia'. It concludes that the process is sometimes characterised by uncertainty and waiting. These findings suggest that transition is not a linear process. We conclude that professionals are able to provide tailored support to individuals and their carers at this uncertain time if they are better informed of the 'journey' from the insights of those who have undertaken it.

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Addendum

This document is an output from a research project that was commissioned by the Service Delivery and Organisation (SDO) programme, and managed by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO), based at the London School of Hygiene & Tropical Medicine.

The management of the SDO programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Although NETSCC, SDO has conducted the editorial review of this document, we had no involvement in the commissioning, and therefore may not be able to comment on the background of this document. Should you have any queries please contact sdo@southampton.ac.uk.