'TELL ME THE TRUTH'

The effect of being told the diagnosis of dementia from the perspective of the person with dementia

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i. Summary

i.i Background

The aim of this research was to explore the effect of being told the diagnosis of dementia from the perspective of the person with dementia. This study came about through identifying a number of different concerns: the debate about disclosure, disclosure practices, the under representation of people with dementia in research and the need to develop psychosocial understandings of the experience of people with dementia.

There is a great deal of debate around the practice of disclosing the diagnosis of dementia to people with dementia, particularly the question of ‘to tell or not to tell’. The debate tends to focus on the views of health professionals and carers (Maguire, et al, 1996; Rice and Warner, 1994). Arguments against diagnosis disclosure include that it will be too distressing for people with dementia to know their diagnosis (Drickamer and Lachs 1992). Arguments for disclosing the diagnosis include people having a right to know their diagnosis, increased opportunity for support and the ability to make plans (Fearnley, Weaks and McLenman, 1997).

The debate around diagnosis disclosure is reflected in low disclosure rates and wide variation in practice. In Scotland almost half to two thirds of general practitioners in Scotland do not tell the person their diagnosis (Downs and Rae, 1996). More recent studies also show an ongoing reluctance to disclose a diagnosis of dementia to patients (Audit Commission, 2000, Vassilas, 1999).

People with dementia have been under represented in research, particularly in relation to the issue of diagnosis disclosure. The views of older people without dementia (Holroyd, et. al., 1996) have been sought on this issue, as have the views of people with dementia who did not know their own diagnosis (Marzanski, 2000), but the views of people with dementia who have experienced diagnosis disclosure were absent from research.

A number of studies have started to explore the experience of people with dementia from the perspective of the person with dementia (Froggatt, 1988, Gilles, 1995, Keady and Nolan, 1995, Harris and Stein, 1998). These studies provide a great deal of insight into the psychology of people with dementia. Kitwood (1993, 1997), has also made an important contribution, particularly by highlighting the need to incorporate social context to our understandings of people’s experience of dementia. There is a need to continue to develop our understanding of the experiences of people with dementia, particularly in relation to issues such as diagnosis disclosure.

i.ii Objectives

Three main objectives for the study were to:
1. explore how people with dementia feel about the way in which they were told the diagnosis;
2. gain insight into the opportunities and limitations offered by an early diagnosis for the person with dementia;
3. guide best practice in diagnosis disclosure.
i.iii  Method

People with dementia were recruited into the research through medical professionals, voluntary organisations and day centres. The inclusion criteria for potential participants was that the person had been given a diagnosis of some form of dementia, that they had been told their diagnosis, that they were in a sufficiently early stage of the dementia that there were able to talk with some level of insight about their experience and were able to freely provide informed consent.

Potential participants were initially approached through the professional we first contacted. The study was explained and permission was sought for a member of the research team to contact them and seek consent. Due to the difficulties in recruiting participants to the study, only 12 of the 24 participant were asked to be interviewed twice (one withdrew from the second interview due to illness). The remaining 14 participants were interviewed once. The interviews were taped and transcribed for the purpose of analysis. Data was analysed using two approaches. The first of these was to look for key themes that arose in relation to the research questions by combined inductive and deductive approaches in order to develop themes and highlight issues arising from the data (Denzin and Lincoln, 1998). The second was the use of case study analysis to provide an understanding of the process and context experienced by participants. The use of two approaches in the data analysis provided added depth to the analysis.

i.iv  Findings

Twenty-four people with dementia participated in the study. The age range was from 44 to 78 years old. Of the 24 participants 11 were under 65 years of age and 13 were 65 years or older. 13 of the participants were women and 11 were men. Twenty-three of the participants were Scottish, one was Welsh. 21 of the 24 lived with a partner or family, and three people lived alone. Due to a number of reasons, including the variation in the practices of diagnosis disclosure, five participants did not know their diagnosis. No person had their diagnosis disclosed to them by the research team.

i.iv.i  Part one: Meeting the objectives

1. To explore how people with dementia feel about the way in which they were told the diagnosis.

Receiving a diagnosis of dementia is often a lengthy process, involving a number of procedures, tests and different medical professionals. It is also a very emotional time when how the diagnosis was shared may be less salient than the shock of knowing. Participants described a number of different feelings they experienced when they were first told their diagnosis, including shock, anger, fear and depression. Some participants also felt some sense of validation from the diagnosis as it provided an explanation for the changes they had observed within themselves.

I thought that was the end of my life, I really did, I honestly did, I thought that was it, I just couldn’t see anything beyond it and as the time goes on a bit and then you realise that it is worthwhile persevering, cause, I really thought that was it I just couldn’t get to grips with it, but however, you get over that stage. (Karen)
The possibility of anti-dementia drugs for people has also had an impact on the processes people go through. For some people the extra testing that accompanies drug therapy can come increase pressure to perform well on memory testing.

*I’ve got this terrible fear of someone taking my pills off me, you know, that kind of, I’m worrying in case I make a muck up, make a muck of them (the memory tests), that’s my main problem.* (Karen)

An important part of the diagnosis process is how much information people want to know about the diagnosis and prognosis. Two main approaches to information emerged from the interviews, one being the person with dementia actively seeking information, and the other, to only seek information as it applied to their situation, in effect just taking it a step at a time.

*I think I know all I want to know.* (Helen)

2. **To gain insight into the opportunities and limitations offered by an early diagnosis for the person with dementia.**

Of the people interviewed who knew their diagnosis, most could identify a number of opportunities gained by learning the diagnosis. These include practical matters such as being able to make plans for the future and taking care of financial and legal matters. Other opportunities included being able to understand the changes within themselves and in behaviour, which may provide the opportunity to find a positive approach to the diagnosis. For some people it provided an opportunity to make the most of their time. When people could be accepting of the fact that they may decline at some point there was often the attitude of making the most of the time they have with the abilities they have.

*I’m playing an active part in society again and I’ve actually given some of these (help) cards out to carers you know, I’ve been speaking to people and their carers didn’t have a card so I gave them a help line card.* (Alex)

For some people, knowing the diagnosis has given them the opportunity to think more actively about ways around the problems they were experiencing, such as, use of daily routine, using a diary and memory aids. Accessing appropriate social support was also important.

*I think I would suggest that that they try and find out (the diagnosis), just because of the level of support I’ve got, I found it very important to be surrounded by people who know what they’re talking about and what was wrong with me and what I might do that other people might find strange.* (Dave)

The participants identified few limitations from knowing the diagnosis of dementia. The limitations that were identified included the impact on self-confidence and restrictions to daily activities. The reduction of self-confidence that some participants described was due to participants becoming more aware of their own limitations. There are few limitations for people with dementia following diagnosis disclosure and the limitations did not outweigh the opportunities provided by knowing the diagnosis for those that could identify them. Also, limitations, such as self-confidence, may not be as closely linked to the disclosure of the diagnosis as they are to the impact of the disease.
3. **To guide best practice in diagnosis disclosure.**

Participants in the study were able to talk easily about how they felt about having been given a diagnosis of dementia. However, it was difficult for people to talk about the practices of diagnosis disclosure as this was difficult to remember. The feedback that was given about practice included allowing the diagnosis to be disclosed over time and in a supported way. Unfortunately not many examples of this happening were provided by participants. Often the positive reports of good practice related to medical staff that were not disclosing the diagnosis, such as community psychiatric nurses.

There were some points raised by participants about good practice. These points reflect the need for disclosure to be done sensitively and to respond to individual needs. These individual needs included the need for information and the need for follow up visits with medical staff.

*Well yes, yes if a doctor gives you a diagnosis he should be able to give you prognosis then.* (Susan)

People in the study were able to identify areas of poor practice, such as the diagnosis not being disclosed soon enough and a lack of information (particularly about prognosis). Some examples of poor practice were highlighted by participants in the study. These reflected issues such as not enough information being given to people, the lack of follow up and contradictory information from different health professionals.

*Well I would have thought it would have been courtesy actually (to have a follow up appointment), but eh, because eh, the amount of questions that can come up, and if you’re looking for answers then you want to have somebody that can give you answers, ... I’d rather hear things up front.* (Phil)

Poor practice often seemed to be the result of a lack of awareness and sensitivity by professionals disclosing the diagnosis. This resulted in people having their diagnosis withheld when they did want to know it. A greater understanding of an individual’s need and the potential impact of inappropriate non disclosure is needed.

*(To know) that there’s a reason for all this odd behaviour, all these arguments, that it was a medical condition that had caused it. Um, knowing myself, I knew there was something wrong, I didn’t think that anybody believed I was ill..* (Alex)

An important issue in the practice of diagnosis disclosure is whether people with dementia should be told their diagnosis or not. We asked participants what their views were about whether the diagnosis should be shared or not. All participants who knew their diagnosis felt that people with dementia should be told their diagnosis, however some did express the view that people in later stages of dementia might not be able to understand the diagnosis and that this should be decided on a case by case basis. Participants also generally felt they should have the diagnosis disclosed to them as soon as possible.

*I got it very early indeed, earlier than most people do, and this is one of the arguments they use for not telling people. They say she wouldn’t know anyway or he wouldn’t know anyway if we told them, but they still should be told. And they say, oh they couldn’t stand it, it’s not them that couldn’t stand it, it’s the carer’s who couldn’t stand it, they’re the people who are keeping it back, they couldn’t take the role of telling them, they don’t want them to know, so they can say, aye, you’re just a bit forgetful, or you’re just this. And to me that is absolutely criminal, you should let the people know and then they know where they are.* (Jack)
Part 2: Developing our understanding of diagnosis disclosure

Participants described a number of different psychological processes. People experienced a range of these feelings depending on the individual. These seemed to represent the individual’s journey between the following processes, with the ability to move through different stages in no linear order. We summarised these processes into the following descriptions; noticing symptoms, diagnostic processes, diagnosis disclosure, ‘crisis’, prognosis, maximising coping strategies, denial and distress.

Social factors were also important in influencing the experiences people had. These social factors included support, medical practice, family or carer attitude, social stigma, accessibility of information, level of awareness and services. Some participants were aware of the impact of their context on their ability and confidence. The potential for positive contexts for regaining and maintaining lost self-confidence was identified. Social support was a key factor in creating positive social contexts for people. This support was found through friends, family, partners and through support agencies. For some people they didn’t necessarily want to access external support, but were pleased to know it was there if they did need it.

Medical practices, including views on diagnosis disclosure held by professionals could be very influential. Some medical practitioners were very understanding and supportive of people with dementia in this study. These practitioners became useful resources for people with dementia and their families.

The debate over whether to share the diagnosis of dementia or not provides a good example of social factors impact on people’s experiences. There are a number of reasons why people might not have known their diagnosis, but when the diagnosis was withheld when the person did want it, psychological distress was caused. This finding is ironic, as often a diagnosis is withheld to avoid causing distress. However most people are already aware that there is something wrong, and in these cases of non disclosure it is the practice of withholding the diagnosis and not the dementia itself that is contributing to the distress. A person’s potential to access maximising coping strategies may also be effected by non disclosure.

I would shoot the person that tried to keep it back from me, I really think its an absolute disgrace, you should be told at the earliest moment, even if people say to you it might be that, we’ll have to test it, even tell them then. Then if you want to ignore it, ignore it if you wish, but it’s your choice, it’s not the doctor’s choice, or the carer’s choice, it’s your choice, and you should be given that choice. (Jack)

The impact of psychological and social factors on each person’s experience were significant. The case studies presented in the research report illustrate how individual experience is moderated by psychological and social factors, supporting the development of a psychosocial model.
i.v Implications

- To continue to develop our understanding of the experience of people with dementia it is important to consider the impact of both psychological and social factors on people’s lives. Developing this understanding will help us to learn about practice issues, such as the effect of diagnosis disclosure on people with dementia.

- Social context plays an important role in people with dementia’s experience: positive social contexts, including social support, can help increase the potential to access maximising coping strategies. Practitioners, as an important part of this context, have the potential to be a positive resource in supporting people with dementia.

- The opportunities from knowing the diagnosis of dementia outweighed the limitations.

- Inappropriate non disclosure of the diagnosis of dementia can cause great distress: non disclosure can prevent people from gaining important self understanding and developing positive coping strategies. The negative impact on the person with dementia and the impact on their relationships with others needs to be considered when making decisions about diagnosis disclosure. Inappropriate diagnosis disclosure also needs to be safe guarded against.

- People need support through the ‘crisis’ that can happen after diagnosis disclosure: This time of ‘crisis’ is often part of a process of learning how to cope with the diagnosis. This is a time in which follow up support, information and advice can be very useful.

- People with dementia can and do find positive ways to cope with their diagnosis, particularly when they have supportive social contexts.

I just thought, well I'll have to take it on board, that's it, no sitting crying into my beer. I'll do the best I've got with what I've got and have a set routine, which I have, doesn't mean I can’t shift it about, but you can see I do certain things on certain days and that gives my life a pattern, so I manage that way. And try the best I can to be positive about it and eh, you know, not think, oh, getting worse even though I can. I've just got to take it day at a time, I can’t do anything else. (Mary)
1. Introduction

1.1 Background

There are a number of key issues that were influential to the development of this research project. These included the debate on whether people with dementia should be told their diagnosis of dementia or not, the current practices in diagnosis disclosure, the way in which people with dementia had been involved or not involved in research on this issue and our current understandings about the subjective experience of the person with dementia. These issues will be discussed in the following section, concluding with the aims and objectives for the current study.

1.1.1 “I would shoot the person that tried to keep it back from me, I really think its an absolute disgrace” (Jack)

The debates around disclosing the diagnosis of dementia with people with dementia are well rehearsed by health care professionals and carers (Maguire, et al, 1996; Rice and Warner, 1994). Arguments that favour the sharing of the diagnosis maintain that sharing will maximise individual autonomy through the provision of necessary information for decision making and advance planning (Drickamer and Lachs, 1992). Further support for disclosing the diagnosis includes the increased opportunity to access appropriate support, new treatments and the fulfilment of the ‘wish to know’. These arguments are firmly grounded in a rights model where individuals have the ‘right to know’ (Fearnley, Weaks and McLennan, 1997). The factors outlined for withholding the diagnosis tend to be grounded in concerns around the claims that making an accurate diagnosis is problematic; that therapeutic options are limited and the level of anxiety a diagnosis may produce in the individual being told (Drickamer and Lachs 1992).

These perceived advantages and disadvantages appear in the research literature as views of various professional groups involved in the debate. To date the views of psychiatrists (Rice and Warner, 1994), GPs (Downs and Rae, 1997; Audit Commission, 2000) and carers (Maguire et al, 1996) have all been reported. However, the literature showed very little in relation to seeking the views of people with dementia themselves about diagnosis disclosure.

1.1.2 Current Practice

In practice, almost half to two thirds of general practitioners in Scotland do not tell the person their diagnosis (Downs and Rae, 1997) while recent guidelines for the primary care management of dementia make no mention of best practice in diagnosis disclosure (Centre for Health Services Research Evidence-based Clinical Practice Guideline, 1998). A recent survey of GP practice revealed an ongoing reluctance to disclose a diagnosis of dementia to patients (Vassilas, 1999) despite increased calls highlighting the positive aspects of giving a diagnosis (Fearnley et al 1997).

In 1994 a survey of Old Age Psychiatrists in the UK asked about their diagnosis sharing practices with people with dementia and their carers. Their findings indicated a wide variation in practice where carers were almost invariably told the diagnosis.
For patients, people with severe dementia were never told; and although there was a tendency to tell moderately affected people, practice was again variable for people with mild dementia. In cases where a diagnosis was given few practitioners followed this with information on the prognosis for the individual (Rice and Warner, 1994).

More recent data from a survey of GPs carried out for the Audit Commission (2000) indicated that only a half of those surveyed felt it was important to look actively for early signs of dementia. Those who did not look for the early signs of dementia felt that there was no point looking for an incurable condition. How this might be reflected in the practice of diagnosis disclosure was shown by Downs and Rae (1997) where, in a sample of 133 GPs, 56% reported sharing the diagnosis with the patient but 97% would tell the carer. Further evidence from carers highlighted the inadequacy of GPs at providing information and support. The Audit Commission (2000) recommended that GPs should be alert to early memory problems using protocols and standardised assessment tools. They should also have training and guidance on how to best inform carers and users and to initiate support services.

It is clear that diagnosis sharing in the field of dementia is still a point of debate with practice remaining variable. In recent years developments in services and drug treatments may be leading to a shift in diagnosis sharing practices. The increase in memory clinics may be part of this shift. Beese (2000) recommends memory clinics as being well placed to develop a more comprehensive and holistic service for people with dementia and their carers. This reflects the findings from Hill et al (1995) survey of what service users wanted from memory clinics. Respondents wanted an explanation of, and advice on, dealing with memory problems. The survey findings also indicated that these expectations were not met. A survey of 20 UK clinics found that only six of them had written or verbal guidelines on what to tell patients and families. Furthermore their use of terms like ‘memory problems’ and the avoidance of the word ‘dementia’ could lead to difficulties (Gilliard and Gwilliam 1996).

The origin of the views and practices of professionals seems to be grounded in the inability to offer an explanation or a solution to the memory problems associated with dementia. It is possible that a shift in attitudes and practices may become a more widespread reality if professionals were able to make more accurate diagnoses and be able to offer some therapeutic interventions. In which case a corresponding increase in diagnosis sharing will occur. This shift would follow a similar pattern to that which occurred in the field of cancer during the 1960s and 70s. Novak et al (1979) compared the attitudes of physicians in 1961 where 90% of respondents indicated a preference for not telling the person with cancer their diagnosis but by 1977 the same survey found that 97% of physicians responding indicated a preference to share the diagnosis. This complete reversal of attitude was related directly to clinical experience. In addition to these social changes an important positive aspect in the sharing of prognostic information was the growing importance of clinical research leading to radical changes in the management and prevention of cancer.

With increasing awareness of dementia, steps towards scientific findings and the opportunities offered by drug therapies may lead to professionals feeling they have something to offer following a diagnosis of dementia. Irrespective of such practical moves perhaps the increased focus on human rights based on models such as the ‘Right to Know’ (Fearnley, Weak and McIlenan, 1997) will lead to practitioners sharing the diagnosis more often with the individual with dementia.
1.1.3 Including The Perspective of People With Dementia

A key element in this rights based shift in the field of dementia is recent attempts to ascertain the views of people outside the health care professional field. To date these have focused on asking people without dementia their views on diagnosis sharing. For example, a study by Holroyd et al (1996) used vignettes to explore the attitudes of older adults’ on being told the diagnosis of Alzheimer’s Disease. The respondents answered questions regarding their attitudes to the vignettes, one of which is about a person with cancer and one a person with Alzheimer’s Disease. Most participants (n= 124, 79.5%) responded that they would prefer to know if they had Alzheimer’s Disease, but the number was significantly fewer than those who would want to know if they had cancer. Among the reasons some subjects gave for wanting to know of the diagnosis of Alzheimer’s Disease was being able to consider suicide.

Research considering three case studies of people who had been given a diagnosis of dementia (Husband, 1999) found that none of the people appeared significantly depressed or expressed suicidal ideation and any anxiety over the diagnosis was reduced over a series of counselling sessions. The participants expressed that they had valued the opportunity to express and discuss fears. Carers of people with dementia expressed similar value in experiencing the opportunity to participate in research (Smith, et al 1998). This study used a postal questionnaire to examine the effect on patients and carers of being told the diagnosis of dementia, and to explore the perceptions of carers and as far as possible patients, regarding their experience of research participation. Results indicated an overall positive response from patients and carers to research participation with most carers preferring to know and being eager for information. Carers indicated that patients and families could benefit from early disclosure of diagnosis. This requires early referral, sensitive and ongoing support and further research into patients’ reactions (Smith, et al 1998).

This call for a better understanding of the views of patients is part of an increased recognition that the views and experiences of the person with dementia need to be included in our understanding of the illness (Cottrell and Schulz, 1993, Downs, 1997). The field of dementia now recognises the role for the individual’s self of sense, person’s rights and the value to be gained from including the perspectives of person with dementia in research. An article by Marzanski recently reflected this paradigm shift describing a questionnaire study with 30 people with dementia (2000). Marzanski’s objective was to discover what the people with dementia felt was wrong with them and what they have been told, by whom and what they wish to know about their illness. It was found that the quality of information received by the participants had been poor and many patients had no opportunity to discuss their illness with anybody. Despite that, almost half had adequate insight and a majority declared that they would like to know more about their predicament. The conclusion was that although patients would like to know the truth, the rights of those who do not want to know should also be respected. Therefore, the diagnosis of dementia should not be routinely disclosed but health care professionals should seek to understand their patients’ preferences and act appropriately according to their choice. Pitt states “although there is probably no point in telling those whose Alzheimer’s Disease is so advanced that they cannot understand their diagnosis, in all other cases the right of those who have presented as patients to know what is wrong with them should be respected” (1997).
In acknowledging a rights based individual model of diagnosis sharing, there is also a need to have individual perspectives of people with dementia included in the debate on diagnosis sharing. Part of doing so is in overcoming the stigma associated with dementia and the related perceived inability of people with dementia to share views due to cognitive decline. Several studies in the late 1990s have illustrated that people with dementia do have clear views on issues and that these can be included in research. In 1998 Robinson et. al. tried to understand the part played by clinical diagnosis for eight people with suspected dementia trying to make sense of their experiences. The findings revealed the importance of a diagnosis for ‘making sense’ of early experiences of memory loss as participants were provided with a means of interpreting and ascribing some meanings to the changes in themselves.

Work by Lyman (1989) presented a challenge to the medical model’s focus on disease progression by focusing on the views of people with extreme impairment, loss and dependency on quality of life and creation of meaning. This work was influential in its ability to illustrate people ‘living with’ rather than ‘dying from’ dementia. This type of work also highlights the problematic nature of much research in the field of dementia, including that on the debate around diagnosis sharing since the individual’s perspective is missing. The significance of this lack of perspective is further highlighted in the work of Sabat (1998) who uses conversations he had with a person classified as being moderately to severely impaired to show that an intact sense of personal identity, an intact social identity (given the co-operation of others) and a desire to be recognised properly all remained. It is this type of recent work that illustrates the ability as well as the necessity to include the views of people with dementia in research.

1.1.4 Developing Our Understanding of the Experience of People with Dementia

Beyond establishing that people with dementia could be included in research and that their views could be elicited, the field of dementia research has worked to understand the subjective experience of people with dementia. This is often characterised by what is called a person centred approach (Woods, 2000). A number of studies have begun to explore this subjective experience, such as Froggatt, (1988), Gilles, (1995), Keady and Nolan (1995) and Harris and Stein (1998).

In 1988 Froggatt highlighted the need to consider social, psychological and biological factors in trying to understand the experience of people with dementia. Froggatt highlights the case of three people with dementia and discusses the importance of considering the impact of social context on the experience of the three people she interviewed. Gilles (1995) conducted interviews with 19 people with dementia and their carers about their experiences. Only three of the 19 people knew their diagnosis of dementia. Gilles spoke with people with dementia about a number of subjects, including symptoms they experienced, the services they were accessing and relationships with carers.

Keady and Nolan (1995) moved to propose a developmental model of dementia where a number of different stages that people with dementia experienced were suggested. These were: slipping, suspecting, covering up, revealing, confirming, surviving/maximising, disorganisation and decline and death.

Harris and Stein (1998) conducted a study in which 17 people with dementia were interviewed. The research explored the concept of the definition and preservation of
self in people with dementia. The impact on self concept and the changing sense of self were explored in the study. People experienced feelings of loss on multiple levels (e.g. independence, roles, competency, memory, relationships). The range of emotional reactions linked to maintaining the sense of self despite the dementia included frustration, anger, embarrassment and humiliation. People with dementia also reported a number of different coping strategies such as using daily routine, lists, humour, support from family, support groups, faith, other unique strategies relating to individual skills. From the research Harris and Stein developed a typology of different reaction patterns:

1. I'll live till I die - fighters, independent, engage in activities that defined who they are.
2. I accept what I have - accepted the diagnosis without much of a struggle and adjusted without change.
3. There is nothing wrong with me - denial, don’t accept diagnosis, denial of symptoms.
4. I’m just struggling to get through the day - covering up, still coming to grips with it
5. I’m giving up - scared, angry, give up

Harris and Stein concluded from their research that the social interactions people with dementia experienced impacted on their sense of self. Examples were provided of the impact of Kitwood’s (1997) ‘perceived malignant social psychology’ in a case study of a man who had restrictions placed on driving, and how the man, in perceiving the negative context, felt the negative impact to his self identify. Maintaining self identity is difficult as it will experience changes due to the dementia, the idea of the defended subject explains some of the coping responses, particularly denial, as people may try to maintain an unchanging self identity, psychologically defending themselves against changes in self identity.

Whilst the above studies provide a great deal of insight into the psychology of people with dementia, work has also been done that highlights the importance of challenging traditional psychological understandings, such as the work of Kitwood (1997). He developed understandings of people with dementia that built on conventional understandings of personality types, such as the work by Jacques (1988) where people were characterised by displaying one or more of the following personality types; dependent, independent, obsessional, hysterical and psychopathic. Kitwood moved towards an ‘ethogenic’ approach, which considered more widely that personality types were a ‘a set of learned resources for action’ (1997: 14). Kitwood argued that coping strategies deployed by people in the early stages of dementia will relate to the coping strategies used throughout their lives. These learned resources enabled the role of social factors to be considered in relation to how people dealt with the dementia. The dementia itself could be responsible for reducing those resources, as could factors external to the person, such as the response of others around them.

Kitwood’s (1997) approach continues to build from psychoanalytical traditions of understanding and also begins to incorporate the importance of social factors. This is an important development in moving towards a psychosocial model of dementia, one which challenges the victim blaming values that underlie what Kitwood would have called a ‘malignant social psychology’. Kitwood described the effects of malignant social psychology as treachery, disempowerment, infantalisation, intimidation, labelling, stigmatisation, invalidation, banishment and objectification (1997).
Earlier work by Kitwood (1993) had described the person with dementia in the following way, \( D=P+B+H+NI+SP \), with \( D \) = dementia, \( P \) = personality, \( B \) = biography, \( H \) = physical health, \( NI \) = neurological impairment and \( SP \) = social psychology. This idea is reminiscent of early psychologists who recognised the importance of context in understanding the psychology of people such as Lewin's (1951) description, \( B=f(P,E) \), where behaviour is a function of the interaction between an individual in combination with their environment (also see Reisse, 1975 for a discussion of dispositional situational and social structural factors, more recently see Cicourel, 1981, in relation to the need for multi level analysis). This earlier work by Kitwood was reflected in a movement by psychologists to include the context of peoples lives into our psychological understandings and provided an important base for his later work.

The implication of the idea of including the social context relation to dementia calls us to understand the individual’s experience of dementia in combination with his or her experiences and social context. Downs (2000) calls for the need for our understanding of dementia to learn from fields such as disability, where social models of understanding have been influential in developing theories that do consider context. The application of a social model of dementia could be the key to moving beyond critiquing the dominant biomedical and psychological models and into new theoretical development (Downs, 2000). This move to include context in the field of dementia has already started and Kitwood’s work provides a good example of this. Continuing to develop a psychological understanding that includes social context was explored in this research. This was particularly necessary as the practice of diagnosis disclosure was an important focus of the research. The impact of diagnosis disclosure on people with dementia needs to consider social context, as the practice of disclosure exists in the social context of people. The response to the disclosure could be both psychologically and socially affected, making it necessary to consider context carefully in this study.

### 1.2 Aims and Objectives

The aim of this research was to explore the effect of being told the diagnosis of dementia from the perspective of the person with dementia. The study explored how people who have been told they have dementia feel about having been told and about the way in which they were told. Such information will help address the gap in the literature about the effect of being told the diagnosis and will guide best practice in diagnosis disclosure.

The three objectives of the study are:

1. to explore how people with dementia feel about the way in which they were told the diagnosis;
2. to gain insight into the opportunities and limitations offered by an early diagnosis for the person with dementia;
3. to guide best practice in diagnosis disclosure.

This report will present the research method, the findings from the three objectives and show the development of a psychosocial model of understanding the subjective experience of the person with dementia. Finally the implications for practice will be discussed.
2. Methods

2.1 Recruiting Participants

The participants included in the study were required to meet a certain inclusion criteria. These were that:

- the person had been given a diagnosis of some form of dementia.
- the person had been told their diagnosis and had retained that information.
- they were considered to be in a sufficiently early stage of the dementia that they were able to talk with some level of insight about their experience.
- the person was able to freely provide informed consent.

The criteria were to be assessed by the professional that referred the person with dementia to the study. The researchers felt that a contact person that had a pre-existing relationship with the person with dementia would be best placed to make an initial assessment as to whether a person would meet the criteria. The definition of who was in the 'early stages of dementia' was difficult to define and we left this to be determined by the contact professional. The use of memory assessment scales were not used so that people would not be excluded from the study on the grounds of memory capacity, making the ability or people with dementia to discuss their feelings of primary importance (as opposed to memory ability).

Participants were recruited from three different Health Board areas in Scotland. Initial recruitment was attempted through old age psychiatry and memory clinic settings. For a variety of reasons, recruitment was very slow in these areas. Some of the barriers to recruitment could have been:

- Concerns from professionals that we may have been evaluating individual practice in diagnosis disclosure.
- Limited ability to assess the inclusion criteria with confidence due to limited knowledge of patients.
- Low rates of diagnosis disclosure influencing potential numbers of participants.

Due to the difficulties in recruiting through psychiatrists the study also sought people with dementia through other sources. This included other primary care professionals, day centre settings and support agencies in the volunteer sector.

Recruiting from a variety of settings was beneficial. It increased the range of people included onto the study. Despite a number of the study participants accessing more than one of the services we used for recruitment, only one person was referred from two different services. This may be due to different services having different levels of knowledge about a particular person with dementia.
Of the 24 people with dementia who did participate in the study they were recruited from the following sources:

<table>
<thead>
<tr>
<th>Setting</th>
<th>Number of people with dementia recruited onto the study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support Agencies</td>
<td>12</td>
</tr>
<tr>
<td>Day Centres</td>
<td>8</td>
</tr>
<tr>
<td>Memory Clinics</td>
<td>3</td>
</tr>
<tr>
<td>Community Psychiatric Nurses</td>
<td>1</td>
</tr>
<tr>
<td>Old Age Psychiatrists</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>24</td>
</tr>
</tbody>
</table>

Across the various recruitment settings people were asked to:

- Identify potential participants from across their case load.
- Make initial contact with the person with dementia and/or their carer to provide information about the study and to seek consent for a member of the research team to contact the person.

When a potential participant agreed to this, a researcher would arrange to see the person and would provide further information about the study. The researcher would then seek consent to interview the person with dementia.

**2.2 Emerging Issues on Inclusion**

Despite the negotiations between the researcher and the referring agency, sometimes people were referred to the study who did not meet the criteria. When interviewing people, they were always guided to disclose their diagnosis to the interviewer, and the diagnosis was only ever first named in the interview by the person with dementia. This was to ensure safety for participants by avoiding the possibility of disclosing the diagnosis of dementia to someone when they did not know they had dementia, contrary to the referring agency understandings about their patient/client. When it became clear in some of the interviews that people did not know their diagnosis, the interview did continue, and the focus of the interview became either about memory problems, or about a general topic that the person with dementia wanted to talk about. Some of these interviews still did provide interesting insight into the research questions and only two were excluded from the final analysis.

The discrepancy between the inclusion criteria we set and the people that were referred to the project may have come about for a number of reasons, including ambiguity about disclosure and resistance to talking about sensitive issues with people with dementia.
2.2.1 ‘Do you think they could tell me?’ (Fiona): Ambiguity about disclosure

The complexity in defining diagnosis disclosure was highlighted by people’s descriptions of their experience of diagnosis disclosure. The variation in diagnosis disclosure was vast, with one couple reporting their diagnosis was given in the form of a booklet called ‘Facing Dementia’ (a booklet produced by the Health Education Board for Scotland) being left with them by a psychiatrist, with the comment that they should perhaps read it. Not surprisingly, this couple was unaware of the diagnosis of dementia, and was confused as to what the psychiatrists action had meant. Other more positive examples included early intervention by a community psychiatric nurse, followed by a consultation with a psychiatrist who provided the diagnosis very clearly. With this variation and inconsistency in practice, people may have referred people with dementia to the study believing that a diagnosis of dementia had been disclosed to them. Disclosure practice will be further discussed in the findings section of this report.

2.2.2 “Nobody’s ever asked how I felt” (Sarah)

There is a strong sense of stigma around discussing dementia with people with dementia. There appears to be avoidance to actually talk directly about the diagnosis and a reluctance to provide details to people about what the diagnosis actually is. In talking with medical professionals who disclose the diagnosis of dementia there appeared to be common practices of naming the dementia with the words the person with dementia uses first, even if it is the wrong type of dementia or only mentioning memory problems, so as to avoid upsetting the person.

These factors combine to create a low level of confidence in knowing if a person does meet the inclusion criteria. Without professionals having more open relationships with people with dementia, they have limited ability to assess factors that were important for inclusion.

In interviewing people, we were careful to make sure a person did know their diagnosis before discussing issues around disclosure. This meant that we also had to follow this practice of not mentioning the diagnosis or dementia before the participant mentioned it. This was done by first talking about changes in memory. This posed a dilemma to the researchers as we did not want to reinforce a practice of avoiding talking about dementia with people with dementia, however the need to ensure we did not unintentionally disclose a diagnosis to a person was considered a priority.

2.3 Interviewing People With Dementia

The initial methodological design intended that interviews would take place with participants on two separate occasions, once during the month immediately following their being given a diagnosis of dementia and a second time three months following the diagnosis. The first interview aimed to explore both the practical aspects of the diagnosis, (such as who gave the diagnosis, terms used, support offered and prognosis given); and the impact of receiving such a diagnosis, (how did it feel, what were their expectations of how knowing such a diagnosis might affect their everyday quality of life and relationships; in what ways, if any, could the diagnosis disclosure
process have been improved). The second interview was to take place within three months of the first interview and elicited their views on having been told the diagnosis and the effect on their quality of life, having been told. Types of plans and actions undertaken by the person in response to the diagnosis were explored. Participants were asked what, in their opinion, are the advantages and disadvantages offered by an early diagnosis.

We needed to reconsider the initial aim to interview people in the month after receiving the diagnosis. The number of people able to take part in the research would have been severely restricted by these criteria. Only two of the final group of participants would have been included if we had not changed this.

Due to the difficulties in recruiting participants to the study, only 12 of the 24 participants were interviewed early enough to allow for the second interview. One of these participants had to withdraw from the second interview due to illness. The remaining 14 participants were interviewed once only. Whilst this was not the original method planned, it did provide the opportunity to compare the experience of interviewing a person on two occasions, as opposed to the one occasion.

The second interviews were typically characterised by increased rapport, sometimes improving the content of the interview. The impact of dementia on people meant that most of the participants did not remember the interviewer or the first interview. Despite this, rapport was increased in the second interview. This could be attributed to a number of reasons, one being that participants often talked about having good days and bad days. Interviewing on two occasions provided an increased opportunity to talk to people on the good days. The interviewer was also able to conduct the interview building on the knowledge gained on the participant from the first interview, assisting the interviewer in knowing what issues to explore with each person. The increased skills and comfort of the interviewer with each participant may also have been a factor in why the second interview was often more informative.

### 2.4 Data Analysis

The interviews were taped and transcribed for the purpose of analysis. Data was analysed using two approaches. The first of these was to look for key themes that arose in relation to the research questions. The second was the use of case study analysis to provide an understanding of the process and context experienced by participants. The use of two approaches in the data analysis provided added depth to the analysis.

#### 2.4.1 Key Themes

Analysis of the interview data combined inductive and deductive approaches in order to develop themes and highlight issues arising from the data (Denzin and Lincoln, 1998). Initial open coding involved a cross-sectional analysis of all the interviews identifying key themes for further exploration. Tactics for generating meaning as outlined by Miles and Huberman (1994) were employed to facilitate coherent identification of the perspectives of the participants. A stage of selective coding, guided by the theoretical concerns that lead the research, was then used to explore issues of diagnosis as they emerge from the data. Analysis of the first round of interviews informed topics for discussion in the second round.
Thematic analysis of the different data sets focused on a detailed exploration of both the actual experience of being given a diagnosis and also on the implications of this on the lives of the people with dementia.

2.4.2 Case Studies

Whilst key theme analysis was useful in providing information that directly related to the research questions, it did not provide the many answers to understanding the processes that people with dementia were describing, or the context in which they experienced these processes. We decided also to use a case study approach to address the potential shortcomings of the key theme analysis. The use of data coding for the development of key themes can result in data becoming removed from its context (Holloway and Jefferson, 2000). In also using case studies we are able to consider psychological processes, such as the idea of the defended subject, where understanding an individual’s story, and the contradictions in that story, may lead us to understand their psychological defences against changing self identity (Holloway and Jefferson, 2000, Kitwood, 1997). This allowed us to consider our research findings alongside studies from psychological traditions, such as Harris (1998), Keady and Nolan (1995) allowing us to build on current understandings of people with dementia by considering context.

2.5 Ethical Considerations

2.5.1 Ethical Approval Procedures

Ethical approval for the project was sought from two area health boards in Scotland. As we did not access participants in the third area through health sector services it was not necessary to seek health board in this area. One area also required ethical approval from the local Social Work department. During these processes we identified a number of issues that related to this project. First, given that by definition people with dementia have memory impairments, it was possible that people referred to our study may have forgotten that they have been told the diagnosis. In order to be sure that we do not introduce the diagnosis to them in our interviews we started by discussing memory problems, going on to ask whether anyone has given a name to their memory problems. If participants did not mention a diagnosis of dementia the interviewer proceeded with a general discussion about their life but did not discuss the diagnosis.

Second, we were aware that the research was conducted at a time of vulnerability and sensitivity for the person with dementia. The study was conducted in accordance with the principle of least harm to the individual and took account of the BSA Statement of Ethical Practice. Anonymity of respondents and the confidentiality of information supplied by them were maintained throughout, with records of names, locations and service provision recorded separately from the other data. Details that might serve to identify individuals or organisations have not and will not be published. In this report pseudonyms are used to describe participants.
2.5.2 Informed Consent

The lessons from the sharing diagnosis project, about involving people with dementia into research, often related to the relationships we can build with people with dementia and people in their lives, such as support providers and carers. It is this relationship building that helped to build safe contexts for people to talk about dementia in their lives. Building these relationships involved a number of factors, particularly the need to negotiate access to people with dementia through key gatekeepers, e.g. service providers. Potentially a source of resistance to the project (through wanting to protect people with dementia), we worked with gatekeepers, including them in the consent process and working on developing a relationship with them. These gatekeepers became assets to the project and could act as someone who could support a person prior to and after the interview, increasing participant safety.

Ensuring participants in the study were taking part and providing fully informed consent was a issue particular to this research. There were two aspects to ensuring informed consent:

a. Knowing that a person with dementia would be in a sufficiently early stage to understand what the research entailed and therefore know what they were consenting to take part in, particularly that they understood that it was a project about dementia and the disclosure of the diagnosis.

b. Concerns that a person would forget about the project between the first contact the research team made and the interview, between the two interviews and even during the interview itself. How do you ensure informed consent if the participant forgets the information about the study?

There was no way of guaranteeing 100% informed consent for this study. The need to balance informed consent, with our commitment not to disclose the diagnosis of dementia to a person when they did not know the diagnosis, were potentially in contradiction. Given this situation we engaged in a process of maximising informed consent as far as possible. This involved using the relationships with gatekeepers to help in achieving informed consent. We also used the gatekeepers to try and ensure the research was conducted in supported contexts. The gate keeper helped as she or he would know the person with dementia better than we could, and could use this in assessing the confidence in informed consent and to be able to provide a pre and post research continuity.

We also ensured the safety of participants by viewing consent as a process throughout which people required continual support. Checking and rechecking consent is necessary, as is a negotiation of consent over a period of time, again this is helped with a support person involved in that process (the gate keeper). Applying the notion of ‘safe practice’ to our roles as researchers was important in involving people with dementia into the research and maximising informed consent.
3. Findings

The findings from the study will be discussed in four sections. First, information about the people with dementia who participated on the study will be presented. Second, the findings relating to the initial three objectives of the study will be presented. Third, a model of how these findings have contributed to our understanding of dementia will be discussed. Finally, information collected at a workshop held to disseminate the findings will be discussed.

3.1 The Participants

Twenty four people with dementia participated in the study. The following table provides some information about each of these people. Each person was referred through a professional who was in contact with them and assured the researchers that the person met the inclusion criteria, (that they knew their diagnosis, and were in sufficiently early stages of dementia that they could provide informed consent).

<table>
<thead>
<tr>
<th>ID</th>
<th>Profile</th>
<th>ID</th>
<th>Profile</th>
</tr>
</thead>
<tbody>
<tr>
<td>01</td>
<td>Karen is 55 yrs old and lives with her husband. She talks openly about having a diagnosis of Alzheimer's and is on Aricept. She was interviewed twice.</td>
<td>07</td>
<td>Shane is 70 yrs old and lives with wife. He talks openly about his diagnosis of multi infarct dementia. Shane was interviewed twice, and had been given a diagnosis of terminal cancer between interviews.</td>
</tr>
<tr>
<td>02</td>
<td>Dave is 45 yrs old and lives with his wife and son. He talks openly about diagnosis of a type of vascular dementia, is on medication to prevent strokes and control depression. Dave was interviewed once and could not take part in a second interview due to illness.</td>
<td>08</td>
<td>Mary is 77 yrs old and lives alone. She talks openly about diagnosis of Alzheimer's. She was interviewed twice and felt her memory was declining rapidly between the interviews.</td>
</tr>
<tr>
<td>03</td>
<td>Alex is 59 yrs old and lives with his wife and children. He talks openly about his diagnosis of multi infarct dementia, which took 8 years to get. Alex was interviewed twice.</td>
<td>09</td>
<td>Harry is 60 yrs old and lives with his wife. He talked openly about diagnosis of Alzheimer's. Between the first and second interviews Harry had deteriorated and was no longer clear about his diagnosis.</td>
</tr>
<tr>
<td>04</td>
<td>Susan is 48 yrs old and lives alone. She talks openly about her diagnosis of Pick's disease, which her sister has also developed. She was interviewed twice.</td>
<td>10</td>
<td>Joe is 73 yrs old and was initially living with his wife but moved to sheltered housing between interviews. He talks about having mild memory problems and Parkinson's. He disagrees with having been given the diagnosis of dementia.</td>
</tr>
<tr>
<td>05</td>
<td>Sarah is 44 yrs old and lives alone.</td>
<td>11</td>
<td>Martin is 80 years old and lives alone.</td>
</tr>
<tr>
<td></td>
<td>Lorna is 62 yrs old and lives with her husband. She talks openly about her diagnosis of Alzheimer’s and currently is on Aricept.</td>
<td>Fiona is 66 yrs old and lives with her husband. She talks openly about having dementia but is confused as to which type it is. She was interviewed twice.</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>06</td>
<td>with her husband. She talks openly about her diagnosis of Alzheimer’s and is on anti-dementia medication. She was interviewed twice.</td>
<td>with wife. He talks openly about having Alzheimer’s and was interviewed twice.</td>
<td></td>
</tr>
<tr>
<td>ID</td>
<td>Profile</td>
<td>ID</td>
<td>Profile</td>
</tr>
<tr>
<td>----</td>
<td>---------</td>
<td>----</td>
<td>---------</td>
</tr>
<tr>
<td>13</td>
<td>Liz is 64 and lives with her daughter. She did know she had some memory problems, but denied knowing what was causing those problems.</td>
<td>19</td>
<td>Rachel is 71 and lives with her daughter. She acknowledges she has had memory problems in the past, but that they have now gone, she does not know her diagnosis and was interviewed once.</td>
</tr>
<tr>
<td>14</td>
<td>Duncan is 56 and lives with his wife. He talks openly about his diagnosis of dementia and is frustrated that he does not know what type it is. He was interviewed once.</td>
<td>20</td>
<td>Alison lives with her daughter and does not think she has any problems with her memory. She does not know her diagnosis and was interviewed once.</td>
</tr>
<tr>
<td>15</td>
<td>Peter is 65 and lives with his wife. He talked openly about his diagnosis of Alzheimer’s despite still experiencing distress about having received the diagnosis. Peter was interviewed once.</td>
<td>21</td>
<td>Alice is 78 and lives with her daughter. She does not think she has any difficulties with her memory at all. She does not know her diagnosis. She was interviewed once.</td>
</tr>
<tr>
<td>16</td>
<td>Phil is 54 years old and lives with his wife. He talks openly about having a diagnosis of frontal lobe dementia and had very recently received his diagnosis. Phil was interviewed once.</td>
<td>22</td>
<td>Janet is 64 and lives with her husband. She has a diagnosis of Alzheimer’s disease and talks about this openly, although she does not like using the word Alzheimer’s. She was interviewed once.</td>
</tr>
<tr>
<td>17</td>
<td>Jack is 68 and lives on his own in sheltered housing. He talks very openly about his diagnosis of Alzheimer’s and has strong views on the diagnosis always being disclosed.</td>
<td>23</td>
<td>Helen is 73 and lives with her husband. She talks openly about having a diagnosis of dementia but does not know what type it is. She was interviewed once.</td>
</tr>
<tr>
<td>18</td>
<td>Lucy is 76 and lives with her husband. She has been given a diagnosis of Alzheimer’s disease and actively seeks information about it. She was interviewed once.</td>
<td>24</td>
<td>Kevin is 73 and lives with his wife, he is unaware that he has dementia and thinks his memory loss may be due to diabetes. He was interviewed once.</td>
</tr>
</tbody>
</table>

3.1.1 Summary

- The age range was from 44 to 78 years old. Of the 24 participants 11 were under 65 years of age and 13 were 65 years or older
- 13 of the participants were women and 11 were men.
- 23 of the participants were Scottish, one was Welsh.
<table>
<thead>
<tr>
<th>Living Arrangements (at time of first interview)</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>With partner</td>
<td>15</td>
</tr>
<tr>
<td>With family (e.g. daughter)</td>
<td>4</td>
</tr>
<tr>
<td>Alone</td>
<td>3</td>
</tr>
<tr>
<td>With partner and children</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>24</strong></td>
</tr>
</tbody>
</table>
Knowledge of Diagnosis | Dementia Type | Number of Participants
--- | --- | ---
Knows Diagnosis | Alzheimers | 10
| Unspecified Dementia | 4
| Vascular | 3
| Picks | 1
| Frontal lobe | 1
Sub total | | 19
Does not know diagnosis | | 5
Total | | 24

3.2 **Objective One: To explore how people with dementia feel about the way in which they were told the diagnosis**

People with dementia were asked about diagnosis disclosure in a number of different ways. It was hard for people to answer directly how they felt about the way in which they were told the diagnosis, so it was necessary to consider the feelings people had about disclosure in a wider sense. Asking people how they felt about being told their diagnosis was more easily answered than having to recall the way they were told their diagnosis and how they felt about that.

3.2.1 Feelings about receiving the diagnosis of dementia

Receiving a diagnosis of dementia is often a lengthy process, involving a number of procedures, tests and different medical professionals. It is also a very emotional time when how the diagnosis was shared may be less salient than the shock of knowing. Of this entire process, the moment of disclosure is often the hardest to remember. People can more easily remember how they felt when they heard the diagnosis, but the process of being told is more difficult to recall.

> Oh it’s either Dementia or Alzheimer’s I don’t know which, well I can’t remember what one she said. (Fiona)

> I can’t think what he said actually because I was so shocked actually at the time. (Susan)

> I suppose I remembered at the time but I don’t remember now it was such a long time ago. I don’t remember much about it at all, in fact I don’t remember anything about it. My memory’s just gone altogether. (Jack)

Considering the difficulty in recalling the moment of disclosure it was difficult for people to say how they felt about how they were told the diagnosis. However, participants did talk about how they felt about what they were told. Mostly the feelings people had about being told their
diagnosis of dementia included shock, anger, fear and depression. Some participants also felt some sense of validation from the diagnosis as it provided an explanation for the changes they had observed within themselves.

I thought that was the end of my life, I really did, I honestly did. I thought that was it, I just couldn’t see anything beyond it and as the time goes on a bit and then you realise that it is worthwhile persevering, cause, I really thought that was it I just couldn’t get to grips with it, but however, you get over that stage. (Karen)

Well, I was a wee bit surprised, but it was like the final piece of a jigsaw clicking into place, there was something wrong with me, to explain all these things that I’d been doing and obsessional behaviour. (Alex)

No I was just shocked, I was just so shocked when I was told I had Pick’s disease and now I just live each day as it comes. (Susan)

Well the first thing of course is to accept it, you’re first reaction is, oh no, that can’t be me. Thing is you see, if I’d had one of these wonderful total recall memories it might have impinged then, but I never did, you know I’ve got friends who can tell you every word of every conversation they had, they bore the boots off you. Now I never had a memory like that and I never thought I’d loose what I’d got, and that’s the only thing that makes me angry. (Mary)

For some participants the feelings of fear related to their prior experience of dementia, mostly caring for parents in later stage dementia.

Totally devastated. I had watched my mum, who was very much older than I was when she took it, so that, sort of made a difference, but she didn’t even know who we were or anything, she would say ‘oh hello’ you’d say ‘hi’, ‘who are you’ ‘its ((me))’, ‘do I know you’ ‘uh huh, you’re my mum’, ‘oh I am not’. She hadn’t a clue, that’s when I first heard that I was in the stages of starting it I got really terrified for a wee while, but as time went on I thought things aren’t changing that much, I mean my memory’s getting worse, I forget to do lots of things and what not, but I can still do everything so its not that bad. (Lorna)

3.2.2 The Process of Diagnosis

For many participants receiving a diagnosis was the last part of a long process of tests and procedures. Some of these procedures were remembered by people, particularly the use of scans and memory tests.

I think that is what lacks with the tests, I felt they never changed over the years that I went they never changed tests I mean always got the same thing, Mr Green and Mr Brown and all that, he’s a butcher, this chaps a green grocer and all that, then you get all the same, Mr Green and Mrs Jones and all that. I find that repetition, I find that quite easy to understand I think. (Shane)

The possibility of anti dementia drugs for people has also had an impact on the processes people go through. For some people the extra testing that accompanies drug therapy can come increase pressure to perform well on memory testing.
AND HOW DO YOU FEEL WHEN YOU ARE DOING THOSE TESTS?
I get up to high doe, because I've got this terrible fear of someone taking my pills off me, you know, that kind of, I'm worrying in case I make a muck up, make a muck of them, that's my main problem, I try not to think about it, but its inbreeding, you know that kind of thing, because um, because I've got them sort of so far I'm frightened not to have it, you know what I mean, I'm scared in case I get it taken off me sort of style, that's why I'm very careful (Karen)

So and I seen another lady and she did a really strict medical and she said I'm fine for it to start, so I've stared this medication. They said it's only for about a half that it works, but I'm really excited, cause I feel that I've got hope, where before I felt that there wasn't any hope. ((My husband's)) quite cautious, cause I'm like lets go home and celebrate, and I was really really excited about it but he says we need to be cautious about it and it's not really a great percentage but I think, I've got another chance there. (Sarah)

3.2.3 Prognosis and Information

An important part of the diagnosis process is how much information is given by the professional providing the diagnosis both about diagnosis and prognosis. Two main approaches to information emerged from the interviews. This indicated that beyond diagnosis disclosure there was an active choice being made about how much people wanted to know about their dementia. It was important that the choice people made was respected by practitioners. The first approach was to seek as much information as possible about diagnosis and prognosis, often from multiple sources.

I'm just trying to work out the philosophy of it. Not the philosophy, the nursing bit, what happens to your body ... I'm just trying to work out why it would actually kill me. I don't know why I would be more susceptible to infections, I'll have to ask. (Sarah)

Waiting on information coming, which isnae a very good sign either if you're waiting on something important, I could have walked to the hospital and got the blimmem sheets for them. I, I just don't have much confidence in any of the doctors there. (Phil)

The second approach that participants had was to only seek information as it applied to their situation, in effect just taking it a step at a time. This approach was typified by responses such as the quotes below.

I don't really want to know, I mean, what's going to happen will happen, if it's not going to happen it won't. Um, and apparently this is something that can slow down and it can escalate and whatnot well I reckon I've stayed, well not stayed at the same level but not changed dramatically for a while, which I'm quite happy. (Lorna)

Well I don't think there's much they can tell me now, maybe in the beginning they could have told me more of what was going to happen or what could happen but not now. (Jack)
3.3 Objective Two: To gain insight into the opportunities and limitations offered by an early diagnosis for the person with dementia.

3.3.1 Opportunities

Of the people interviewed who knew their diagnosis most could identify a number of opportunities gained by learning the diagnosis. These include practical matters such as being able to make plans for the future and taking care of financial and legal matters.

Yes I've had time to sort of, well I don't know just tidy up the decks and this sort of thing and maybe write to people that I've been meaning to write to for years and I haven't, but I don't say anything to them but you know I just feel as though I'm sort of going round the edges tidying up and for me. (Lucy)

Other opportunities included being able to understand the changes within yourself and in behaviour, which may provide the opportunity to find a positive approach to the diagnosis.

I would say deep down, yes tell them, people can understand what's wrong with them, know why they're so bewildered and they can also, as I say, make plans for financial and even, just the same if you were told, you've got a week of your life left, what would you do with it. (Alex)

Everybody can take it, everybody can take on an awful lot more than you think. You get it and after you've got it, sure, you're sunk for a bit, and that's only to be expected, and maybe at that point they say maybe I wish they hadn't told me, but you realise it's the best thing that could have happened. They tell you, put your life in order and that's it. Then if you want to ignore it, ignore it if you wish, but it's your choice, it's not the doctor's choice, or the carer's choice, it's your choice, and you should be given that choice. (Jack)

For some people it provided an opportunity to make the most of their time. When people could accepting the fact that they may decline at some point there was often the attitude of making the most of the time they have with the abilities they have. This included becoming involved in volunteer work, planning overseas trips (Canada, Australia, Amsterdam), and doing things people always wanted to do (helicopter rides, flying a sesna).

I'm playing an active part in society again and I've actually given some of these (help) cards out to carers you know, I've been speaking to people and their carers didn't have a card so I gave them a help line card, 24 hours, I'm doing a wee plug here, 24 hours. (Alex)

For some people, knowing the diagnosis has given them the opportunity to think more actively about ways around the problems they were experiencing, such as, use
of daily routine, using a diary and memory aids. One participant commented that the use of these strategies can result in what feels like an improvement.

Well I don't think there’s any harm in telling them as long as they’re not too severe you know the Alzheimer’s because the only thing is that when you’ve just got it mild there’s every chance it will improve you know? That’s the way I look at it anyway and you get in the habit of certain articles or items that begins with a letter and try to remember it the next time you see it, that’s a T what is it, like that helps. But I’ll be all right. (Martin)

Some people found that by knowing their diagnosis, they were able to access increased amounts of appropriate social support. This was in a number of forms, including day centres, support services, counselling and community psychiatric nurses. For many people it was helpful to have someone to talk to if they wanted to. For some people it was nice to be able to attend day centre type setting, where they could meet other people with dementia.

I’m quite happy to go (to the day centre), I mean I like the company, and we can have a good laugh and we key each other on about being stupid things you say, I’m more stupid than you, oh no your not, I’m even more stupid than you, they start silly arguments about everything and its fun, its fun, I think everybody, most of them, maybe two don’t, but I think everybody else realises what’s happening and they joke, which to me is better, good fun. (Lorna)

I think I would suggest that that they try and find out (the diagnosis), just because of the level of support I’ve got, I found it very important to be surrounded by people who know what they’re talking about and what was wrong with me and what I might do that other people might find strange. I wanted people to know why I was doing that, albeit I might not understand it myself, at least there’d be somebody there that could explain why I was doing certain things. (Dave)

I haven’t really talked, we just have talks, just chats to you and all the rest of it, it, I haven’t really, it’s, the nurse comes with the tablets and always spends quite a time just speaking to me, talks away and all the rest of that, and that helps too. (Karen)

3.3.2 Limitations

The participants identified very few limitations from knowing the diagnosis of dementia. The limitations that were identified included the impact on self confidence and restrictions to daily activities, for example driving.

The hardest thing about the whole lot is the things they took off me. All my enjoyment they took it away from me. They took my car off me, took my license off me for the car, they took my gun off me, they took my fishing off me…Everything I try to do I get shot down at, everything, everything I try or want to do, I cant even take my granddaughter out for a walk. And I go loopy with that, I mean I go through the roof about that. (Duncan).

The reduction of self confidence that some participants described was due to participants becoming more aware of their own limitations. For some people this was the uncertainty of not knowing if they were repeating themselves or forgetting things. Loss of self confidence for these reasons could be connected to diagnosis
disclosure, however it could equally be connected to the way in which most participants were aware of their symptoms pre diagnosis. Participants were generally clear that the limitations did not outweigh the opportunities provided by knowing the diagnosis.

*I don’t know how to describe it, eh. I know I’m not reliable, because I forget everything. And that’s the worst, my worst problem with memory, um, and yes I write things down, yes (my husband) writes things down and that’s fine if you remember to see the list, that’s fine if you remember there’s a list written.* (Lorna)

There are few limitations for people with dementia following diagnosis disclosure and the limitations did not outweigh the opportunities provided by knowing the diagnosis for those that could identify them. Also, limitations, such as self confidence, may not be as closely linked to the disclosure of the diagnosis as they are to the impact of the disease.

### 3.4 Objective Three: To guide best practice in diagnosis disclosure.

Participants in the study were able to talk easily about how they felt about having been given a diagnosis of dementia. However, it was difficult for people to talk about the practices of diagnosis disclosure as this was difficult to remember.

#### 3.4.1 Good Practice

The feedback that was given about practice included allowing the diagnosis to be disclosed over time and in a supported way. Unfortunately not many examples of this were provided by participants. Often the positive reports of good practice related to medical staff that were not disclosing the diagnosis, such as community psychiatric nurses.

*I have seen her (the CPN) and thanked her, cause it was really good that she did that, as soon as she said something to Dr X he came right away, so they’ve been excellent, as soon as they suspected it they’ve been really excellent.* (Sarah)

Participants were sensitive to the issues surrounding diagnosis disclosure, and when asked if they could suggest ways in which disclosure could be done a typical response was one of empathising with the difficulty of this task.

*I think it would be quite tricky to do, I don't know, how would they do it, there's no sort of way you could do it, without, I think it would be quite difficult actually* (Sarah)

There were some points raised by participants about good practice. These points reflect the need for disclosure to be done sensitively and to respond to individual needs. These individual needs included the need for information and the need for follow up visits with medical staff.

*The bottom line is, the patient has got to be in the right receptive mood to be told, where and when. I mean you don’t tell somebody in the middle of a bus queue, so maybe a wee attractive room, not a, something dreary, but maybe*
a room with flowers on the wall, and carpets and cushions and things. No phone, nice and relaxing. I don’t know. (Alex)

Well yes, yes if a doctor gives you a diagnosis he should be able to give you prognosis then. (Susan)

To draw conclusions about best practice around disclosure we need to increase our understanding of the experience of receiving a diagnosis of dementia. Through this, practice may be able to become more responsive to people with dementia’s needs.

3.4.2 Poor Practice

People in the study were able to identify areas of poor practice, such as the diagnosis not being disclosed soon enough and a lack of information (particularly about prognosis). Some examples of poor practice were highlighted by participants in the study. These reflected issues such as not enough information being given to people, the lack of follow up and contradictory information from different health professionals.

Well I would have thought it would have been courtesy actually (to have a follow up appointment), but eh, because eh, the amount of questions that can come up, and if you’re looking for answers then you want to have somebody that can give you answers, … I’d rather hear things up front, I, I think that if you’re an outgoing person, you would want to know what’s up front so you can make arrangements or whatever. I mean, there was another thing. The last time I was at the doctor’s and eh, I went in and we were talking about the (overseas) trip and eh, oh aye, I says to him, well, I’m thinking about going to (overseas). ‘Well go now’. What does that mean, go now, so right away you’re looking for a pen for a will or something, go now. I mean that was a bit of a shock. (Phil)

She said we’re only testing twenty people anyway and you’re not one of them. She said because if your Alzheimer’s was caused with the stroke, this pill doesn’t work, but if Alzheimer’s caused the stroke the pill will work, and as we don’t know, you’re not going to be tested. And I said oh that’s too bad, so I’ve lost my two years, she said, well what more do you want, you’ve almost had your three score years, and ten. Well thanks very much. (Jack)

I was just told I had Pick’s disease, I mean Dr X told me I used to be very intelligent and now you’re just of average intelligence, that’s how he explained it to me. (Susan)

Poor practice often seemed to be the result of a lack of awareness and sensitivity by professionals disclosing the diagnosis. This resulted in people having their diagnosis withheld when they did want to know it. A greater understanding of an individual’s need and the potential impact of inappropriate non disclosure is needed.

(To know) that there’s a reason for all this odd behaviour, all these arguments, that it was a medical condition that had caused it. Um, knowing myself, I knew there was something wrong, I didn’t think that anybody believed I was ill, I thought maybe the doctor thinks oh here he comes again with all these sort of aches and symptoms, I have sort of proof know that I did have a proper medical condition. (Alex)
3.4.3 Views on Diagnosis Disclosure

An important issue in the practice of diagnosis disclosure is whether people with dementia should be told their diagnosis or not. We asked participants what their views were about whether the diagnosis should be shared or not. There was not a huge variation in the views expressed, although there was variation in how strongly the views were held. All participants who knew their diagnosis felt that people with dementia should be told their diagnosis, however some did express the view that people in later stages of dementia might not be able to understand the diagnosis and that this should be decided on a case by case basis. Participants also generally felt they should have the diagnosis disclosed to them as soon as possible. Some participants felt that this was an individual choice, where whether people wanted to know their diagnosis or not should be respected.

I got it very early indeed, earlier than most people do, and this is one of the arguments they use for not telling people. They say she wouldn't know anyway or he wouldn't know anyway if we told them, but they still should be told. And they say, oh they couldn't stand it, it's not them that couldn't stand it, it's the carer's who couldn't stand it, they're the people who are keeping it back, they couldn't take the role of telling them, they don't want them to know, so they can say, aye, you're just a bit forgetful, or you're just this. And to me that is absolutely criminal, you should let the people know and then they know where they are. Sure it's a terrible sight when you see what happens to you in the end you know, if it runs its length, but it may not run its length, anything else could happen before then. (Jack)

DO YOU EVER WISH YOU'D NOT BEEN TOLD THAT IT'S -
No no I couldn't have gone on for all these years without knowing what it was. SO THE HARDNESS OF DEALING WITH IT HASN'T BEEN A GOOD ENOUGH REASON TO NOT KNOW?
No [[whisper]] no. No I had to know. (Peter)

No, I suppose if there's anything wrong with me I'm better finding out. I think personally its uh, individuals, one wants to know, one doesn't. It's a very hard think, its their decision, it's no a collective decision. (Phil)

No there's nothing worse than thinking that say the man in your life or your mother or something else knows something about you and they're protecting you that's a horrible feeling. (Lucy)

I mean after all if you've got some illness you're told aren't you usually. If you've got for instance Diabetes or something like that you're told so what's the difference really? It's an illness. (Helen)

3.5 Developing our understanding of diagnosis disclosure

In attempting to answer the original objectives the importance of developing our understanding of the experience of people with dementia became clear. Considering we wanted to explore the impact of a practice such as diagnosis disclosure on people with dementia it seemed appropriate to develop a socially and psychologically informed model. There are a number of psychological processes that people with dementia experience and these, as they emerged from this piece of research, will first be discussed. We will then discuss the role of social factors on people's
experience, for example, practice around diagnosis disclosure. Finally a model that incorporates these two aspects will be presented.

3.5.1 Psychological Factors

The literature on dementia to date has had a particular focus on the psychological processes that people may experience. We found that the psychological processes that participants discussed were consistent with the literature (Keady and Nolan, 1995, Harris, 1998). We observed a number of different processes that people described. These seemed to represent the individual’s journey between the following processes, with the ability to move through different stages in no linear order. We summarised these processes into the following descriptions:

- Noticing symptoms

The overwhelming majority of participants had noticed initial symptoms. These included forgetfulness, problems handling money, repetitiveness, having difficulties finding the right word and forgetting names. This is consistent with the findings of Keady and Nolan (1995). People felt confused and distressed by not knowing what was causing their symptoms, with some people considering explanations, such as cancer.

> At the time, no but when you have time to think about it you think well, at least you know what’s wrong with you, if you’re no your going off your head, you know at least there’s a reason for what you’re doing, or not doing, or forgetting to do, you’re not just going totally round the twist, you know, which is where the stage I was at. I was, no I’m losing my brain, going, you know. And of course (my husband) was getting more and more frustrated because he hadn’t a clue what was wrong either. (Lorna)

> Well you see it’s in my nature, I’m more frightened of the unknown than of the known. I can be in control if it’s something that I know about and that I can understand just vaguely enough I feel I’m still in control whereas if it was something and they said oh we can’t tell you, we can’t tell you I’d rather hear, you know I’d go up the wall. (Lucy)

Despite many participants noticing symptoms, only one participant had suspected that they had dementia. This meant that people considered a wide variety of explanations for the changes they were experiencing, such as cancer, hearing loss and brain tumours.

- Diagnostic process

The diagnostic process can be fairly long and drawn out. Several people in the study had been through processes that had taken 7 or 8 years. This was longer than most peoples experiences. The processes usually started with visiting the GP, and moved through referrals, memory tests and scans. The amount different people involved in this process can make it very difficult to remember what has happened and when. It is at this stage that an individual starts to interact with new social contexts such as medical staff, encountering the views of professionals such as GP’s on diagnosis disclosure.

- Diagnosis disclosure
As discussed in the findings section relating to Objective 1, recall of the disclosure is often very difficult.

- **‘Crisis’**

Although people might have difficulty in remembering disclosure, they could more easily remember how they felt after being told the diagnosis. This time was characterised by what seemed like a crisis stage, this involved dealing with the immediate response to learning the diagnosis. In the findings related to Objective 1 these were the feelings that people described after diagnosis disclosure and include shock, anger, fear and validation. The feelings people experience during this crisis time are often strong, and coming to terms with the dementia can become a significant part of a person’s life. This focus on the dementia may result in people no longer acknowledging the skills and abilities they do still have.

> I don’t think deep down I’ll ever fully accept it but I’ve got it and there’s nothing I can do about it and if it’s called Alzheimer’s then that’s what I’ve got. (Peter)

- **Prognosis**

People dealt with seeking information regarding their prognosis in very different ways. This was often characterised by the way in which people sought or avoided information.

> I don’t really know anything about it other than it’s a memory problem. That’s basically all I know, and it won’t get better, it will only get worse, is there anything else to know? Is there? (Lorna)

- **Maximising coping strategies**

Many people went through the previous stages described above and were able to access maximising coping strategies. These have been reported by Keady and Nolan (1995), and in Woods (2000) Keady and Nolan are reported to have been ‘struck by the efforts made by a number of those interviewed to cope and optimise their function’. We share this view, as many people engaged in positive attitudes, adaptations to daily living, strategies and new activities in the face of their dementia. In this stage people tended to re-prioritise the dementia in their lives by putting their dementia into the perspective of only being a part of who they were as people. This is a change from the crisis period, where coming to terms with the diagnosis can take a priority over other aspects of self. This left room for moving beyond limitations imposed by the disease and concentrating on what skills, abilities, roles and relationships were still present.

> You are a person, you are what you are, you can’t change it, live with it, get on with it, get on with your life don’t go to bed and lie there in mill and can’t go out and can’t do this, that’s your first reaction, forget it, be as you’ve always been cause that’s all you can do you can’t change it, it’s not going to go away, so get on with the rest of your life just as you always did. (Lorna)

> I just say you get on with what’s left when you don’t know how long you’ve got but no body does. There’s no one definite certainty I’ll die from Alzheimer’s, I may get knocked down by a bus tomorrow but so could anybody else, you’ve just got to look at it that way. But then lots of people may have something
they don't even know about, a time bomb ticking away .. at least I know I’ve got one thing and I know. (Jack)

Oh we’re full of all these clever dodges we Alzheimer’s. We’ve got to be haven’t we. You try and beat it, find ways round it. The one thing I won’t be is pessimistic about it, because there’s no good pretending it won’t get worse. It will get worse, and that’s when sheltered housing or whatever will come into it all. (Mary)

I mean no diagnosis needs to be your whole life. (Susan)

Just, live the life you’ve always led. You can’t do any harm not worrying about things, you don’t have to, you don’t have to. And eh, I suppose, one thing is that there is somebody worse than you, you’re not all, there’s somebody worse somewhere than you. (Shane)

• Denial

Denial was used by participants at different times, both prior to and following diagnosis disclosure. The debate about disclosing the diagnosis or not often argues that disclosure removes the right to exercise denial as a coping strategy. However, these findings indicated that people were able to use denial at any point and in a number of ways. This could be by denying that the dementia had an impact on daily living, or even denying the diagnosis of dementia. Disclosure of the diagnosis did not mean denial could not be used by people with dementia.

You keep thinking things yourself and then, and you’re too scared to really come across anything I mean. But here I am, I just put my head in the sand and that was it really, that was my way of doing it. (Karen)

No I think I’ve got quite a good memory. Not a good one, but a good one for my age. (Joe)

My memory, I forgot that bit. I get, you know, if there are two or three people, and I listen to one, and I can’t remember what the other one said, you know. AND DO YOU KNOW WHAT’S CAUSING THAT? It was noise, it was just noise in the mill that I worked in, and in that time we didn’t have ear defenders. (Harry)

• Distress

Participants experienced distress in a number of ways, in coming to terms with the diagnosis and in relation to daily frustrations. In this model distress was also caused by the practice of the diagnosis being withheld from people when they had the desire to know the diagnosis. The impact caused by a diagnosis being withheld caused distress for a number of reasons, including not being able to understand changes within yourself, and the impact of unexplained changes in behaviour on relationships with others. The group of participants who had experienced the distress of the diagnosis being withheld often reported improvements in depression and stress after the diagnosis was disclosed.

An example of this is Dave whose words are italicised in this description. Dave felt it was to know his diagnosis, particularly when I had the mental health problems, because the two crossed over so much that I felt it was important to know what was actually wrong with me. I mean it might have been, at the time, I didn’t understand it and being depressed I couldn’t understand it, but I still feel I should have the
He had been experiencing bad depression and at one point his wife actually came in and found me trying to hang myself from the hatch in the loft. However the suicidal feelings subsided as following the diagnosis disclosure he received increased appropriate support.

A further example of this is Alex (Participant 03), who fought for 7 years to receive his diagnosis. Great pressure was put on his relationship with his wife due to the unexplained behaviour he was experiencing. The effect of this tension was depression to the point of Alex feeling suicidal.

I couldn’t stand her, the lies that she told, and the terrible accusations which I now accept that she was right, and I was right because I just couldn’t remember them. … Had I been told earlier possibly things in the house would have been a lot more, uh, in harmony for a number of years. (Alex)

3.5.2 Societal Factors

Psychologically people went through a number of experiences, including noticing symptoms, seeking the diagnosis, feeling upset about the diagnosis, finding positive coping strategies, experiencing distress and using denial. People experienced a range of these feelings depending on the individual. Social factors were also important in influencing the experiences people had. These social factors included support, medical practice, family or carer attitude, social stigma, accessibility of information and services.

Some participants were aware of the impact of their context on their ability and confidence. For some people they found environments such as day centres a place where they could engage in conversation and activities with others with similar problems. This was important for regaining and maintaining lost self confidence.

Well the only thing I would say time can show improvement you know and I think a lot depends on your environment. If you get involved with conversation and different things that helps a lot you know. (Martin)

The level of social awareness that people had about what dementia was played an important role in understanding and coping with the diagnosis. Many people had an awareness of people with dementia in more advanced stages, particularly if their experience was of parents who would have been likely to have received much later diagnoses. For some people this prior knowledge was helpful in that it increased awareness of the dementia onset.

Well I suppose you see, I shouldn’t say we’re lucky, but in a sense we are lucky because my mother had it and we were more aware of what was happening so we were able to do something about it. (Helen)

For others, if their only knowledge of people with dementia was of the advanced stages of dementia, a very negative picture of dementia was created. People also felt that there was stigma attached to dementia. When people felt this stigma it had a negative impact. For some, this stigma meant they kept their diagnosis secret.

I think there’s maybe a stigma to dementia, em, and you know if I do tell people it will be Alzheimer’s. To all the family I’ve said Alzheimer’s. Its just you get a funny feeling when you say dementia. I know I shouldn’t. (Sarah)
Dementia, you think its somebody that is mad, ... sometime, you know the actually sound of the word made me think it was that way, that, ... I remember the first time I heard that and I thought oh, I don’t know about that at all. (Karen)

I’m frightened of being chased in the street with kids shouting demented, you’re demented. Cause there’re two kids round here that pestered me recently. I think if they just got to know they would torment me. (Alex)

Social support was a key factor in creating positive social contexts for people. This support was found through friends, family, partners and through support agencies. For some people they didn’t necessarily want to access external support, but were pleased to know it was there if they did need it.

She’s my best friend as well as my wife. (Phil)

It is good to talk about it. It would be good to talk to someone my own age who’s just been diagnosed as well. (Sarah)

The Doctor, that was the doctor that gave me the paper, he was a nice chap as well, but for all the niceness he came up with absolutely nothing, gave me a diagnosis of (dementia) and that was it, and there was not support till I met (a support worker). (Dave)

When there was an absence of support for participants this was likely to have a negative impact on people with dementia. The role of family relationships was particularly important. A supportive family and or partner was very positive, but the relationships participants had with people in their lives is not always conducive to support. When this family or partner support is absent, or if the relationship is strained there can be a negative impact on people with dementia. This can reduce self confidence and increase isolation through the impact of the dementia not being understood. Positive social factors influenced people by supporting them to find positive ways of coping. Where positive support was not available for people through family relationships, it was even more important that alternative support was available.

Another thing I found is that (my wife) doesn't trust me anymore. Where she maybe talk with me about things before, she makes the decisions and doesn't trust my judgement or memory, which is a wee bit daunting. It does take away a bit of confidence. (Alex)

Medical practices, including views on diagnosis disclosure held by professionals could be very influential. Some medical practitioners were very understanding and supportive of people with dementia in this study. These practitioners became useful resources for people with dementia and their families.

What (my doctor) said, which is just exactly how I feel, but um, if I'm given a lot of information at one time I cant take it all in, where if I'm just given a bit of information at a time I don't have to maybe remember what’s been said, because he was saying to (my husband), ‘just try to give her a wee bit of a time’ and that's just it. Because even watching a programme I forget what the beginning. (Sarah)

When medical practices were not supportive of people with dementia a potentially useful resource could become a very powerful obstacle for participants. The views
held by professionals on diagnosis disclosure could be obstructive for people wanting to know and understand the changes in themselves. Medical practitioners had a lot of power over determining what people knew about their diagnosis, and indeed whether they even knew their diagnosis. This was apparent through the research as the information provided to us by medical practitioners often illustrated how information which participants wanted to know about their diagnosis was being withheld from them. If disclosure practices did not reflect the wishes of the person with dementia, this could cause psychological distress for people.

*I would shoot the person that tried to keep it back from me, I really think it's an absolute disgrace, you should be told at the earliest moment, even if people say to you it might be that, we'll have to test it, even tell them then. Then if you want to ignore it, ignore it if you wish, but it's your choice, it's not the doctor's choice, or the carer's choice, it's your choice, and you should be given that choice.* (Jack)

*But my own doctor never told me. Looking back, would it have been helpful, I don't know, because there's two sides to it, one, its some bits in the past I was feeling so bad I was suicidal, very suicidal on a couple of occasions, possibly the doctor might of feared that saying that might have put me over the brink, I don't know, uh, maybe the doctor just made a blanket decision to tell nobody.* (Alex)

The debate over whether to share the diagnosis of dementia or not provides a good example of a contextual factor relation to the model we will present. There are a number of reasons why people might not know their diagnosis, but when the diagnosis is withheld when the person does want it, psychological distress is caused. This finding is ironic, as often a diagnosis is withheld to avoid causing distress. However most people are already aware that there is something wrong, and in these cases of non disclosure it is the unsupportive social context and not the dementia itself that is contributing to the distress. This distress is illustrated by the fear of what is happening and a lack of explanation for changes in behaviour which impacts on close relationships. A person’s potential to access maximising coping strategies may be effected by this.

3.5.3 Developing a framework of understanding

We developed the following framework to help guide our analysis and to build on the knowledge we have about the experience of people with dementia and how that will relate to the issue of diagnosis disclosure. The model signifies some of the processes that people went through prior to and following diagnosis disclosure. The impact of psychological and social factors on each persons journey were significant and this model attempts to integrate these factors which have already been presented in the findings. We will introduce Harry, and use his case study to help explain this model. Throughout this discussion Harry’s words will be italicised.

First, we will explain the different terms used in the model. Most of the terms have already explained in the preceding description of psychological and social factors. The terms that describe the axis of the model will be briefly explained:

*Desire and ability to know diagnosis* - this axis on the model refers to the combined influence of an individual's desire and ability to know or understand their diagnosis. The terms desire and ability have a complicated relationship and this combination is not to imply that desire reflects ability. This axis is meant to reflect the combined
influence of these quite different factors. The one thing these factors do have in common is that they are determined individually, and are a reflection of a person’s psychological and cognitive states. When the combined factors result in someone wanting to know and being able to understand their diagnosis this rates ‘high’ on the axis, low desire and ability to know rates ‘low’.

**Social context** - this axis is closely linked to the preceding discussion on social context. Again this is an axis which refers to the combined influence of a number of different factors. These were presented in the section on social factors and include the impact of family, carers, medical practice, social stigma and social support. When these aspects of social context are present in a positive sense and support the person with dementia, the combined impact of the social context is nearer the ‘positive’ end of the axis. When the combined influence is less supportive of the person with dementia, the impact is nearer the ‘negative’ end of the axis.

![Diagram of the Process of Receiving a Diagnosis of Dementia](image)

We will now present the case study of Harry to illustrate the model above. This is a description of Harry’s journey through a number of different processes and these will be marked on the model to correspond to Harry’s story. Harry’s words are in italics through this text.

Harry is 60 and has received a diagnosis of Alzheimer’s disease. He lives with his wife, they have two sons, one of whom sadly got killed quite a few years ago. Harry first started to notice that his memory was changing while working in a timber yard. Initially thinking he was having problems with his memory Harry went to his GP. At this stage of the process he is noticing symptoms and is gaining some awareness that there is a memory problem (**H1**). He has a supportive wife and GP, and is eventually referred to a psychiatrist, this is the first step in changing Harry’s social context as he now has a medical person who can provide a diagnosis involved. His desire to know what is wrong grows as initial suspicions of hearing loss are ruled out. Harry was surprised to receive the diagnosis of Alzheimer’s disease (**H2**), at first Harry had difficulty understanding what Alzheimer’s was. He felt the explanations he was given were *gobbledy gook*. He had never had exposure to what Alzheimer’s disease was in his social context, *I’d never seen it written, you know*, and this made it more difficult to understand, *it’s a hard thing to come to terms with it you know.*
Harry had an increasingly supportive social context as he was given good information from the psychiatrist and put in touch with a day centre which has been a source of social support. The influence of his relationship with his wife was also important. Harry went through a crisis stage (H3) which for him consisted of anger, it's like eh, I used to shout at it, you know, because I didn't want it and then the more I saw the psychiatrist the quieter and the calmer I got, you know, and eh, I'm okay with it now, you know. Beyond the crisis stage Harry handled the prognosis stage by actively seeking information (H4), I was always looking for information.

For Harry he felt he had come to terms with the diagnosis and felt that people should be given their diagnosis of dementia, I just about broke my heart when I found out but I've come through it and I'd rather know, yeah. I'd rather know. He appeared to be engaging in maximising coping strategies, such as having a positive attitude, safe expression of anger and good communication with his wife (H5). The combination of Harry's personality and his increasing desire to understand what was happening combined with an increasingly supportive social context, this appeared influential in the development of the maximising coping strategies.

Over time Harry experienced some decline in his ability to remember and understand his diagnosis and moved in his journey again to exercising denial about his diagnosis (H6). He had created two alternative explanations for his memory loss, one being problems with hearing and the other being the impact of the death of his son. Harry also re-framed the interview to being about deafness despite deafness never being mentioned by the interviewer, (and here we are, supposed to be talking about deafness, you know, I always get on to this, you know, talking about my son.)

The feelings of loss for his memory and for his son are entwined for Harry. When his son died, I lost something that I could never have again. The use of combining talking about memory loss and the loss of his son may be a way to communicate the feelings of loss Harry has about his memory, making this use of denial potentially an effective way to communicate.

We can see that Harry progressed in his story across the model in one particular way. Every individual story differed depending on the combination of factors, both psychological and social. Alex’s story moves in a very different path across the model. Alex is 59 years old and lives with his wife and their teenage children. He noticed his memory changing at work eight years ago (A1), I was having trouble doing my work, and I would forget people’s names, people I had known for an awful long time. When Alex went to his GP with concerns about his memory it took years for the GP to take his concerns seriously (A2). Eventually Alex paid to see a consultant privately, who told him You’ve just got hardening of the arteries and its normal for people of your age, and uh, and makes you a bit forgetful. Through all of this time Alex was experiencing increased strain on his relationship with his wife. As neither of them understood the changes he was experiencing and this led to conflict cause I couldn’t stand her, the lies that she told, and the terrible accusations which I now accept that she was right, and I was right because I just couldn’t remember them.

Not understanding the changes within himself and the increased difficulty at home, nobody speaks to you, you’re just shut in a corner, contributed to Alex’s feeling of distress, depression and reduced self confidence (A3). These feelings were in part created for Alex by the social context he was in. He wanted to know what was happening to him, and the medical practice he encountered did not support him in this, which in turn, contributed to the distress.
Despite not disclosing the diagnosis to Alex, the consultant had referred him to a support agency in the voluntary sector. They advocated with the consultant to disclose the diagnosis, and eventually Alex was told his diagnosis (A4). Alex felt many different feelings, including initially feeling quite depressed, he also felt *vindicated*. Knowing the diagnosis also temporarily eased the conflict in the home as his wife realised *I hadn't been a right bastard all those years, that I was ill, the same way I realised she wasn't a right bitch all those years, and that eh, things, that eased immediately.*

Through the support agency Alex has been involved in a number of different activities, including volunteer work and re-learning photography (A5). He feels that the support he received helped him to become involved in life again, *I needed somebody to take me by the hand, to be the optimist.* The tension in the home has increased as the family deal with the daily impact of the dementia on Alex's memory and behaviour.

For Alex, not knowing his diagnosis caused a lot of distress, particularly in his relationship with his wife. He also recognises that having been told his diagnosis meant he could get support from external sources. *I wish I'd been told earlier, because it would have, we could have lived in a lot more harmony and we could have got access to these nice people in Alzheimer's a lot sooner.* This support was crucial in Alex accessing his diagnosis and becoming engaged in maximising coping strategies.

### 3.6 Dissemination Workshop

As part of the feedback and consultation within this project a Feedback Day was held in Edinburgh on October 12th 2000. The people invited to this day included people with dementia and their families, service providers from the voluntary and statutory sectors, GPs and psychiatrists, Community Psychiatric Nurses (CPNs), and researchers. The morning sessions involved presenting the preliminary findings from the project and presentations from people with dementia who had been involved in the research and on the diagnosis project. In the afternoon the participants worked in small groups of 5 or 6 people to look at the recommendations they would like to see from this project around the disclosure of dementia. It is these recommendations that are presented in the next section.

#### 3.6.1 Recommendations from the Dissemination Workshop

From five small working groups their recommendations were summarised into the following themes:

Sharing the diagnosis is an individual process in which:

- the process of sharing has to give primary consideration to the individual,
- there is choice over when and how to be involved,
- sharing the diagnosis is a process and it is essential to allow enough time to share the diagnosis over a long period of time as appropriate to the individual,
- follow up support for answering questions is important,
- the environment is comfortable especially having privacy, time and information available to share.
There are key social factors to be taken into consideration when sharing the diagnosis. These include:

- respecting the individual's choice and right to a diagnosis
- responding to individual needs and interests and recognising that these might change over time
- the urgent need to breakdown the barriers created by stigma and lack of understanding around living with dementia

There are important structural and service factors that need to be considered when sharing the diagnosis. These include:

- the need for services and staff to provide a supportive environment where individual needs are given priority;
- the need for services to collaborate and work in an honest way with service users,
- to provide a key person to co-ordinate the sharing and follow up support process,
- to provide counselling where requested,
- to ensure a consistency in how terminology is used,
- to recognise that some individuals will have existing support networks that can be drawn on,
- to have education and training in order to be able to respond to individual needs and interests concerns questions time-frame,
- top focus on developing collaborative services where the focus is on support and prevention rather than crisis management.
4. Implications

To continue to develop our understanding of the experience of people with dementia it is important to consider the impact of both psychological and social factors on people’s lives. Developing this understanding will help us to learn about practice issues, such as the effect of diagnosis disclosure on people with dementia.

4.1 Implications for Practice

• There is a need to move to practices that have a psychosocial understanding of people with dementia.

The debates that surround the issue of diagnosis disclosure tend to split into a dichotomy of whether to share the diagnosis of dementia with people with dementia or not. The findings from this research support moving from the ‘to disclose or not to disclose’ question to developing a psychosocial approach to disclosure practice. To do this, practitioners need to become more aware of the role they play in diagnosis disclosure, understanding the negative impact that inappropriate non disclosure can have.

• Social context plays an important role in people with dementia’s experience.

Many participants provided examples of how positive social contexts, including social support, can help increase the potential to access maximising coping strategies. Practitioners, as an important part of this context, have the potential to be a positive resource in supporting people with dementia. Finding ways to increase social support to people with dementia is important.

• The opportunities from knowing the diagnosis of dementia outweighed the limitations.

The people with dementia interviewed in this study generally felt they wanted to know their diagnosis and identified a number of positive opportunities provided by knowing the diagnosis. These include the opportunity to plan, make decisions, make choices, gain support and develop positive coping strategies. The limitations identified related to restrictions on activities of daily living and the impact on self-confidence. The opportunities appeared to outweigh the limitations. Finding ways to support people in adjusting to changes in daily activities could be helpful in addressing this. Providing support to help people with dementia to identify the skills and abilities that they still have, and encouraging people to be less deficit focused, may help regain lost confidence.

• Inappropriate non disclosure of the diagnosis of dementia can cause great distress.

All people in the study knew that something had changed with their memory or behaviour and often sought explanations for these changes. Not having the diagnosis disclosed can not only cause great distress but this can also prevent people from gaining important self understanding and developing positive coping strategies. The negative impact on the person with dementia and the impact on their
relationships with others has to be considered when making decisions about
diagnosis disclosure.

- Inappropriate diagnosis disclosure needs to be safe guarded against.

Whilst participants in this study did support diagnosis disclosure, many felt that non
disclosure could be appropriate in some instances, such as when the dementia is
very advanced. This finding highlights the need for practice to equally avoid
inappropriate disclosure. However this concern that participants had, should not in
itself be the reason to continue practices of inappropriate non disclosure.

- People need support through the ‘crisis’ that can happen after diagnosis
disclosure.

Participants identified that there can be a time of ‘crisis’ following diagnosis
disclosure. Despite this ‘crisis’ time, participants still wanted to know the diagnosis.
This time of ‘crisis’ is often part of a process of learning how to cope with the
diagnosis. This is a time in which follow up support, information and advice can be
very useful.

- People with dementia do find positive ways to cope with their diagnosis.

Knowing the diagnosis of dementia can cause distress, but positive social factors can
help people to find positive ways to deal with the diagnosis. Many people with
dementia find positive ways to live with dementia post diagnosis.

I just thought, well I’ll have to take it on board, that’s it, no sitting crying into
my beer. I’ll do the best I’ve got with what I’ve got and have a set routine,
which I have, doesn’t mean I can’t shift it about, but you can see I do certain
things on certain days and that gives my life a pattern, so I manage that way.
And try the best I can to be positive about it and eh, you know, not think, oh,
getting worse even though I can. I’ve just got to take it day at a time, I can’t
do anything else. (Mary)
5. References


Marzanski, M. (2000). Would you like to know what is wrong with you? On telling the truth to patients with dementia. *Journal of Medical Ethics*. 26, 108-113


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6. Appendices

6.1 Appendix 1 - Consent Form

Sharing the Diagnosis of Dementia Research Project
Centre for Social Research on Dementia
University of Stirling

Consent Form

This form is to help us to check that I have mentioned everything to you that you might want to know about this study. It is also to show that you have agreed to being interviewed and that I have explained to you what is involved in taking part. One copy will be kept for our records and one copy is for you to keep.

Have the following points been properly explained to you:

- You are free to withdraw from this study at any time without giving any reason?
- You have received an information sheet about the project.
- You understand that the research will involve one interview only.
- The interview will be audio taped.
- Anything you tell me will be kept completely confidential unless we discuss otherwise.

I have understood the above points and give my consent to be interviewed for this project.

Signature:  
Name:  
Date:  

Researcher:

Signature:  
Name:  

Contact details:
Centre for Social Research on Dementia
University of Stirling, Stirling FK9 4LA
Telephone: 01786 466 300
6.2 Appendix 2 - Information sheets

Sharing the Diagnosis of Dementia Research Project
Centre for Social Research on Dementia
University of Stirling
Patient Information Sheet

The Centre for Social Research on Dementia at University of Stirling is doing a research project about the sharing of the diagnosis of dementia. Dementia is a term used to describe a range of conditions that cause problems with memory and thinking, such as Alzheimer’s Disease, multi-infarct / vascular and Lewy Body dementia.

This research wants to ask people who have been given a diagnosis of dementia about how receiving the diagnosis has affected your life. We want to know about your experience of receiving a diagnosis and ask you your opinion on whether doctors should tell people their diagnosis or not.

If you would like to be involved we would ask to interview you two times, once initially and then again three months later. Each interview should take approximately one hour. Every interview will be kept completely confidential. We will arrange with you where and when you would like. We are more than happy to visit you at your home.

If you decide to take part in this research you can change your mind about being involved at any time. Deciding not to be involved at any point will not impact on any of the treatment or care that you receive.

If you would like to talk with us about what would be involved we would be pleased to hear from you. If you would like to involve a person who cares for you in contacting us or discussing what is involved in the project then please do so.

We can be contacted at the below address and phone number:

Rebekah Pratt or Heather Wilkinson
Centre for Social Research on Dementia
University of Stirling
Stirling FK9 4LA
Telephone: 01786 466 300
6.3 Appendix 3 - Full Case Studies

6.3.1 Case Study: Participant 01 - Karen

Well I knew myself that there was something, I went to the memory clinic, and I didn’t realise they were looking for tumours, and that’s, that started me off them you know, cause I wasn’t expecting it, I thought they would just show you how to do things better and all the rest of that, I didn’t expect to have that you know, and it really, that was me.

Karen initially knew something was wrong, but didn’t know what it was. After spending some time actively denying that there was a problem she decided to explore what was wrong, hoping to access some help. *I knew I wasn’t getting any better unless I did something about it and that’s why I went to the memory clinic.*

Karen is 55 and lives with her husband in a nice suburban area, close to a large city. When I first visited Karen it was approximately nine months after she had first received the diagnosis of Alzheimer’s disease. Their consultant told her and her husband the diagnosis at their home. Due to the stress of this experience, *I was up to high doe, you know, she cannot remember much of what happened in that visit.* She does remember that *I just thought that was the end of my world, that was it as far as I was concerned really, at that particular time.* She now takes Aricept and this has had a positive effect, improving her speech, and in turn increased her confidence as before she *just used to hang about the house* and now makes regular day trips on her own. The only ill-effect from the medication is when she has to take memory tests, *I get up to high doe, because I’ve got this terrible fear of someone taking my pills off me, you know, that kind of, I’m worrying in case I make a muck up, make a muck of them, that’s my main problem.*

Karen was a secretary for many years. She described in our second interview how dementia affected her work. She used to do fantastic things to cover up her memory loss at work, *I used to try and look so people wouldn’t know what was wrong with me and things like that, and I went on like that for a long long while.* She became an expert at covering up, fearing embarrassment if people knew something was wrong.

The impact on her life is that *och, my memory’s bad, sometimes better than others though,* and the impact of this varies day-by-day. Karen’s husband now helps more around the house, doing things that she can no longer do, like cooking and housework, which she sees as not always being a disadvantage, *I couldn’t cook anyway, all that I made, it was rubbish.* Their relationship hasn’t changed except for *he gets more work put on to him kind of thing.* She no longer drives after having a couple of bad experiences with driving. She finds walking good exercise. The impact on her daily life can be fairly bad some days, but Karen takes the good with the bad really. And feels that *at least I’m still alive and that’s the main thing isn’t it.* Karen finds that she cannot read any more and so *I just have taken to the television and that.*

*Oh yes, I’m going back to the way I was before really to a certain extent. Yeah, its just sometimes you’re better than others. Some days are better than others, really its not exactly terrible bad. You know, just sometimes, you feel as if you know about it, but however, there’s not a lot you can do. You just have to accept it and just try to go round about it sort of style*
One of the ways Karen copes with her Alzheimer’s is to minimise it by comparing it to what it could be and rationalising that its not bad, it could have been an awful lot worse. When she was first told she felt that was the end of my life, I really did, I honestly did, I thought that was it. I just couldn’t see anything beyond it and as the time goes on a bit and then you realise that it is worthwhile persevering, cause, I really thought that was it. I just couldn’t get to grips with it, but however, you get over that stage. But it has helped an awful lot with the pills, it definitely has. … The other thing that Karen does to minimise the impact of her dementia is to remind herself it could have been worse, it could have been something worse, I could have had cancer.

She used to be so embarrassed. She felt that she couldn’t go to visit people and I couldn’t do this and I couldn’t do that because I was, cause, I could get the words and that out. This is the most noticeable difference that Aricept has made for Karen. Now she is open with people about her diagnosis. I tell people, because I feel its the best way, actually I mean people know what you are like and the rest of it and there was no way I was going to hide it or anything, I thought the best thing’s to bring it out, because it’s nothing to be ashamed of and that, I’m quite happy with that. This wasn’t always the way, as pre-diagnosis Karen had engaged in a lot of covering up to hide her problems, particularly with memory, from her work mates. She feels that people have reacted by being all very nice, very helpful for me including at the local park where she walks her dog. She feels that her friends still treat her the same.

Karen has limited knowledge about how the Alzheimer’s might progress and despite having all these things going through your mind she is quite clear that there is only so much information she wants to know about it. I really don’t know that much about it anyway you know, I sort of put my head in the sand, I tend to do that sometimes. I don’t think I need any more (knowledge), it just makes it worse sometimes to have a bit of knowledge sort of style. She felt she just wanted to take things as they come in relation to information for example, if something is nasty it will soon come in enough time. If it’s something serious I don’t want to know. I think that’s the best way, keeps you from worrying the rest of your life. Karen was reluctant to talk about any plans she has made for the future, as at the moment it’s not too bad.

Karen got through the hard time she had after receiving the diagnosis by trying to accept it. She finds that it is just best if she tells people about her diagnosis and there’s no problem really. She still gets up to high doe and all the rest of it, but she finds that on the whole its not too bad. She sees this as all being a part of having Alzheimer’s Disease. Talking to a support worker from an Alzheimer’s organisation also helped her dealing with it. She finds talking to people who are involved with Alzheimer’s make a difference, they know what they’re talking about.

Faced with the choice again about whether to find out the diagnosis or not, Karen would just bring it out in the open actually, I think that’s the best way to do it, because its not a stigma really, its just a case of you know, you just, I think that’s the best way to do it rather than have people wondering is it right or is it not right sort of style. I think it is better at getting it right and over and done with. She could not identify any reason to not find out the diagnosis, I just think its better for it to come out. Initially she had felt I’d rather not know, but then that’s the cowards way, you’ve got to do it sometime, so you’re better getting it over and done with, and out of the cupboard sort of thing.

When Karen decides to put my head in the sand it sometimes helps her to just to blank everything else out, which sometimes helps her get on with things. Karen spoke about dealing with the crisis stage as going through the feeling that there is nothing else you can do, you can run around or you can go up. So that’s the only thing you can do really.
Initially it was hard, really to start with I was just in the dumps all the time, I just couldn’t see my way out of it sort of thing, but uh, as the time goes on you get used to it actually.

Karen used to think of Alzheimer’s as something a really old person would get, and did used to wonder, why me? She would rather describe her illness as having Alzheimer’s than as having dementia. Dementia makes her think of somebody that is mad, you know the actual sound of the word made me think it was that way. I remember the first time I heard that and I thought oh, I don’t know about that at all. To her the word Alzheimer’s sounds better. The phrase memory problems is not one Karen would want to use to describe herself as having, she would just say Alzheimer’s, call a spade a spade. She felt this made things a bit clearer and a bit easier.

Karen explained that she is now more positive about the Alzheimer’s. I think it’s because I was up to high doe oh, most of my life, and it was never diagnosed and that, and there was nothing that I could do. You’ve just got to accept it really, you’ve no choice really. So you’ve just got to make the most of what’s there and that’s it. It’s not good to get down, so you might as well just go with it, yes.

Part of becoming more positive, was to try and place the Alzheimer’s into perspective in her life and just try to put it out of my mind. Initially she couldn’t see anything beyond it. She now finds she doesn’t even think about it a lot of times, it just sort of comes and goes, sometimes I don’t feel maybe all that great, it’s a bit hard sometimes, but most of the time’s all right, you can get about it.

Karen has had difficult times with coming to terms with her diagnosis and now appears to use a mix of acceptance and denial to make sense of both the diagnosis and prognosis. She accepts the diagnosis, but chooses to only have limited information about the prognosis. This compliments her strategy of taking things in stages and her “get on with it” approach.

You could spend the rest of your life doing nothing really because you’re maybe scared and just in case, I think you have to do it as it comes really, and get as much out of life as you can really.

6.3.2 Case Study: Participant 02 - Dave

Dave is a 45 year-old man who was diagnosed with an uncommon form of a vascular dementia. He lives with his wife and adolescent son. Dave is in the early stages of the dementia, he is still very able and continues to drive. Dave is involved in a support group for people who have used the mental health system. He became involved with this group after experiencing depression prior to the dementia.

Dave had initially thought his memory problems were being caused by his depression, but he became increasingly aware of it getting worse. He particularly noticed at the group he attends that a lot of meetings I was supposed to go to, I wasn’t turning up to and things like that. However the group is very understanding of this. Since receiving his diagnosis Dave has found that my depression’s actually cleared up. He thinks this has to do with being involved in so many other things and with the increased attention that has now been given to his medication.

A diagnosis was given for the dementia in November 1999. When Dave received the diagnosis, he found it difficult to access information on this particular type of dementia. One junior doctor had provided him some information about his type of dementia and the senior
consultant wasn’t very happy at all that he had given me that. Dave’s consultant did not tell him that his diagnosis was of a form of dementia, it was an Alzheimer support worker who heard him speaking at a workshop that eventually told him. The reasons Dave thought the consultant didn’t provide information was, I feel that they don’t want to tell you anything because there’s so much that might not happen, but as far as I was concerned there’s a lot that probably would happen.

The day-to-day impact of the dementia is that if I think too long about what I’m trying to do in any one week I get very very confused and uh, just, I can’t for example, I get up in the morning and I can’t think what to do, but I always switch the television on because its got the date and the time, and I can remember what day it is. That’s the only reason I put the telly on first thing in the morning. Another daily issue is incontinence caused by the dementia. This initially was quite embarrassing because it was bad incontinence and it was both my bladder and my bowels. I found that quite difficult to deal with and I found it difficult for my wife and son. Dave also found his motivation is nil. This includes finding it hard to be motivated to do the grocery shopping. Dave’s mother had Alzheimer’s and his memories of her decline are not pleasant. He initially worried that he might become like his mother, but he doesn’t worry so much about that now.

The relationships Dave has with his family can be strained at times. Although his son understands my problems, well I think he understands, well he knows I’ve got a memory problem and get mixed up very easily he finds that he’s another person that complains about me asking the same question over and over again, as does his wife. The strain on his family was noticed by Dave. He had decided to not go on a family holiday with them, in case I wasn’t well enough, and brought them down. Dave would like his wife to have a greater understanding of how he feels, if only she knew how I was feeling inside, because I’ve got this, I don’t mean a life sentence, but there’s something hanging over me that could be construed as not a very nice thing. But I’ve got this sort of, just got to get on with life.

There is not enough information provided about Dave’s particular form of dementia. He feels that they could give me the likely prognosis, that would allow me to maybe make plans for the future. This lack of information also means others don’t understand sometimes just how mixed up you can become. This issue of people not understanding his dementia was quite important, his wife doesn’t really know that much about it and his GP says that there’s nothing wrong with me. This denial from his GP meant it was difficult accessing a discount on his community tax. Legal and financial matters have all been granted power of attorney to Dave’s wife. He only considered this after attending a dementia awareness conference. It was being at this conference that made him aware of the issue of financial and legal matters, such as the need for someone to have power of attorney for him.

When asked if he ever wished he didn’t know his diagnosis, Dave talked about how he feel it’s important, particularly when I had the mental health problems, because the two crossed over so much that I felt it was important to know what was actually wrong with me. I mean it might have been, at the time, I didn’t understand it and being depressed I couldn’t understand it, but I still feel I should have the opportunity to know. He had been experiencing bad depression and at one point his wife actually came in and found me trying to hang myself from the hatch in the loft. However the suicidal feelings have subsided now he is receiving more support, and has had his medication reviewed.

Dave is not embarrassed to tell anybody that I have a problem with my memory or a depressive illness, I mean I’m a great one for talking about it. Dave’s advice he would give to other people who might be experiencing similar problems was that they try and find out, just because of the level of support I’ve got, I found it very important to be surrounded by
people who know what they're talking about and what was wrong with me and what I might do that other people might find strange. I wanted people to know why I was doing that, albeit I might not understand it myself, at least there’d be somebody there that could explain why I was doing certain things. The support that Dave receives from both the group he attends and an Alzheimer support worker have meant that he is not so frightened of it as he was initially. Accessing this support has made a substantial difference for Dave in dealing with the dementia. He highlights the support you can access as one of the reasons that knowing the diagnosis can be so important. Dave could think of no reason why he should not have been told his diagnosis.

Dave would have preferred to have been told the diagnosis earlier. He feels then he would have known what I was doing, or what I would do, should the condition get any worse he also felt knowing earlier would have given him the opportunity to have then made up my mind of what I was wanting.

But it was things like getting lost, it was difficult to explain to people, I just knew there was something that I, I actually knew there was something wrong with me just after I had my stroke, cause I felt as though I wasn’t there, just a very strange feeling, I can’t put it into words.

6.3.3 Case Study: Participant 03 - Alex

I was brought up to think dementia is someone running around naked staring at the moon, now I know that’s not true now, socks are kept on.

Alex is 59, he used to work as a civil servant and it was at work eight years ago that he started to realise something was wrong with his memory he was finding I was having trouble doing my work, and I would forget people’s names, people I had known for an awful long time. The first step to getting the diagnosis was getting his GP to take his concerns seriously and to refer his case to a specialist. This took approximately eight years. Eventually, Alex paid to see a consultant privately due to his difficulties in getting a referral. Once he accessed further medical advice it was still a struggle to get information about what was wrong, I was told, oh I’ve just got hardening of the arteries and its normal for people of your age, and uh, and makes you a bit forgetful.

The process of receiving a diagnosis was lengthy, with referrals through a number of medical professionals until the diagnosis was finally disclosed. When Alex was told the diagnosis he was stunned because it was the first time I had been told there was something wrong with me.

I knew there was something wrong, I knew there was something wrong for a long time, but I couldn’t put my finger on it. You start to think is it all in your mind, or have you got a brain tumour, and at least I knew what I was fighting then. But my own doctor never told me. Looking back, would it have been helpful, I don’t know, because there’s two sides to it, one, at some bits in the past I was feeling so bad I was suicidal, very suicidal on a couple of occasions. Possibly the doctor might of feared that saying that might have put me over the brink, I don’t know, uh, maybe the doctor just made a blanket decision to tell nobody. So it was a surprise to be told that, but not a shock. She was just labelling something that was there.

Alex was a wee bit surprised, but it was like the final piece of a jigsaw clicking into place, finally he had something to explain all these things that I’d been doing and obsessional
behaviour. One of his initial reactions was to compare himself to his mother who has advanced Alzheimer’s thinking, is that me in a year or two? Alex now feels that he will never reach the stage his mother got to, I’m going to die anyway, before I get to the advanced stage that my mothers got, you know I’ve got circulation problems and other problems, so I feel its academic, I’m not going to reach that stage.

When Alex was finally told his diagnosis I felt vindicated. He also felt I felt a wee bit down, with many different thoughts running through his head, but I was glad I was told, cause you can deal with it. I’ve often said, if you know what you’ve got, you can deal with it, I’m not saying you can cure it or get round it, or perhaps you can deal with it, and what way you deal with it is up to yourself, sit at home and vegetate or “get a life” as the young kids say now.

The day-by-day difficulties that Alex experiences are particularly to do with memory and money as sometimes in shops I can get in difficulties. Alex has also had to give up driving. His is disappointed that he can’t drive anymore. He also sees that not being told his diagnosis meant he was driving when it might have been a risk to him. By not telling the diagnosis maybe the doctor was doing what she thought was best but, eh, and it turned out she was wrong, because it would have had more peace at home, I would have been more alert to the fact that my driving was suspect.

Alex first got involved in various activities when the welfare rights benefits person from an Alzheimer organisation visited him and he offered a wee hand at a fund raising event. This initial involvement has given him the confidence to be involved in a number of different activities. He is retraining himself to be able to take photographs with support from an Alzheimer organisation who give me somebody to take me out around places to take pictures. He has also been involved in helping stock information leaflets in local GP surgeries about dementia. This involvement in various activities made a very positive difference in Alex life and this difference was facilitated by one support worker saying yes, just one word, if she’d have said no, or we’ve got plenty of help, we’ve got more help than we can do with I would still be here, where as she said oh yes, that’ll be fine. That one word. That moment changed my life.

Alex was clear about the possible impact of depression, he felt if somebody’s being told I think they should consider starting anti-depressants. He also sees doing things like, relearn a skill or learn a new one as important as you need to get your confidence back. He lost confidence after he found he could no longer do some tasks that he had previously been able to easily do. Conflict in the family home had also affected his confidence as he had felt that nobody speaks to you, you’re just shut in a corner.

Alex accepts that there’s things I can’t do, and it would be dangerous to do them but is focusing on non-dangerous things I can do. He highlighted that someone might have dementia, but the brain was fertile, he is concerned that people haven’t been trained that people have feelings, just they forget, even old people with dementia, they still have feelings. Alex felt that to get a wee bit of confidence encourages creativity. Alex has expressed his creativity through photography and through music. For him, this is an important part of trying to be a trail blazer to show that you don’t sit at home getting into a rut, get back into life and do things you used to do you liked, try to go for something you’ve always wanted to do.

Alex feels there are people who are well known who have dementia and they won’t let on because of the so-called stigma. If there was less stigma, Alex feels people could be encouraged to start using their brains, and therefore be less of a burden to their carers. The
role of the initial Alzheimer support worker who encouraged Alex into activities was valuable. Without her, he felt it wouldn’t have happened, because I was just sitting here looking at a blank screen. It wouldn’t have happened, I needed somebody to take me by the hand, be the optimist.

Alex tells family or friends about his diagnosis, I’ve made it plain that I’ve got this and I must say that I’m treated normally, you know, that I’m not treated as an idiot. But in his local neighbourhood he does not tell people. He is frightened of being chased in the street with kids shouting “demented, you’re demented”.

Alex lives with his wife, and three of their four children. The relationship that Alex has with his family has been strongly influenced by the dementia. Initially when he was not told his diagnosis it caused great conflict, cause I couldn’t stand her, the lies that she told, and the terrible accusations which I now accept that she was right, and I was right because I just couldn’t remember them. He also felt had I been told earlier possibly things in the house would have been a lot more, uh, in harmony for a number of years.

The diagnosis being withheld had caused great conflict and they both saw knowing the diagnosis as the key to changing the conflict. It meant that his wife realised I hadn’t been a right bastard all those years, that I was ill, the same way I realised she wasn’t a right bitch all those years, and that eh, things, that eased immediately.. It wasn’t the same, friction seems too mellow a word, stormy and sparky, so that again helped. This reduction of conflict was a temporary reprieve to the strain created by understanding and living with the dementia for both Alex and his wife. Visiting Alex on a second occasion, approximately three months later, there had been a change in their relationship.

(My wife) says I’m a handful to look after. She says I’m a handful to look after, it’s exhausting. That’s what she says, I’m not saying I agree with it. I don’t know why, I don’t look for much or demand much and I’m so easy to get on with it’s unbelievable.

Alex felt that he was slightly better since my last visit, however his wife didn’t agree. Although Alex felt that some that bits of my brain are dead, he felt that in some areas there was improvement, other bits are taking over. However his wife believed that although there were some improvements, the area’s that had declined were now much worse. The difference of opinion was reconciled by having to agree to differ. This was not the only issue that we don’t see eye to eye on.

At the same time maintaining he was slightly better, Alex had reduced the amount of activities he was involved in, I haven’t been feeling A1. He felt that his decline was due to being on holiday and one day I did go out till I got bitten by the midges and I think they poisoned me, because I haven’t felt the same since. This rationale for not feeling A1 was not one his wife agreed with, which she showed by both verbally disagreeing and by laughing at his explanation, believing the decline being due to having further mini strokes.

Alex has been given a mobile phone by his wife to help address issues of risk. The family wants him to use the phone if ever he gets lost or has a mini stroke. He finds it both hard to remember how to use the phone, and is also reluctant to use it, I thought if I phone, she’ll panic and say I’m staying in the house. His wife obviously worries about him, and Alex worries that if he uses the phone, he could lose his independence by being restricted to the house. This causes some conflict.

Alex found that before I would have hidden my feelings, whereas now I tend to say what I think. Alex felt that the kids treat me like dirt now, they order me about. This seemed more
of an issue now than it had been on my previous visit. His wife felt this was because he was now more difficult with them, particularly in being less compliant to their requests that he do things like change his clothes. I don’t like clean clothes, they’re less comfortable. I don’t mean dirty smelly clothes, I leave them a wee bit.. I feel like they are taking away my life, I don’t have a voice anymore, I don’t have thoughts any more. I’m told how I’m thinking, I’m told how I’m feeling, it’s all wrong.

Alex feels all he is told at the moment is the word no. Alex asked his wife in the interview what if someone told you what to do. I know there’s brain cells dead, but I feel as though there’s other ones taking over. My feelings aren’t dead. If the dementia progresses, Alex explained, I don’t want to be a burden to my wife and family. He feels he might avoid this burden by going to live on his own. His wife pointed out to him that this was not likely to be possible for him. That he could go into care if it was getting a burden.

Alex feels that his wife doesn’t trust me anymore. This is particularly in relation to his judgement or memory. She no longer consults him on decisions, but tells him I’m dealing with it, and that’s her answer for anything, I’m dealing with it. His wife does this because she finds that Alex asks too many questions and isn’t accepting of her opinion. He feels this is due to people with dementia need longer time to absorb things, they need things repeated, and a wee bit more time spent explaining so it sinks in. She doesn’t do that anymore, there isn’t the time for it, it’s just cut and dried and you’re left wondering what’s going on. Alex also feels that he is excluded from dealing with phone calls, despite recognising that he finds it difficult to communicate via the phone.

Alex has another important family relationship with his mother, who has fairly advanced Alzheimer’s. Alex sometimes cares for her and finds he has to place restrictions on her. I’ll have to say, you can’t get that, ‘why not’, ‘I like it’, its all this aggrieved voice and I realise I’m doing to her what (my wife) does to me. Alex feels that he will try to work it around with her, and sees her resistance to being told what to do, as she still wants this wee bit of independence.

Alex thinks that apparently some doctors seem to think it takes so long to diagnose properly, that’s why it takes so long to tell you, and recognises that it is a dilemma making the decision whether to tell someone the diagnosis or not. He believes that despite it breaking medical confidences that someone in a person’s family should at least be told as soon as possible and if that had happened with him what a difference it’d made. He knows his doctor might have realised that I had been suicidal at times but he didn’t know if that was why the doctor had not told him or whether maybe she doesn’t tell anybody, I don’t know, can’t very well question a doctor. However he does feel that when you’re blundering about hurting inside, eh, somebody should have done something. One of the things Alex would like to see is improved diagnosis techniques, that’s where they must have a better system put in place. Alex talked about the need for wider awareness of the signs of dementia, so that this can get picked up quicker. For him a sign was stopping taking pictures.

In terms of how the diagnosis is disclosed, Alex suggested the doctor get somebody to come and see you would that be okay with you, and then having somebody trained to come and break it to you, not just this usual doctor stuff - good morning, you’ve got dementia, cherrio,
too bad, how sad. He felt that people my generation might instantly picture themselves as
having very advanced dementia once told the diagnosis, because that may be their only
knowledge of Alzheimer’s.

The aspects that were important to Alex about disclosure were the person is to be told, pick a
time and place. He didn’t think the doctor was necessarily the right person to provide the
diagnosis. The person has got to be in the right receptive mood to be told, where and when. I
mean you don’t tell somebody in the middle of a bus queue, so maybe a wee attractive room,
not, something dreary, but maybe a room with flowers on the wall, and carpets and cushions
and things. No phone, nice and relaxing. I don’t know.

Alex feels that well basically I think you’re looking at is, the bottom line is, should people be
told.

I would say deep down, yes tell them, people can understand what’s wrong with
them, know why they’re so bewildered and they can also, as I say, make plans for
financial and even, just the same if you were told, you’ve got a week of your life left,
what would you do with it. So I’ve looked at it like I’ve got certain time with my
brain left what am I going to do with it.

6.3.4 Case Study: Participant 04 – Susan

I wasn’t having problems with my memory, it was my appearance actually that my
eldest sister said I wasn’t quite right and suggested I go to my doctor. I went to my
doctor and he referred me to a clinic. I saw a doctor there two or three times and I
was told I had Picks disease. It was a real shock to me when I was told I had Picks
disease.

Susan is 48 and lives on her own. She didn’t notice the first signs of Picks disease in herself,
it was her sister who first pointed it out to her. Susan used to care for her sister who also has
Picks disease. She is more advanced than Susan and now lives in a nursing home. Despite
having cared for her sister Susan was unaware of the first signs in herself. She said it was a
real shock when she was told the diagnosis.

Susan is very sad I’ve got Picks disease and I feel me having Picks disease is what’s stopping
(my sister) coming home. Susan doesn’t think her sister is very happy to be in the nursing home
cause she’ll not talk to anybody. I don’t feel (my sister’s) happy there, I think she’s settled, she realised she’s got to stay there, but um, I don’t think she’s happy.

Susan deals with having Picks disease by trying to just live each day as it comes. She is
involved in voluntary work and spends a lot of time visiting her sister. She does have a care
assistant come once a week, but she feels she is very independent. Susan knows she wants to
be looked after in her own home. Her estimation is I don’t think I’ll reach going to (nursing
care) for another six or seven years actually, because I got my diagnosis very early, whereas
(my sister) was diagnosed pretty late.

Having cared for her sister means that Susan is very afraid I’ll go like (my sister) actually. She
has limited information about what her prognosis is and she wants to know about her
future. I want to be at my 50th birthday next August, I want to enjoy it, and I want to be like I
am now when I’m 50. I want to be like I am now when a bond I’ve got matures in 2004. I
want to, I mean I want to be like I am now in 2004, I mean I’ve got a life insurance policy
that matures in 2005, I want to be like I am now in 2005.
For Susan the best way to deal with the Picks disease is to not think about the fact I’ve got dementia. I don’t think, I’ve got dementia, I mean it’s not occupying my mind that I’ve got dementia. I just tell people I’ve got dementia.

Susan feels it’s very sad that I’ve got dementia but at the same time, it just doesn’t cross my mind actually that I’ve got dementia, it doesn’t cross my mind. She is only sad when she thinks about it, particularly when she thinks that if she hadn’t developed dementia she might have been able to care for her sister in their home.

The reasons why Susan feels it is good that people know their diagnosis includes being able to take care of financial matters. I’m in the process of getting a power of attorney made up and yes, I mean, for um, I mean I’m okay at the moment, I’m still dealing with my own financial affairs but I’ll have a power of attorney that can be implemented as and when I’m no longer capable of dealing with my own financial affairs. So yes, I mean in that respect I suppose getting an early diagnosis has been okay. Susan had known about making a power of attorney from having made those arrangements for her sister. I mean, just it’s allowed me to put my affairs in order actually.

Susan’s only thoughts on why not to disclose the diagnosis was if they’re going to think about it all the time. Not if their thoughts keep turning to dementia. She found she was able to not dwell on it by using the approach of I refuse to think about it actually, I refuse to think about it. I mean, I’m okay at the moment so I mean, I’ll think about it as and when I need to think about it, um, I’m okay. This was not denial of having dementia, it’s reality that I’ve got dementia, more her way of keeping it in perspective in her life.

Susan does not feel that she has enough information about Picks disease. She had arranged to visit a nurse who is involved in her sister’s care to find out more about it. Her doctor had explained that I used to be very intelligent and now you’re just of average intelligence, that’s how he explained it to me. I don’t think he knows about Picks disease. She would like to know information about the prognosis. She felt that if a doctor gives you a diagnosis he should be able to give you prognosis then. At the time of being told the diagnosis I just didn’t think to ask actually about the prognosis.

Another way in which Susan was dealing with the dementia was through her religious beliefs, I’m doing a retreat over 12 weeks actually, praying to God that I’m okay when I’m 50, that I’m okay in 2004, and I’m okay in 2005. I’m asking God to make me not sad that I’ve got dementia. For Susan it has been a time that’s just made me accept it that I’ve got Picks Disease.

Day-by-day Susan does not think the dementia effects her. I mean, I’m still doing things so, I mean I’ve got Picks Disease [[laugh]] so what [[laugh]] so what. Some of the difficulties she does face is I do find that sometimes, I’m finding difficulty speaking, well not speaking, but finding words. Which is very frustrating.

Three months on, Susan had visited her sister’s nurse to ask more information about Pick’s disease. The nurse she talked to really convinced me that, yes I mean I was basing my knowledge on Picks Disease on how my sister had gone and (she) convinced me that, well she said I was unique. This was very helpful as I was basing my thoughts on how I could go by how (my sister) went so, I mean, the fact I was shocked when I got the diagnosis I think it was coloured by (my sister) all the time. It was coloured how (my sister) had gone.
Susan would now advise people who have received a diagnosis to talk with somebody who knows about Pick's Disease. Perhaps it would have been helpful to me at the time when I first got the diagnosis. For her, talking to the nurse helped Susan as she just needed to be told again that I was unique.

Susan had experienced some difficulties in getting a reduction on her council tax. She had to fill in a form that insisted that I class myself as mentally, or severely mentally impaired. She had difficulty in getting her doctor to sign the form as I’m not yet severely mentally impaired.

Her visits with her sister have become more difficult. She cries every time I visit her. I don’t know if I’m going to go back to see her cause she cries all the time so I’ll see when I visit her this afternoon if she’s going to cry or not. This crying was upsetting me actually.

Susan feels that even if it’s bad news, doctors should still tell a patient what’s wrong with them, shouldn’t they. For Susan she tends to describe her diagnosis to people as dementia because people don’t know what Pick’s Disease is. Well, I would hope that people would realise what dementia is because I mean it is more, people are more aware these days of diseases of the brain actually, dementia.

It has been Susan’s experience with her sister that has had the greatest impact on her experience of having Pick’s disease. She had pushed for her sister to get a diagnosis due to the employment agency attempting to place her sister into employment, that’s what finally made me take (my sister) to the doctor so that her sister would have her benefit changed to the incapacity benefit. To do this she needed a diagnosis. However, Susan recognises that although she wanted to know her diagnosis, her sister didn’t want to know. Susan believes this difference is due to their different personalities, as she is someone who has always wanted to know the reasons for things happening.

I mean no diagnosis needs to be your whole life.

6.3.5 Case Study: Participant 05 – Sarah

Nobody’s ever asked how I felt, (the doctor) said, “I’m sorry it’s Alzheimer’s”, and then that, that was it. They’ve never stopped and said how do you feel about it. ...I always put a face on, everybody says, oh you’re always cheery and that, but I just, people really don’t want to know maybe, and it builds up and you just put a face on.

Sarah is a 44 year-old woman. She used to work as a nurse before she injured her back, an injury that now means she has limited mobility. Sarah lives with her husband in a suburban area. They have two children who no longer live at home.

When Sarah first noticed she was having problems with her memory she was depressed due to my back condition and thought the memory loss might be due to medication she was on for the back pain. She estimates it was about two years ago that the problems started. Sarah had her memory problems noticed very early. She was visited by a community psychiatric nurse, due to the depression, and mentioned her memory problems to the nurse, she got the psychiatrist to come to visit me... he did a memory test and that’s when I started to be a bit concerned.

This was the start of the process of getting a diagnosis of probable Alzheimer’s Disease. The psychiatrist initially told her husband who didn’t want to keep it from me, so he told me. Sarah then started to attend a memory clinic. When disclosing the diagnosis to Sarah, the
psychiatrist told her that they didn’t need to do any surgery, because they were looking for a brain tumour; he said you don’t need surgery, and I said does that mean it is Alzheimer’s, and he said yes, he was very sorry to say but yes it was.

And then, well basically I didn’t believe him. I know it, he was really good, I wasn’t doubting his word, but I just couldn’t believe that it was, being so young and that as well. I had thought it was the medication and I said to him are you sure its not the medication, and he said definitely not.

Sarah’s GP was reluctant to accept the diagnosis of Alzheimer’s, he said, I don’t know if you have got dementia, I don’t agree, I’m sure he said this, he said, I don’t agree with the specialist, and right away I thought, yeah, that’s great, I mean that’s great. Sarah eventually asked a different psychiatrist if she would do a second opinion, which confirmed the first psychiatrist’s diagnosis of probably Alzheimer’s. I was upset at the time, but I did still think, maybe they’ve made a mistake.

When I first visited Sarah she knew my memory is getting worse, and I know I’m doing silly things but she was still not totally convinced she had Alzheimer’s disease. She knows from things she does and her memory difficulties that it is Alzheimer’s, but its difficult to admit to it, if that makes sense. I mean its not bad all the time, you know, sometimes I feel that there’s nothing wrong with me I feel great, and, but, some days there is, its a funny feeling that I’ve got.

Sarah’s initial reaction to the diagnosis was to attend to her husband, this allowed her to not think about it. I just wanted to put it away. Sarah has told her family about the diagnosis and they have all reacted in different ways. Her mother doesn’t want to know, she says, she just can’t handle it at all, she’s just shut off about it. The rest of the family have been upset about it and tend to talk with Sarah more about it. As with her husband, Sarah has been comforting her adult children and helping them to come to terms with it. I have to keep it in because I’m just too busy looking after everybody else. But I don’t know if that’s just a nurse, I’ve always been like that. Sometimes being around people who want to talk about the Alzheimer’s upsets Sarah. She sometimes finds if I go to my mums in the morning there’s no talk about it, no mention of it, so I feel a bit better, like I’m getting away from it.

Day-to-day she has noticed that she can’t work out any money, can’t do my housekeeping, can’t go to the shops. I just can’t do it now. She has also noticed that she can’t do her own medications, I’m not able to do that, which is a difficult thing to accept as she used to be a nurse. Sarah gets frustrated at not being able to do things, not being able to remember things and the other day I was just ready to scream at myself. I can’t remember what it was or what I had done, but I had done something and it really got to me.

Realising she was doing things that were not making much sense left Sarah feeling upset really, I was upset. Sometimes she uses her sense of humour to get her through and is able to laugh at some of the things she has done. Being aware of these silly things means that she tries to hide a bit from (her husband) because of him being so upset and feeling that I just don’t think he’s handling things, so what to do eh.

Information about the prognosis was given to her husband, which he has passed on to Sarah, he had asked how long we’ve got, we’d have together before I’d need to be put into a home, and (the doctor) said we’ve got eight years, so that’s quite frightening. Her husband was also given a book about dementia and he won’t let me read it. He says I’m better not reading it because it will get me upset. Sarah would like to know more, but I still don’t think I’ve
accepted that I’ve got it. I keep, like I say to (my husband), just put it at the back of your mind, and do what I’m doing.

Sarah is grieving the fact she might not see her grandchildren, I’ve never said to (my daughter), but she’s been married for four years and I’d love her to have children now, but she’s really into her career, I just wish she would. That’s the thing that I’m really really desperate for.

There has been some planning for the future done in terms of financial plans, power of attorney, and in Sarah expressing what type of care she would like. I’ve told them I want to go into a home, that I don’t want to be a bother to them, especially (my husband), because it’s going to be really hard caring 24 hours a day, so I’ve said that to them, and I’ve made him promise that he has to do that. So it’s good in the sense that I can plan. Other future plans are for travel, overseas holidays and spending time with her family.

Sarah would like to speak to other people with dementia, especially young people like myself. This interview was the first time I’ve spoken about it.

I was suicidal with my back, you know, because that was my career, everything, and I really did want to commit suicide and (my husband) had to hide the medicine from me, I was quite ill. I don’t feel depressed now. I feel fine, but its frightening to think, I just don’t want to think maybe eight or nine years times, I won’t have my family, I won’t know them. When I sit and think about it it’s too frightening.

Sarah doesn’t tell people that she has Alzheimer’s. All the family are absolutely not to tell anybody because I’m embarrassed about it. However, she sometimes thinks she should tell people as she once walked by someone who I knew, and I walked by this man and never spoke to him, and it was (my husband) that said, oh there’s whatever his name was, and I didn’t recognise him. She often finds people say hello and she does not recognise them. People wave to me in cars and I wave and I say - who’s that, its really, don’t know, its really embarrassing. People just wave I wave back at them.

The diagnosis disclosure was done really well, um, he took his time and explained things, what he wanted to explain, he explained things, I think he was really good. Sarah feels it was good to know the diagnosis early because they’ve got me on the medication really quick, hopefully it will work, it has also meant she can prepare your family for it as well and get all the official things done. Sarah could not think of any reason to not be told the diagnosis. No matter what illness it would be, whether it would be cancer, I would want to know, definitely.

Sarah deals with the diagnosis by trying to put it at the back of your mind and just get on with things she does this because if I think about it, I’m scared, and I feel that I’m missing out on such a lot of my life. Despite trying not to think about it much Sarah found that talking about her experience of Alzheimer’s was good for her. Its good to get it out.

Sarah has started anti-dementia medication and although they said it’s only for about a half that it works, but I’m really excited, cause I feel that I’ve got hope, where before I felt that there wasn’t any hope. She is desperate for it to get into my system.

Three months on Sarah felt that she had finally come to accept that the diagnosis of Alzheimer’s Disease. The progress with the medication has been slow. Sarah has been adjusting to the medication as I felt a bit sick initially and the dose I’m on now is a working dose. It is still too early to know if the medication is working. Sarah has noticed though when I came back from holiday and that I couldn’t remember how to work my hairdryer or
the phone or things. The wait involved with the medication is difficult. I’m just terrified in case it gets the better of me, I’m really scared.

Sarah continues to do a lot of covering up. When she goes to the shops there was a good few people spoke to me and I just hadn’t a clue who they were. She covers for this by making sure to speak to everybody and wave to everybody but I haven’t a clue, so, that’s horrible. I really hate that. She is also good at covering up in conversations, if I forget a word, I put the word thing in it. I get away with that loads and loads, nobody notices

On reflection, Sarah can see that when I was first told, how can I put it, it was like it was me, but I was in the distance and it wasn’t me. I had to do things, sign form things for our daughter to deal with my finances when I’m not able to, but I find that, for some reason, easy to do. But now all the things to do have been done, she is finding she is now actually accepting the diagnosis. She now feels that it is definite.

She has contact with a support worker but more than anything Sarah wants to be able to talk to someone in her situation and of a similar age. Being so young means that it is difficult to find someone in the same circumstances as herself. It also causes her to feel bitter sometimes. Upon seeing an older couple at the memory clinic she thought, at least he’s lived to that age and he’s got it now.

I’m not lucky enough to win the lottery but I’m unlucky enough to get this. Sarah feels angry and bitter about having Alzheimer’s. Despite this, she still would have wanted to know the diagnosis as soon possible. She feels it was really the psychiatric nurse that first suspected it and did something about getting Sarah a diagnosis. For Sarah, it is the possibility of the medication helping her, that made it worth knowing as soon as possible, but if there was no medication for it and no help at all, then I’d rather have not known just now.

Sarah would rather that the word Alzheimer’s was used to describe her illness. I think there’s maybe a stigma to dementia, em, and you know, if I do tell people, it will be Alzheimer’s. All the family I’ve said Alzheimer’s. Its just you get a funny feeling when you say dementia. I know I shouldn’t. The words, memory problems, don’t describe it well enough for Sarah, as it’s not just memory problems. She also avoids saying the word ‘disease’.

Sarah wants to know more information about Alzheimer’s. She is just trying to work out the philosophy of it. Not the philosophy, the nursing bit, what happens to your body, that’s just the nurse bit coming out of me. I’m just trying to work out why it would actually kill me. I don’t know why I would be more susceptible to infections, I’ll have to ask. She will probably ask her GP about this (a different GP to the one that would not accept the diagnosis from the psychiatrist). This need to know information is not the same as her husbands. Whilst Sarah wants to know all she can, her husband doesn’t want to know any more information just now. On their holiday together Sarah found a book about Alzheimer’s but her husband wouldn’t let me read it. So I had to put it down. I was a bit angry, because its my body.

Sarah knows that if I’m given a lot of information at one time I can’t take it all in. Where if I’m just given a bit of information at a time, I don’t have to, maybe remember what’s been said. This also applies to reading books and watching television programmes, so she has now stopped reading.

I didn’t know it was terminal, it was (a support worker) that said to me one day (that) I was terminally ill and I never ever looked at it like that, and I’ve never really thought much more since being told I was terminally ill. You feel cancer or
something if you’re terminally ill, but uh. I don’t know why I said that but I was quite upset about that.

6.3.6 Case Study: Participant 06 – Lorna

Very little bothers me, (laughs), very little. As you get older you just find its a waste of time and a waste of effort. You know things you can’t change, why get in a big state about it. Takes a while to get there, but it’s sensible once you do.

Lorna is 62 years old and lives with her husband. She is close with her family and often cares for her grandchildren. She thinks the grandchildren know she has dementia. The wee girl, we’re going out she says ‘now grandma do you want to tell me what you need, and I’ll make sure you get it’. I say no, I’ve got a note, ‘what if you lose the note grandma’.

Lorna first noticed that her memory was changing at work. She eventually gave up her job so that she would not be an embarrassment to myself. Lorna also thinks she may have annoyed other people a lot with asking them the same questions or them having to tell me over and over again. It took a wee while for it to dawn on me. Before Lorna knew the diagnosis she felt sheer frustration all the time, tears, anger, I just couldn’t figure out what on earth was wrong.

Lorna does not remember the exact process she went through in getting her diagnosis. She received the diagnosis of Alzheimer’s oh, must be, at least two years ago. Probably about that. When she was told the diagnosis she felt devastated, totally devastated. Part of the reason for this devastation was Lorna’s fear that she would become immediately like her mother who was not diagnosed until she had advanced dementia. If I hadn’t, how can I put it, if I hadn’t seen my mum, I wouldn’t have been worried at all. Lorna is on anti dementia medication, which although she knows it may not work, it gives her some hope.

When Lorna initially received her diagnosis, she did feel suicidal. The support of friends and having time to come to terms with the diagnosis, helped her get through this. Lorna also felt almost ashamed when I first heard. (My husband) says there’s nothing to be ashamed about and it’s like I know, I’m like I know. But I was told and I thought why, it’s nothing I’ve done. No, you do feel like that, idiot.

Her attitude is now more positive. You either sit at home and become a vegetable or just get on as best you can, it’s just what I think. Lorna doesn’t want any sympathy, she just wants to be able to get on with life as normal. I don’t want sympathy from anybody. I don’t need sympathy from anybody. Eh, I don’t think it does any good anyway, just makes you tearful and things when people start feeling sorry for you and whatnot. Its just, I think you’re better without it. Lorna feels that she has had no choice but to accept her diagnosis. I don’t think I have any option but to think that’s what Alzheimer’s is, loss of memory isn’t it. Although she accepts it she experiences frustration, particularly when she gets the shopping wrong, I get so angry with me.

The impact of Lorna’s daily life is directly related to her memory, I mean I can still do everything, that’s the annoying thing. It’s just remembering to do it. Lorna’s husband will try to help her by writing out notes for her as reminders of things to do, but she finds that I’ll forget the notes. Lorna doesn’t feel their relationship has changed, but she does feel that he gets frustrated with her at times.
Lorna thinks the diagnosis is something *I think you have to know, otherwise you don’t know what you’re coping with.* However, she thinks that being told the diagnosis is upsetting and it may be best to tell people only when they are starting to worry or when you start letting people down. Lorna has told friends about the diagnosis, to whom it is *no big deal.* No, *I’m the only one that gets upset about it, nobody else does.* Some people react to her diagnosis by considering it an illness, but to Lorna *I don’t feel I’m ill, I just feel I’ve got a bad memory.* *And that’s the way its going to stay.* She does not tell people she doesn’t know well as it’s *not a big problem, so why bother telling people you don’t see a lot.*

Lorna attends a day centre and one of her coping strategies is to compare herself to others. *I think I’m lucky compared to a lot of people, because it seems to have happened quite quickly to people.* Comparing also makes Lorna feel, at times, that she is *a fraud* for taking a place in the day centre. She worries someone who might *need it more than I do* could be attending. Lorna enjoys the lunch club she attends and feels that she is more of a helper *because, I am definitely not anywhere at the stage of most of them.* The groups do a number of activities together including day trips and swimming. It also provides her a place where she can talk to others. *I think you feel better if you talk to somebody for a start.*

When Lorna first received her diagnosis the DVLA tried to take her drivers licence. She successfully fought them and continues to drive. *I went to the licensing, because I immediately got my licence taken away, but no, I thought, you’ve got to prove to me that I can’t do it and I’ll be very happy not to. So I went up, drove round, and not a problem. I said, thank you.*

Lorna finds her frustration and stress are helped by walking *miles with the dog.* Having the dog has *made a difference, a great difference.* The people you meet too, you do down to the park with a dog and everybody’s brother talks to you. *They do. Everybody talks to you when you have a dog, so that’s its own company.*

Lorna feels that she does not *really know anything about it other than it’s a memory problem. That’s basically all I know, and it won’t get better. It will only get worse.* *Is there anything else to know? Is there?*. She does not really want to know any more information about Alzheimer’s. *What’s going to happen will happen, if it’s not going to happen it won’t.*

One of the negative aspects of knowing the diagnosis for Lorna, was that she felt it confirmed that she was *not reliable, because I forget everything.* *I don’t think that there’s anybody who, not wants to be stupid, to appear stupid or not caring what you’ve said to them. But you do, you’ve just forgotten what you’ve said to them, it’s not that you didn’t care what they said, you just forgot what they said.*

One of the ways Lorna tries to overcome her memory loss is to *go through the alphabet.* *A lot of the time I remember what it was I wanted to do or say or phone, if I just go through the alphabet.* *It’s my way of trying, I mean it doesn’t always work.*

*The way I described it to a friend of mine, I says, “well to me it’s something that’s wrong with me, but there’s nothing wrong with me”. She says, “what do you mean?” I said, “I can’t explain it, but there’s something wrong, but there’s nothing wrong because I can still do things, but I can’t remember to do them. I can’t remember if I’ve done them. If you ask me to do it I’ve no problem doing it. So its it, I suppose its better that way than another way, I don’t know. as long as I can still do things I’m quite happy.”*
6.3.7 Case Study: Participant 07 – Shane

The difficulty I’ve got now, as you can hear, as I speak, well it’s not a stutter, but eh, I know what I want to say clear as a bell in my head but its getting it out, I can’t get my thoughts out in paper, I know what I want to say, but, I have difficulty in expressing myself. I know I’ve got, you can see it’s slowly having an effect. My memory is quite good, but then the one thing wrong with the memory aspect is that a person over the years can condition himself to have good memory. Remember if you meet somebody you remember that and its often hard to tell if what you’ve got is a knowledge or is it a false memory. You know its hard to put into words sometimes.

Shane is 70 years old and lives with his wife on a housing estate. Shane used to work as a civil servant. Shane and his wife have six children between them from previous marriages. Shane hadn’t noticed that he was starting to show the early signs of dementia, it was his wife that had noticed it. Because of this when I was told I was quite surprised. Shane’s dementia is multi-infarct dementia, caused by a stroke. When he was told about the dementia I didn’t relate it to that yes.

Despite the surprise at the diagnosis I knew there was something wrong, but I thought it was memory cells, I was just forgetting what had gone on before, and I was, I couldn’t remember, especially names of people, I knew them, but I couldn’t put a name to a lot of them.

The daily effects of the dementia are varied, the thing that Shane notices most is the difficulty he has in expressing himself, my brain has always been very clear, but as you know it doesn’t always come out. When this happens well, it just exasperates me, I do get a bit, I get a bit fed up with that, but I realise now that it is a condition, a form of dementia and I’ve just got to live with it I think. He also finds he is not very good at taking his medication, I’d take one and I realise it was to my benefit and I would take all the pills. He is also resistant to washing, both himself and his clothes.

One of the ways in which Shane deals with the dementia is to compare himself to people who have got a bit more advanced dementia than themselves, I realise I’m very lucky its not got worse yet, but I suppose over the next few years, I can’t see it getting better now. Shane does recognise that he may decline and together they have organised for a power of attorney and to move into sheltered housing. Shane’s prior knowledge of dementia was senile dementia, its normally old people, sticking out in a home, this had initially caused him to worry that, it hit you and that was it, you had it, you had it.

Shane feels that I never got it properly explained which had made it difficult for him to accept the dementia. He also had a problem in that he would do quite well on memory tests, I think that is what lacks with the tests, I felt they never changed over the years that I went they never changed tests I mean always got the same thing, Mr Green and Mr Brown and all that, he’s a butcher, this chaps a green grocer and all that, then you get all the same, Mr Green and Mrs Jones and all that. I find that repetition, I find that quite easy to understand I think. Despite doing well on the tests he was not doing as well in real life situations. One example his wife gave of this was one day he came home and thinking he could smell gas, he went looking for the gas leak with a lighter. Shane is starting to accept the fact he had dementia as he is now noticing the effects of it more, my reactions are slowing down, he also looses track of time and has restricted mobility.
Shane is someone who has never worried about things in his life. His wife thinks this is because he has never really taken responsibility for things, a theory which Shane himself agrees with. With this in mind, there are difficulties between Shane and his wife in knowing whether he can no longer do some tasks, especially around the house, because of the dementia, or because he is avoiding taking responsibility for things you don’t know what is dementia at the time and what is not. When I asked Shane about not taking responsibility he explained it was something he had done really all my life I have just done it the way it’s done now, there’s really very little that concerns me ((both laughing)). This shifting responsibility also happened in the interview with Shane finding it easier to have his wife answer questions for him, Shane felt this was because , I have supreme confidence in (my wife). And if there’s anything, I leave it to (my wife).

Shane’s relationship with his wife has changed. She is in an increasing carer role, feeling she is less of a wife and partner, and more of a mother to Shane, who agrees with her description of their relationship, that’s right. This change makes his wife angry at times and Shane also feels I get fed up with it yes. When she is angry Shane feels angry too, it’s just there’s no way out of it.

Shane would rather know that he had dementia, he does feel it means you can prepare yourself, you know, you can think ahead, you can think what’s going to happen eventually yes. Shane hopes that his dementia might just level out but he also knows that it could decline, I read some thing in the papers some time ago, and it said dementia, slowly, the older you get it normally gets worse. Because I don’t think there’s anything that can stop you from doing it.

You see, I don’t think anybody likes to know that they’ve got dementia. No matter who you are. I don’t think anyone likes to know.

Shane attends a day club for people with dementia. This is where he is in contact with people in more advanced stages than himself. We have got some ladies there, nice ladies, but I think they are, if I hadn’t known then I would have known that they have dementia. I think and the look, I mean looks don’t say anything, but they are not as quite as forthcoming, you know if you are speaking about something, uh, they go once again eh, get the brain cells working, and I think they’ve got the complaint I’ve got as well, you know, getting things out, saying them.

Shane and his wife have told their children about the dementia, however the children have been reluctant to accept it, they just think I’m a bit daft ((laughs)). Shane had been hiding the council tax bills, hoping to help his wife by doing this, they then owed quite a lot of money. Once it was explained to Shane how he hadn’t been helping as he had intended, he felt awful.

Shane and his wife joke about the frustration they sometimes feel. Through talking and joking they communicate well about how they feel.

Shane’s wife: I feel like throwing you out the window sometimes.

Interviewer: That would be quite a fall from here.

Shane: Yes but I’d land on my feet.

Three months later I visited Shane and his wife again. Since I last saw them they have been through a difficult time as they have found out that Shane has terminal cancer. He has been
given approximately six months to live. The dementia is now less important than it was before as both Shane and his wife are focusing on the cancer.

Shane is trying to be positive about the cancer diagnosis, *oh, life’s going on all the time. When you’ve been ill and that and you get better, you’re feeling better, it just springs from there, you feel great. Sometimes you might be a bit down and out you know, but I normally feel great.* He does know the cancer is terminal, *I don’t think it will ever cure itself,* but is trying to be positive about it, *I’ll always have it, but it might mean I’ll have it to a lesser extent.*

Shane never felt very worried by the dementia of course, *I never felt anything about the dementia, I never thought it effected me a lot, oh I know it does, I know the concentration’s gone and one or two things, but nothing drastic, but its not like, I can remember things, I’m coherent.* And there had not been any progression in the dementia in the three months between interviews, *I don’t think the dementia’s got any worse, I’m sure it hasn’t.* The cancer, *this new thing,* made the dementia seem unimportant.

You see, at the moment, *I can think quite clearly, if something comes into my mind, I could hold a conversation with myself and be quite an intelligent one,* I can still work out what is going on around about me, *what is going by,* its not as if I’ve no recollection, *I do. But does it, just sometimes I cant form the words to say it. I want to say something and the word won’t form.*

Shane and I discussed the fact that some people weren’t told a diagnosis of cancer for the same reasons they sometimes aren’t told about dementia. Shane felt about that cancer that *I’m quite glad I knew about it, it’s the sort of thing that nobody likes to know, but if it has to be it has to be. I know I’ve got it, I know it won’t go away, it could be controlled up to a certain point, you know, a certain point, I wouldn’t imagine they could cure it,* I’ve five, ten years off, *but I won’t go that far.*

Shane’s advice to people who have been told a diagnosis of dementia is to *just forget it.* This advice does not mean Shane thinks people should be told, *its good to know a full diagnosis,* there is no point in keeping wee bits from me if you’ve got to know them, but to then be able to forget about it if you want to.

*Just, live the life you’ve always led. You can’t do any harm not worrying about things, you don’t have to. you don’t have to. And eh, I suppose, one thing is that there is somebody worse than you, you’re not all, there’s somebody worse somewhere than you.*

6.3.8 Case Study: Participant 8 – Mary

*I’ve got friends I think I told you, they’ve got total recall, they bore the boots off you. They tell you every word and they can’t talk in shorthand at all. I never had a memory like that. I never had a good memory. It was just an everyday working memory. And it (losing my memory) was just a gradual thing. I can’t peg it down and say it was in December 1982 or anything, it was just a gradual thing.*

Mary is 77 years old and lives by herself. Her husband died some years ago. She has a son, daughter-in-law and grandson who live in the same city, *they’re solid gold, they really are.*
Mary’s son has been very supportive. Ever since her husband died, he has helped her with managing financial matters.

Mary doesn’t remember being told the diagnosis very well at all. She knows she was told, but she can’t remember the details, I must have been, because I wouldn’t have known what it was. I just thought I was losing my memory, which I didn’t have a lot to start off with, and somebody must have told me I had Alzheimer’s and this must have been when I went, I must have gone to that clinic.

Mary’s initial feeling were:

Shock, shock, and then I just thought, well I’ll have to take it on board, that’s it, no sitting crying into my beer. I’ll do the best I’ve got with what I’ve got and have a set routine, which I have, doesn’t mean I can’t shift it about, but you can see I do certain things on certain days and that gives my life a pattern, so I manage that way. And try the best I can to be positive about it and eh, you know, not think, oh, I’m getting worse, even though I can. I’ve just got to take it day at a time, I can’t do anything else.

Day-by-day Mary struggles with her memory and with repeating things, I know I repeat but I can’t help it, it just comes out. To deal with the Alzheimer’s, Mary has a schedule. Well, the best way for me, is to keep to a very tight routine. Each day of the week has associated tasks, from pension collection, shopping, seeing friends, doing volunteer work, each day of the week has a structure that she works towards. She also organises her house by placing important things on a shelf by the front door. Mary uses diaries. I’ve got diaries all over the place, I’ve got one beside my bed, I used to have one in the bathroom, but I thought that was a bit extreme. Its just a question of having a pen and the diary there and writing it down when you think about it. See, if you don’t do it when you think about it, it’s gone. If she gives herself time she finds she can recall some things she has forgotten. You see if you flog your memory often enough, sometimes it will, it doesn’t always, but it does come back.

At times in the interview, Mary drifted into telling stories. One of these was about her experience working for a charity for 25 years and the great fun she had doing that. Other stories are of loss, of her father dying, her brothers going off to war, her own illness during the war, and later her mother dying. So I’ve had a good life and a happy life but there’s been some awful tragedies in it too. But everybody’s got to die sometime, haven’t they.

Mary has told her family and friends about the Alzheimer’s. Yes, I’ve told every single one of them. Yes, I think it’s important that they know and they are very sympathetic and very understanding, because I know I repeat myself, I keep on doing it.

Mary wonders how other people with Alzheimer’s feel about receiving the diagnosis and how they cope day to day. I do wonder about people, how they reacted to a situation like this, because its, it’s pretty sick making when you think about it you know. To loose your memory, it’s such an important part of you’re life. For Mary, she felt that her memory wasn’t so great to start with, and that has made her feel cheated. Because I thought, well, it’s a bit much, you know. I never had that hot a memory anyway. Whoever you are up there, you could have left me with what I got. But it didn’t work that way you see, so there you are. So you just have to get on with it don’t you.

Mary’s initial reaction to the diagnosis was I got angry and then I accepted it. It’s all I can do, and make the best of it, and as I say, keep a schedule, that’s the best thing for me. The same things on the same days. And you get by that way. Despite her initial feelings of anger,
Mary would rather know what it is, that it is Alzheimer’s, that it’s a known disease. By knowing her diagnosis she feels she has to accept it and accept the limitations it puts upon me. Mary seeks information about Alzheimer’s because there may be something that can be of help for you.

Three months on Mary had noticed my memory is getting steadily worse, but I have to accept there is nothing much I can do about it. There’s not a key you can turn, memory come on, memory go off, it’s just gone, that’s it. This decline has obviously been a concern for her immediate family. They have approached Mary about future plans for her care, the children have been looking into it, some form of sheltered housing or something like that. Thinking about possibly needing sheltered housing came as rather a shock because I hadn’t thought that far ahead. I don’t think they want to push me into anything. They just told me what they’re doing, and that’s fine. I have to take that on board, but I don’t really have it on board yet. Mary does accept that it’s progressive, it’s not going to get any better and realises this may mean she loses her independence at some stage.

Mary talked more about her coping strategy of having a routine. It is still generally working for her, I mean with all the planning in the world things can still go wrong. However she sometimes finds the routine feels like its sort of a boring life. Part of the reason for these feelings is that Mary used to be a great girl for (doing things) off the top of my head but she knows she can’t do that and manage the Alzheimer’s as successfully as she is. She feels the fun’s gone out of things now.

Mary talked about her daughter-in-law’s mother, who also has Alzheimer’s disease, and Mary finds it is interesting how, two people of similar age and background, react totally differently. It’s all a matter of character I suppose. Where Mary is very accepting and is trying to manage the impact of Alzheimer’s in positive ways, her daughter in law’s mother is in complete denial about her diagnosis, which I think is defeatist in a way. I think, she thinks by denying it, that it’s going to go away, but of course it ain’t going to go away. Mary believes they deal with Alzheimer’s in different ways because, we’ve got different characters. She thinks that everybody has to find their own way of dealing with it. People as individuals change so much. You could never give a blanket, “do A B C and D” and all will be well.

There is a lot of me that says, don’t let this beat you old girl, find a way round it. Mary has become increasingly inventive in rising to this challenge. Her latest strategy is a series of cards she has written out. Each one has the day of the week on it. Every night before she goes to bed she puts the card at the top of the pile to the back, showing what day the next day will be. When she wakes up she can see the cards, so today is Tuesday, so I won’t do it now, I’ll do it on Tuesday night and it will be Wednesday when I wake up. That keeps my straight. Despite her increasing difficulty with her memory, only once did it go wrong. I’d been out to dinner with someone, and although I’m not a drinker I enjoy a drink and I’d had one. I had too much I think, I didn’t change the card over, and it threw me right out.

Mary feels it is better to call her Alzheimer’s by its proper name as opposed to using the phrase “memory problems”, I mean I know I’ve got Alzheimer’s. If they like to call it memory problems, it is a euphemism isn’t it. No, call a spade a spade. Memory problems doesn’t necessarily imply Alzheimer’s and it confuses the two. No, I’ll stick with Alzheimer’s because that covers everything.

I feel I’m doing the best I can, I’ve thought a lot about this. I’ve got it, I must take it on board, but not let it spoil my life. I mean, do the best I can with what I’ve got left.
I’ve always tried to do the best I could through life generally, that’s where it came from. Nobody can do more than that, can they?

Mary enjoyed talking about her experience. Its been absolute bliss, because other people don’t understand, and sometimes you get the sense that they feel uncomfortable with you, you know, not that you’re a foreign being exactly, but that Alzheimer’s sort of marks you off in a way.

Oh we’re full of all these clever dodges we Alzheimer’s. We’ve got to be haven’t we. You try and beat it, find ways round it. The one thing I won’t be is pessimistic about it, because there’s no good pretending it won’t get worse. It will get worse, and that’s when sheltered housing or whatever will come into it all.

6.3.9 Case Study: Participant 9 – Harry

But, I’ve never ever lost my sense of humour. I like the guys in there. I really believe that I know more about it than most of these guys, because I don't think they want to know. That's my opinion of course, you know, and I wanted to know, just in case there was something that I was doing that I shouldn't be doing, you know. Maybe I says to (my wife), one thing when I went to the doctor, I come back and (my wife) says, we were both working at this time, and she says how did you get on at the doctor, and I said great. I've got to drink more beer. Seemingly it's a cure to the thinking, it's a cure. And she walked into the kitchen. She says you're a bloody liar. (Interviewer: That's worth a go, isn't it.)

It was, it was worth a go.

Harry is 60 and has received a diagnosis of Alzheimer’s disease. He lives with his wife. They have two sons, one of whom sadly got killed quite a few years ago. It killed him. You see it’s not one thing that I’ve got to remember, you know … that's why I stammer, it’s the worst things I’m trying to get out you know.

Harry first started to notice that his memory was changing while working in a timber yard. Initially, I though it was noise that had done this to me, you know. He went to his doctor only to find out that it wasn't that. His doctor referred him to a psychiatrist and he kind of came along with this diagnosis, that I had Alzheimer’s disease and I just about flopped on the floor. Although I knew very little about it, you know, but I started reading about it and got more information from different doctors and they told me that I was never gonna be the brain of Britain you know. I try to make fun of it you know. But it’s a hard thing to come to terms with it you know, and that was a way back, and I think I've come to term with it, you know I can joke about it.

At first Harry had difficulty understanding what Alzheimer’s was. He felt the explanations he was given were gobbledygook. Harry explained he didn’t understand Alzheimer’s, because he had never heard of it before. The thing is, I did go to the psychiatrist and he told me that Alzheimer's is a disease and I said I can't even spell it, but I can spell most words. I'd never seen it written, you know.

The first thing Harry thought when he was told his diagnosis was how do I tell my wife. Harry feels that he is now coping with the diagnosis, but initially he felt angry. It's like eh, I used to shout at it, you know, because I didn't want it and then the more I saw the psychiatrist the quieter and the calmer I got, you know, and eh, I'm okay with it now, you know. I think I'm okay with it. He identified that anger was how I used to solve things. You
know, when I was young. He now sees that he used to think shout loud enough and it’ll go away, you know, but it doesn’t, you know.

As he worked through his anger, Harry finally felt that he had come to accept the diagnosis. He worked through his anger in his own way, even going down to the beach and shouting at the waves or something like that to express himself. Day-by-day the Alzheimer’s affects his memory and some of his problem solving abilities. It can also cause his speech to stammer and stutter.

For Harry, since seeing the psychiatrist this was the first time I’ve actually sat down and talked about it and I’m finding it really difficult. You know, I cope with this fairly well until I have to talk about it. Harry’s wife has been very supportive of him, she is a terrific listener, you know.

Harry attends a day centre for people with dementia. Yeah. They're nice people in there. It's just they've got a terrible disease, you know. Harry felt that people should know their diagnosis, including his fellow attendees at the day centre, despite it being heart-breaking news.

They think that you're sort of semi-intelligent, that you're going to know that there's no cure for Alzheimer's disease, but I think everybody should be sat down and told, you know, everybody that's got it. And these guys in there, the nicest guys in the world, soldiers, airmen, sailors, you know, they had all that rubbish where and you couldn't get information about so and so in the army or navy and things like that. We're not, you know, we're not soldiers any more, but why shouldn't you tell them, these guys, what they've got and how bad it is and, you know. Then again, they'll say there's some people that couldn't cope with it. How do they know that, you know. I coped with it, a case of, I just about broke my heart when I found out but I've come through it and I'd rather know, yeah. I'd rather know.

Harry would also rather know from friends, doctors, people that know, than some idiot coming up and saying you've got Alzheimer's disease, you know. He does worry that I think I'll die earlier than I should, because that's a notion I've got in my head, you know, but that's no big deal. Harry thinks there is potential to tell people information about their diagnosis in groups. He feels that at the day centre we work as a group, we're together. I can't see why I can't get a group together so that if somebody takes it really bad they've got friends. Yeah and I think it's holding hands more or less. I mean I'm not being stupid or anything, you know. It's like holding hands. If somebody falls or, you hug them, you know, I don't know.

Harry tells friends and family about his diagnosis. Some of the neighbours that he and his wife are close to also know. He feels that the people close to them are super people, you know and don’t treat him any differently because of it. Harry recognises that his wife has got to unwind and what have you, you know, so I suppose she does talk about it to the neighbours. Telling people provides support for his wife. Telling people the diagnosis was not quite enough for Harry, as he found many people didn’t understand what Alzheimer’s was.

But I think there’s got to be more talking about it, you know, because, you know, because neighbours we have, friends and neighbours, they know I've got it but they don't know what it is. I can’t, you know if you've got a broken leg, at least you can see the plaster and that and then everybody says how did you get that, you know, and I can say, well I fell off the pavement drunk.
Harry would like to understand more about Alzheimer’s disease himself and he thinks there should be answers, you know, and I suppose all the intelligent people that are working on this are trying to find an answer, but I used to sit on my own and say, “why me”, you know. The information that Harry has about Alzheimer’s is definitely not enough. Oh yes. I was always looking for information. Doctors don’t give you enough information, do they. Harry also felt that there was misinformation as well you know, we’ll not tell him that, you know.

Not knowing information, not knowing what was causing his memory problems was terrible. I mean the doctors, they say, they’ve got this information from the hospital, you know, your own doctor, we’ve got this information from the doctor, you’ve got Alzheimer’s disease and I said what the hell is Alzheimer’s disease and he tried a couple of pot shots at telling me and I didn’t know. After I went out of the doctor’s surgery I hadn’t a clue, you know. Okay, I thought I fell on my head a few times, I’ve been kicked in the head a few times, you know, when I was young, but I still thought, what the hell is he talking about, you know, and I think that should get through to doctors. Harry did not have information about his prognosis. Harry’s future plans at the moment are more connected to recreation, I’m going on holiday in a fortnight.

Three months on I visited with Harry again. He has experienced some decline since we last met. On the first visit Harry spoke very openly about the diagnosis of Alzheimer’s. He had described how he first thought that his memory loss was related to hearing loss through his work, but was clear that it was not the cause of the memory loss.

Now Harry had a number of different explanations for why he has some difficulties with his memory, all explanations that related to some type of loss. The first of these was the situation with my work which meant he now had deafness. Harry also framed the interview to being about deafness despite deafness never being mentioned by the interviewer. (And here we are, supposed to be talking about deafness, you know, I always get on to this, you know, talking about my son.)

Harry: Anyway, what do you want to talk about, other than, was it just the deafness you wanted to talk about.

Interviewer: I was interested in if you have ever had any problems with your memory.

Harry: My memory, I forgot that bit. I get, you know, if there are two or three people, and I listen to one, and I can’t remember what the other one said, you know.

Interviewer: And do you know what’s causing that.

Harry: It was noise, it was just noise in the mill that I worked in, and in that time we didn’t have ear defenders.

Harry felt that the deafness meant that in conversation if I turn away and you keep on talking, you know, I can’t remember what was said, you know. It also means at times with his wife, I had to keep asking what she said. Harry could no longer remember the medical advice he had been given. He has decided that he shouldn’t worry about it, now I’ve had an ulcer and things like that and I thought this is silly, its only deafness. Why worry about it and get more ulcers, so I just thought to hell with it, you know. I’m just going to get on with your life.

Harry worries about upsetting his wife by making any fuss about his hearing/memory. My wife’s going through a hard period and she doesn’t need to start worrying about my hearing you know, although she was the one that said we should really get something done and I said,
what can we get done about deafness. I says, if I skin my knee you put a plaster on it, but what can I do.

As the interview progressed Harry became unsure that his memory problems were caused by hearing loss. The next explanation he offered was connected to the death of his son. It is very important to Harry to be able to remember his son. He is finding that I sometimes get the dead one mixed up with the, my (other) son. It seems to Harry, that while grieving for his son, his memory started to change. That’s what, that’s the root of everything I believe, loosing my son. I don’t think it’s deafness or anything like that, I think it’s the love and affection that was lost from the one that died. One of the reasons this event seems likely to have caused memory loss for Harry, is because of the importance of, keeping the memory, that’s what I think it is.

The feelings of loss for his memory and for his son are entwined for Harry. I always thought it was because (my son) died, and with (my son) dying I thought that’s the thing that’s gone, you know, but it was my memory that was going. So, I take the memory loss along with the loss of my son. Something happened you know, eh, I said that to my wife as well, you know, at the start of my loosing my memory, it was because I missed my son. When his son died, I lost something that I could never have again. It seems likely that when his son died, Harry started having memory loss investigated and it was considered possible that the loss of my son triggered off a memory block at first.

Harry is realising that he is declining. His wife is planning a six-week holiday away without him and Harry feels that I might be really selfish but I don’t think I could cope for six weeks without her. At the end of the interview we discussed how it feels to know you might not be able to cope with caring for yourself, and then Harry said after explaining two different reasons for his memory loss:

Maybe I was being selfish but when you’ve got this Alzheimer’s thing, you tend to be selfish for lots of things you know. Yeah, yeah, see sometimes everything rolls off the tongue, and there’s other times when I turn my head and I don’t know what people are talking about and that’s the bit that really bugs me you know, when you can’t remember five seconds ago, you know and I tell Elizabeth these things you know, and all she can say is it’s part of what you’ve got, you know. And I usually say why and she says, “I don’t know, you ask too many questions”. However, other than that, I’m happy. You know we lost a son. He’ll be missed forever. But my (other) son, he loves me, you know.

6.3.10 Case Study: Participant 10 – Joe

You see everybody forgets something. I usually know what day it is and I can still count quite good.

Joe is 73 years old and was diagnosed with Parkinson’s 17 years ago. He also has been diagnosed as having dementia, although the type of dementia is not known. Joe is fairly well informed about the Parkinson’s disease, knowing that you can’t get any better with this Parkinson’s disease. He was given the diagnosis of dementia only about two or three years ago.

Joe doesn’t really agree with the diagnosis of dementia well, I think I’ve still got quite a good memory. He has some problems with his memory but feels that, I mean, everybody forgets some things. I think it happens to everybody. The impact of the dementia on Joe is limited,
he does think I just forget things. Occasionally I forget what day it is, but not very often. He does sometime have trouble with his medication, I do forget to take them at the proper times.

For Joe this memory loss is more likely caused by just my age I suppose. Joe attends a day centre where some people are a lot worse than me. Joe enjoys the day centre. Its the only entertainment I’ve got. It’s smashing. It makes me forget my pain at times. Joe really has the most difficulty with his Parkinson’s disease, this is what really impacts his daily living the most. He feels his dementia is all right. Knowing I was wanting to talk to people about dementia he commented, I think you should have taken the ones that are really bad.

Joe lives with his ex wife we don’t get on very well because I’m short tempered and get agitated quite a bit. I don’t think I’m doing wrong, but it gets her upset. We’re hammer and tongs with each other. Joe thinks his agitation is to do with the disease I’ve got. He does occasionally go into respite care. Its supposed to be a respite for me, but there’s no place like home.

Three months on, Joe was still of the same opinion about his dementia, well everybody’s got some memory problems. No I think I’ve got quite a good memory, not a good one, but a good one for my age. It is still the Parkinson’s disease which impacts him more. Since I last saw Joe, he has moved into respite care full time as the wife fell and burst her knee and she had to get steel pins put in and she’s got two crutches. So instead of her looking after me, I was supposed to look after her, but I’m not able to do that. Joe was not sure what was going to happen to him. He didn’t think he would be allowed back home, but he felt he might not be accepted to stay in respite accommodation because I’ve been ringing for assistance during the night and they don’t like that, because you’re supposed to be able to look after yourself. Joe was waiting to hear what would happen to him and felt I’ll just accept it as it comes, I’ll have to be somewhere.

Joe started to talk about his relationship with doctors, well I’ve nothing against them, and I should get a jab every six weeks, but I never been for six months. The jab is for B12. I suggested to Joe that this could be effecting his memory, and Joe thought well it could have something to do with it, and age must have something to do with it, because nearly everybody over 60 forgets quite a bit. Joe doesn’t want any more information about his memory problems. I’m no interested, I’ll just take things as they come, because I don’t think it’s bad. Joe mentioned the difficulty in knowing if he had a memory problem was that you don’t know when you loose it, cause it’s forgot. I remember some good times, I forget all the bad times

I don’t know if this conversation’s any good to you or not. I can’t tell you anything I forgot.

6.3.11 Case Study: Participant 11 - Martin

I felt it in myself, I knew. I was forgetting things I shouldn’t have forgotten you know, and I was hoping it would have improved, but it didn’t it got kinda worse. But I’m not too bad you know, I’m not extreme, extremely bad, I can... just certain things, I’ve seen me lying in bed at night and have gone through what I’ve been doing during the day, you know, recollect you know

Martin is 80 years old and lives with his wife. Martin has a touch of Alzheimer’s. He doesn’t remember how he got his diagnosis but he does know he has Alzheimer’s. Martin feels that my wife, she brings it up more than I do. For him he didn’t look at it as being Alzheimer’s, but seemingly it is. Martin thinks his wife brings it up more because she doesn’t get a decent
reply you know and maybe she asks me to try and remember something and it doesn’t ring a bell, you know.

The day-to-day impact of the Alzheimer’s mostly affects Martin’s memory. There are times that Martin notices he doesn’t remember as well as others. It can be spasmodic, you know. Sometimes I’m alright for a while, and then other times, you know it’s certain times, certain things I don’t recollect, you know. One way Martin copes with the loss of memory is with a practice I’ve got, especially if I’m thinking myself and I can’t recollect. I go through the alphabet and start with an a and b or a c and I’ll go that way hoping it will ring a bell you know. Sometimes it clicks there, uh huh. Martin had to give up driving because he was finding he couldn’t recollect how to get back and was more aware of the traffic.

Martin doesn’t mind the idea of telling some people that he has Alzheimer’s, I don’t mind, it’s a thing, ... It’s not contagious and it’s a personal thing. If I don’t want it mentioned to the company, then I don’t mention it. Only his wife knows he has Alzheimer’s. He has two son’s but he has not told them, as its not bad. He doesn’t mention he has Alzheimer’s to his family, but suspects that they know. I don’t say it, no. I don’t mention it. I let them pick it up. [[laugh]] They say, “oh his mind’s away.”

Martin still feels that it was mild. I’m not bad. I remember most things, I think. He does not think he has got any worse I’ve just stayed much the same. When Martin was told that he had Alzheimer’s disease he didn’t think it was Alzheimer’s. I thought it was a bit drastic you know, at the time, you know. I know I was forgetful and things, but I didn’t know it had come to Alzheimer’s you know, and even now I don’t believe that I’ve got it.
Martin is starting to wonder if the doctors have got it wrong, because although he does have memory problems, he doesn’t think it’s that bad. He still uses the method of going through the alphabet to jog his memory, but at times he will also put it out of my head if I forget it, I just put it down as well as opposed to actively trying to remember something.

Martin doesn’t let it worry me. I just say to myself, it’s fate that some things I recollect and some I don’t. The Alzheimer’s never used to worry Martin, he used to get annoyed and say, why is it I don’t remember? It was only so and so and I just couldn’t recollect you know. Now he treats it with the attitude of, well, I’ll either remember it or I won’t. I don’t let it worry me you know.

Martin discussed memories of his childhood. In particular the cottage he spent some of his childhood in. He is pleased that I recollected it was like that and takes his ability to recollect earlier memories as one of the reasons to say to myself well I’m getting better, I’m getting better, you know. Martin feels that his Alzheimer’s has improved with his improved confidence. I don’t think it’s as bad as what it used to be, to be truthful. I think it’s, I got more confidence and I try and avoid being stupid like. Martin feels like I’ve got over the worst. Martin also felt that the right environment with conversation and different things has helped him to improve.

This minimising approach could be seen as Martin being positive about his condition. Och aye I don’t look at it as something that’s drastic. I keep saying to myself, I can only improve, you know. Despite talking about being able to only improve Martin also acknowledges that Alzheimer’s is a progressive illness. I know I can go bad, but as long as I make sense and that, I’m quite happy you know.

No no no I just got faith that I’m improving and encourage myself that way and if I do get the odd occasion I can’t remember, I don’t let it worry me you know. I just say oh well either it will come back or maybe later on or ring a bell, something will trigger it off.

Martin does think people with dementia, as long as they’re not too severe, should be told their diagnosis as it might provide the opportunity for people to improve. Considering his advice to encourage improvement is based on having a good environment, a positive attitude and some techniques to help compensate for memory loss, this seems good advice.

Oh aye I think that you have got to be, try and get self confidence, self assurance of what you’re saying and if you can’t remember it at the time, just give it a bit of thought and see if it comes back to you.

6.3.12 Case Study: Participant 12 - Fiona

Just accept it how it is, accept how it is, hen. Some days are better than others.

Fiona is 66 and has dementia. She has been married for 42 years. Her husband helps to care for her. He’s very good to me, he cooks all my meals because I’m hopeless. However, sometimes he gets to me. Well, I’m not saying we suffer each other, we put up with each other. Fiona has always lived in Edinburgh. She recounted to me the places she has lived as a way to test out her memory. Oh listening to that, did you not realise that I was just wasn’t quite with it. It takes me a wee while to remember and I’m surprised that I did remember as much because normally it cuts off. This time I’ve actually got right through.
Fiona finds she will start saying something and then it cuts off and I’m struggling and I can see the word, but I can’t get it through my tongue. I can’t get my tongue around it. She finds I can remember back the years more easily. Fiona does get frustrated, but I get over it by counting off. I say forget it, I’m not going to mention it and then about 10 minutes later it comes out. For Fiona, she has given up pushing it and has decided if she cannot remember something, I’m no going to fight with it and that’s it. Other daily impacts are caused by her memory, I can’t write, I can read very slowly but I can’t write. However, Fiona does feel that she is not too bad because you really can remember most things I think.

Fiona is sick of seeing doctors. In fact, I’ve given up on them. I’ve told them about the memory loss but they don’t seem to be interested in it. Fiona doesn’t remember her exact diagnosis. I’m not sure because I can’t remember exactly what they’ve said and what they haven’t. I mean, this thing I’m telling you, the now, I think you’d have to ask my husband about it because I can’t remember. She knows she has had some small strokes. She had one while she was driving, which was very frightening, so I can’t drive again.

Well nobody’s told me the diagnosis, but Fiona knows she has got to accept it. Fiona would like to know the diagnosis as I’m not saying I’m not worried because sometimes when I lie in my bed at night, I say will I be waking up in the morning well I go to sleep it doesn’t matter anyway so if I didnae waken up it would be too bad. One of the difficulties is that Fiona thinks that even if the doctor spent more time with her explaining the diagnosis I wouldn’t be able to remember all that.

The dementia hasn’t effected Fiona’s relationship with her husband at all. He very rarely gets frustrated with me. Fiona has a daughter and a son, both know she has memory problems. But my son he doesnae realise just how bad I’ve been. I know that. Fiona doesn’t tell them much about her memory problems because she doesn’t want to worry them. Fiona has told her daughter, but otherwise I don’t spread it around an awful lot. Her daughter helps her out at Bingo, at the bingo she’s watching my books in case I miss a number out.

Fiona attends a day centre and asked one of the staff members there to tell her what her diagnosis was. I says to her, I said, come on tell me truthfully is it Alzheimer’s. She says, yes. I says, well that’s all I want to know. I can go to my pal and say that’s what it is and that’s it, I’ll accept it as long as it doesn’t get too bad.

Interviewer: So its Alzheimer's.
Fiona: Alzheimer’s, what’s the other one.
Interviewer: Multi-infarct.
Fiona: No.
Interviewer: Dementia.
Fiona: Dementia
Interviewer: Its dementia.
Fiona: Oh its either Dementia or Alzheimer’s I don’t know which.

When Fiona was told that she had dementia by the day centre staff member she thought thank God somebody said it outright, face to face, that that’s what’s wrong with you. Fiona told her daughter that the staff member had told her it was Alzheimer’s. Her daughter says yours isn’t the Alzheimer’s where you’re going down. She says, yours must be the one where its affecting your brain. I said I haven’t a clue. Fiona does think they should tell you so you’re not in limbo you might say. You know there’s something wrong, but you can’t put your finger on it.
She has some idea that it is progressive, thinking one of these days it’ll leave me (her mental ability) and I’ll probably end up in a home somewhere. It’s terrible eh, when you think about it. However, she tries not to think about the future, no I’ll leave that blank, no I dinnae want to ken about it. It’ll just happen and that’s it. She worries particularly about physical decline, being able to contain yourself, washing yourself, cleaning yourself.

Three months later I visited Fiona again. Still having difficulty remembering her diagnosis, I can’t remember what anybody calls for. I gather it’s a form of Alzheimer’s or something like that. I don’t know. Fiona did remember there being some mention of it recently, referring to the day centre staff member telling her the diagnosis. Oh, I was just glad that somebody had found a reason for it because I was beginning to wonder just what the heck was wrong with me. Fiona feels that one thing that has progressed. I’m remembering wee bits whereas before I used to forget all about it. Well some things are getting a wee bit better, not a lot, but a bit better.

Fiona feels terrible because I can’t write my name or write a message. Despite this, Fiona feels that her memory is not too bad and that others might underestimate her ability. A support worker recently rang to arrange to see Fiona, and insisted on speaking to her husband to make the arrangement. I felt you’re not trusting me to give a message, which was unfair, because she could have trusted me but she didn’t.

Fiona had spent some time in a different day centre, but didn’t like it due to the restricted hours of smoking, cause I can’t stand being told “You can’t smoke”. During the interview Fiona told me she was gasping on a cigarette right now and I went to fetch an ashtray for her. Whilst I was away she had been looking out the window, and despite difficulty in being able to read when I returned she told me about the sign she saw outside the window.

Fiona: Dementia Project, that’s the first time I’ve ever seen that.
Interviewer: Is that right?
Fiona: Uhum so it must be Dementia I’ve got.
Interviewer: Right
Fiona: It must be. They keep telling me that [laugh]

For Fiona the word dementia used to mean somebody gone doolally. When I asked her what she thought of the word Alzheimer’s she said, I don’t think of it a lot, no I don’t think of it a lot but I gather, we keep on getting told I must be in the throes of it possibly.

Fiona felt that not knowing what was wrong with her was wicked. That was wicked. And despite the fact she now has difficulty remembering the diagnosis, she has got used to the idea now that there’s something wrong with me and I’m coping a bit better, I think that’s it. However, she still has some difficulty remembering what is wrong and whilst able to acknowledge at times that it is dementia, she also finds it’s an awful thing to have that fear at the back of your mind that I’m gonna end up with Dementia or something like that.

Fiona doesn’t force her memory as the more you try the worse it’s getting. You’re better if you can make your mind a blank over it and then all of a sudden it will come out. I keep trying and trying to remember things and I’m not much good at it and then I give up and I think, why the hell bother to try and force my memory into it. Fiona hasn’t a clue what to say to anybody that’s got it, you’ve just got to struggle on.

Oh it’s frightening. It is frightening when it happens to you. At first I thought, oh well, it’s just my age I’m going through that time of life, but it was happening too often so I’ve learned to cope with that. Occasionally yet I find I can’t get the words
out, but as I say recently the words have come a lot easier. Well I'm talking to you now and I think I'm sensible.

6.3.13 Case Study: Participant 13 - Liz

I am really quite happy as I am. I can't see that I've got any awful problems or anything. I don't think oh dear, you know cause I go and get the messages and go and do this and go and do that and I'm fine.

Liz is 64 years old and lives with her daughter. Liz's daughter told me that her mother has been given a diagnosis of dementia but now does not acknowledge it. Liz does know that there are times when she has trouble remembering some things and she also has difficulty in finding the right words at times, but nothing that I think there's anything wrong. Oh I do silly things I suppose too. I mean I just go off and go off doing shopping things, but that's nothing, bad is it?

Liz does not wonder about what might be causing her difficulties, cause I'm so used to just being me as me. Liz does not remember having ever been to a doctor about her memory loss. I haven't seen one, I don't think I've seen one. Liz does not want to know what is causing her difficulties either.

Yeah well, I feel myself I'm all right because I don't go Ohhhhh I don't go on about things 'cause I just like people and I enjoy, well my daughter would say she would say... my daughter's all right so, she's all right but I don't know. [[laugh]]

Liz has a very active life and I will until I go “boom” yeah I'm quite happy with that. Liz has a support worker visit her, but she does not really like the worker, I just don't find her right. There's something about her. Liz also attends a day centre for oldie goldens.

At first I thought, uhm I don't like things like that, but they're so nice, they're really nice. So I enjoy that and things, you know, like that I like to know, I enjoy things of that kind of things. Now what else uhm?[[laugh]] I think everybody's so happy with each other. It's just good you know, it's really good. That's a nice place to be and so I always go to that 'cause it's excellent.

Liz relies on her daughter, I'm so lucky I've got my daughter, to help her when she can't remember things. She will tell me she'll tell me then, then I'll know what's what. Sometimes it is hard to find the right words which is a pain in the butt because it is so annoying and I sometimes say “Just a minute I'll tell you in a minute” because I have to do that and then I think oh .... She thinks, oh, 'cause I don't like anything like that to happen.

Liz is worried that people might think she is a nutter, although she knows, I'm not a nutter yet. She also worries people might think she is doolally, and does a lot of covering up to conceal when she is having difficulties.

'Cause if I was really all doolally [[laugh]] you would be running away, but I'm not like that. [[laugh]]

6.3.14 Case Study: Participant 14 - Duncan
When I was working, I knew. I would go and get materials for a job like, and I would go to get materials, and I had been doing this for years like, and I would come back with half the materials. And I could see I had forgot half the materials and I would have to go back and get the rest of them, where I never ever done that. That was the first indication that I got that it was the memory. ..... but I never put any significance to it, I just put it down to odd days, but I started to have too many odd days.

Duncan is 56 and lives with his wife. Duncan has been given a diagnosis as near as they can that it’s a strain of dementia, that is it. They have not been successful in finding out what type of dementia he has. It’s took them three years to get the diagnosis of dementia. Duncan’s wife was the first person to tell him that he might have dementia, she told me long before they told me. She had the experience of being a care assistant for older people, some of whom had dementia.

Duncan has experienced changes in both his memory and behaviour, which his wife has often seen first hand. I don’t know how she’s put up with me, I don’t know. One of the behavioural changes is aggression. A problem which is also compounded by seizure’s that Duncan has, where he has no control over his actions. He now has my happy tablets, they calm me down. Duncan is on a cocktail of drugs and it has taken a lot of work to get the right combination. I’d just get kinda used to a tablet and they would say that one’s no use, so they’d start weaning me off that one. Duncan also loses track of time, and had been lost a number of times. The worst was when he disappeared for 10 hours but I had no idea where I had been.

Duncan and his wife seem have a good relationship with their GP. He will find out how Duncan is from both of them. Duncan finds his wife mentions more to the GP than he does because half the things I wouldnae tell him, half of them because I’ve forgot them, that’s mostly the reason. I never tell him because I’ve forget about it.

Since Duncan’s wife warned him it might be dementia, it wasn’t a shock when the consultant told him that’s what it was. When his wife initially told him it could be dementia, I told her where to go like, and then when they came out with it, I had to just accept it. Prior to knowing the diagnosis Duncan had put his wife, put her through pure hell for three year, unknowingly like. Their relationship has now improved, since they both know what has caused the changes in Duncan.

The doctors have told Duncan that he doesn’t follow any pattern, this is what’s baffling them. I don’t run to a pattern. He has been through a number of diagnostic procedures, including a brain biopsy, but the results have all been inconclusive of what type of dementia Duncan has.

For Duncan one of the hardest things to deal with is the things they took off me. All my enjoyment they took it away from me. They took my car off me, took my license off me for the car, they took my gun off me, they took my fishing off me. He feels that his wife and doctor do not allow him to do anything he wants to do any more. I can’t even take my granddaughter out for a walk. Duncan finds this very upsetting, I mean I go through the roof about that. There is one social activity that he is still allowed to do, going to the pub with friends once per week, and Duncan feels that is the only time I’ve won, I’ve tell them if they take that away from me, that’s it, they’ve took everything else from me, they’ve got to leave me one pleasure.

Not knowing that his diagnosis of dementia made Duncan agitated about things because I wasnae getting any answers. Even now it is frustrating that he does not know what type of dementia it is, I’d love to know what type of dementia it is, but they cannae tell me. After
everything I’ve done and that, they cannae tell me. One of the reasons that Duncan wants to know is he would like to ken what’s in front of me. I would like to ken.

There was no negative impact to finding out his problems were due to dementia for Duncan. He does tell people about his diagnosis, oh aye, it doesnae bother me. I mean I’ve got dementia, but I’m still the same person and they need to accept that, it’s up to them. He thinks other people should be told when they have dementia. I mean that’s what they’ve got. Dosnae matter what colour they paint it, that’s what they’ve got. At the end of the day it’ll no go away, it doesn’t matter what you call, it’ll no go away, that’s it. Duncan felt that for people with dementia they’ve still got to face it at some point, you shouldnae kid them on.

It has been important for Duncan to find a way to accept that he has dementia, and to also accept that he has epilepsy. For Duncan accepting the diagnoses allows him to get on with it. Once he accepted it, Duncan found that his got on a lot better. He does still get a bit agitated, but nine times out of ten, I’m not too bad, am I?

Duncan doesn’t think the relationship he has with his wife has changed at all, but she feels that she has become less like a wife and more like a carer. Duncan does acknowledge that at times she feels as if she is like a hired hand and knows that he has caused (his wife) a lot (of bother)

The neurologist that disclosed the diagnosis was good, he takes his times with you, doesnae try to bash you on. Sits and explains it to you, draw it for you if you like, go back over it, and no like some that try and push you through. He takes his time. Duncan still sees him from time to time to do tests and the neurologist will say if it’s slightly worse.

I don’t think I can give advice to anybody on how to accept it. I’m just lucky that she (his wife) picked up for it, I’m lucky she stood by me and that I still live with her. Not many people would have stuck out the way she stuck out, so ... ... I admire her a lot for getting through that time. No I don’t think, I don’t think there is anything you can really tell anybody about that, I think its up to the individual, nature,

6.3.15 Case Study: Participant 15 - Peter

I’d never even heard the word until somebody said I’d got it.

Peter is 65 years old and lives with his wife. Peter used to be a salesman and first noticed his memory changing at work. Peter does not remember anything about the process of getting the diagnosis, I don’t have a memory at all. He does remember knowing that there was changes in his memory. I knew there was something wrong, but I didn’t know what it was and there’s no pain to it, so, it’s not, it’s not there all the time and I don’t think I’ve really got much worse with it. Peter is currently on anti-dementia medication.

Receiving the diagnosis did provide some explanation for what was happening for Peter. I won’t say it was a nice experience going to the consultant, but once I knew then at least I knew where I was, ’cause I was going about for so long and didn’t know where I was at all. One of the reasons Peter feels it is so hard to remember details about the Alzheimer’s is that there’s no pain, no pain at all.

The daily impact on Peter is just my memory, not in any other way. Just can’t remember things. I’ve always got to be told, just can’t remember anything at all. Sometimes this
makes Peter feel angry and made him wonder why me? Peter gave up his drivers licence and he does miss the independence. Peter also feels it is very difficult at times to accept how the Alzheimer’s has changed his life. Oh yeah, we get there, but I just feel it’s difficult to, you know, to think for yourself. Somebody’s got to think for you, what to do, where to go, why did you do this, why did you do that? Because, I can’t remember.

Peter and his wife a very close and are facing the Alzheimer’s together. He feels he couldn’t have done without her. Peter tells family and friends about the Alzheimer’s and finds that like himself, people don’t know much about it. Peter does not feel that he knows how to cope with the Alzheimer’s at all. He also recognises that some family and friends don’t know how to cope either. I don’t know how other people expect me to cope with it, but I think they find it difficult sometimes to cope with it. I’ve got it. There’s nothing else I can do about it.

Peter feels that there is not much that can be done to help him. I’ve no option, none at all, and hopefully in the future for some people who get it, there will be an option. But I can’t see an option for me.

The only reason Peter feels that doctors should withhold a diagnosis of Alzheimer’s is if someone specifically says they don’t want to know what’s wrong with them, which I feel is sad and wrong. I just can’t understand if somebody’s like that.

Peter had attended a day centre for a short while, but he didn’t find the travelling there worth it. When you got there you did nothing. He does attend a support group and it’s fun uhm, yeah, it’s okay. Peter also has a befriender who takes him out on day trips.

Peter feels he has no strategies for coping with the Alzheimer’s. There’s no way really and there’s no support and back-up or anything like that around so you’ve just got to make your own decisions and do your own thing you know? Peter has noticed that he has become a lot quieter now, finding it difficult to have conversations. He thinks this is just part and parcel of the illness as I see it.

In relation to information Peter feels, I suppose if I was honest, I’d say no, I don’t know enough about it. However, he does not feel that there’s much they can tell me now, maybe in the beginning they could have told me more of what was going to happen or what could happen but not now. Peter would rather that doctors used the word Alzheimer’s over descriptions such as memory problems.

I don’t think deep down I’ll ever fully accept it. But I’ve got it, and there’s nothing I can do about it and if it’s called Alzheimer’s then that’s what I’ve got.

Through the interview Peter was quite distressed. It is clear that he does not know how to deal with the Alzheimer’s. It has made a significant impact on his life. Despite the pain of this, Peter he is very clear that it was important for him to know the diagnosis.

Interviewer: Do you ever wish you’d not been told that it’s Alzheimer's.
Peter: No no I couldn’t have gone on for all these years without knowing what it was.
Interviewer: So the hardness of dealing with it hasn’t been a good enough reason to not know?
Peter: No [[whisper]] no. No I had to know.
6.3.16 Case Study: Participant 16 - Phil

Well its something that, I’ve always been relatively healthy and to have someone coming in with an attitude of, och aye, its dementia is what it is, no cures its just, you just get on with it sort of thing.

Phil is 54 years old and lives with his wife. They have children, but they have not left home. Phil noticed gradual changes in his memory, particularly when at work his position changed, becoming more complicated and demanding. Because the changes in Phil coincided with these changes at work, initially he thought he was suffering depression and stress due to his work well, with being under quite a bit of stress I suppose that was the first sort of symptoms.

Phil had a lot of contact with his doctor, who tried to help his depression and stress with medication. Phil did find that his doctor was very supportive and helpful along the right lines. The changes in Phil were gradual and he underwent further tests to determine what was happening. Eventually he was told that he had frontal lobe dementia.

Oh I’ve had a lot of rough and things, but eh, the biggest surprise I got was when the last time I was up and eh, at the hospital and I’d just been through a brain scan and the doctor comes in and says, right that’s it, you’ve got dementia. I’d never, that had never ever crossed my mind. And he says there’s no magic cures there’s no surgery involved there’s nothing, it takes its own road. And that was I would say the biggest shock I had.

Phil was shocked by the diagnosis as he had no idea that dementia was even something that was being tested for. He does not feel he has enough information from the doctors and the lack of information has meant that Phil doesn’t have much confidence in any of the doctors there.

Phil was not very pleased with the hospital system, you go through and you’re just on a conveyor belt system, when they go in they send you through. He feels they could have said, well look, there’s a possibility you have something a bit more serious wrong with you and we’re doing a scan to verify it, to allow him to be more prepared. Phil would have liked more time with the doctors to ask questions. He feels that it would have been courtesy actually to have had a follow-up appointment. Phil has a counsellor who visits him and he finds that definitely helps. She was in the room with them when they learnt of the diagnosis.

Phil had received his diagnosis three months before I met him and was still trying to come to grips with it so, I can as much as possible carry on with a normal life. Phil feels the support he has had from his wife has been the key in coming to grips with it all, she’s my best friend as well as my wife. Daily, Phil is effected by the dementia by sometimes I might pronounce the words wrong or something like that and difficulties with his memory.

Phil does wish he would have known the diagnosis earlier, particularly as he had spent the last four years thinking it was stress and depression he was experiencing. As long as its no progressing fast then I would like to know. If its slow in progression then that’s going to give me a bit more time. Phil felt that if there’s anything wrong with me I’m better finding out, although he thought finding out the diagnosis was an individual choice as not all people might want to know. Phil has been doing things he always had wanted to do, such as paragliding and diving. He and his wife are also organising travel that they have always wanted to do.
Uh, well I would like to know, as I say, if its progressing fast, if its giving up, if its progressing slowly then its giving us more time together, so that would be good to know that. And, we’d have a heck of a good time with what we have.

Phil would like more information about his dementia, it wouldn’t do any harm. The information could be a disaster or it could be a good thing, we’re in the position where we’re hoping it’s a good thing. He feels more information might help them with coping with it.

They have not told friends yet about the dementia, they feel that their friends have all been good at accepting it is stress and depression and that suits for now. There are times where Phil and his wife still feel down about the dementia, one of the things they do to get through this is to spend time together, to go walking and to spend time with their grandchildren. We’re fortunate that eh, we’ve not got a lot of hard days, we like to go for a walk in the evening, have a blether, we get out and about and thinking.

So aye, I’d rather hear things up front, I, I think that if you’re an outgoing person, you would want to know what’s up front so you can make arrangements or whatever

6.3.17 Case Study: Participant 17 - Jack

Everybody can take it, everybody can take on an awful lot more than you think. You get it and after you’ve got it, sure, you’re sunk for a bit, and that’s only to be expected, and maybe at that point they say maybe I wish they hadn’t told me, but you realise it’s the best thing that could have happened. They tell you, put your life in order and that’s it. Then if you want to ignore it, ignore it if you wish, but it’s your choice, it’s not the doctor’s choice, or the carer’s choice, it’s your choice, and you should be given that choice.

Jack is 69 years old and lives on his own in sheltered housing. Jack first started to notice that something was wrong with his memory when he was working. He was noticing his sense of balance was effected. He decided to get this checked by his doctor and after a period of three or four months, visiting his doctor, two different hospitals, staying in hospital for tests for 13 days, having scans and a MRI, he was diagnosed, I went into the hospital and I saw the doctor there and he says we’ve found out what it is at last, you’ve got Alzheimer’s. That was it.

Although he was pleased with the doctor that gave him the initial diagnosis he is now under a psychiatrist with whom he does not have a very good relationship. He once complained after a long wait for his initial appointment and feels she didn’t like me very much to start with.

She said we’re only testing 20 people anyway and you’re not one of them. She said because if you’re Alzheimer’s was caused with the stroke, this pill doesn’t work, but if Alzheimer’s caused the stroke the pill will work, and as we don’t know, you’re not going to be tested. And I said oh that’s too bad, so I’ve lost my two years, she said, ‘well what more do you want, you’ve almost had your three score years, and ten’. Well thanks very much.

Jack feels that he is not living the life I would like to live. But he is making the most of his life as much as he can, including spending time travelling. He is not supposed to be travelling on his own, but he has been arranging and going on holiday by himself despite this. He feels the more I do, I feel the more I take responsibility for myself, I feel or else I’ll go
down hill. He did go into the sheltered housing, but only so he would be closer to his daughter, but he has refused home help and is trying to maintain his independence. Jack has also started painting and has had advice from an artist to help him. For Jack there has been advantages in knowing his diagnosis, it has meant that he can organise his financial affairs, make his will and organise a power of attorney.

When Jack was initially told he had Alzheimer’s he was a bit down and gradually got a bit worse over that day you know, when I was thinking, this is the end and this is it, I wonder how fast it will go. Jack has noticed changes within himself, any odd job I do maybe takes me a whole day that would have taken me half an hour before you know.

Jack now has a very positive attitude to his Alzheimer’s, yeah, well, maybe I just say you get on with what’s left when you don’t know how long you’ve got but no body does. There’s no one definite certainly I’ll die from Alzheimer’s, I may get knocked down by a bus tomorrow but so could anybody else, you’ve just got to look at it that way.

Jack feels that people should be told they have dementia at the earliest possibility. He feels if he hadn’t been told he might have continued working, which could have been dangerous. I would shoot the person that tried to keep it back from me, I really think its an absolute disgrace, you should be told at the earliest moment, even if people say to you it might be that, we’ll have to test it, even tell them then. He feels that when doctors wait too long to tell the diagnosis people find out that it’s too late to be able to do things because their memory’s gone completely.

Jack is very aware of the debate around whether the diagnosis of dementia should be disclosed or not and has very strong views that people have a right to know if they have dementia.

This is one of the arguments they use for not telling people. They say she wouldn’t know anyway or he wouldn’t know anyway if we told them, but they still should be told. And they say, oh they couldn’t stand it, it’s not them that couldn’t stand it, it’s the carer’s who couldn’t stand it, they’re the people who are keeping it back, they couldn’t take the role of telling them, they don’t want them to know, so they can say, aye, you’re just a bit forgetful, or you’re just this. And to me that is absolutely criminal, you should let the people know and then they know where they are. Sure its a terrible sight when you see what happens to you in the end you know, if it runs its length, but it may not run its length, anything else could happen before then.

Jack knows people will be upset at learning their diagnosis, sure they’ll be upset, don’t expect them to have a party, no, they’ll be upset because they’ll worry. But he feels that people get through this and learn to cope, after that they’ve just got to get on with it, there’s nothing else they can do, there’s nothing about it, they can’t stop it. Jack’s has spoken with other people with dementia they’ve come to the same conclusion as me, right now, you’ve got it, it’s gonna kill you, but not today, so lets get on with it today and lets get today’s enjoyment or whatever you like, and don’t think about what’s going to happen tomorrow or the next day. Live today. As I say although you’ve got it it hasn’t killed you so get on and enjoy.

Jack is very challenging of the role carers and doctors have in diagnosis disclosure, and feels they may be responsible for people not learning about their diagnosis. I push once again the fact that everybody should be told, no matter who they are, what age, they should be told, even, the only time I would say not to bother telling them, if they are so far gone that by the time they find out they don’t know what you’re talking about anyway, but there’s not many like that, but there’s some that are a lot further along than they should be before they are
diagnosed. That’s because carer’s are protecting them so long before they seek medical help and maybe the doctor’s messing about too long before he does anything too.

Jack does believe that people do have a right to deny their diagnosis, but that people have to make that decision for themselves, people may have the right, but I don’t think anyone else has the right to deny them. Jack does think that people can make a decision to deny it after disclosure, after that if you choose to forget it, put your head in the sand, that’s up to you, some people may, but it would be very few people who would do that, most people would face it.

I went to a meeting where a man stood up and said that, that his wife had it and she didn’t know she had it and he didn’t want to tell her for her didn’t think she could stand it. and I said that’s rubbish. Everybody can stand it, what else can they do.

6.3.18 Case Study: Participant 18 - Lucy

Well you see it’s in my nature, I’m more frightened of the unknown than of the known. I can be in control if it’s something that I know about and that I can understand just vaguely enough I feel I’m still in control whereas if it was something and they said oh we can’t tell you, we can’t tell you I’d rather hear, you know I’d go up the wall.

Lucy is 76 and lives with her husband. They have a lot of family living close by to them. She does not remember when she first started to notice her memory was changing. Her husband persuaded her to visit the doctor despite her initial reluctance to go. Lucy’s memory of the process of getting her diagnosis is quite confused, I don’t think I saw a doctor did I? Well I don’t remember that at all. All I can remember of him (the psychiatrist) is was this building and this little place, you know and you were waiting for me outside.

Lucy had never heard of Alzheimer’s before. When she was first told she didn’t take much notice quite honestly. I thought it was just one of these new diseases that had been discovered you know… he tried to explain it but it didn’t make sense to me you know? It didn’t click with anything that I’d ever heard of before so I’ve ignored it ever since. Lucy has noticed that her memory is deteriorating and that her temper is getting worse as she is more sharp tempered. However her temper and behaviour has improved since she received a diagnosis.

Lucy doesn’t think she wants to know any more information about Alzheimer’s, I mean it doesn’t give me any bother at the moment, I'm not in any pain and I'm not sort of nervous I'm not anything else and if I'm going to die of Alzheimer’s I might as well die of that as something else you know. On the other hand Lucy talks about her quite active attempts to find out more information about Alzheimer’s. This includes trying to find books in the local library about it, I just wanted a few facts that’s all.

Lucy did want to be told her diagnosis oh yes definitely, oh definitely. I’ve always had a hatred of knowing that people weren’t telling me what I should know. She feels she has accepted the diagnosis which is part of her personality, I tend to accept things as they are a bit don’t I? Part of this acceptance is from her belief that there isn’t a thing you can do about it, what’s the point of making everybody else miserable about it too you know?

One of the reasons Lucy has wanted to know her diagnosis is that it has meant I’ve had time to sort of, well I don’t know just tidy up the decks and this sort of thing and maybe write to people that I’ve been meaning to write to for years and I haven’t, but I don’t say anything to them but you know I just feel as though I’m sort of going round the edges tidying up and for
me. Knowing the diagnosis has also meant that Lucy has got something to fight with. Nothing to fight with except my dignity and making sure that the children are all right and my husband’s all right and, you know.

Having not heard of Alzheimer’s before Lucy believes they could have got away with not telling me, but that would not have been what she wanted. She feels it is only fair on her husband to know, and he would never know and not tell me, that’s the sort of deal we’ve got or had through the years you know. The idea of having the diagnosis withheld is one that Lucy thinks is horrible, there’s nothing worse than thinking that say the man in your life or your mother or something else knows something about you and they’re protecting you that’s a horrible feeling.

Lucy does not tend to tell friends about her diagnosis, although her husband has been telling friends. She does not mind that he has done this commenting to him, you’ve done it very well I must say, you’ve managed to bring it into the open without having a great big sort of fuss. Friends and family have been quietly helpful to Lucy in daily tasks such as shopping.

One of the difficulties for Lucy in understanding the disease is her lack of physical symptoms, it’s a difficult one, because you don’t feel ill you see that’s the trouble. I haven’t lost any weight and I don’t feel ill and I don’t lose my breath and I don’t have indigestion and I think well you know [[laugh]] you can’t die.

Lucy feels that it is important for people to be told their diagnosis, I think if you’re going to die it doesn’t matter how upsetting it is to be told that you are you must be given the chance to approach that death in your own way ’cause everybody’s got, what’s the word, obligations and perhaps if you’ve got a sister you’ve quarrelled with for instance, which I haven’t, but say you had a sister you’d quarrelled with and left her home in a huff I think, I’ve come across one or two people I’ve who have made up with them just to keep their conscious clear and I said do you think there’s anybody up there who matters very much and they’ve said no but you never know [[laugh]] if I don’t do it there will be.

At 76 years old, Lucy feels that she comes from a generation that has been through a lot over their lives, including war. She thinks these experiences contributed positively to her personality and way of dealing with things like Alzheimer’s now. She does feel that her identity is changing, over her life she has been a mother and was used to being needed or relied upon, and now well you get to feel eventually I think that you have nothing more to offer. From now on I have very little to offer and taking everything in the way of help and that annoys me a bit but I’ll work it out somehow.

No I refuse to there’s no point there’s nothing I can do about it but forget it. There’s no point in going round being dreary. In fact I think I prefer it to having an illness and hospitals and people visiting and all the rest of it you know?

6.3.19 Case Study: Participant 19 - Rachel

So my memory’s all right, sometimes I go, I’ve got to write a line if I go shopping ... .. to see what’s needed, but since I’ve stayed with my daughter I dinnae really need to do that now. I’ve got a good life you know.

Rachel was referred onto the study from a day centre, where they believed that she knew her diagnosis and had insight into this. Rachel believed that she had suffered some memory loss due to the shock of her husband’s death, however she was confused as to when he died,
approximating it to be between one and three years ago. She remembers having been to a memory clinic, and does acknowledge that she goes every now and again.

Rachel thinks her memory has improved, its coming back again, and the problems she has are the sorts of memory problems everyone has. Rachel feels that the company she has at the day centre has helped her improve her memory. If ever her memory problem seemed worse again Rachel wouldn’t like to know what was causing it. I dinnae think so, I think I’m sort of, no, I think I’m with it now. When Rachel was aware of her memory loss she used to say to myself I think I’m going barmy, you know, a bit off my head. Rachel seems happy to use denial about her dementia.

But it’s not as bad as, I mean, like, if I go shopping I write down, I still write down what I need, but everybody does I think because you come out of the store and you’ll forget for something, maybe something that you need.

6.1.1 Case Study: Participant 20 - Alison

Alison is 78 years old and attends a day centre. Staff there referred Alison onto the research with the assurance she was aware of her diagnosis of dementia. Alison lives with her daughter and has obvious memory loss. Alison does acknowledge she has some memory problems, but believes them not to be out of the ordinary.

Interviewer: Do you have any forgetfulness at all?
Alison: No not really, if something, I mean, if I do something I mind it, sometimes, you know what you’re like yourself, oh I dinnae mind that, do you mind this, no, oh aye, it comes to you, if you think about it comes flooding into your mind.

She believes her memory problems could be related to lack of concentration. Alison repetitively tells the story of her childhood and the area she grew up in. She reframed the interview to be about this topic and not about memory loss.

If you concentrate something will, I mean it’s just like your young, you’re working you go to school, and sometimes you forget even your lessons, all through school. You have happy times, you have sad times don’t you.

6.1.2 Case Study: Participant 21 - Alice

Alice, 85 years old, was referred onto the study by the day centre staff who believed her to be aware of her diagnosis of dementia. Alice felt she had no problems with her memory at all, and gave as proof of this that she can remember where I was brought up, all the way up. She also mentioned that she can remember her school days. Alice thinks everybody has their ups and downs like everybody else and you just get on with it really

Let me think, um, to be honest there’s some things you’d rather forget, but otherwise (laugh), otherwise it is fine.

Alice mostly likes going to the day centre but I must say, I don’t like having my time mapped out, you know, for me, which goes against the grain just once or twice. Alice does talk about her acceptance of decline but mostly in relation to physical ageing.
Well we’ve all got to accept some things don’t you, and the fact that you’re not as, oh, well, physically capable as you might have been once upon a day, otherwise, I’m pretty normal.

6.1.3 Case Study: Participant 22 - Janet

Janet is 64 and lives with her husband. She did not want to be audio taped in the interview, this case study account has been taken from notes made by the interviewer during the interview.

Janet had been noticing changes in her memory for some time before she sought a diagnosis. She had been actively covering up for her memory loss and had done well in making sure her friends had not noticed for quite some time.

Janet’s mother also had Alzheimer’s. The family did not know the diagnosis until the Alzheimer’s was very progressed. Janet and her sister had thought that their mother had just become very bad tempered. Janet felt that knowing the diagnosis would have helped her to understand the changes in her mother better. It was after her mother died that she first noticed her memory problems getting worse. Her GP felt this could be normal due to the grief of her mother dying. However, the memory problems only became worse, and Janet was eventually referred to a consultant.

The diagnosis is not completely clear. One consultant described the changes in Janet to be due to probable Alzheimer’s. Another described her as having blood clots on the brain which may lead to Alzheimer’s. Not knowing what the exact diagnosis is sometimes suits Janet. She feels she would rather say she had blood clots on the brain as people may understand that better than if she says she has Alzheimer’s. It has been useful to have two different ways to describe the changes in herself to others.

Despite not always wanting to tell others her diagnosis, Janet did want to know what her diagnosis was, and felt that knowing her diagnosis was positive. For Janet, receiving the diagnosis was a way to move on from her initial denial of her problems, to being able to do something about it. She is currently on anti dementia medication and has received support as a consequence of the diagnosis. It has been positive for Janet to feel she is doing something about her memory problems. She is also reassured by knowing there is support available for her.

6.1.4 Case Study: Participant 23 - Helen

Well to be honest I’m more aware of it because my mother’s had it so I was more aware of what was happening.

Helen is 73 years old and lives with her husband. She first noticed that something was changing within herself when she was forgetting things. Helen feels she noticed changed in herself very early as her mother had dementia, which had made her more aware of what initial symptoms were. Helen and her husband had cared for Helen’s mother until she went into residential care. Her mother has not been aware of her diagnosis.

Initially Helen was reluctant to seek a diagnosis for her memory changes, I didn’t want to know. She has suspected it was dementia and didn’t think there was anything that could be done. One of her sons had heard of anti dementia medication and pushed her to talk to a doctor about it. Eventually a diagnosis was given and Helen is now on anti dementia
medication. This seems to be helping at this stage. She has had a good experience of her consultants and has found them to be very helpful

Initially after the diagnosis Helen felt a bit depressed I suppose but not much else you can do about it is there? She also felt at the beginning yes you feel very frustrated but I’ve come to terms with it. Part of coming to terms with it has included getting to the stage now where I can’t remember too bad. Helen does not want sympathy from people, she feels that you’ve got to get on with your life.

Helen generally views her experience of caring for her mother as beneficial experience in terms of understanding dementia. I mean the fact that we’d been through it all with my mother made you much more aware of what was happening, if you’d never experienced it you wouldn’t be so aware would you? However this awareness has not always been positive, particularly when at first I thought oh gosh am I going to go the same way as my mother and finish up in (residential care) or some place like that you know.

Helen thinks it is important to know your diagnosis, well I think I’d rather know what was wrong with me than go along in the dark. Helen thinks people with dementia should be told. I mean after all if you’ve got some illness you’re told aren’t you usually. If you’ve got, for instance, Diabetes or something like that you’re told so what’s the difference really? It’s an illness.

Generally she copes with the diagnosis by just trying and put it in the back of your mind. This apparent contradiction of wanting to know the diagnosis, but coping by putting it to the back of your mind reflects Helen balancing her need to know with a need also to sometimes use denial about the dementia.

Helen does not really want to know any more information about the dementia, I think I know all I want to know. She is not really interested to know what type of dementia it is. Helen does have clear information about the prognosis.

Well I’ll not get better you know that I won’t get better. Hopefully it could be controlled but I don’t think it will get better will it?

Helen and her husband had some minor difficulties in their relationship prior to the diagnosis, mostly due to coming to terms with the fact it was becoming apparent she was developing dementia and the impact of this on Helen’s behaviour. However the support Helen has had from her husband, son and daughter in law, has been very helpful. There are times when her son doesn’t understand the impact of the dementia, encouraging his mother to try to concentrate more, oh aye concentrate, concentrate he’s a joker [[laugh]] he is the one that I spent years trying to get concentrating at school. [[laugh]]

Helen is open with friends and family about the diagnosis, well I think you're better to bring it out in the open than try and hide it I mean what’s the point in hiding it, if people know then they understand if you’re well repeating yourself for a start.

I’ve got to the stage I think what’s the use of worrying [laugh]. It’s happened. I get frustrated at times but there’s no point in getting unduly worried is there. It’s happened.

6.1.5 Case Study: Participant 24 - Kevin
Kevin is 73 years old and lives with his wife. Kevin was referred with an assurance from the professional that referred him to the study that he knew his diagnosis of dementia. About 18 months ago Kevin noticed that he was experiencing changes within himself. He was experiencing paranoia, particularly towards his wife. It was the paranoia that prompted him to initially seek medical help.

Kevin knows that there is something that has changed within himself but he does not understand quite what. His wife has noticed he suffers short-term memory loss, however Kevin feels that well I don’t feel my memory is all that short. He doesn’t really notice the things his wife describes in relation to his memory. Kevin has been put onto medication for his memory and for the paranoia. He does not really remember visiting a consultant, but does recall details about his visit when prompted by his wife.

Kevin feels it is just tuff luck that he doesn’t know what has caused changes within himself. He has mixed feeling about this lack of knowledge, yeah, they don’t give me a lot of information, no, but eh maybe that’s a good thing. Kevin would like to speak to someone about his problems, but he does feel that maybe they don’t have the time to do it, but er that’s only my gripe.

Kevin believes the memory changes cold be due to having diabetes. Kevin has had a number of tests to determine what is wrong but they didn’t say and it’s a closed shop when you go into these places you know they never tell you anything. Kevin finds that there are times that he does not understand why medical staff are testing his memory when they check on what he believes to be his diabetes.

No it’s er I find it er I get asked questions about things that don’t seem to me to have any bearing on my condition.

Kevin feels that the initial symptoms of paranoia are past now and are best forgotten. During the interview Kevin’s wife described behaviours he has, such as wandering between rooms in an agitated way. Kevin was surprised by this, commenting, you’ve noticed that? Kevin’s wife also waited for him to tell me where they had just been on holiday, and he found that he can’t remember. He does remember how uncomfortable the bus was for the trip though.

Kevin gets around memory problems with the support of his wife, all I’ve got is my wife to fall back on. It is a great mystery to Kevin and his wife what might be causing memory problems. Kevin and his wife were visited by a consultant, who left them the book ‘Facing Dementia’, but did not provide the diagnosis, he just left the book. Well, it is, when they give you something like that, you think, oh my goodness what’s this? Both Kevin and his wife were confused as to why the consultant had left them this book, yeah, it seemed odd at the time but I don’t know but we’ve never seen him again.

Kevin would like more information about his problems. When Kevin’s wife asked him in the interview if he would like to know what his diagnosis was he replied, of course, of course.