

Leading the fight
against dementia

Alzheimer's
Society

Dementia

Out of the
shadows

October 2008

Dementia

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Contents

Acknowledgements	iv
Preface	v
Foreword by Terry Pratchett	vii
Executive summary	xiii
Introduction	1
1. Diagnosing and dealing with dementia – setting the scene	3
2. Methodology	9
3. Research findings	15
4. Conclusions and recommendations	49
5. Selected references and further reading	59
Appendix 1 – Executive summary of literature review	61
Appendix 2 – Topic guide – focus groups	69
Appendix 3 – Interview questions	71

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Preface

The Department of Health in England will soon launch a national strategy to combat the impact of dementia. It will aim, initially, to raise awareness of dementia, encourage earlier diagnosis and improve the quality of care. Similar initiatives have also been announced in Wales, Scotland and Northern Ireland.

The success of a strategy is usually dependent upon its implementation and for that we need to know how best to address the needs of those living with dementia. There can be no better way of doing that than listening to the words of those who have to live with it every day of their lives. That is what this report aims to do.

For too long dementia has remained in the shadows. At the Alzheimer's Society we have a Living With Dementia programme. It encourages those who have dementia, or care for someone who does, to be heard on all matters to do with dementia, so that they can have an impact on the policies being developed for dementia and the treatments provided. The very name of the programme underlines our belief that people can still live a full life following a diagnosis.

The programme has enabled those who live with dementia to be a powerful voice in making the case for dementia to become a health priority, for it to be given the attention it deserves and for government to respond to the needs of the 700,000 people with dementia in the UK and their carers.

This report is another step towards bringing dementia out of the shadows. Last year the Alzheimer's Society published Dementia UK, a definitive report on the impact dementia has on our nation. Now this report, Dementia: Out of the shadows, puts into words the reality of what it is like to live with dementia.

A handwritten signature in black ink that reads "Neil Hunt". The signature is written in a cursive, flowing style. Below the signature is a horizontal line that starts under the first letter and extends to the right.

Neil Hunt
Chief Executive, Alzheimer's Society

Foreword by Terry Pratchett

Seven hundred thousand people who have dementia in this country are not heard. I'm fortunate; I can be heard. Regrettably, it's amazing how people listen if you stand up in public and give away \$1million. This report goes some way to redressing that situation and allows others to tell you all about dementia.

I regarded finding I had a form of Alzheimer's as an insult and I decided to do my best to marshal any kind of forces that I could against this wretched disease.

I have posterior cortical atrophy or PCA. They say, rather ingenuously, that if you have Alzheimer's it's the best form of Alzheimer's to have. This is a moot point, but what it does do, while gradually robbing you of memory, visual acuity and other things you didn't know you had until you miss them, is leave you more or less as fluent and coherent as you have always been.

I spoke to a fellow sufferer recently (or as I prefer to say 'a person who is thoroughly annoyed with the fact they have dementia') who talked in the tones of a university lecturer and in every respect was quite capable of taking part in an animated conversation. Nevertheless he could not see the teacup in front of him. His eyes knew that the cup was there; his brain was not passing along the information.

This disease slips you away a little bit at a time and lets you watch it happen.

When I look back now, I suspect there may be some truth in the speculation that dementia (of which Alzheimer's is the most common form) may be present in the body for quite some time before it is capable of diagnosis. For me things came to a head in the late summer of 2007. My typing had been getting progressively worse and my spelling had become erratic. I grew to recognise what I came to call Clapham Junction days when the demands of the office just grew too much to deal with. I was initially diagnosed not with Alzheimer's but with an ischemic change, a simple loss of brain cells due to normal ageing. That satisfied me until the next Clapham Junction day. I went back to my GP and said that I knew there was something more going on.

Fortunately, she knew well enough not to bother with the frankly pathetic MMSE test and sent me to Addenbrookes Hospital, Cambridge when, after examination of my MRI scan and an afternoon of complex testing, I was diagnosed with PCA – an uncommon variant which had escaped the eagle eyes of the original diagnostician.

When Milton's Satan stood in the pit of hell and raged at heaven, he was merely a trifle miffed compared to how I felt on that day. I felt totally alone with the world receding away from me in every direction and you could have used my anger to weld steel. Only my family and the fact I had fans in the medical profession, who were able to give me useful advice got me through that moment. I feel very sorry for, and angry on behalf of, the people who don't have the easy ride I had. It is astonishing how long it takes some people to get diagnosed (they write to me). I cannot help but wonder if this is because doctors are sometimes reluctant to give the patient the stigma of dementia since there is no cure.

I was extremely fortunate in my GP. I think she was amazed to find that of the two specialists in my area, one had no experience of PCA and therefore did not feel he could not help me and the other would only take on patients over 65 – I was clearly too young to have Alzheimer's.

I remember on that day of rage thinking that if I'd been diagnosed with cancer of any kind, at least there would have opened in front of me a trodden path. There would have been specialists, examinations, there would be in short, some machinery in place. I was not in the mood for a response that said, more or less, 'go away and come back in six years'.

My wife said 'thank goodness it isn't a brain tumour' but all I could think then was 'I know three people who have got better after having a brain tumour. I haven't heard of anyone who's got better from Alzheimer's.'

It was my typing and spelling that convinced me that the diagnosis was right. They had gone haywire. Other problems I put down to my looming 60th birthday. I thought no one else had noticed the fumbling with seat belts and the several attempts to get clothing on properly, but my wife and PA were worrying.

We still have the occasional Clapham Junction days, now understood and dealt with. I have written 47 novels in the past 25 years, but now I have to check even quite simple words – they just blank on me, at random. I would not dare to write this without the once despised checker, and you would have your work cut out to read it, believe me.

On the other hand – and this is very typical of PCA – when the kind lady who periodically checks me out asks me to name as many animals as I can, I started with the rock hyrax, the nearest living relative to the elephant, and thylacine – the probably extinct Tasmanian marsupial wolf. That's the gift or the curse of our little variant. We have extreme problems handling the physical world but we can come pretty close to

talking our way out of it so you don't notice. We might have our shirts done up wrong, but might be able to convince you it's the new style.

I felt that all I had was a voice, and I should make it heard. It never occurred to me not to use it. I went on the net and told, well, everyone.

I wish I could say it was an act of bravery. It wasn't and I find that suggestion very nearly obscene. How brave is it to say that you have a disease that does not hint of a dissolute youth, riotous living or even terrible eating habits? Anyone can contract dementia; and every day and with a growing momentum, anybody does.

It occurred to me that at one point it was like I had two diseases – one was Alzheimer's and the other was knowing I had Alzheimer's. There were times when I thought I'd have been much happier not knowing, just accepting that I'd lost brain cells and one day they'd probably grow back or whatever. It is better to know, though, and better for it to be known, because it has got people talking, which I rather think was what I had in mind. The \$1 million I pledged to the Alzheimer's Research Trust was just to make them talk a bit louder for a while.

It is a strange life, when you 'come out' people get embarrassed, lower their voices, get lost for words. Journalists, on the other hand – I appreciate that other people living with the disease don't get so much of this – find it hard to talk to me about anything else, and it dominates every interview: Yes, I said I had PCA ten months ago, yes, I still have it, yes, I wish I didn't, no, there is no cure. I can't really object to all this, but it strange that a disease that attracts so much attention, awe, fear and superstition is so under-funded in treatment and research.

We don't know what causes it, and as far as we know the only way to be sure of not developing it is to die young. Regular exercise and sensible eating habits are a good idea but they don't come with any guarantees. There is no cure.

So we hope – more hope than would fit in Pandora's box, where it was the last thing.

We hope very carefully, that a half-way cure will arrive. Researchers are talking about the possibility of a whole palette of treatments or regimes to help those people with dementia to live active and satisfying lives with the disease kept in reasonably permanent check in very much the same way as treatments now exist for HIV. Not so much a cure therefore as – we hope – a permanent reprieve. We hope it will come quickly, and be affordable.

In the meantime we hope for Aricept, which is not a cure but acts as a line of sandbags against the rising tide of unknowing. However, it is available free only to those in the moderate stages of the disease: others must pay £1,000 a year, which I do. Eligibility is determined by the MMSE test, and it would be so easy for a patient in the mild stage to cheat their score into the free zone that I take my hat off to those too proud or responsible to do so. I cough up. NICE says the change it makes at my stage is minimal, but we don't think so in our house, where those little changes make the difference between a dull day and a fine day. The disease is, after all about small changes, and it may be that individuals may indeed be individual.

And that is nearly it for hope at the moment. When my father was in his terminal year, I discussed death with him. I recall very clearly his relief that the cancer that was taking him was at least allowing him 'all his marbles'.

Dementia in its varied forms is not like cancer. Dad saw the cancer in his pancreas as an invader. But Alzheimer's is me, unwinding, losing trust in myself, a butt of my own jokes and on bad days capable of playing hunt the slipper by myself and losing. You can't battle it, you can't be a plucky 'survivor'. It just steals you from yourself.

And I'm 60; that's supposed to be the new 40. The baby boomers are getting older, and will stay older for longer – will expect to stay younger for longer. And they will run right into the dementia firing range. How will a society cope? Especially a society that can't so readily rely on those stable family relationships that traditionally provided the backbone of care in previous generations?

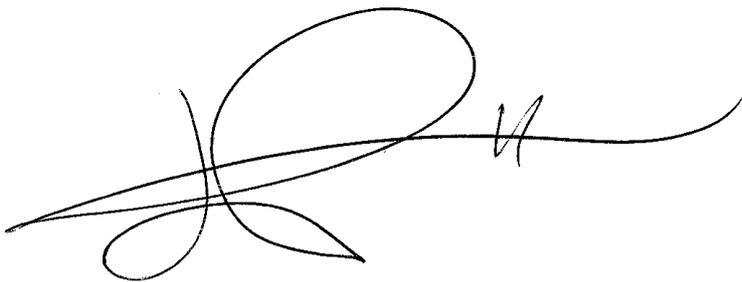
What is needed is will and determination. The first step is to talk openly about dementia because it's a fact, well enshrined in folklore, that if we are to kill the demon then first we have to say its name. Once we have recognised the demon, without secrecy or shame, we can find its weaknesses. Regrettably one of the best swords for killing demons like this is made of gold – lots and lots of gold. These days we call it funding.

I believe that the D-day battle on Alzheimer's will be engaged quite shortly and a lot of things I've heard from experts in the field, not always formally, strengthen that belief. It is a physical disease, not some mystic curse; therefore it will fall to a physical cure. There's time to kill the demon before it grows.

I want to thank the Alzheimer's Society for publishing this report and bringing closer the day when the funding we need is made available.

This report is part of the Society's Living With Dementia programme, which I'm pleased to see has the support of Comic Relief. A member of the Society once said at a conference: 'I am not dying of dementia – I am living with dementia'. And so the programme was born; to help those with dementia tell it like it is to the rest of the world and help influence for the better the lives of all of us with this 'embuggerance'.

What follows are the words of others who have dementia. Bringing dementia out of the shadows.

A handwritten signature in black ink, consisting of a large, stylized 'T' and 'P' followed by a horizontal line and a small flourish.

Terry Pratchett OBE
Author

Executive summary

This report describes a research project that explored the experiences of people with dementia and their carers (usually members of their family) of finding out they had dementia, the assessment and diagnostic process and how they, together with their families and friends, have adjusted and coped since being diagnosed. Investigating the possible benefits of being diagnosed early was an area of particular interest to the researchers.

The research took place in 2008, a time when dementia has an increasingly high profile for a number of reasons. These include an ageing population and increasing numbers of people believed to have dementia but still, worryingly, low rates of diagnosis, concerns about the quality of care and treatment for people with dementia and the imminent publication by the government of England's first national dementia strategy.

The research was undertaken by the Mental Health Foundation and commissioned by Alzheimer's Society. It involved a literature review, seven focus groups in different locations around England, and eight one-to-one interviews. A total of 61 people participated in the research, 32 of whom had dementia. The primary focus of the research was on the experience of people with dementia and it was undertaken in a way that aimed to facilitate their participation as much as possible. However it was recognised that at times people may have difficulties recalling their experiences and therefore the contribution of carers was also important.

Findings

The research covered four main areas. Firstly it investigated the different dementias that participants had and the length of time they had had them. All the most common forms of dementia were represented by participants. Most of the participants had been diagnosed for two or three years and had received the diagnosis at a relatively early stage.

Secondly, it looked at people's experience of finding out that something was not right and the experience of going to see their doctor. People reported noticing a number of dementia-related symptoms. Some people became concerned because of physical illnesses or symptoms. For some the process of getting a diagnosis was quite quick but for many participants it was a long, protracted and at times distressing experience. This was for a number of reasons but particularly because of dismissive, unhelpful or

uninformed responses from GPs and doctors working in specialist services. Even when dementia was diagnosed people were often left with little or no support, information or advice about what to do or where else they could seek assistance.

Thirdly, the research looked into people's lives after receiving a dementia diagnosis and the ways in which their lives had changed. Family and friends were particularly important in providing support to people, as was Alzheimer's Society, though help from health and social care services was mentioned much less. People described a range of practical and psychological coping mechanisms that they had developed themselves to cope with having dementia. Many of the practical coping mechanisms involved stimulating the mind. In terms of psychological adjustment, the emphasis on 'acceptance' was of particular note. This was not at the expense of other coping strategies such as retaining control, or 'getting on with it', but did seem to be particularly important in enabling people to come to terms and adjust to having dementia. However, while there were commonalities, coping mechanisms and strategies were also often very specific and customised to the individual. Many were also of great help to carers.

Finally, the research asked people's views on the key ingredients for a 'good' diagnostic process and experience, and the issue of stigma. A number of features were identified of a 'good' diagnostic process, some of which were quite generic such as good communication and being listened to. Others were more specific to the experience of people with dementia, such as doctors knowing when to refer on for more specialist assessments and taking into account the views of carers. While there were mixed views about how dementia was reported by the media and there was a belief that coverage was improving, there was a general concern that the wider public were still getting a skewed picture. The experience of people such as those participating in the research was not felt to be adequately portrayed, adding to ignorance of the condition and the stigma that surrounds it.

Themes

Four main themes emerged from the research.

- Early diagnosis was important and enabled people with dementia and their carers to understand what was wrong, begin to adjust to it and find ways of coping with it. However the variation in people's experience was of real concern and the negative experiences that people described were perhaps indicative of why so much dementia goes undetected. Given that the majority of people with dementia are not diagnosed, and the distress and difficulties this causes, the response of health services needs to improve significantly.

- A number of key features of a ‘good’ diagnostic process for dementia were identified by participants. These features may be helpful to reinforce or improve clinical practice, but might also provide guidance for people who are concerned that they might have dementia or who are being referred for specialist assessments, giving them helpful tips for what they can expect, look for, or ask for as part of a ‘good’ diagnostic process.
- An important array of both practical and psychological coping mechanisms and strategies that participants had found to be very helpful emerged, but when and how these were used seemed very dependent upon the individual and their circumstances. These coping mechanisms and strategies, alongside an acknowledgement of individuals’ styles and preferences, potentially offer professionals and carers a wide range of ‘tools’ that can be used to support people with dementia as well as their carers.
- The stigma of dementia was very pervasive. Media representation of dementia often did not help but the research indicated that the reaction of people close to them, as well as the responses of professionals, had a more detrimental impact on people with dementia and their carers.

Recommendations

Five major recommendations arose from this research. These are listed below and spelled out in full on pages 56–58.

1. Improve public understanding of dementia.
2. Improve GPs’ understanding of dementia.
3. Develop better specialist diagnostic assessment services for dementia.
4. Provide information which is timely and accessible.
5. Develop stronger peer support networks to help people cope.

Introduction

This report is aimed at people with a particular interest in the field of dementia such as policy makers, opinion formers, the media and people with dementia and their families, as well as those working in the field, such as professionals and researchers. It describes a research project undertaken with people with dementia. The research explored their experiences of finding out they had dementia, the assessment and diagnostic process, and how they, together with their families and friends, adjusted and coped following the diagnosis.

The research was carried out in 2008 at an important time for anyone affected by or interested in the issue of dementia. As well as several important reports that raised the profile of dementia in the last couple of years, in 2008 the government is due to publish England's first ever national dementia strategy. The devolved administrations in Scotland, Wales and Northern Ireland have also indicated they intend to make dementia a national priority.

The research uses the concept of 'psycho-social well-being' to describe people's mental, emotional and practical situation, as well as their responses to having dementia and receiving a dementia diagnosis, or indeed in caring for someone with dementia. While all forms of dementia are conditions that get progressively worse and there remains no cure for any form of dementia, an objective of the research was to investigate the potential benefits of an early dementia diagnosis on a person's well-being and in what ways well-being can be maintained.

Aims of the research

With this in mind the research aimed to:

- identify issues that may affect psycho-social well-being prior to a diagnosis, in order to understand the overall journey to a diagnosis of dementia
- explore how having a diagnosis of dementia affects a person, their carers, friends and family (for example, their ability to make decisions) and identify the methods people use to manage this process
- examine what methods people use to maintain activities meaningful to them (for example work or self-management) after receiving a diagnosis of dementia.

It is worth noting here that this is not the first time that the Mental Health Foundation has been involved in research with people with dementia, exploring their experience of

diagnosis. In 2001 the Foundation published *Tell me the truth* (Pratt, R and Wilkinson, H, 2001), and the similarity of several of its key themes to the findings of this research are striking. It is hoped that the combined power of studies such as these will have a positive impact on the development of services for people with dementia and their carers in the future.

The report contains five chapters. Following the introduction, Chapter 1 gives some background to the research in relation to dementia, diagnosis, stigma and the policy context. The latter is particularly relevant in light of the imminent publication by the government of a national dementia strategy for England.

Chapter 2 describes the methodology used in the research. Chapter 3 describes the key findings from the research. Chapter 4 draws conclusions and presents four key themes that merge from the findings together with recommendations.

A note on language

This report mainly uses the term ‘dementia’ or a ‘person/people with a diagnosis of dementia’. Those involved in the writing and production of this report acknowledge that there are a number of different types of dementia that affect people in different ways. However the term ‘dementia’ is used for the sake of brevity. It is also acknowledged that ‘dementia’ may not be the preferred term for some people and carries stigma with it, as the report identifies. Indeed this came up at the first focus group event, and at subsequent events the researchers acknowledged the difficulties around language and were as sensitive as possible in the words they used when doing the research, especially where it was not clear if participants had actually been diagnosed with dementia. However ‘dementia’ is the most easily understood term and the simplest way of describing a complex set of symptoms and conditions. Indeed, as Terry Pratchett has said, ‘If we are to kill the demon, then first we have to say its name’. It is hoped that this report, the words of the people in it, and the findings that have emerged may in their own right help challenge some of the stigma associated with the term ‘dementia’.

The report also uses the term ‘carers’. This denotes family, friends and anyone else who may be involved in providing unpaid care, assistance and support to the person with the dementia. However it is acknowledged that carers have their own lives and identities, and that nearly all the carers who participated in the research also had longstanding, intimate or close emotional relationships as family members, not just as carers, with the person with the dementia.

1. Diagnosing and dealing with dementia – setting the scene

Few would dispute that any form of dementia can be deeply distressing for both the person with the condition as well as their family and friends. All types of dementia are progressive, involve physical and mental deterioration, usually over the course of several years, and culminate in the person's death, either directly or indirectly. It has been estimated that there are approximately 700,000 people in the UK with some form of dementia, the most common being Alzheimer's disease, experienced by about 62 per cent of people with dementia (Alzheimer's Society, 2007a). The next most common form is vascular dementia, experienced by 27 per cent of people with dementia. Mixed dementias, fronto-temporal dementia, dementia with Lewy bodies, Pick's disease, and Korsakoff's syndrome account for the remaining 11 per cent. While there are significant variations between the different types of dementia (Alzheimer's is commonly associated with loss of memory, whereas vascular dementia may have more effect on physical movements or communication because it is caused by strokes damaging different parts of the brain) the symptoms for all forms of dementia become more severe over time and the person becomes increasingly dependent on others for care and support.

Despite enormous amounts of research little is known about the causes of dementia, although it is known that vascular dementia is brought on as a result of a person experiencing a series of strokes (though not all people who have strokes will get vascular dementia). Looking after the cardiovascular system through good diet and exercise may therefore reduce the risks of vascular dementia. However the biggest risk factor for dementia – getting old – is something neither we nor the NHS can do anything about. At present it is estimated that one in fourteen people over the age of 65 has some form of dementia but this rises to one in six for those aged over 80 (Alzheimer's Society, 2007a).

Because ageing is the biggest risk factor for dementia, and in the UK we have an ageing population that is growing both in number and in relation to the proportion of younger people, the challenge presented by dementia is one of growing concern. It is estimated that because of Britain's ageing population and increasing longevity the number of people with dementia will double to 1.4 million in the next 30 years (Alzheimer's Society, 2007a). The King's Fund has estimated that the cost of dementia will rise to £35 billion in England alone by 2026, suggesting a total of £40 billion for the UK as a whole (King's Fund, 2008).

While finding the causes of dementia is proving very difficult, so too is the quest to find a cure. Not a week seems to go by without a report in a national newspaper of a 'breakthrough' in preventing or treating at least one form of the condition, ranging from diet and exercise through to laser treatments and infra-red scanning of the brain. There are treatments licensed for Alzheimer's disease which help some people with dementia to cope with the symptoms of the disease. However, there is little evidence that these actually halt the progression of the disease itself. These drugs have been the subject of fierce debate and the current guidance from the National Institute for Health and Clinical Excellence (NICE) does not recommend using these treatments for people in the early stages of Alzheimer's disease. In the absence of any treatments that prevent the deterioration caused by the condition, the last few years of many people's lives are spent in care homes and hospitals. It is estimated that two thirds of care home residents have some form of dementia (Alzheimer's Society, 2007b), yet sadly care homes and general hospitals are often woefully lacking in the skills and expertise to care for them properly and reports are regularly received of neglect, negligence and mistreatment.

However it is important to note that while dementia is predominantly a condition associated with old age, it is estimated that at least 15,000 people in the UK below the age of 65 have some form of dementia. Given the limits of research data, this number is likely to be an underestimate by up to three times. The assessment, diagnosis and provision of appropriate care and treatment for younger people with dementia, pose particular challenges. This is partly because their numbers are small and therefore dispersed geographically, but also because their life circumstances are likely to be different to those of older people – they may still be in work, with young families and mortgages to pay.

Diagnosis

Diagnosing most forms of dementia is by no means straightforward and the implications of this process for someone's psycho-social well-being are potentially complex. These issues are discussed in more detail in the literature review that was commissioned as part of this research (see Appendix 1 for the executive summary of the literature review).

However there are some important points to note. Firstly, dementias are conditions that GPs do not normally diagnose. If a GP recognises possible signs of dementia in a person they will often refer them to an old age specialist consultant, such as a psychiatrist. The specialist may diagnose or make use of more specialist dementia assessments, involving tests, and possible scans, often at a memory clinic. However, older people may be receiving treatment for a physical condition either as a hospital in

patient or as an out patient and indicators of dementia may be identified through that route, particularly if it is a related field of medicine such as neurology.

Secondly, dementia is a condition which is greatly under-diagnosed – it is estimated that only a third of people with any form of dementia actually get a formal diagnosis. There are thought to be a number of reasons for this including:

- GPs not always having the skills or expertise to identify the symptoms in order to make a referral to a specialist for a full assessment and possible diagnosis
- reluctance of many doctors to diagnose a condition where it is difficult to do so with absolute certainty
- concern among healthcare professionals, especially doctors, that there is nothing that can be done to cure a person with dementia so there is little point in making a diagnosis, or that it would be too distressing for the person to be diagnosed – so-called ‘therapeutic nihilism’
- recent debates and guidance about limiting access to dementia medication which can slow the progress of the condition, which mean that if a diagnosis is made there is no guarantee the person will have access to even the limited pharmacological treatments that are available
- a diagnosis not being made because symptoms such as memory loss are assumed just to be signs of old age
- conversely, a diagnosis not being made where younger people are showing symptoms, because it is believed that dementia is an illness only associated with old age. Typically, these people are mistakenly diagnosed with depression.

Despite this, there is considerable evidence to show that receiving a diagnosis of dementia can be very helpful for a number of reasons. These include:

- more time for the person with the dementia diagnosis and their carers to come to terms with and adjust to the diagnosis
- more time and opportunity to consider and provide care and treatment options
- more time and opportunity for the person with the diagnosis and their carers to make future plans and arrangements (especially regarding financial and legal matters) before the condition becomes more severe
- enabling better use of specialist services such as dementia services, geriatric medicine, and neurology
- preventing or delaying transition into institutional care.

While there are clearly a number of good reasons for making as early a diagnosis as possible the actual impact on an individual’s psycho-social well-being may still be hard to predict and, as the literature review points out there several factors, or ‘variables’ that need to be taken into account. These seem to relate to individuals’ own personality and circumstances as well as the way in which the diagnosis is provided.

Stigma

‘Stigma’ means having some form of mark or sign that denotes disgrace or discredit. It is widely acknowledged that all forms of mental illness and conditions can be stigmatising and this has a damaging influence on the well-being of a person with the illness or condition. Recent research by Alzheimer’s Society has indicated that 50 per cent of adults in the UK believe there is a stigma attached to dementia. But as the authors of the literature review also point out, stigma operates at two levels:

‘externally – in wider society and the media – and internally, within people themselves, a concept called ‘self-stigmatisation’

Certainly there is considerable evidence to show that there is deep and profound stigma associated with a dementia diagnosis which both causes and partly reflects the reality of people’s experiences – loss of status and family and friends, social exclusion, mistreatment and dwindling mental and physical abilities. For most people with dementia who are part of the older generation and therefore also affected by ageist views in society, the impact of stigma, in addition to the affects of the dementia itself, can be enormously damaging to their psycho-social well-being. This is further compounded by the effect of self-stigmatisation, whereby people with dementia may view themselves as ‘lesser’ people.

At an external level it is certainly not difficult to see how stigma affects dementia simply through the use of language. ‘Dementia drags its victims down by the head’, ‘devastating’, ‘heart breaking’ and ‘a living death’ are just some of the headlines and terms that can be found in the media to describe dementia. These are supplemented by other phrases in common use such as ‘senile’ and ‘ga ga’. There is also the desire on the part of many people, including those with a dementia diagnosis, their carers and professionals, to avoid using terms such as ‘dementia’ or ‘Alzheimer’s disease’ because of the stigma they carry, or indeed, to avoid making or accepting a diagnosis altogether for this reason. Clearly this desire does not fit comfortably with an emphasis on early diagnosis and intervention.

Towards a national dementia strategy

With the publication of *Forget me not*, the Audit Commission's report on older people's mental health services (Audit Commission, 2000) and the National Service Framework for Older People (Department of Health, 2001) dementia began to become a priority for public policy in the UK. In the last couple of years the profile of dementia has risen significantly in both the media and policy terms, particularly as a result of the publication of several key reports and guidance, including:

- Supporting people with dementia and their carers (National Institute for Health and Clinical Excellence and the Social Care Institute for Excellence, 2006)
- Dementia UK (Alzheimer's Society, 2007a) – a research report on the costs and prevalence of dementia that the Alzheimer's Society commissioned from the Institute of Psychiatry, Kings College London, and the London School of Economics and Political Science
- Improving services and support for people with dementia (National Audit Office, 2007)
- Home from home (Alzheimer's Society, 2007b)
- See me, not just the dementia (Commission for Social Care Inspection, 2008)
- Always a last resort (All-Party Parliamentary Group on Dementia, 2008).

Consistent messages that emerge from these reports include the increasing challenge that dementia poses to health and social care services because of the rising numbers of people affected, the importance of overcoming existing obstacles to early diagnosis and intervention, and the need to improve the consistency and quality of care and support for people with dementia and their carers.

It is against this background and an increasing clamour from the media, families and organisations representing people with dementia and their carers, as well as care providers, professionals and politicians, that the government announced in 2007 that the first ever national dementia strategy was to be produced in England to create a coherent plan for the care and treatment of dementia. Subsequent to this both the Scottish and Welsh administrations also declared dementia to be national health priorities for their respective countries and a similar announcement has recently been made in Northern Ireland. The minister responsible for the England strategy, Ivan Lewis MP said at the time:

'We can no longer ignore dementia, or pretend that it is an inevitable part of the ageing process. A strategic, cross-cutting approach is vital if we are to deal with the challenges and consequences of dementia as a society' (Department of Health, 2008)

In late 2007, before the House of Commons Public Accounts Committee David Nicholson, Chief Executive of the NHS, said that dementia was now a health and social care priority in the same way as cancer and heart disease.

Following informal consultation with key stakeholders a draft national strategy for England was published for public consultation in June 2008. The strategy contains three key themes:

- improving public and professional awareness of dementia
- better early diagnosis and intervention
- ensuring high quality care and support.

Few people who are involved in the field of dementia would challenge the importance of these objectives. The real challenge lies in actually ensuring that the strategy is more than just fine words but will be implemented in a way that really makes a difference to those with dementia and their families. The proof of the pudding will lie in the eating.

2. Methodology

The research was carried out on behalf of Alzheimer's Society by researchers from the Mental Health Foundation. The Mental Health Foundation is a UK charity that undertakes research and development projects on mental health and well-being, and issues affecting people with mental health problems of all ages. It provides information to people with mental health problems, people with dementia, their families, and practitioners involved in their care as well as the general public. It also carries out campaigning and lobbying work on mental health issues.

The Foundation has its own programme of work issues affecting people with a diagnosis of dementia and has produced research reports and information for people affected by dementia (see references). In carrying out this work it particularly values the direct experience of people with a dementia diagnosis and was therefore especially pleased to be asked to undertake this piece of research on behalf of Alzheimer's Society.

There were three elements to the research.

- A literature review, led by Alisoun Milne, an Independent Consultant in Social Care and Senior Lecturer in Social Gerontology at the University of Kent. The literature review was used to inform the focus group research and interview schedule. An executive summary of the literature review can be found at Appendix 1.
- Three focus group events held during the summer of 2008 in London, Bristol, and Rotherham, incorporating seven focus groups made up of people with dementia and carers.
- Eight one-to-one interviews also, carried out over the summer of 2008, with individuals with dementia and/or their family carers.

Participants

A total of 61 people participated in the research, 32 of whom had dementia.

In total 56 people participated in the focus groups, excluding researchers and staff from Alzheimer's Society. The majority of people who participated came with a carer who also attended the focus group. Participants at each event were as follows:

- London – 15 participants in total (nine men with dementia)
- Bristol – 24 participants in total (nine men and two women with dementia)
- Rotherham – 17 participants in total (six men and two women with dementia).

Eight people participated in the interviews – three men, four women and one carer of a woman with dementia. Three of the male interviewees also participated in the focus groups.

Focus groups

Participants for the focus groups were recruited by Alzheimer's Society via their centre in London. Local branches of the Society in the locations where the groups were to be held were contacted and asked to invite their members to participate. Members of Alzheimer's Society's national Living with Dementia Group, made up of people with a dementia diagnosis, were also invited to participate.

The groups were held at Alzheimer's Society's centre in London, and local community venues in Bristol and Rotherham.

Each event involved a brief introduction by Andrew Ketteringham, Alzheimer's Society's Director of External Affairs, to explain the context of the research. This was followed by an explanation, given by one of the Mental Health Foundation's researchers, of how the focus groups would operate. Participants were then split into two or three focus groups and each group met briefly before lunch. This enabled them to familiarise themselves with the location of the room in which the group was taking place, meet other members of the group, receive further information about the group from the researchers and ask any questions.

The actual focus groups took place after lunch and lasted for an hour and a half. People were free to take breaks if necessary and there were refreshments and additional support available from Alzheimer's Society staff if needed by participants. Each focus group was facilitated by a researcher from the Mental Health Foundation and followed a topic guide with nine main questions (see Appendix 2). Participants in the group were given these questions, together with some supporting 'prompt' questions, in the session before lunch on the day of the focus group so they could familiarise themselves with what was to be discussed and had something to refer to during the focus group.

All the focus groups were mixed groups involving both people with dementia and carers. In planning the focus groups it was recognised that this might have some limitations, but, it was important to involve people with more advanced dementia in the groups and it was felt that this would only be possible if carers attended the group with them. However when introducing the research and in explaining how the focus groups would operate it was emphasised that the voice of people with dementia would always be given priority. The facilitators for each group tried to ensure as far as possible that the people with dementia in the group were always given the opportunity to share their views about the topic being discussed.

Interviews

Eight one-to-one interviews were conducted (although one was with the carer of a person with dementia, not the person themselves). Participants for the interviews were recruited by Alzheimer's Society via their centre in London, which contacted some local branches of the Society asking them to invite their members to participate. Members of Alzheimer's Society's national Living with Dementia Group, made up of people with a dementia diagnosis, were also invited to participate. Interviews took place at a variety of locations including Alzheimer's Society centre, local branches, the person's own home, and over the telephone where this was appropriate.

Interviews lasted about 45 minutes and were conducted according to an interview schedule with 11 key questions, as well as follow up questions for the interviewer to use as prompts if necessary (see Appendix 3).

Ethical issues

Ethical issues were carefully managed in this research honouring human rights, legislation requirements and local policies on researching vulnerable people. Informed consent was actively negotiated with participants, along with exercising confidentiality and the right to withdraw from the study at any stage. Participants were sensitively debriefed when difficult emotions arose and were given appropriate information on accessing help locally if it was needed later.

All participants were asked to give their consent to participating in the focus groups or interviews and were free to withdraw at any time. For the focus groups and face to face interviews participants were provided with an information sheet about the research and asked to complete a consent form. None of the participants withdrew their consent or withdrew from the research.

Methodological limitations

It should be noted that there were some limitations to the research. It was not a random sample of people with dementia as participants were self-selecting. This suggests that participants were more likely to be people with dementia and their carers who were at least comfortable discussing their experience of dementia and diagnosis, as opposed to people who were very uncomfortable or denied their dementia or diagnosis. It also meant that the sample tended to be weighted towards people with less severe symptoms of dementia rather than those in the later stages of dementia. This is understandable given the cognitive and physical symptoms experienced by people in later stages of dementia and is indicative of one of the more fundamental

challenges of undertaking research with people with dementia. However this did mean that it was difficult to make any significant comparisons between the experiences of people who had received a dementia diagnosis at a relatively early stage and the experiences of people who had been diagnosed at a later stage (though, realistically, the experiences of the latter would be more likely to be communicated by a carer rather than the person themselves).

While the primary focus of the research was on the experience of people with dementia, both people with dementia and their carers use the services of Alzheimer's Society's local branches, and therefore the majority of participants attended with their carers. There were also practical reasons for this. It was assumed that participants did not have previous experience of being involved in research and for many, the focus groups took place in unfamiliar locations, so being accompanied and supported by their carer was extremely important. It was also probably part of the reason for almost a 100 per cent attendance by those who had indicated they were coming. One of the interviews however had originally been intended to involve the person with dementia but took place with their daughter instead, without the person being present. This perhaps indicates the need for closer liaison between researchers and Alzheimer's Society and the person with dementia, to ensure they are supported to give their views and that carers fully understood the reasons for conducting the research in this way.

Carrying out research involving people with dementia is also challenging because of the effect of the dementia may have on their ability to remember, and in the case of the focus groups, to follow the discussion and participate, especially when they are surrounded in most cases by strangers. This was where carers could play an important role in providing the researchers with information. However, as already stated, it remained very important to ensure that people with dementia could participate, particularly on more subjective issues, and that carers did not dominate the conversation.

The researchers were mindful of these challenges and in the preparation for the research, and in actually carrying out the interviews and focus groups, took advice from Alzheimer's Society to ensure that people with dementia could participate as fully as possible. The ways in which the focus group events were structured, the information provided and the facilitation of the groups were all designed to enable this and to ensure that their views were heard as a priority. However the research showed the importance of ongoing support to enable people with dementia to participate in research, particularly given that they won't know the researchers and the research process is likely to be unfamiliar and possibly confusing.

The sample was also skewed because a higher number of men than women with dementia participated. This may seem surprising, as there are twice as many women living with dementia as men, and there is fairly good evidence to show that there is a greater resistance on the part of men to acknowledge health problems or seek help for them. However one reason for the greater incidence of dementia among women is that they tend to live longer than men and the risk of developing dementia rises with age. This may mean they have less close support available from carers and are therefore less able or willing to participate in research of this nature. More speculatively, given the high number of female carers who accompanied the men taking part in the research, it might also have been the case that the carers played an active role in encouraging and supporting the person to participate.

There were also very few participants from black or minority ethnic (BME) backgrounds despite the fact that some BME groups are thought to be at greater risk of developing certain kinds of dementia, most notably vascular dementia. This may be a reflection of the membership of many branches of Alzheimer's Society and may also reflect the self selection process for the research.

It should also be noted that, in the case of a few participants, it was unclear whether or not they had actually received a dementia diagnosis, or were aware of their diagnosis, even when they were accompanied by a carer. This may have been a reflection of genuine uncertainty or lack of information from the doctors and other professionals they had seen, particularly where they had only recently sought help and come into contact with Alzheimer's Society. It may also have reflected some concerns or possible discomfort on the part of carers to actually state the diagnosis in front of the person they were caring for because the person themselves hadn't been told, had forgotten, or might become distressed to hear it said.

Despite these limitations it is important to say that all the focus groups and interviews yielded extremely rich and important information as is reflected in the findings. While the ability of people with dementia to participate did vary, it was still possible to conduct the interviews and groups as planned, get answers to the questions posed and facilitate informative discussions on the topics discussed. This is a tribute to all the participants in the research. At times during the research issues arose that caused some individuals to become upset. This was anticipated because clearly very sensitive issues were being discussed but through careful facilitation, the support of Alzheimer's Society staff and the strength of the individuals themselves, no one dropped out of the research and everyone was able to continue to participate.

3. Research findings

This section describes the key findings from the research. Findings are reported broadly in the sequence that questions were asked in both the focus groups and interviews. Priority is given to reporting the views of people with dementia.

The findings are in four main sections:

- types and duration of dementia
- getting a dementia diagnosis
- adjusting to having a dementia diagnosis
- general questions.

Types and duration of dementia

The questions in this section focused on the types of dementia that people had and for how long they had been diagnosed.

1. Could you tell me what kind of dementia you have?

People described a range of diagnoses. A significant number had Alzheimer's disease but also vascular dementia, mixed diagnoses, fronto-temporal, and dementia with Lewy bodies. A few individuals, especially in the focus groups, didn't know or hadn't been given a diagnosis, nor were their carers (if present) able to provide this information.

2. How long have you been diagnosed with a dementia?

For a number of participants with dementia, particularly those who had been diagnosed for some time, it was not always possible for them to remember how long they had had the condition but the response of carers was helpful in these situations. The length of time described ranged from seven months up to ten years but in some cases (including a couple of people who said they had been diagnosed several years previously) it was not always clear if people were describing the length of time they had experienced symptoms of dementia, or the time since they were formally diagnosed.

The majority of people had been diagnosed between one and three years previously but a significant number had been diagnosed for longer than three years. Some people talked about noticing symptoms or changes in personality going back as far as twenty years which they attributed to the dementia.

Getting a dementia diagnosis

The questions used in the first part of the focus groups and interviews concentrated on people's experiences of finding out about their diagnosis, particularly their experience of the actual assessments and diagnostic process.

3. Thinking about your diagnosis – what first made you think that there might be something not right?

This question aimed to explore people's experience of noticing that something was not right, as a starting point for them discovering symptoms of dementia and in the majority of cases, actually getting a dementia diagnosis. As with the previous question a number of participants with dementia, particularly those who had been diagnosed for some time, were unable to remember the symptoms they first noticed, and the response of carers was helpful in these situations.

Responses to this question fell into two main categories: memory/cognition problems and physical problems.

Memory/cognition problems

Several participants recalled an event or series of events involving forgetting things.

'I used to have a very good memory and suddenly I found that words that I knew the meaning of I was not able to give their meaning...that told me something was wrong' (person with dementia)

'I knew my brain wasn't what it used to be because I've always remembered when I gave birth to my girls and one time I thought "I can't remember what their birthday is"' (person with dementia)

'I was having difficulty in remembering things that I knew that I knew and beginning to have arguments with the wife as to where she had told me things, asked me to do something or she had done something on my behalf and I'd say "no you didn't"' (person with dementia)

For some this involved forgetting skills or expertise at work. One person who was a professional singer recalled walking out on stage to perform publicly.

‘To sing a song that I have sung 100 times before to the music I have heard 100 times before and I am standing there thinking “what the hell am I doing here and what am I going to sing?” This started to happen more and more and when you are out on that stage on your own and you don’t know what you are doing . . . it is a terrifying prospect’ (person with dementia)

Others described getting confused, or being worried about changes in their ability to carry out everyday tasks.

‘If I was getting dressed in the morning I would put my clothes on and I would guarantee you there was at least a pair of trousers, a shirt or a hat and a coat and it had all gone on upside down, back to front’ (person with dementia)

‘I was struggling at work . . . I was losing track and losing control of the class which is something I had never done. I became disorganised, which again is something I have never done’ (person with dementia)

Some carers also described how they noticed changes in the personality of the person with the dementia.

‘He would get angry at things, it was terrible going out in the car . . . he would lose his temper. It was so unlike him, his personality changed in my eyes’ (carer)

‘There was something I said to him and he went berserk, turned very nasty . . . It wasn’t like him. I’m not saying we didn’t have arguments, of course we do, but it was a different one and I thought this is not right’ (carer)

Physical problems

A few participants noticed or believed that a physical illness or physical symptoms first led them to think that something was wrong. For one person this arose from a specific incident.

‘I suffered an assault which gave me head damage . . . almost immediately I noticed I was having problems with remembering things and things disappearing from my memory’ (person with dementia)

Another person remembered having frequent headaches over a period of time and then things becoming worse.

‘I used to end up having headaches and just taking ibuprofen or whatever just to kill it and I would probably have six a day just to kill the pain...over the period of Christmas I got the bug and it was just then I said to...my wife that I have got to go to the doctor’s now, I can’t cope with this’ (person with dementia)

Other reasons

Other things that made people think something was wrong included having difficulties communicating effectively, including repeating themselves or experiencing the symptoms and/or treatment of depression but finding that treatment did not relieve the dementia-related symptoms.

There was considerable consistency in the responses of people with dementia (where they were able to remember) and their carers (if present). However there were some differences between the perceptions of carers and people with dementia – carers may have noticed problems sooner and in some cases this led them to worry because of changes in the person’s personality or caused friction with the person (though this was often the case where the person with dementia could not remember noticing the first indicators of something not being right).

4. How long after you thought there might be something not right did you go and see your doctor?

As already discussed ‘going to the doctor’ because of concerns about possible dementia is likely to involve several appointments, seeing probably at least two doctors and undergoing various assessments. This was reflected in the answers that people gave to this question as people tended to describe a process, or series of appointments, rather than it being a simple ‘one off’ consultation. However, because many of these answers involved describing what happened during this extended process they are reported under the findings for question 5.

As with the previous question, several participants with dementia found it difficult to remember so carers often provided the information.

For most people it was quite a quick process (ie less than a year) because people were experiencing distressing symptoms or were worried about changes in their ability to remember or communicate.

‘I can’t remember exactly but it wasn’t very long, just a few days to make the appointment...I wanted to know what caused it [loss of memory] and if there was something I could do to stop it’ (person with dementia)

Some participants who had been working and had to give up work before they knew what the problem was had gone to see their doctor almost immediately. Others described a bit of a delay.

‘It was about...three or four months after I retired’ (person with dementia)

For a few others it was quick because they had to see a doctor because of physical problems.

‘I think I had a rude awakening to it, I was on holiday and had a fall...I had to have x-rays as I hit my head against something. From that they found out that I had dementia’ (person with dementia)

However for some participants it was a longer process, in several cases more than a year, often because it was more with hindsight that participants realised that something more serious was wrong.

‘Mine was probably two weeks like I say from when I had that bug and went to the doctor but if we look back on now I probably had what I’ve got for four or five years’ (person with dementia)

5. What happened when you went to see your doctor?

Again, as with the previous questions, several participants with dementia found it difficult to remember so carers often provided the information.

This question, taken together with some people’s response to the previous question, evoked a lot of discussion and extensive interview responses. As already indicated in the answers to question 4, for many participants ‘going to the doctor’ and getting an actual diagnosis was quite a protracted and complex process, particularly as symptoms

changed or progressed. This often required the person with dementia and/or their carer to be persistent and proactive. Overall, there was a considerable mix of experiences but a very significant number of people described long, frustrating and distressing processes involving doctors.

Dismissive or insensitive responses from GPs

Frequently these difficulties began with the GP. Several examples were given where symptoms or health concerns described by the individual and/or their carer were dismissed by GPs whose responses were dismissive, unhelpful or uninformed. In some cases they did not take symptoms seriously or told people that it was just a natural sign of ageing.

‘[The GP said] when you pass 70 you can expect to lose your memory a little bit’ (person with dementia)

‘I consider that I didn’t get a service from, not from the doctor, my own GP. From my own GP I just got patted on the head’ (person with dementia)

‘We had an appointment with the local GP anyway, over a different matter and while I was there I said you know, I told him the symptoms and he pooh poohed it’ (person with dementia)

‘General practitioners after all are exactly that, general practitioners and so they cannot be expert in everything, but they don’t seem to have a general sensitivity to dementia as an illness’ (person with dementia)

‘Surely they should be getting more training and then if [they] can’t understand it...pass it on to the neurologist or psychiatrist rather than put you on tranquillisers’ (person with dementia)

‘I am not saying he is an uncaring GP but he didn’t know’ (carer)

‘The GP said, “Oh well, we all get old sometimes”’ (person with dementia)

‘We had gone to him [the GP] for a lot of things and he was always telling [the person with dementia] that it was in his mind, he hadn’t got these problems, he needed to pull himself together’ (carer)

‘It takes so much encouragement, so much guts to go to the doctor... so then to be fobbed off is something huge’ (carer)

General service difficulties

More generic difficulties with GPs were also described, such as seeing different doctors.

‘There are so many GPs at the surgery, about ten or 12, you don’t see the same doctor twice now, it is a clinic not a surgery and you have got an awful job to see the doctor you want’ (person with dementia)

Additional, more generic difficulties that were identified (including situations where people were referred to see a specialist) involved waiting times, short consultations, variations in standards of services (some participants attended the same hospital for similar appointments but the service received and frequency varied considerably because they were under different consultants – a very local case of the ‘postcode lottery’) and communication problems where the doctor was not understood by the person.

‘It is no good five minutes and then [they] say “cheerio” . . . , “there is nothing else we can do for you”’ (person with dementia)

‘You got some consultants that you can’t always understand’ (carer)

‘A quiet manner and then medical jargon and you know it’s not very helpful at all. And particularly when you are in a situation you don’t understand’ (carer)

Misdiagnosis or insensitive responses from consultants

Even where a referral was made to a specialist the next stage was not always a very positive experience for several participants*. One participant was actually told by the specialist that he was just ‘lazy’. Another specialist came across as uninterested in the person – ‘only thing they were interested in was the beautiful new building’. Several participants described being misdiagnosed with depression.

‘You are depressed because you are in the pits. Your life’s breaking down, surely they should be looking for the answer to your depression... [I] don’t get depressed for nothing’ (person with dementia)

For another person who was prescribed antidepressants this eventually proved too much.

* Even in the time between carrying out the research and writing this report one participant has had their diagnosis queried by a specialist consultant and is being reassessed.

'He wasn't listening to me, so I literally threw them at him and said, "If you like them so much, you take them, because I am not taking any more anti-depressants. You are not listening to what is happening to me"' (person with dementia)

When a diagnosis was made, specialists did not always do so sensitively.

'I would say his bedside manner was absolute zero and I have stopped several times and tried to think what was it I was wanting or expecting. A bit of stability, a bit of sincerity, a bit of general concern. The best he could come up with was, "well it's Alzheimer's, what do you expect?" I got no more, no less which again, I wasn't very impressed with, not from a consultant' (person with dementia)

'I've just been told you've got Alzheimer's and they walk out [it] is absolutely bloody disgusting' (person with dementia)

'He came back immediately, sat there, and within two seconds of him telling [you] your life's gone, your life's changed... "sorry, you've got Pick's, prognosis five to ten years" but there is nothing "this is who you have got to see now", or "this is where you go to now" or you know, "sorry". You go home' (person with dementia)

'Just before we were going home we said, "actually you know, there must be some name [for the condition]", and they said, "yes, you have got Alzheimer's"' (person with dementia)

'They keep telling you that there is nothing we can do for you. It is something you have got to live with and there is nothing they can do for you' (carer)

Another was told his diagnosis in what he described as an uncaring and unsympathetic way, and told he could not have any medication.

'It was appalling the way they did it and there was no thought' (person with dementia)

A carer described finding out over the phone, having not heard back after a scan was done and ringing up herself.

'I got the diagnosis on the phone by somebody I had never met telling me your husband has Alzheimer's and vascular dementia. That was probably the worst possible way. That was absolutely infuriating' (carer)

Participants with early onset dementia often reported more negative responses from specialists. One interviewee was told by her psychiatrist that she was 'too young and too bright to have dementia' and that 'they didn't feel I was in the right age group'. Other unhelpful responses from services for people with early onset dementia included the following.

'Every time I approached the doctors about the problems I was having at least two of them said to me, well you can't have Alzheimer's, you are too young' (person with dementia)

'I was told to go away and don't be a silly woman' (person with dementia)

And for someone else who had early onset.

'Because [the person with dementia] was younger at the time of diagnosis the GP didn't ever consider dementia' (carer)

Having to be proactive and persistent came through as an important theme when dealing with doctors.

'It was a fight and a battle every single step of the way' (person with dementia)

'It was only when I went and really sort of pounded the desk and demanded in a rather aggressive way that, well I have got this far' (person with dementia)

For some people this was because the person themselves was reluctant to go to the GP and the carer initiated it.

'I instigated him going to the doctor because I knew there was a problem' (carer)

'I went to my doctor who is also [the person with dementia's] doctor and voiced my concerns' (carer)

Some participants did make the point that they themselves didn't have the knowledge or information to know what to do.

'You can walk into a general practitioner's and you can pick up a leaflet on cancer but can you pick up a leaflet on dementia? Very unlikely' (person with dementia)

‘I think one of the problems is that we did not know what the right questions were, it was not something we had ever dealt with before...you didn’t know what was going on...you did not know what you were entitled to’ (carer)

Several participants described poor interactions with doctors (including specialists), during which they were patronising, didn’t listen to the person with the dementia, only spoke to the carer and ignored the person with the diagnosis, or vice versa.

‘The doctor speaks to [the carer] first before they speak to me and this happens quite a lot’ (person with dementia)

‘The thing I find when you got to a consultant is that they direct the question at the patient who’s not fully aware of what’s happening and the answer coming [from the appointment] all the time “I’m just forgetful”’ (carer)

Inappropriate responses from GPs and specialists

Several participants reported receiving no support, advice or information from the doctor after being given the diagnosis. One younger person with dementia was told that she wouldn’t be able to have a community psychiatric nurse because they were ‘too busy’ and that she was ‘not as bad as most of the people they are supporting’.

‘Initially we had no support whatsoever. Having said that we didn’t ask for any after the diagnosis’ (carer)

‘We were both suffering from depression because of what he was going through and he was taking it out on me so when we got to the hospital we were depressed and then when they told us that as well, [that there was nothing that could be done] we came out and we thought, “where do we go from here?”’ (carer)

Several people expressed their concern about reliance on the various clinical assessments and tests the person has to do, without the assessment involving a view of the ‘whole person’. Examples were given of where it induced anxiety or the activities seemed uncorrelated to a person’s life (although no participants actually disputed the diagnosis that had emerged from these tests).

‘Nobody thought to consider my background...nobody wanted to know about that, ‘oh no, that doesn’t matter, let’s just look at you now’. I think the difficulty is that you need a snapshot of how you were to

compare it to how you are. They have no interest in that' (person with dementia)

The worries/needs of carers were also often overlooked and some felt they should have been more involved in the assessment process, or provided with more information.

'I think the word Alzheimer's puts like a fear in you, like cancer does, the word cancer puts a fear in you and the word Alzheimer's was, to me it was like, well you know, I couldn't believe it. But we've coped' (carer)

'He is completely different, I said [to the doctor] you have to listen to the carer you cannot make an assessment in a ten minute conversation' (carer)

'I was firing questions at the [doctors], how bad is he going to get, what will happen, and all I really got was shrugging the shoulders and saying, "well, we don't really know"...I came away thinking what's going to happen now. They never gave me really any help or anything...I think they became indifferent' (carer)

'I just wanted somebody to listen to me and they weren't prepared to do that' (carer)

'They didn't give me enough information. I came away thinking "what do we do now, where do we go from here?" I have a prescription in one hand and a note for blood tests in the other and nobody has said what the CAT scan showed...nobody has given me that information. I am the person who is going to deal with [husband with dementia]' (carer)

Expectations of diagnosis from GPs and specialists

However several participants did make a number of more positive comments, mostly in passing, about their experience of services (even though it resulted in a diagnosis of dementia). These included being taken seriously by healthcare professionals, appropriate referrals being made swiftly and sensitively, being given helpful information about dementia and the treatment and services available, acknowledging the carer's concern and good, clear communication.

There was a widespread understanding that GPs often wouldn't have the knowledge or expertise to diagnose dementia, but also feeling that they should know how to respond appropriately to someone with genuine concerns indicating dementia. Participants also said that positive responses from or encounters with doctors helped people adjust to finding out the diagnosis and beginning to cope, even though many also experienced, quite understandably, considerable upset.

'It was useful to understand things, like I couldn't effectively do various things' (person with dementia)

'He is a good doctor. I recommend him...He did everything for us' (carer)

'I came out with piles of pamphlets of help, different things to go and see' (carer)

'If anything was destined to make you feel better it was the actual attention they gave you' (person with dementia)

Others had similar experiences that were more positive.

'The only bad experience I suppose was the waiting time which is months to see a consultant' (person with dementia)

'When I went to see my doctor I explained to him how I was feeling and how my head was and what it felt like and he within a week got me an appointment to see a neurologist up at Brighton and then I saw three consultants in one day in an hour' (person with dementia)

'You will go to your GP and the GPs...are the only people who are really interested in you, with the greatest respect of the consultants, etc and so forth they will give you the answer but then you are passed on and passed on' (person with dementia)

'[The GP] has been very positive in supporting both of us really. When this problem occurred he referred [the person with dementia] straight away to the memory clinic and stuff so he obviously saw something in her that he felt he should deal with straight away. When consultants and people have done tests on her and written to him he has always been in touch with us to let us know what is going on. He is very positive' (carer)

Some carers also reported more positive experiences of the process.

'We went to the GP in September, [he] had a scan in October and we got the diagnosis in December' (carer)

'I think if everybody feels that if something is being done and there is an effort being made by various doctors then you know you are happy about it' (carer)

'I have had no problems with doctors whatsoever believe it or not' (carer)

‘He did take himself [to the GP]...He just went and I must admit the doctor did refer him straight away’ (carer)

‘We got some appointments [at the memory clinic] and that is really all that the GP had to do’ (carer)

Reaction to getting a dementia diagnosis

Perhaps predictably, many participants experienced negative emotions when they were told the diagnosis, including disbelief, shock, anger and despair.

‘I couldn’t believe it because I have always had a good memory. The worst was when they told me I would not be allowed to drive a car’ (person with dementia)

‘I felt I had a shock...I just thought it can’t be. I said it’s for other people’ (person with dementia)

‘All emotions just broke through for a period of about six months’ (person with dementia)

‘The angst and anger that I went through during the diagnostic process...I could have actually gone and thumped people’ (person with dementia)

‘When I first received the diagnosis I was quite depressed although I knew something was wrong’ (person with dementia)

‘I said, “I can’t believe because it’s only for old people”’ (person with dementia)

‘[The person with dementia] said “if it’s true I might as well kill myself”’ (carer)

Carers’ reactions to their partner’s or relative’s diagnosis

‘[The consultant] said it is dementia and I just burst into tears because I was so, I half expected it but it is still a terrible shock’ (carer)

‘It really upset me. I had to go on a tranquilliser’ (carer)

‘Just absolutely devastated’ (carer)

‘I just sat there and tears just rolled down my face’ (carer)

Several participants described some positive aspects of getting a dementia diagnosis. A sense of relief was identified by several participants, which came from knowing what was wrong.

‘It was as if the thunder clouds had been taken away because they had given an answer to me why I was treating my family so like a louse that I was’ (person with dementia)

‘I was diagnosed reasonably early so the progress such as it is, has not been in jumps at a time, it is small incremental changes and at least I am sat here’ (person with dementia)

‘I was relieved really that what I was trying to convince people had been verified’ (person with dementia)

‘It was a relief...to know all the bits and pieces, that’s what it was’ (person with dementia)

‘The best thing for us was when he got the diagnosis and we had a title...we could say we know what it is and it is better than just wondering what the heck’s going on and not knowing’ (carer)

‘My initial reaction was disappointment because I had been hoping it was something else. But both of us, it is very interesting really, both of us felt liberated by it’ (carer)

There was some agreement that emotional ‘coping’ styles, particularly in relation to gender in the focus groups (where nearly all the people with a diagnosis were men), played a role in dealing with receiving a diagnosis, but this varied from individual to individual.

‘It is quite strange because dementia seems to hit people in very different ways. There are little threads of commonality in it, but everyone is affected in a slightly different way’ (person with dementia)

Male and female responses to diagnosis

For a few participants the emotional impact was felt much more by female carers (usually a wife or partner) than by their husbands/partners who had received the diagnosis, who were quite dismissive.

‘I don’t really feel anything really. I mean I feel now as I did five or ten years ago. I am doing all sorts. I can drive. I mow the garden. I can decorate’ (person with dementia)

'I feel that I put too much on [his wife's] shoulders' (person with dementia)

'He never discusses anything with me at all...I don't get a word out of him, day in or day out...He is hard work, he is' (carer)

'He can drive, he can go out and do the garden, and you know, he won't accept it. I had a job to accept it myself when he has done things like that' (carer)

Some men participating were certainly philosophical, even quite flippant.

'The only good thing with it was we knew something was wrong and we were prepared for the worst. So like, obviously we got the worst, it wasn't that bad' (person with dementia)

'I still have a memory so that's the good part, I forget that I have got dementia' (person with dementia)

Access to services and medication

Several participants reported the benefit of getting an early diagnosis in relation to being able to access services. One person was referred to a programme for people recently diagnosed with dementia.

'It was organised by various people from the Alzheimer's Society and carers, and they explained to the people what kinds of dementia there were, and what happens, and how you can help it by healthy living and all this, it was really good' (carer)

Although the research was not specifically investigating people's experience of medication, inevitably the subject came up. Several participants reported being prescribed medication such as Aricept, Reminyl, and Exelon which can temporarily improve or stabilise the symptoms of Alzheimer's disease. Getting diagnosed early was felt to be beneficial because of (potentially) getting access to medication sooner which, 'seem to work better the earlier you take them' (person with dementia).

Several participants reported the beneficial affects of being prescribed these drugs, including an exchange between a carer and his wife.

Carer 'I think you felt that the medication was helping didn't you?'

Person with dementia 'I feel a lot better, bit by bit...but it did the job. Yes'

Other positive comments about medication.

‘The drugs have made a huge difference. An absolutely huge difference. I mean, I wouldn’t be talking to you now if I wasn’t taking the drugs’
(person with dementia)

‘Everybody can see the drugs are working because she is more her normal self...it has given us the ability to do what we want to do’ (carer)

However for others, the experience of being prescribed medication was less positive.

‘In the end, you know, there was a...reluctance, ...almost a point blank refusal to even consider me receiving any medication...I was being heard until I was saying the things they did not want to hear’ (person with dementia)

A carer recounted a story of her husband being prescribed Reminyl and then being taken off it because the doctors did not see it having any effect. The carer had a different view, ‘so I said you have only spoken to him for ten minutes. I live with him, I think you should be asking me whether there is any difference and I said there is...for all the three reasons that you put him on it, I said all those things have changed’. The carer went on to say that her husband had told the doctors that he still played a racket sport, whereas in fact he had not played that sport for 18 years and had a number of serious physical conditions as well as the dementia. The carer concluded that, ‘You know you’re the person that the doctor should ask’, although her husband added, ‘or get a second opinion’.

Adjusting to having a dementia diagnosis

The questions used in the third part of the focus groups and interviews concentrated on people’s lives after receiving a dementia diagnosis and the ways in which their lives had changed. The questions also focused on ways that people had been able to adjust and cope with the dementia. Findings for the two questions in this part of the research are reported together as there was a significant overlap in people’s responses.

6. How did you adjust to getting a diagnosis?

7. What do you think makes some people better able to adjust to a diagnosis of dementia than others?

Participants described how they had adjusted and coped, as a result of getting a diagnosis and with the progression of the dementia, together with some of the challenges they faced.

Support of family and friends

In terms of adjusting, the support of family and friends was described by many participants (including carers) as being enormously important, both emotionally and practically. Knowing other people with a dementia diagnosis and getting peer support from them was also very helpful for several participants. For a couple of people, giving support to others with a diagnosis was also important.

‘I would say our family, our children’ (person with dementia)

‘The family have been marvellous to us so my daughter, gives [the spouse] all the paperwork from me’ (person with dementia)

‘I rely greatly on my wife and my carers...I’d be in terrible trouble without them’ (person with dementia)

‘My son has helped a lot with the finances and everything that [he] used to deal with, which like you, I am having to delay with all that now’ (carer)

‘Be honest to yourself and to your friends because there is a lot of support if you are open with them. I mean some of them will walk away and can’t deal with it but an awful lot of people will help’ (person with dementia)

‘Friends...and everybody, professional people had to help me get through or obtain the treatment I was entitled to’ (person with dementia)

‘Today I have met people who are in very much the same boat as I am with things they can and can’t do it...so for me it’s a relief, a bloody relief to find that there are other people in the same boat as me’ (person with dementia)

‘I think I’ve been part of a group that regularly goes together and since I’ve got to know other people and I think of it as being “we’re all in it together”, and therefore I don’t feel lost...and that’s very helpful actually’ (person with dementia)

‘Having family does make a big difference’ (carer)

'You [husband with dementia] like to go for a drink of beer with blokes'
(carer)

Although support from family and friends was not always perceived by carers to be what was most helpful.

'He can still go out on his own, you know, locally, and he's fine but really needs attention but not mine. Because he doesn't talk to me because I've heard it all before but he will talk to anyone else and so going to the day centre it seems that the care is there, they're happy to listen to him'
(carer)

Health and social care services

Helpful support from professionals was mentioned by one or two participants (especially around medication and practical help, for example around welfare benefits).

'That was a wonderful feeling to know there were people, in the right area who absolutely cared for you' (person with dementia)

'The memory nurse she was very good wasn't she. She gave us lots of information we didn't know or wouldn't even have thought of you know, but she was excellent' (carer)

Participants gave examples of a lack of joined up working between health and social care services and the importance of having assistance from an identified professional or paid worker was mentioned.

'I was bewildered, I really was, and we both were and in that situation you are not at your best and you do need someone to point the way, it's as simple as that' (carer)

Though one participant described how a social care worker came to visit him to arrange his care plan.

'So I said, "fine, the health service have done my care plan", he said, "oh have they, who did that?" So I told him the nurse who had done it and he said "oh, can you give me her telephone number?" I said "I'll do better than that, I will get her on the phone and you can talk to her". So I actually got her on the phone, put the phone in his hand so that he could actually talk to my health worker' (person with dementia)

Support from Alzheimer's Society

The support received from Alzheimer's Society received considerable praise (although this was to be expected given that most participants were recruited through local Alzheimer Society branches):

'If it had not been for the Society then perhaps I would have given up and sat in the chair and lost interest' (person with dementia)

'The only person, the only direct contact I actually have with any help whatsoever is [a member of staff] at the Alzheimer's centre' (person with dementia)

'The Alzheimer's Society are absolutely brilliant' (carer)

'The Alzheimer's Society are wonderful' (carer)

'It's the only thing that has helped me, has been the Alzheimer's Society' (carer)

Receiving useful information

Knowing what was happening, and being given the right information were seen as important tools to help the process of adjustment.

'Having the right information' (person with dementia)

'As you have been diagnosed there should be a follow up with information on what you have got, how do you cope with it, what to look for, what's gonna happen what's not gonna happen' (person with dementia)

'I think the doctors need to give you more information as to what it's all about' (carer)

Practical ways of coping

Practical things that helped people to deal with dementia and maintain a quality of life (sometimes as distractions, sometimes as ways of coping or exercising the mind) included activities such as crosswords, Sudoku, jigsaw puzzles, walking, bicycle rides, dog walking, gardening, bowls and listening to music. Writing things down to help remember them was given as an example by a couple of people as a helpful coping strategy. One person went to India soon after getting the diagnosis, another joined a choir and took up playing the cello and piano again.

'It is great also because if I watch the TV I get tired but if I am doing a jigsaw I don't doze off, so I like doing jigsaws' (person with dementia)

'I do crossword puzzles every day' (person with dementia)

'I listen to classical music' (person with dementia)

'I would tell them what the doctor told me to do, the doctor said you should walk...because it helps your brain. So it is worth doing when you get older, don't let your brain go down when you are getting older, just go out walking' (person with dementia)

'He does spend a lot of his time doing jigsaw puzzles and he loves Sudoku, he does that' (carer)

'He can still do numbers and maths and all that sort of thing' (carer)

'He uses his memory for going places, you can still ask can't you and he never gets lost' (carer)

However activities and other practical coping strategies had to be adapted depending upon the capability of the person and the extent of the dementia.

Coping psychologically

An attitude of acceptance seemed to be agreed as important – accepting what the diagnosis meant, would mean in the future, and also what was being lost from the past.

'I'd got to the stage where I've accepted my lot – I'd got to make the best of my capabilities' (person with dementia)

'We don't have much help as such it was just really we accepted it' (person with dementia)

'I was depressed for a while and finally accepted that OK that is the way things are. I think I am [now] alright most of the time' (person with dementia)

'You learn to accept it and get on with it...it's there, it's not going to be changed, there is nothing you can do about it, there is no point in fighting it' (person with dementia)

Acceptance was also indicated in this exchange between a person with dementia and their carer.

Person with dementia '[Getting the diagnosis] was a bit of a shock'

Carer 'But he is the opposite now, he has accepted it now'

However acceptance meant different things to different people. This ranged from quite a passive, philosophical approach, to doing their best to retain control over their life, right through to being an active campaigner on the issue, where dementia had become a central part of a person's identity and life. The following exchanges between participants give a flavour of this. The first one is between two participants, both with a dementia diagnosis, where Person A is an active member of his local Alzheimer's Society branch.

Person A 'Alzheimer's is my life and with lots of people...'

Person B 'Well I am not going to let it rule mine'

Person A 'No it doesn't rule it, it is my life'

The second exchange is between a person with dementia and their carer.

Carer 'Why don't you say what you said to me the other day?'

Person with dementia 'What's that?'

Carer 'That you don't think about tomorrow'

Person with dementia 'No, I don't'

Carer 'You don't think about tomorrow or the next day or even next week and we never plan anything, just cope with what's happening in the house today. Just think about today...He didn't say it in those words but that is exactly what he meant'

Several participants also emphasised the importance of 'getting on with it'.

'The thing is I know what I've got and so there is no point in starting boo-hooing about it' (person with dementia)

'I don't think every day, 'oh gosh, I have got Alzheimer's or something like that, I just carry on' (person with dementia)

In turn, 'getting on with it' required determination, a focus on the positive, and retaining control wherever possible.

'But determination is still there you see. Use it or lose it' (person with dementia)

'Be persistent' (person with dementia)

'I've got to do the things that I always wanted to do NOW. Not wait until six months' time. This has focused our lives quite significantly into doing those things now' (person with dementia)

'I think a positive outlook. Not letting it get you down. It's there, you can't change it, but to hell with it' (person with dementia)

'Live your life as you want to' (person with dementia)

'Keep control of what you are doing' (person with dementia)

'I prefer to manage than to be managed' (person with dementia)

'Not to focus on the things that he can't do and to try and focus on the things he can do and to find new things for him to do' (carer)

Using humour to cope

Being able to see the funny side of life was an important characteristic for people with dementia and carers.

'As regards coping with it, I laughed my way through it. I can use something like selective remembering and I can use that as an excuse with all my friends. I can select what I want to remember and I can select what I don't want to remember and use that...I get away with it, ha! ha! and it's not going to beat me' (person with dementia)

'I always say that one should retain a sense of humour' (person with dementia)

'This is part of the game. Laughter' (person with dementia)

'Some of the things he does I just, it sounds stupid, it makes me laugh and it makes me cross, but I know I keep repeating but we are fine' (carer)

'You wouldn't get through the day if you didn't laugh. We laugh at the daftest things' (carer)

Some participants thought that being older and/or retired made it easier.

'I found a new life, coming out of the old, it isn't a better type of person but there's another type of person and it was nice to come away from the hurry scurry of life...So I think that helped me as well' (person with dementia)

'I have been retired for 25 years...I think there was more readiness in me bodily' (person with dementia)

Other factors mentioned were being an organised person (but being over-organised or a 'control freak', as one person with dementia put it, was thought to make things more difficult).

Challenges and difficulties

Challenges included forgetting who people were, no longer having the attention span or ability to concentrate on activities they used to do (particularly if, because of their personality or job they were used to paying attention to detail, or they led an active life), not being allowed to drive, not going on holiday, frustration and short-temperedness, depression, no longer being able to deal with domestic finances and other domestic tasks, unpredictability, loss of friends, stigma and not wishing to disclose their diagnosis.

'When we see people they say hello to me and I say who's that, he says do you recognise them, I say yes I recognise their face but I don't know what their name is. I always say hello but don't tell them that I don't know who they are' (person with dementia)

'I have also lost handling things like knives and forks' (person with dementia)

'He used to do crosswords and then I noticed that he wasn't finishing them' (carer)

'He used to be an engineer and he was very precise in everything he did and now when he gets problems doing things he gets very frustrated. Very frustrated. He gets angry and he'll shout at me, "I never used to be like this"' (carer)

'He was a very predictable person and now he's not and that is very hard to accommodate. You don't know how they are going to react, which we always did before' (carer)

'Would it be happening even if you haven't got the dementia, the getting angry, I think it is because he won't accept it' (carer)

The issue was raised of the effect that dementia had on people's personalities, and the unpredictable changes which in turn, might affect a person's pre-diagnostic ability to accept and adjust. For example, a person might become more emotionally volatile. This

included the issue of depression and the impact this had, although some participants felt that they were prone to depression for unrelated reasons and this did not affect their ability to deal with the dementia.

‘I don’t particularly get depressed about having the condition of dementia, I get depressed full stop’ (person with dementia)

External factors which made it harder to adjust included ensuring people living alone were supported and got the right information, and also the enormous amount of confusing or technical information about dementia available via the internet.

‘It is dependent on whether the people have got families to be with them...to get the information. If you have got...single people with dementia with no aid at all how will they know where they need to go?’ (person with dementia)

‘You go on the internet and you sit there and you will be addled with all these words and you don’t know nothing about it...it’s all big words and you don’t understand’ (person with dementia)

Particularly for the men in the sample, adjusting to not being allowed to drive because of the dementia and the difficulties this created (especially where their wife/spouse did not drive) was a feature in several discussions.

‘The worse thing is, the first thing they said was I must not drive’ (person with dementia)

‘I miss not being allowed to drive. It is terrible’ (person with dementia)

One participant had decided to pre-empt this process by making the decision themselves.

‘I think on balance, I think it would be better if I did not drive and actually mentally, it is much better that I make that decision than somebody makes that decision for me. Psychologically it is very good that I am actually in a position where they said OK you can drive and just left it at that and I turned around and said well, thanks very much but I am not actually going to drive’ (person with dementia)

Furthermore not all participants with dementia had been required to stop driving, and for one participant keeping her car symbolised a degree of independence even though she did not drive often.

‘That is a little symbol of my independence that I am hanging to while I still can...it’s a symbol of normality’ (person with dementia)

Negative reactions from friends and families

Telling friends and family about a dementia diagnosis was an important part of the adjustment process for many participants – but for several people it did result in the loss of friends and being stigmatised or avoided, or even not believed, all of which were unhelpful and upsetting. There were very different approaches taken to disclosure and dealing with the consequences. These seemed to hinge very much around different personalities and social relationships.

‘The worst part was telling the kids. One daughter...just doesn’t want to know, the other one is in denial, and my son knows more than I do’
(person with dementia)

‘My son is looking but he doesn’t know me, my daughter...never mentions it’ (person with dementia)

‘I told all my friends and family from the onset and I said to my friends and family if you see any change in me, don’t ignore it tell me’ (person with dementia)

‘People can be more helpful’ (person with dementia)

‘We decided right at the beginning that everybody should know’ (carer)

‘Wrongly I tried to hold this to myself and keep it between [the person with dementia] and me and try to deal with it. Typical man you see, you’ve got a problem, I’ll resolve it...Once I shared it they all understand what the problem is now and I get a lot of support from my family’
(carer)

‘A lot of people were very surprised at [him] admitting he had it. I didn’t think he would and I admire him for admitting it. Not so long ago on the bus he did something, he said to someone yes, sorry I’ve got dementia, I thought he is very brave. I personally think if you can admit it and talk about it, that’s half the problem. You can get the help you need. It is nothing to be ashamed of’ (carer)

Provision for the future

Interestingly, making practical plans for the future did not feature strongly in people's responses, though one person commented.

'I need to make those decisions while I have enough mental capacity to be able to do that and to understand the implications of it before I get too far down the line. So it has given me the time to think about that. That is important' (person with dementia)

Carers also felt that admitting to having the diagnosis and letting others know was important to the person, but also to them as carers – it was seen as half the problem solved.

'I think it depends upon the personality of the person you care for and as with you...the carer. I do. It can easily drag you down, it can' (carer)

'Different people have different levels of being able to cope' (carer)

Carer's reactions

Carers described considerable loss and difficulty adjusting. Issues raised included the loss of spouse's identity, often not being recognised by them, loss of friendship and relationships, loss of independence and self-esteem, or for some the 'double whammy' of failing physical health as they too grew older and additional mental health difficulties (such as depression) they attributed to the dementia diagnosis of their spouse.

'They may turn into somebody completely different that you can't predict' (carer)

'I find it hard to cope with all the paperwork. I dread the post coming' (carer)

'I think the powers that be don't realise that when someone has dementia the partner who is caring for them also has their own mental problems' (carer)

A few participants responded to the question about what enabled some people to cope and adjust more easily than others.

'Some people are better at coping with just anything' (person with dementia)

‘Not everybody can cope with the term “dementia”’ (person with dementia)

And one person interviewed thought there were two ways in which people related to getting a diagnosis – those who are ‘just going to get on with it’, and those who ‘will just deny anything is going on at all’.

General questions

The questions used in the final part of the focus groups and interviews were more general, asking participants their views on the key ingredients for a good diagnostic process and experience, and the issue of stigma.

8. Thinking about your own experience, what makes for a ‘good’ process of getting a dementia diagnosis?

A number of key components were identified and met with broad agreement.

Being taken seriously and being listened to

‘When somebody approaches the doctor they should take notice of what the patient is saying. They shouldn’t dismiss them... There has to be a reason for it’ (person with dementia)

‘Doctors, nurses, all of them must have sufficient time given to the patients to talk to them’ (person with dementia)

‘To be taken seriously’ (person with dementia)

Early, swift diagnosis

The person involved must have enough time to talk and be listened to.

‘[If left] it is too late because you have lost your mental capacity to be able to make those decisions about how you want your life to be’ (person with dementia)

‘A quick diagnosis’ (person with dementia)

‘Referred swiftly to somebody who can specialise in it for the diagnosis to be made within a reasonable amount of time’ (person with dementia)

‘Somebody who can give it to you and answer your questions and has got time to do that’ (person with dementia)

‘I think they need [to be] diagnosing much earlier and take notice of it because I think there are lots of channels that could be avoided if the first time they saw you, they got down to business and meant it. Not just fob you off’ (person with dementia)

‘If your GP can’t do it the quicker you can see somebody who does know something. We went too many times’ (carer)

‘You should get an appointment within so many weeks, you should get a follow up and you should be told gently and kindly’ (carer)

Clear communication

Health professionals should ensure they clearly explain what is happening to the person with dementia and their carer. Also, better communication and co-ordination between services, for example between GP and consultant or between health and social care services.

‘A rolling programme of communications with the patient after the consultants added their say and after the GPs had their say’ (person with dementia)

‘You could do with a professional in a room like this just saying this is what it entails, this is what this means, this is what that means’ (person with dementia)

‘Everybody needs a social worker or a community psychiatric nurse or something. Some point of contact at least every couple of months really so that also, if they have a problem there is a person there that they can call in between times’ (person with dementia)

‘There is a terrific void still between the provision of health and the provision of social care...The two aren’t joined up’ (person with dementia)

Knowledge demonstrated by GPs

GPs should know what to do or how to refer for a more specialist assessment.

‘A doctor who is more knowledgeable, more understanding of it’ (carer)

‘If GPs are saying they haven’t got the confidence to diagnose dementia then the health service ought to do something about it because he or she is your first point of call they should recognise signs and symptoms of dementia. Whether they refer you on or not is up to them, they can refer you to a specialist or a consultant where you can have a brain scan or your can have an IQ test or you can have both, or you can have whatever it needs, but I think the first point of call is your GP and if they are not trained then they should be’ (carer)

Being offered a holistic picture

Assessments should not rely entirely on tests but also enable a more holistic picture of the person, and people should have the option to be seen at home. This could also be helpful in terms of learning to adjust and cope.

‘They need to listen to people more than actually relying on tests’
(person with dementia)

‘People should come and assess you at home but they shouldn’t ask you take this from 100 [ie do a subtraction test], they should ask you about the everyday things that you do, ‘where would you put this when you have finished with it?’ (carer)

‘It would be useful if they could do everyday things, how to get from A to B you know, outside your house’ (carer)

Assessments should also take into account the views and needs of the carer.

‘Knowing that you...are under a consultant that will listen to you, have time for you’ (carer)

‘The therapy and care of your carer is just as important as the therapy and care of yourself because the psychological load that is placed on the carer is absolutely enormous’ (carer)

Information and focus on what the person can still do

‘The system needs to remember that there is life after diagnosis and it’s as simple as that’ (person with dementia)

Information, support and follow-up should be offered. Several participants described being left with little or no advice or information immediately after their diagnosis.

‘To have somebody there that you can actually access because I think I needed more support going through the diagnosis and possibly for a short time afterwards’ (person with dementia)

‘I think there is an inevitability that the diagnosis can’t be made by a GP, the diagnosis must be made by the second sector but then as you rightly say, it should be given back to the GP, the GP should be the person who in collaboration with the second sector, continues the well-being and therapy’ (person with dementia)

‘I think the doctors need to give you more information as to what it’s all about’ (person with dementia)

‘As you have been diagnosed there should be a follow up with information on what you have got, how do you cope with it, what to look for, what’s gonna happen, what’s not gonna happen’ (person with dementia)

‘Just explain it a bit more, like when he said, “I will refer you to the memory clinic” you know, another two or three sentences, I just want to put you in the picture as to what will go on there, what it’s for, what the set up is’ (person with dementia)

‘Most important of all to be given all the information they need about not what’s just happened but what is likely to happen and where can you go for assistance’ (carer)

‘To be given all the information they need about...what is likely to happen and where you can go for assistance’ (carer)

Some negatives were identified including stigma, lack of information and support following a diagnosis and concern for one’s family.

9. Do you think the way that dementia is talked about in the media has helped you?

While the issue of stigma emerged from the discussion on this particular topic, it had also come up elsewhere in the interviews and focus groups. This section also reports those views.

Impact of personal stories in the media

There was general agreement that dementia was getting more coverage in the media and this was broadly felt to be a good thing, both in terms of raising its profile and providing more information about dementia

The publicity around high profile people with dementia such as Terry Pratchett, Tony Robinson's mother, Norman Wisdom and Iris Murdoch was thought to be a reason for this, as were powerful documentaries about individuals such as Malcolm and Barbara Pointon.

'A few more Terry Pratchetts could be useful' (carer)

'The more, as you say, it's talked about, about well known people having it, the better it's accepted as part of life' (carer)

However it was also important 'to see the ordinary face, my ordinary face, your ordinary faces out there as well saying the same sort of thing' (person with dementia).

'More coverage of ordinary people saying what it is like a) for them to have dementia and b) for their carer/partner to say what it is like to be caring for them having dementia' (person with dementia)

'I think it needs more people to do it [be interviewed by the media] because they have to get rid of the fact that it's just "senile dementia"' (person with dementia)

Negative portrayals of people in the media

However there was a lot of concern expressed about the type of coverage dementia received. There was concern that it often focused too much on negative portrayals of people with dementia, especially those in late stages – 'dribbling and nodding' as one person with dementia put it, going on to say that media coverage is 'sad'.

'It's as though that's it, you are dribbling and nodding, and that's Alzheimer's. That's the picture of Alzheimer's. But we are sitting all here talking perfectly normally. We have got Alzheimer's of some form, we are not nodding and dribbling' (person with dementia)

'They always show them [people with dementia] in the worst state' (carer)

People wanted the negative views about dementia turned into something more positive, such as everyday portrayals of what 'life after diagnosis' was like – and showing that it was often just about 'getting on with it'.

‘Any publicity can be turned to make it positive instead of negative, the last thing we want to do is lose publicity’ (person with dementia)

‘We are not sort of dramatically waiting for the end if you like, we have got life to live and it is just slightly different to other people’s lives’ (carer)

However portrayals in soaps, such as *The Archers* were felt to be useful, particularly because of the extended storyline involved, and examples were given of more positive local reporting.

Several people made comparisons with how cancer used to be reported some years ago as well as the different reactions that the different conditions evoke in people.

‘It was horrific talking about cancer...so dementia is going through that now’ (person with dementia)

‘If you had a serious illness like a heart complaint or whatever you would be channelled off into the right channel...This doesn’t happen with dementia’ (person with dementia)

‘Far more than cancer, far more, and the stigma that is around it is so judged on and people still do not talk about dementia, they still try to avoid it’ (person with dementia)

‘You are just as likely of getting dementia as you are getting a haematoma or lung cancer or whatever else. If there was that sort of attitude by society, then this would make the whole process of actually getting the diagnosis a lot easier. So you know it is all part of the stigma isn’t it?’ (person with dementia)

‘You don’t get the same empathy that you would get if you were terminally ill’ (carer)

Offering false hope

Media coverage often focused on new ‘cures’ for dementia, raising people’s expectations and hopes. But then nothing more was heard about them, or people’s experience of them were not so positive.

‘When they are putting these things in the paper they have got to think of the damage they are doing to people who are desperate for a wonder cure. I mean, let’s face it, we are all desperate, like it or not’ (carer)

Creating stigma

There was also the view that there was still too little coverage of dementia in the media and this had contributed to ignorance, fear and misunderstanding which in turn led to stigma.

‘Sometimes they think of you as you as gaga and [speaking slowly] “can you do this, can you do that?”’ (person with dementia)

‘Everybody I have met has been absolutely amazed that a) I can still talk and still think, and b) that I have a diagnosis of dementia. They do not understand it. I think that is indicative of what the public is like’ (person with dementia)

‘For a start, most people don’t even know what it [dementia] is and to say to them you’ve got it, that’s the end’ (person with dementia)

One participant gave the rare example of a person with dementia he knew who was 35 years old.

‘I still think people get the impression that Alzheimer’s is: 65, retiring, and then you get it’ (person with dementia)

Additional stigma and discrimination was described in terms of neighbours and friends stopping talking to the person with dementia.

‘As for neighbours there are some that are OK and others that they see you coming up the road and they will hide from you because they don’t want to talk to you’ (carer)

Some carers described the perceived additional stigma of dementia coming under mental health services, and for that reason not wanting to be associated with other forms of mental illness that were perceived to be more stigmatised, such as schizophrenia.

‘When the [appointment] letter arrived and it said on it “mental health” you didn’t want to know because I think that perhaps people of our generation, there is stigma to mental health. Mental health means insanity’ (carer)

Several participants felt it important to challenge stigma by refusing to ‘hide’ relatives with dementia from the public.

'I have known people who have had dementia in the family and they have been rather ashamed to take them out into a restaurant...because they weren't eating very well and they weren't behaving very well but I still think it is better to let people see what the illness is like and the more people that know about it the more perhaps we can deal with it better'
(carer)

4. Conclusions and recommendations

A number of key themes emerge from this research which reflect several issues identified in the literature review and elsewhere in the dementia field.

Participants

As already discussed in the section on methodological limitations, the people who participated in this research were self selecting and almost by definition, those who had dementia still had the cognitive abilities to contribute to the research, albeit at differing levels. This was very important for two reasons. Firstly the research was quite explicitly intended to focus on the experience of people with dementia (rather than carers or professionals) and the reported findings illustrate this with the amount of information that people with dementia provided. Secondly it meant that participants with dementia were mainly people who had experienced an early, or relatively early diagnosis (for those that had been diagnosed) and were therefore in a good position to talk about the issues that early diagnosis involved.

Because people with dementia were the primary focus of the research, it did not concentrate on carers' issues. Nevertheless, the researchers recognised and acknowledged that without the support of carers many people with dementia may well not have participated in the research, and carers' knowledge and experience was often very important in providing a different or more comprehensive picture in response to the questions asked. Indeed some of the carers who participated appeared to bear more of the emotional brunt of coming to terms with, adjusting to and coping with the person's dementia than the person themselves. This often, but not always seemed to be the case where a female carer, usually wife/partner, was supporting a man with dementia perhaps reflecting traditional perceptions about the nurturing/caring roles of women. For these reasons the views of carers have been included throughout the findings. The contributions of carers in the focus groups and interviews were such that they could merit a research report in their own right, however it did not seem appropriate to focus too much on their responses where participants with dementia were able to give their views independently.

Importance of early diagnosis

Most of the participants with dementia who took part were able to respond to the questions posed by the researchers and contribute their views and experiences. Despite significant differences in how long they reported they had either been diagnosed or had the symptoms of dementia, most had either been aware of the symptoms from an early stage and/or had been diagnosed relatively early. This included several participants who had early onset dementia. The testimony of the carers present seems to support this, although in some cases the testimony differed in detail from that of the person with the dementia, as one might expect in a research project of this nature.

Many of the results from this research tallied with key findings from other research, including *Tell me the truth* (Pratt, R and Wilkinson, H, 2001). Despite many people understandably experiencing some negative emotions when they found out they had dementia, as well as experiencing stigma and a subsequent lack of support, none of the participants said with hindsight they wish they had not been told. 'Getting on with it' would appear to be as good an adage for the process of getting diagnosed as for coping with life following a diagnosis.

The real frustrations around diagnosis seem to have stemmed from the negative experiences of many of the participants when they sought help from their GP and/or were referred to specialist services. Complex, protracted and confusing assessment processes, unhelpful or dismissive responses, misdiagnosis, being told that they were too young to have dementia, poor communication and lack of information (for both the person and their carer) were frequently reported, all of which were unhelpful to the person's psycho-social well-being (as well as that of the carer). If this had been a consistent experience among all the participants then there would at least be a clear baseline from which to start considering what the causes might be and how to improve services. However, the disparity in experiences reported, with some participants reporting quite positive contact with GPs and specialist services (including, often swift diagnosis/referral processes), would seem to reinforce the concept of a 'postcode lottery' when it comes to the assessment and diagnosis of dementia. Given the seriousness of the condition and the impact it has on the lives of individuals and their families, this does not seem acceptable.

It is well-established that there is an enormous under-diagnosis of dementia in this country (National Audit Office, 2007). Some of the accounts related by participants in this research suggest reasons for this, such as some doctors appearing to lack expertise and being unable to respond appropriately (e.g. referring someone for a specialist assessment) when approached by someone with concerns about possible dementia. It certainly seems odd that people had to emphasise qualities such as persistence and being pro-active in order to acquire a highly stigmatising diagnosis for such a major

condition. The research also suggests that given that most participants had approached their doctor at a fairly early stage of dementia, the fact that they were still relatively symptom-free was seen as evidence that nothing significant could be wrong. It therefore seems reasonable to suggest that a default position for GPs, when someone comes to see them with symptoms indicating dementia, should be to automatically ensure that an assessment for dementia takes place – or be able to show extremely good reasons for not following this course of action. On the basis of this research, whether this is done by the GP or by a specialist would not seem to be an issue from the research – the important thing is being taken seriously and getting an appropriate, swift response. Dismissing a person's concerns (particularly on the basis of age alone) where there is good evidence to indicate at least the possibility of dementia is not a satisfactory response.

As the research shows, with the appropriate support and information people are able to find ways of coping and adjusting to a dementia diagnosis. The research seems to support the view that where people get a positive response to their concerns from doctors, an appropriate assessment process is followed and they can access other supportive services, such as Alzheimer's Society, people are likely to feel reassured and possibly even relieved. This in turn, seems important in maintaining a person's psycho-social well-being at a potentially traumatic point in their life. While the research indicates that this process may need to take into account if possible, issues such as the person's age, gender, and social relationships, as well as that of their carer(s), it could be concluded that there must be far greater consistency and standardisation in both accessibility and response of GPs and specialist services involved.

Diagnostic process

In addition to the specific emphasis placed upon early diagnosis, the research revealed some important findings about the diagnostic process in general and what people saw as the key elements of a 'good' diagnostic process. These included:

- doctors and other professionals taking the person seriously and listening to them
- the person having enough time to talk and be listened to
- clear communication – doctors and health professionals making sure they clearly explain to the person with dementia and their carer what is happening. Also, better communication and co-ordination between services, for example GP and specialist services, health and social care services
- GPs knowing what to do/how to refer for a more specialist assessment
- not relying entirely on tests but getting a more holistic picture, including the option to be seen at home – also providing an opportunity to provide advice on adjusting and coping

- always taking into account the views of the carer (unless the person with dementia has mental capacity and refuses consent) – but only as a ‘second opinion’ in addition to the views of the person with dementia
- taking into account the needs of carers
- ensuring there is a focus and information on what the person can still do
- providing information, support and follow-up after diagnosis.

How these features can be communicated to doctors in order to reinforce good practice or be better incorporated into practice needs careful consideration, taking into account the specific pressures and demands on doctors. However they may also form the basis of useful guidance for people who are concerned that they might have dementia or who are being referred for specialist assessment, on what they can expect, what they should look for and what they should ask for as part of a ‘good’ diagnostic process.

Coping with dementia

With no cure in sight for any of the dementia conditions there can be little disagreement that for the foreseeable future a dementia diagnosis appears to represent a fairly bleak prospect for many people. Yet this research, as with Tell me the truth (Pratt, R and Wilkinson, H, 2001), has shown that both people with dementia and their carers have been able to find practical ways of coping and adjusting, as well as psychological strategies to deal with the diagnosis.

Practical coping mechanisms and strategies

As might be expected, the support of family and friends was clearly identified as being very important in enabling people to adjust and cope to having a dementia diagnosis. Support from Alzheimer’s Society was also mentioned a number of times. However, fewer references were made to the support received from health and social care services. Although the research did not specifically ask about people’s experiences of these services they might be expected to feature more if they were playing important roles in people’s lives. However, given that many people reported a lack of follow up or assistance following a diagnosis, this may also be reflected in the lack of input received from health and social care services. Ongoing support from family and friends, with additional support from organisations like Alzheimer’s Society is clearly crucial, although there is no reason why the health service given sufficient resources, shouldn’t be able to play a more significant role. Dementia is a long term condition and therefore providing information, advice and support to people with dementia and their families would seem to be a perfectly valid role for health (and social care) services to perform.

None of the coping mechanisms and strategies described by participants, such as jigsaw puzzles, listening to music or walking, are complex or expensive. However it is difficult from research of this nature to know how effective they really are, especially as dementia becomes more advanced. Most of them appear to be ‘home grown’ or passed on by word or mouth. Interestingly, despite the battery of tests and assessments that the medical establishment have in place to determine whether someone has dementia or not, there was very little evidence in the research to show that people got advice and guidance about these coping mechanisms and strategies from professionals. While it is true that the research did not specifically ask about help or support provided by health and social care services, the fact that there was relatively little mention of them still seems somewhat surprising. Despite the dominance of medical input as part of the assessment and diagnostic process, there seemed to be little that health professionals were able to offer once a diagnosis had been made. The main exception was the prescription of medication such as Reminyl, Exelon or Aricept which several participants described as being extremely helpful. However views on prescribing these drugs varied significantly, doubtless reflecting the debate surrounding the National Institute for Health and Clinical Excellence guidelines. However, given that debate, the likely impact of receiving a dementia diagnosis, and the seriousness of the condition, it would seem all the more important that professionals are aware of these coping mechanisms and strategies and ensure that they are communicated to people with the diagnosis and their carers.

The research does not indicate a desire on the part of people with dementia or their carers to see a diversion of resources away from research into cures or more effective treatments for dementia but there was a strong demand for better information and support. Perhaps, if professionals are not already doing so, they might be well advised to familiarise themselves with the types of coping mechanisms and strategies described in this research and pass these on to the people with dementia and carers that they come onto contact with. After all, it is difficult to envisage any significant harm being experienced by someone with dementia as a result of encouraging them to do crosswords or jigsaw puzzles.

Psychological coping mechanisms and strategies

When participants discussed how they came to terms with a diagnosis of dementia, the strong theme that came through was ‘acceptance’. Again, this seems understandable in the absence of a cure or effective treatment. Acceptance also seemed to be important for carers. The fact that it was a self selecting sample was also probably significant – it is unlikely that people with dementia who were not prepared to accept a diagnosis, let alone the condition, would participate in research such as this. Yet acceptance was not at the expense of other qualities such as determination, retaining as much control as possible, a sense of humour and ‘getting on with it’.

However there was a strong sense from many of the participants that it was usually the process of acceptance that made the adoption of other psychological coping mechanisms possible. It also seemed to play an important role regarding some of the practical implications of dementia, for example stopping driving or telling family and friends. Taken together, these seem to be very important factors influencing people's psycho-social well-being immediately following a diagnosis and in the period thereafter. The literature review suggests that a process of acceptance and adjustment might occur more smoothly for those individuals who have had previous experience, prior to developing dementia, of coping with challenges and difficulties in their lives. The research did not explore this in detail although some individuals did indicate that having a generic ability to cope or adjust to things in life was helpful, and that this could apply as much to carers as it did to people with dementia.

The process of acceptance and the adoption of other coping mechanisms, manifested themselves a variety of ways. There was the suggestion, for example, that age (particularly in relation to whether someone was retired or not) and gender were factors to take into consideration with older, retired participants, particularly men, having perhaps a more accepting, stoical response to a diagnosis. However the fact that many more men with dementia than women participated in the research makes this fairly speculative. There were certainly female participants, and younger people with dementia who were also fairly philosophical, even where the latter had experienced real difficulties getting diagnosed because of perception about their age in relation to dementia. The process of disclosing a diagnosis and the reaction of those immediately around the person with dementia also seemed to be important. Complex and often problematic dynamics occurred where family members had difficulties accepting the diagnosis, which usually made it even harder for the person with dementia to cope.

Acceptance, or 'getting on with it', therefore might mean quite different things in the lives of different individuals, as was also shown by the adjustments people made in their lives, ranging from being quite passive and 'quietly' getting on with things to being very active and getting involved in campaigns and media work. This may also relate to the different coping styles identified in the literature review ('self adjusting' or 'self-maintaining') but within the context of a process of acceptance having already taken place. However one thing that did come through was that the coping mechanisms people adopted did seem to be particularly helpful when they were held by both the person with the dementia diagnosis and their carers (if they had one).

This would appear to support the importance of professionals and other individuals and organisations recognising the different sets of variables that should be taken into account when providing care and support to a person with dementia (conceptualised

as ‘personal psycho-social algorithms’ by the authors of the literature review). These provide important indicators of how individuals (including carers) can be given psychological support and advice to help them adjust to dementia. A valid role for services should therefore be to support people (including carers), at the appropriate time and pace to accept the dementia and identify their preferred coping mechanisms and strategies. This should include addressing the issues that arise when disclosure to family and friends generates additional problems for the person with dementia because of a lack of acceptance. People were ‘living with dementia’ not ‘dying of dementia’ – supporting and enabling people to do this should be the primary focus of the services they are in contact with.

Stigma

Although participants were only asked specifically about stigma in the final question, it was noticeable that the issue permeated much of the research. Indeed, based upon the research it might be concluded that the negative and inconsistent responses that people experienced from GPs and other services were reflections of the stigma associated with dementia, which manifested itself in unhelpful, uninformed or dismissive responses. Given the lack of a cure or effective treatments were these responses and indication of an attitude of ‘nothing can be done so there’s no point in doing anything’? For a condition that is so enormously under-diagnosed this research certainly indicates worrying attitudes, values and beliefs about dementia among professionals.

The research also shows the ‘double whammy’ effect of misunderstandings around dementia and age. The findings show that people were either not being diagnosed because the symptoms were dismissed as signs of the person’s old age, or they were not being diagnosed because they were relatively young and dementia was incorrectly thought only to be a condition of old age. It is hoped that general ageism against older people is not also at play here, however the rather brusque and insensitive scenarios that some people described hardly suggest the respectful and sensitive attitudes that a diagnosis of this nature should elicit. However, given the stigma and prejudice that participants had experienced within their social networks of friends and neighbours, perhaps it should not be surprising to find it among some professionals as well. These attitudes may reflect the views of several participants in their belief that dementia is currently viewed by many people in the same way that cancer was ten to 15 years ago.

Participants also observed a number of unhelpful ways in which dementia had been portrayed by the media, although there was also the recognition of the important role the media could play in raising the profile of dementia and informing the wider public. The view of participants was that this was still at a fairly embryonic stage where, with a

few honourable exceptions, dementia was mainly understood and portrayed only in its most severe form, or through announcements of ‘wonder cures’ that then sank without trace. This research shows that there is an array of coping mechanisms, styles and strategies, devised by ordinary people and their families, which occur mainly because of early diagnosis of dementia. Some participants suggested that there should be more portrayal of ‘ordinary people’ with dementia and their lives in the media. Certainly the increasing numbers of people with early diagnosis would provide the potential to do this, perhaps providing an opportunity to give a more holistic picture of the impact of dementia and reflect some of the coping mechanisms and strategies that people use.

Recommendations

1. Improve public understanding of dementia

It is clear from this research that people with dementia and their carers often notice symptoms gradually and this may delay them seeking help. This leaves them in a poor position to take control of their lives and plan for the future.

Improving public awareness of the symptoms of dementia needs to be addressed as an urgent priority. Given the scale of dementia this will require a significant programme of public awareness activity to explain what dementia is, the importance of an early diagnosis and the fact that there is help available.

A range of partners including the government, charities, services and employers need to work together to improve awareness of dementia and to deliver a reduction in the levels of stigma attached to the condition.

2. Improve GPs’ understanding of dementia

The accounts of people with dementia in this report show very clearly that GPs’ knowledge of dementia and their ability to respond effectively and sensitively vary enormously. This means that diagnosis can be slow, ineffective and more emotionally difficult than it needs to be.

Given that GPs are likely to remain an important part of the pathway to diagnosis, improving GPs’ understanding of dementia needs to be regarded as a priority.

Pre- and post-registration training for GPs needs to focus on recognising the symptoms of dementia, the importance of an early diagnosis, the fact that people want and need a diagnosis and how to talk sensitively about dementia in an unhurried, empathetic manner.

Consideration should be given to how the quality and outcomes framework for GPs, which currently requires GPs to keep a register of people with dementia, could be developed further to incentivise screening and specialist assessment.

3. Develop better specialist diagnostic assessment services for dementia

One of the barriers to effective diagnosis is the lack of specialist diagnostic services. Improving the availability of memory services which can provide people with a definitive diagnosis of dementia and tell them what type of dementia they have needs to be addressed.

To ensure that access to such services is improved and does not always rely on GPs acting as gatekeepers, access to memory services should be open and members of the public should be able to refer themselves. Effective triage needs to be in place to screen people and avoid the need for everyone to have expensive specialist assessment.

Given the stigma attached to psychiatry and mental health services it is important that memory services are community based as far as possible and that the language used to describe them is sensitive.

4. Provide information which is timely and accessible

The importance of access to good information about dementia and about local support was one of the themes that people with dementia and carers were very clear about in the research. Currently there is varied access to information and after diagnosis it can feel as though there is a black hole in provision of information and support.

The government, services and the voluntary sector need to work together to understand what information is required before and after diagnosis and the most effective ways to improve access to that information.

In order to facilitate better access to information and services a network of dementia advisers for people with dementia needs to be developed to act as local named contacts.

5. Develop stronger peer support networks to help people cope

It is clear from this study that people with dementia and their carers want help to live their lives to the full, only making use of statutory services when they need them. One of the greatest sources of support identified by people with dementia in this research was access to other people with dementia and their families following diagnosis. The reported benefits included emotional peer support, information, advice and practical tips about how to cope day to day.

Local commissioners and the voluntary sector need to work together to support the development of a range of peer support networks. In addition, at a national level, there is a case to develop further online support networks for people with dementia and their families.

5. Selected references and further reading

Selected references

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Further reading

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Appendix 1

Executive summary of literature review

Literature review written by:

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The full review and references can be found at alzheimers.org.uk/outoftheshadows

Introduction

This literature review forms the first stage of a two stage research project investigating psycho-social well-being for people with a dementia diagnosis. It has a particular focus on understanding the potential benefits of an early diagnosis and brings to the fore the experiences of people with dementia and their families.

The review methodology includes a search of academic electronic databases, specialist sources of evidence and hand searching of grey literature (unpublished research).

Context of the review

Dementia is a major cause of disability amongst older people; its negative impact on those with the disease and their families is profound. Approximately 700,000 people have dementia in the UK, a figure projected to rise to over 1.7 million by 2050.

Dementia is an umbrella term used to describe a family of brain disorders that have in common a loss of cognitive function that is progressive and eventually severe. The most common types of dementia are Alzheimer's disease, vascular dementia and dementia with Lewy bodies. The risk of Alzheimer's disease is highly correlated with very old age.

For the purposes of the review 'early' is taken to be early in the development of dementia or when symptoms are relatively mild. 'Late' is at a stage in the dementia trajectory when the person is experiencing a significant level of cognitive impairment.

Detection of dementia, particularly in its early stages, depends on pattern recognition, deductive reasoning and accumulation of diagnostic evidence from multiple sources. The different dimensions of the illness intersect with other facets of the person's life and self in a way that is distinctly individual.

Early intervention and diagnosis

Only a third of all people with dementia receive a formal diagnosis at any time in their illness. There is increasing consensus that diagnosis of dementia should be made as early as possible (see National Institute for Health and Clinical Excellence and Social Care Institute for Clinical Excellence Dementia clinical guideline 42, 2006). Although pharmacological treatments are limited, the literature strongly evidences the value of early diagnosis and intervention in improving the independence and quality of life for a person with dementia, as well as their carers, and delaying care home admission.

Early diagnosis also allows people with dementia the chance to make a number of key decisions and come to terms with the illness at a stage when they can still understand its implications. It is also what the majority of people want.

Existing guidance expects GPs to screen for dementia and specialist services to diagnose and treat (see National Institute for Health and Clinical Excellence and Social Care Institute for Clinical Excellence Dementia clinical guideline 42, 2006). Services currently focus primarily on the severe end of the continuum. To implement an early intervention agenda, more needs to be done to engage primary care, establish a network of memory services, invest in community mental health teams for older people, and enhance social services support.

Quality of life, psycho-social well-being and dementia

Definitions of 'quality of life' amongst older people with dementia and older people without are surprisingly consistent. Pivotal elements are 'good social relationships' and reasonable health. People with an early diagnosis of dementia appear to be as 'satisfied with life' as the mainstream population.

Psycho-social well-being is a combination of internal factors, such as beliefs and values, feelings and emotions, and external factors – how a person experiences the environment they are in. These factors are also influenced by a person's personality and the quality of their social relationships. Wider social influences such as the effect of stigma are also relevant. Psycho-social well-being therefore forms a very important part of a person's quality of life.

While some evidence exists for the therapeutic and practical value of early diagnosis, less work has been done on its psycho-social benefits for people with dementia and their carers. The majority of evidence is qualitative and is located in psychologically orientated research and dementia-specific journals.

Dementia varies in its impact on individuals. Both the rate of cognitive deterioration and the person's capacity to adjust to diagnosis affect well-being; this suggests that well-being is amenable to enhancement.

Psychological concepts

Recent work examining coping styles amongst people who have recently had a dementia diagnosis found that they display one of two 'coping styles' – a self-adjusting coping style that tends to be associated with awareness of cognitive change, help seeking, and heightened emotion; and a self-maintaining coping style which is linked to lower levels of emotion, minimal reaction to diagnosis, and maintaining 'life as usual'.

The 'process of coping' is also important. People who receive a diagnosis appear to go through three stages of adjustment: registering cognitive change, finding an explanation, and either acknowledging that there is something wrong or denial.

Low levels of awareness amongst people in receipt of a diagnosis may not be a clinical feature of the dementia itself but an expression of a self-maintaining coping style. If a person is deemed to be unaware due to their dementia, they are more likely to be excluded from discussions about their treatment and future decisions. Even disclosure itself may be subverted.

The fact that a self-adjusting coping style can be built on, or developed anew, places additional emphasis on the need to diagnose dementia early. Not only does this opportunity offer time to adjust but also time for interventions that may facilitate coping capacity. Intact meta-memory (awareness of memory problems) is an important determinant of the efficacy of support strategies. People with early stage dementia are much more likely to retain this function than those in the later stages. The early diagnostic 'window', also affords the person's relatives time to come to terms with the illness and seek out information and support.

If dementia diagnosis is predicated upon a person's awareness of cognitive decline then for those people who adopt a self-maintaining coping style diagnosis will be later

if at all. Early treatment and practical opportunities are thereby lost including interventions that could have bolstered the person's coping ability.

'Stress inoculation' is also a useful concept. Broadly, a person who had had to deal with small stresses throughout their formative years develops a more effective way of managing stress. As a dementia diagnosis is undoubtedly stressful, it seems reasonable to assume that stress inoculation could be a factor that moderates how effectively an individual manages a diagnosis and its aftermath.

This dovetails with 'psychological resilience' – the ability to bounce back from negative experiences. Resilience tends to be positively associated with optimism and extroversion; resilient people tend to react more positively to bad news including diagnosis of an illness and can adapt better to their changed situation.

'Help seeking behaviour' is also relevant. People who pursue screening for other illnesses are more likely to seek help when they have concerns about cognitive function. Intention to screen could reasonably be interpreted as a willingness to discuss cognitive problems; this is not only linked to a self-adjusting coping style but is more likely to result in an early diagnosis.

Dementia diagnosis and disclosure

There are three perspectives on the diagnostic process and in particular disclosure: those of the person with the dementia diagnosis, the relative or carer, and the professional.

Perspectives of people with a dementia diagnosis

Although there is some variation in people's attitudes to disclosure, the majority regard diagnosis as a relief as it offers an explanation for cognitive loss. Surprisingly, only a small minority report being shocked but this does not necessarily reflect the upset and distress that the symptoms may cause prior to diagnosis, as well as people's experiences post-diagnosis. Nevertheless, actual diagnosis has the potential to bolster psycho-social well-being.

Despite concerns about potential harms, recent work suggests that most individuals and their families do not experience adverse psychological reactions to diagnosis. For those who do experience anxiety and/or depression symptoms either remain stable, or decline, shortly afterwards.

Psychological research on ‘benefit finding’ supports this. Positive emotions not only result from favourable events but unfavourable ones as well, provided the individual can find meaning or benefit from the experience. Benefit finding has been found to occur around the diagnosis of a chronic illness. Interventions which build on benefit finding have been demonstrated to improve outcomes.

The ‘common sense model of illness representations’ is also instructive. Whereas healthy people tend to perceive the diagnosis of a medical threat as wholly negative, evidence suggests that people with the actual condition often hold more realistic views. Concerns about adverse psychological reactions to a dementia diagnosis are usually raised by relatives rather than the person themselves. Negative emotional responses are in fact more likely amongst people who have not been told their diagnosis; people often feel confused and want to ‘make sense’ of what is happening. This is associated with a self-maintaining style of coping.

The primarily medical ‘process of diagnosis’ needs to accommodate the emotional and psycho-social facets of the person’s journey alongside clinical care. Much can be done, if a diagnosis is given sensitively at an early stage, to alleviate distress, encourage positive reappraisal and bolster adjustment.

Perspectives of families and carers

Most carers favour their relative being told their diagnosis. Whilst the principle of truth telling is the dominant rationale, for many relatives fidelity to the relationship – of being true to the person with dementia – is also important. This is particularly the case for spouses. In terms of carers, evidence is unequivocal; the majority want to know their relative’s diagnosis. It allows them to move forward, and acts as a ‘gateway’ to accessing treatment, services and support networks. Delays in diagnosis – or no diagnosis at all – are viewed as profoundly unhelpful. Carers need time to talk through their concerns and appreciate empathy, patience, time and honesty. Advice and support given to a relative at an early stage promotes the psycho-social well-being of both the person with dementia and their carer.

Relatives and people with dementia want clear unambiguous information about diagnosis, symptoms, treatments, the illness trajectory and services, and more opportunity to discuss concerns with staff. Not being given sufficient time around disclosure is a particular concern.

Stigma and self-stigmatisation

Receiving a diagnosis is a social event as well as a psychological one; disclosure allocates the person with the condition to a new, devalued and stigmatised group. Stigma has been identified as exerting a damaging influence on a person's well-being. It operates at two levels: externally – in wider society and the media – and internally, within people themselves, a concept called 'self-stigmatisation'.

One of the key roles of early intervention services is to challenge stigma. Stigma is deepened by avoidance of the use of terms such as 'Alzheimer's disease' or 'dementia'. However it should be acknowledged that some individuals' preferred coping strategies involve avoiding these terms and referring to it as a 'memory problem'. There is a considerable educational and public health challenge in countering the profoundly negative image of dementia.

The roles and perspectives of professionals

Most of the evidence about 'professionals and diagnosis' is drawn from research with doctors. A dominant tension in medical discourse is that between the doctor's obligation to disclose a diagnosis versus a duty of care to do no harm to the patient.

The disclosure of an illness like dementia is a process not an event, and one that incorporates the provision of both practical and emotional support to the person and their families over a number of consultations. Empathy and understanding are core elements of good diagnostic practice. 'Positive person work' has been evidenced as countering the impact of neuronal losses in a realistic, accepting way.

Good practice guidance emphasises the need to diagnose dementia early in order for treatment options and services to be explored at a point when they are most likely to be effective. People with a diagnosis of dementia who feel more included in decision making, report higher levels of well-being and adjustment.

Even when doctors are committed to 'disclosure' there is considerable variability in practice. People's experiences are mixed. The dominance of the biomedical view of dementia which emphasises 'functioning' may be at odds with promoting psycho-social well-being and social aspects of care.

Reasons for withholding a diagnosis are threefold. A diagnosis may distress the person with the condition. This is an unsustainable position as people suffering from other progressive neurodegenerative diseases are told their diagnosis at the earliest opportunity. Time constraints are a second barrier and a third is lack of competence in dementia diagnosis and disclosure.

Psycho-social consequences of late diagnosis

The authors found no evidence specifically relating to the impact of a late diagnosis although it is tautological in that it denies the person with dementia the psycho-social opportunities of an early diagnosis. Adjustment challenges facing the person with late stage dementia are significant: the loss of meta-memory, limited communication and verbal skills and minimal capacity to retain information.

At present, the psycho-social world of people with late stage dementia is little understood. While we know that early access to support by carers can delay care home admission for the person with dementia, the potential of early diagnosis to promote the psycho-social well-being of carers is largely overlooked.

Early onset dementia

Early onset dementia refers to people under the age of 65 diagnosed with dementia. The impact of dementia on the lives and well-being of younger people is multi-dimensional and long term. Commonly reported effects include compromised independence, social isolation and loss of job. The concerns of spouses include fear of dependency, caring demands, and financial strain.

As early onset dementia is a rare condition, delays in diagnosis and assessment are not uncommon. Doctors find it particularly difficult to disclose a diagnosis to a younger person. That this population is often treated by a dementia care system designed to meet the needs of older people is an additional challenge.

People with dementia from black and minority ethnic groups

Very few older people from black and minority communities seek help for dementia until late on in the disease trajectory. One of the consequences of this is the loss of opportunities for early diagnosis and preventive treatment. Some recent work has been done to develop culturally appropriate diagnostic and screening instruments which may help facilitate early intervention.

Conclusion

Whilst the practical benefits of early diagnosis are well established work on psycho-social benefits has only just begun. Evidence suggests that we underestimate the psycho-social potential of people in the early stages of dementia: most are capable of not only adjusting to a diagnosis but can cope, or learn to cope, with the implications of the illness.

People in the early stages are also capable of insight and can decide when, and how, they need help. Treatments and support services can be offered at a time when they are most likely to be beneficial. Disclosure removes uncertainty and provides relief for many people. It also provides a 'gateway' into the next phase – the 'coming to terms with' stage and the maintenance or promotion of psycho-social well-being for both people with the diagnosis and carers.

How well a person adjusts to and manages both the symptoms of early dementia and a diagnosis will vary according to their particular circumstances. Variables include the person's pre-morbid personality, level of resilience, coping skills, previous life experience (especially exposure to stress) and whether they have a supportive partner and/or family. The type of dementia the person has, speed of deterioration, and specific symptomology are also influential. Adjustment is also facilitated, or not, by the manner and pace of diagnosis, the expertise of clinician(s) and the levels and types of support available for the person and their relatives. Combining these variables together can be conceptualised as a 'personal psycho-social algorithm', as a way of describing how their impact will vary from individual to individual. In words attributed to the late Tom Kitwood:

'once you've met one person with dementia...you've met one person with dementia'

Whilst the overarching argument for the importance of early diagnosis remains intact, it is important to recognise that an individual's 'personal algorithm' is an important determinant of outcome, including psycho-social well-being.

Appendix 2

Topic guide – focus groups

Types and duration of dementia

1. Could you tell me what kind of dementia you have?
2. How long have you been diagnosed with a dementia?

Getting a dementia diagnosis

3. Thinking about your diagnosis – what first made you think that there might be something not right?
 - When did this happen?
 - How did you feel about this?
 - How did you cope with it?
4. How long after you thought there might be something not right did you go and see your doctor?
 - Do you wish you had gone sooner?
5. What happened when you went to see your doctor?
 - How did this make you feel?
 - How did it affect your family and friends?
 - What support or advice did the doctor give you?
 - Was it helpful?

Adjusting to having a dementia diagnosis

6. How did you adjust to getting a diagnosis?
 - What helped you with this – particularly in managing your well-being?
 - Who helped – eg family, friends, professionals?
 - What didn't help?
 - Have those adjustments in your life changed since the diagnosis?

7. What do you think makes some people better able to adjust to a diagnosis of dementia than others?
 - Are some people better than others at coping with difficult things?
 - Can people be helped to cope or adjust better?

General questions

8. Thinking about your own experience, what makes for a 'good' process of getting a dementia diagnosis?
 - Who should do the diagnosis?
 - When should it be done?
 - What support should be offered?
9. Do you think the way that dementia is talked about in the media has helped you?
 - Has it ever annoyed or upset you?

Appendix 3

Interview questions

Types and duration of dementia

1. Could you tell me what kind of dementia you have?
2. How long have you been diagnosed with a dementia?

Getting a dementia diagnosis

3. Thinking about your diagnosis – what first made you think that there might be something not right?
4. How long after you thought there might be something not right did you go and see your doctor?
5. What happened when you went to see your doctor?

Adjusting to having a dementia diagnosis

6. How did you adjust to getting a diagnosis?
7. What do you think makes some people better able to adjust to a diagnosis of dementia than others?

General questions

8. Thinking about your own experience, what makes for a 'good' process of getting a dementia diagnosis?
9. Do you think the way that dementia is talked about in the media has helped you?

