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National Audit Office

Final Report - Dementia Focus Groups Findings



PRICEWATERHOUSECOOPERS 

Government and Public Sector

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Executive summary

Background & terms of reference

1. Dementia is a set of symptoms: 'evidence of a decline in memory and thinking which is of a degree sufficient to impair functioning in daily living, present for six months or more'. This may be accompanied by a decline in emotional control, social behaviour, motivation and/or higher cortical functions. Onset of the disease may be from age 45, but usually not before 65¹.
2. There are some 650,000 people with dementia in England². With an increasingly ageing population, a steady increase in the number of people with dementia is expected over the next 25 years. Although dementia in people under the age of 65 is comparatively rare, there are over 18,000 younger people with dementia in the UK.
3. The recently published Wanless Report concluded that the UK must expect to devote a significantly larger share of its national income to health and social care over the next 20 years. In particular, it highlighted the growing needs of an ageing population and the shortcomings of the current social care system in relation to older people.
4. The Commission for Social Care Inspection (CSCI) in its 2005-06 report³ identified that the increase in the number of older people with mental health problems receiving services is an ongoing cost pressure with the cost of services for this group being consistently higher than for physically frail older people. As with its report in 2004-05, CSCI also indicated that carers continue to be largely unrecognised for the role they play in supporting social care. The report identified that 4.7 million people over the age of 18 were carers in England, 70% of the people cared for were over 65 and 471,000 carers reported they were in poor health and of these, 30% were aged 65 plus.
5. The National Audit Office (NAO) is currently undertaking a range of work examining services available for older people. As part of this programme of work the NAO commissioned PricewaterhouseCoopers (PwC) to conduct three focus groups with people with dementia and their carers. The objectives (terms of reference) of the research were to identify:
 - The main issues affecting people with dementia and their carers (in order of priority if possible);
 - The practical changes that could be made to bring improvements to the lives of people affected by dementia; and
 - The impact that such changes could have on the lives of people affected by dementia.
6. In order to address the specified terms of reference, a programme of qualitative research was designed. In total three focus groups were conducted. One focus group was conducted with

¹ *Dementia Tutorial: Diagnosis and Management in Primary Care*, Alzheimer's Society

² *UK National Audit Office publications: Work in progress: Maintaining good health for older people with dementia in England*, 2006

³ *The Commission for Social Care Inspection: The state of social care in England 2005-06*. December 2006

people who were diagnosed with early stages of dementia and the remaining two groups were with carers of people with dementia. This was in line with NAO specifications for the research. In undertaking the work the Alzheimer's Society had offered to help the NAO recruit participants for the focus groups and on appointment, PwC worked with the Society to facilitate this.

7. The following paragraphs in this Executive Summary provide summary findings by the terms of reference for this project. In reviewing the findings, it is important to note that they provide an 'insight' into the views and opinions of a small number of people with dementia (4 people with dementia) and carers (16 carers), who reside within England. Therefore the findings and recommendations detailed throughout this report may not be representative of the views of all people with dementia and their carers within England. It is suggested that the findings and recommendations (contained within this report) should be augmented with the wider programme of research, which the NAO are currently undertaking and which aims to capture the views of a proportion of community mental health teams, GPs, as well as further service users and carers.

The main issues affecting people with dementia and their carers

8. A large number of issues were raised by focus group participants ranging from the length of time for correct diagnosis to be achieved through to the lack of flexibility regarding the delivery of care services and at times limited interaction with health and social care professionals. The prioritisation of these issues varied depending on whether the participant was a user or a carer, the length of time they had been experiencing service provision as well as the range of services they had direct experience of.
9. Overall we found dissatisfaction with the diagnosis process to be high on the list of issues affecting people with dementia. In addition, the recent NICE announcement⁴ which ruled that NHS patients with newly diagnosed, mild Alzheimer's disease should not be prescribed dementia drugs was raised as a major concern for these participants.
10. In summary, the issues most commonly identified by focus group participant type as requiring priority action were:

Dementia service users

- The length of time taken for a correct diagnosis to be given and providing appropriate treatment as soon as possible thereafter; and
- Ensuring, where possible, that the care provided enhanced the ability of the person with dementia to maintain a level of independence.

Carers

- The lack of support experienced throughout the diagnosis stage including interaction with healthcare professionals;
- The financial constraints of caring and being prepared for a coping with the effect that providing full-time care can have on a marriage and family relationships;

⁴ News Release (23 January 2006) 'NICE guidelines: dementia drugs to be denied to those in the mild and severe stages of the disease'. NICE recommended that donepezil (Aricept), galantamine (Reminyl), and rivastigmine (Exelon) should be used as a treatment of moderate Alzheimer's disease only. The fourth drug, memantine (Ebixa), which was used to treat more severe stages of the disease is to be withdrawn from the NHS. It is no longer available on prescription and the only way people would receive it would be as part of clinical research trials. Accessed via <http://www.alz.co.uk/media/nr060123.html>, 3/1/07.

- The lack of a single point of contact to discuss problems and source further information; and
- Carers of those with dementia, who were now cared for in a residential or nursing home or a hospital environment, also highlighted the lack of specific dementia care training for a number of staff in these organisations.

The practical changes that could be made to bring improvements to the lives of people affected by dementia

11. A number of practical changes were outlined by group participants which they strongly believed could improve the lives of people affected by dementia. These can be summarised as:

- Improvement in the length of time for a correct diagnosis;
- Provision of a relevant information pamphlet on the day of diagnosis, for example the Alzheimer's Society booklet;
- Identification of a single point of contact for all people with dementia and their carers to help assist in preparing and dealing with a dementia diagnosis as well as helping to plan for what the future may hold;
- Increasing Government funding towards staffing and development of further services;
- Providing dementia care training for health and social care staff including care home staff, consistent with such staff's roles and responsibilities;
- A joined-up approach to the delivery of care by service providers and the opportunity for service users and carers to have input to this process;
- Provision of more flexible care services to meet the needs of local service users and their carers;
- Greater provision of respite care facilities;
- Provision of a smaller and more consistent team of home care staff to minimise the anxiety caused to local service users and their carers;
- Continuation of Alzheimer's drugs to newly diagnosed people and those currently with a mild form of dementia;
- Development of tailored care provision for local service users who are aged between late forties and late fifties;
- Support for the formalised provision of carer support groups;
- Increased carer allowance;
- Simplification of forms when applying for benefits and service provision;
- Programme to increase awareness and understanding of dementia amongst the general public; and
- Improved promotion of existing local services in order that there is a better awareness of current provision and also what is available in the future as the needs of service users increase.

The impact that such changes could have on the lives of people affected by dementia

12. The practical changes identified by focus group participants were viewed as paramount by them to bringing improvements to the lives of people affected by dementia. It was considered, by all participants, that the implementation of some or all of these improvements would hugely improve the day to day lives of those with dementia and their carers.
13. The following detail in Table 1 demonstrates (with direct quotes provided alongside) a number of areas identified for change and why participants indicated changes were necessary to improve their experience to date.

Table 1: Areas for change and why

Areas for practical change:	Focus group participant quote
<ul style="list-style-type: none"> Increasing Government funding towards staffing and development of further services 	<p><i>A post-code lottery shouldn't exist so if I move all the benefits move with me.</i></p> <p><i>Person with early stage dementia</i></p> <p><i>My experience in the care home was 2 staff for 11 patients – this is a disgrace. I go into shave him, cut his hair and feed my husband because there is no-one else to do it.</i></p> <p><i>Carer aged over 45 years</i></p>
<ul style="list-style-type: none"> Providing dementia care training consistent with roles and responsibilities 	<p><i>Some professionals have the attitude that dementia is 'just memory loss and just forgetting things'. But there is a behavioural side of things too – they need a specialised knowledge and understanding for this.</i></p> <p><i>Carer aged 18 to 44 years</i></p>
<ul style="list-style-type: none"> A joined-up approach to the delivery of care 	<p><i>I receive different phone calls from different professionals about the same issues, and no-one knows anything about the others. It's just a continual round of questions.</i></p> <p><i>Carer over 45years</i></p>
<ul style="list-style-type: none"> Provision of a smaller and more consistent team of care home staff 	<p><i>The lack of continuity in the care staff that visit my mum to give her medication confuses her.</i></p> <p><i>Carer aged between 18 and 44 years</i></p>
<ul style="list-style-type: none"> Development of tailored care provision for service users aged between late forties and late fifties 	<p><i>My husband is 58 and I'm the sole carer. I had to give up work to look after him because of the lack of any facilities for younger people with dementia. The Social worker and Psychiatric Nurse have been trying to find ways to help me get back to work.</i></p> <p><i>Carer aged 18 to 44 years</i></p>
<ul style="list-style-type: none"> Programme to increase awareness and understanding of dementia amongst the general public 	<p><i>One of the things we experience is people's disbelief that you have dementia because you're appearing normal. It's so frustrating.</i></p> <p><i>Person with early stage dementia</i></p>
<ul style="list-style-type: none"> Simplification of forms for benefits and services 	<p><i>When you start to make enquiries, there are 30 page documents which ask the same questions and they are difficult to fill out correctly.</i></p> <p><i>Person with early stage dementia</i></p>

14. The detail in Table 2 demonstrates (with direct quotes provided alongside) a number of areas identified for change and how participants indicated such changes can have an impact for the better on their lives.

Table 2: Areas for change and how this would be a positive impact

Areas for practical change:	Focus group participant quote
<ul style="list-style-type: none"> ▪ Improvement in the length of time for a correct diagnosis 	<p><i>Once everything was set in motion, I couldn't believe the speed with which we got the diagnosis – however, I feel like we were the exception rather than the rule.</i></p> <p><i>Carer aged 18 to 44 years</i></p> <p><i>Everything takes so long – appointments are months away. But when your world is falling apart, you don't want to wait four months to see someone. I felt like hammering on the door and saying we don't have that long!</i></p> <p><i>Carer aged 18 to 44 years</i></p>
<ul style="list-style-type: none"> ▪ Provision of a relevant information pamphlet on the day of diagnosis 	<p><i>The Alzheimer's Society Booklet is very good – it is specific to this location, very informative. Thank God they've got this now.</i></p> <p><i>Carer aged over 45 years</i></p>
<ul style="list-style-type: none"> ▪ Identification of a single point of contact for all people with dementia and their carers 	<p><i>All councils should be able to nominate someone in social services to be highly trained in the subject and they would become the key contact for all in the local area with dementia. This would stop you going around a merry-go-round.</i></p> <p><i>Person with early stage dementia</i></p>
<ul style="list-style-type: none"> ▪ Provision of more flexible services to meet the needs of users and their carers 	<p><i>There is a lot of talk about patient centred care. It's about making that real, putting the person at the centre and making them feel valued, loved and living their life as independently as possible.</i></p> <p><i>Person with early stage dementia</i></p>
<ul style="list-style-type: none"> ▪ Greater provision of respite care facilities 	<p><i>It would make my life more controllable and manageable – it's a cycle – if the carer has support and regular breaks, then they feel better and can cope better.</i></p> <p><i>Carer aged between 18 and 44 years</i></p>
<ul style="list-style-type: none"> ▪ Continuation of Alzheimer's drugs to newly diagnosed individuals 	<p><i>The only thing that helped was those tablets that they've stopped. They made him calmer, easier to control – now they've stopped them, what are we going to do?</i></p> <p><i>Carer aged over 45 years</i></p> <p><i>I'd rather have the benefit early on rather than waiting until I'm in the moderate stage. Who wants the disease slowed when it's too late to enjoy the benefit.</i></p> <p><i>Person with early stage dementia</i></p>
<ul style="list-style-type: none"> ▪ Provision of carer support groups 	<p><i>Make the system more cost effective by giving carers the correct levels of support and they will be able to manage at home for longer – in the long term this would save the government money. Otherwise, it's a sticking plaster on an open wound.</i></p> <p><i>Carer aged 18 to 44 years.</i></p>
<ul style="list-style-type: none"> ▪ Increased carer 	<p><i>Financial recompense for the carer role – we want to do the caring role but without the financial support I am constantly thinking that I</i></p>

Areas for practical change:	Focus group participant quote
allowance	<i>should be going back to work. Carer aged 18 to 44 years</i>
<ul style="list-style-type: none"> ▪ Improved promotion and awareness of existing services 	<i>My experience was completely different – I got great support and all the information I needed. I can't believe that we are all in the same geographical area and yet the services are so different. Carer aged 18 to 44 years</i>

Initial recommendations for discussion and further consideration

15. As a result of these findings consideration should be given to the recommendations listed below. Whilst the information gleaned from the participants in the focus groups undertaken is useful in providing very powerful and important instances of practical experiences of service provision and dealing with the effect of a dementia diagnosis on an individual and their close relatives, they are examples of a number of individual experiences. Without wider research and further discussion these findings and resultant recommendations should not be interpreted as being necessarily representative of all people with dementia and their carer experiences in relation to dementia service provision.

Recommendations:

- Promotion of a timely diagnosis process with specific training to assist GPs in achieving a correct diagnosis as early as possible;
- Specific dementia care training for health and social care staff in line with their roles and responsibilities;
- Consider providing each individual with dementia with a single point of contact (this person would provide support and information to both the person with dementia and their carer);
- Information should be easily accessible through most health and social care professionals and available as soon as diagnosis has occurred. In particular, clear information should be provided in relation to the following areas as soon as possible after diagnosis:
 - Managing finances;
 - Preparation of wills;
 - Practical advice about finances and entitlements;
 - Information on how the disease will progress;
 - Information about local services; and
 - Information about services which are free and those that require a fee.
- Consider implementing local networks to enable carers to share their experiences, this could be through formalised carer support groups being in place;
- Provide tailored and flexible care services, in particular, to suit the needs of those aged 50 to 60 years who have dementia;
- Improve co-ordination and integration between service providers and the promotion of increased interaction between such providers and carers for individuals with dementia;
- Improved focus and support for the carer assessment process including the actual

implementation of identified support to meet carer needs, for example phone support, respite care, talking therapies etc;

- At Governmental level maintain an ongoing review of funding and latest research into the provision of dementia services;
- Review existing documentation and forms to apply for services and benefits to determine if simplification and further assistance in their completion can be provided; and
- Introduction of a programme to inform and improve the general public's understanding of the impact and effects of dementia.

1 Background and terms of reference

Background

- 1.1 There are some 650,000 people with dementia in England. With an increasingly ageing population, a steady increase in the number of people with dementia in England is expected over the next 25 years. The Alzheimer's Society estimates that by 2010 there will be about 870,000 people with dementia in the UK. This is expected to rise to over 1.8 million by 2050. Although dementia in people under the age of 65 is comparatively rare, there are over 18,000 younger people with dementia in the UK⁵.
- 1.2 In general, there has been an increasing focus on the care of older people including a number of articles in national newspapers about care homes, access to state funding and dementia care in the community. The recently published Wanless Report concluded that the UK must expect to devote a significantly larger share of its national income to health and social care over the next 20 years. In particular, it highlighted the growing needs of an ageing population and the shortcomings of the current social care system in relation to older people.
- 1.3 The Government has recognised that older people and their families want more services for strokes, falls, mental health, long term conditions and emergency care. The next phase of health and social care reform is expected to place older people's needs at the centre and involve them and their representatives in care planning⁶.
- 1.4 The *NSF for Older People Progress Report* highlighted that the NHS spent around £16 billion on people over the age of 65 in 2003/2004, accounting for 43% of the total NHS budget. In the same year social services spent around £7 billion, which was 44% of their total social services budget. At the same time the Wanless Report revealed that despite positive changes in health service for older people, further action was required in several areas, including mental health. Aspects of mental health services for older people have been highlighted as needing improvement including person-centred care, age equality in access to the range of services available and treating people with dignity and respect⁷.
- 1.5 A key finding in the NSF study was the existence of age discrimination in the provision of mental health services – the study highlighted an 'organisational division' between mental health services for adults of working age and older people, pointing to the fact that out-of-hours services for psychiatric advice and crisis management for older people are not as developed as those for adults of working age. Some good practice examples have, however, been identified by CHI⁸ in its 2003 report, such as holistic support to carers of people with dementia and training and education on the needs of people with dementia for healthcare professionals⁹.

⁵ The Alzheimer's Society Position on Demography. Available at http://www.alzheimers.org.uk/News_and_Campaigns/Policy_Watch/demography.htm

⁶ *A New Ambition for Old Age. Next Steps in Implementing the National Service Framework for Older People*. Report from Professor Ian Philip, National Director for Older People, Department of Health.

⁷ *Living well in later life. A review of progress against the National Service framework for Older People*, March 2006, Commission for Healthcare Audit and Inspection.

⁸ Now the Healthcare Commission.

⁹ *What CHI has found in: mental health trusts (Sector Report)* Commission for Health Improvement, 2003

- 1.6 The Alzheimer's Society is the key stakeholder in providing care and research for people with dementia and their carers. The charity provides information and education, support for carers, and quality day and home care. It funds medical and scientific research and campaigns for improved health and social care services and greater public understanding of dementia.
- 1.7 As part of the consultation for the National Framework for NHS Continuing Care and NHS-funded Nursing Care in England, the Alzheimer's Society recommended that the Framework should address mental health needs more adequately based on a comprehensive assessment of mental health needs of patients¹⁰.

Terms of reference

- 1.8 This specific piece of work undertaken by PwC contributes to a wider study by the NAO into the services available for old people. The NAO commissioned PwC to undertake three focus groups with people who had dementia and with carers of people with dementia. The objectives of this piece of research were to identify:
 - The main issues affecting people with dementia and their carers, in order of priority if possible;
 - The practical changes that could be made to bring improvements to the lives of people affected by dementia; and
 - The impact that such changes could have on the lives of people affected by dementia.

¹⁰ *Response to the Consultation on the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care in England*, September 2006, Alzheimer's Society.

2 Our approach

Overview of our approach

- 2.1 In order to achieve the specified terms of reference, a programme of qualitative research was designed. In total three focus groups were organised and conducted. One focus group was conducted with people who were diagnosed with early stages of dementia and the remaining two groups were with carers of people with dementia. This was in line with NAO stipulations for the research. Table 3, below, provides detail of the achieved criteria for each focus group.

Table 3: Focus group criteria

Type of group	Location	Rural/Urban	Age	Other criteria	No. of participants
People with dementia	Throughout England (Living with Dementia Network)	Mixed	-	<ul style="list-style-type: none"> A selection of people who use different care services 	<ul style="list-style-type: none"> 4 people with dementia 3 carers
Carers of people with dementia	London – Tower Hamlets Branch	Urban	45 years +	<ul style="list-style-type: none"> Group should include some carers who have their own health/social care issues Carers to a selection of people who use different care services 	<ul style="list-style-type: none"> 6 carers
Carers of people with dementia	Birmingham – South Warwickshire Branch	Mixed	18-44 years	<ul style="list-style-type: none"> Group should include some carers who have work/family commitments in addition to caring Carers to a selection of people who use different care services 	<ul style="list-style-type: none"> 7 carers

Topic guide design

- 2.2 A topic guide was designed to meet the terms of reference stated within the research brief. This guide was discussed at the project initiation meeting and approved prior to the commencement of the focus group discussions by the NAO.

Recruitment

- 2.3 The Alzheimer’s Society kindly offered to recruit participants for the three focus groups through their branch network and this was agreed with the NAO. Two groups were organised within the London area and the other carer group took place in Birmingham. Approval of the locations was sought from the NAO prior to the recruitment of the groups.
- 2.4 Upon selection, Richard Berry (Alzheimer’s Society) initially made contact with the branches to inform them that a PwC contact would approach them to organise the logistics of each focus group and advise them on the recruitment criteria required when inviting some of their members to attend.

Fieldwork and reporting

- 2.5 All three focus groups were conducted between the 20th November and 1st December 2007. The groups were moderated by Lorna McLernon (PwC) and each group lasted between 1 ½ and 2 hours.
- 2.6 A write-up of each of the focus groups has been completed by PwC and provided to the NAO. These write-ups detail the main topics discussed and as with this report, provide anonymised quotes from participants.
- 2.7 A report (this report) collating the findings from the three focus groups has now also been drafted and its structure is set out below.

Structure of report

- 2.8 The structure of this report hereafter is:
 - Section 3 sets out the Key findings of the research in relation to the diagnosis stage and the provision and distribution of information;
 - Section 4 sets out the Key findings of the research in relation to the current care services which people with dementia receive and the level of support provided to the carers of people with dementia;
 - Section 5 sets out the Key findings of the research in relation to the main issues that affect people with dementia and their carers, and considers the views of focus group participants in relation to changes to current service provision; and
 - Section 6 sets out initial Recommendations for discussion and further consideration.

Disclaimer

- 2.9 It should be noted that this piece of qualitative research provides an 'insight' into the views and opinions of a small number of people with dementia (4 people with dementia) and carers of people with dementia (16 carers), who reside within England.
- 2.10 Therefore the findings and recommendations detailed throughout this report may not be representative of the views of all people with dementia and carers within England. They are useful in providing insights into the experiences of a variety of individuals and should be considered and interpreted within that context. However, it is suggested that the findings and recommendations contained within this report should be augmented with the wider programme of research, which the NAO are currently undertaking, which aims to capture the views of a large proportion of community mental health teams, GPs, as well as further service users and carers.

3 Key findings – diagnosis and information

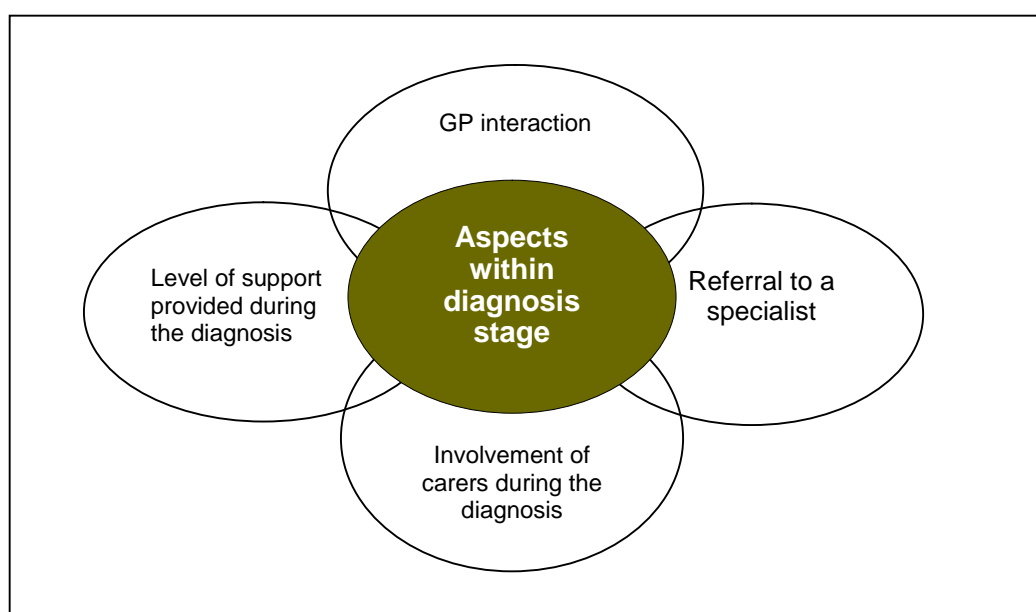
3.1 In this section of the report we discuss the experiences of those with dementia (i.e. local service user) and the carers of people with dementia in relation to:

- The diagnosis stage; and
- The provision and distribution of information.

Diagnosis

3.2 Several aspects were discussed with regard to the diagnosis stage, these are depicted in Figure 3.1 and then summarised in the paragraphs that follow.

Figure 3.1: Aspects within diagnosis stage



GP interaction

3.3 The GP was the first point of contact for many participants who were concerned about the deterioration of their own or a close relative's health. Mixed experiences were encountered, with some participants noting a relatively quick GP referral process which led to a confirmed diagnosis and other participants enduring a very lengthy process with the GP before receiving a referral to a specialist. It was evident, amongst the majority of group participants, that a lengthy diagnosis period was more commonly experienced.

3.4 For many individuals, it was necessary to frequent the GP clinic on a regular basis, before an individual GP recognised the deterioration in the person with dementia and considered referring them to a specialist and / or a memory clinic.

I had been taking my brother to the GP for two years with his symptoms and it was only when a locum GP came to the surgery that he referred him to a day centre. He spent 9 weeks in the day centre before he was diagnosed. Carer aged over 45 years

It took 6 months to diagnose my husband from the time the doctor thought something wasn't right to the actual diagnosis. But he should have been diagnosed 4 years earlier than this, but doctors kept putting me off. Carer aged between 18 and 44 years

- 3.5 For those participants who experienced a prompt diagnosis, they attributed this to the proactive nature of their GP and their GP's ability to schedule appointments with a specialist within a short timeframe.
- 3.6 A number of these early diagnoses were triggered by a secondary complaint for the person with dementia or an accident and consequently the attending GP or consultant referred the individual onto a memory specialist.

My GP recognised my symptoms very quickly after a small accident. Since then we've been looked after very well. Person with early stage dementia

We've had great sympathy along the line. It was only a chance comment at a diabetic clinic when my wife asked the consultant to give me back my memory. He referred me to a specialist centre – a Neuropsychology Centre (wait of a year and 2-hour examination). A report was sent to the original consultant and within 2-weeks I was on Aricept and the results have been brilliant. Person with early stage dementia

- 3.7 The diagnosis of younger individuals between the age of 50 and 60 years was considered to be extremely slow and difficult to obtain. Within the focus group discussions, four group participants recalled their experiences, one participant had early stage dementia and three were carers to their spouses who ultimately were diagnosed with a form of dementia.
- 3.8 These individuals had experienced frustration as they found their GPs were not willing to recognise the possibility of their spouse being affected by dementia, solely due in the carer's view to their spouse's age profile not matching the medical view that dementia predominantly occurs to individuals over the age of 65 years.

At one end you've got you're too young to have dementia, and at the other you've got you're 75, what do you expect? Person with early stage dementia

Very little support - because my wife was so young, the GP wouldn't accept what I said about her behaviour – the GP made me feel like a villain. Carer aged between 18 and 44 years

Referral to a specialist

- 3.9 All participants were referred at some point in time by their GP to a specialist centre such as a Neuropsychological Centre or a Memory Clinic. For some of these participants they received scans and in some cases psychological testing. For others this was not necessary for them to be diagnosed.
- 3.10 For a few participants, once 'in the system' obtaining a specific diagnosis of the exact form of dementia was still a difficult and long process. Although it became evident that an individual had a form of dementia, a number of carers were aware that their relative encountered a period of continuous tests and consultations which resulted in the elimination of certain types of dementia but did not immediately provide an accurate diagnosis. This was the experience of a number of the participant carers whose spouses were finally diagnosed with Vascular

Dementia, Lewy Body Dementia or Frontal Lobe Dementia through the elimination of other types of dementia.

I feel it's a situation where it's diagnosis by default – they have eliminated everything else, so it must be this. Carer aged between 18 and 44 years

It wasn't until I was at the hospital that I was diagnosed with vascular dementia as a result of the stroke. Through them I got day care and transport to and from the day care centre. Person with early stage dementia

- 3.11 The average length of time to diagnosis was regarded as too long by all group participants (both those with dementia and carers). This delay was attributed to the time taken by GPs to agree to refer individuals and also the waiting lists for them to receive a consultation from a specialist and the associated scans or psychological testing required thereafter. For group participants the length of time for a diagnosis to be confirmed ranged from a few weeks to 5 years.

In my area there are no services. It took 3½ years to get my diagnoses. I was referred around in circles with a diagnosis of depression and eventually was, through the Alzheimer's Society, given an appointment with a psycho-geriatrician and after tests diagnosed. Person with early stage dementia

I feel we received more support once we got into the system and the diagnosis was made – before that stage, I feel that the GP dragged their heels. Carer aged between 18 and 44 years

- 3.12 Participants strongly voiced the importance of a timely diagnosis both for the person who has dementia but also for the associated carer and wider family circle.
- 3.13 It was noted that the delay of diagnosis prevents the prescription of valuable anti-dementia drugs. Both participants with dementia and carers were adamant that the earlier these prescription drugs are provided the longer the person with dementia can deter the progression of the disease.

The diagnosis is a very long process. By the time the diagnosis was made, it was too late to try drugs to treat it. Carer aged between 18 and 44 years

Everything takes so long – appointments are months away. But when your world is falling apart, you don't want to wait four months to see someone. I felt like hammering on the door and saying 'we don't have that long! Carer aged 18 to 44 years

- 3.14 Prior to the confirmation of a diagnosis some participants stated they felt very alone and doubted their own sanity as they encountered many health professionals and friends who did not believe that there was a problem implying that either the person with dementia and/or their carer were exaggerating or making up the situation.
- 3.15 A diagnosis was regarded as the first step for some families to come to terms with the behaviour of the individual and to react positively to the situation with medication and organising appropriate care depending on the individual's current needs.

Involvement of carers during the diagnosis

- 3.16 Carers strongly advocated the importance of their involvement throughout the diagnosis stage. As carers are often one of the first groups of people to notice the deterioration in their relative's condition they considered that they could provide the GP with invaluable information.

Consequently, these carers felt that if their GP had involved them more in the process, and listened to them, a diagnosis may have been issued earlier.

- 3.17 As the sole carers, participants highlighted that they should be made fully aware of the current health of their relative and their associated needs to ensure adequate care is provided.

If you don't know what's going on, you can't help them. Carer aged over 45 years

If you are not in the system, it is difficult to understand what is happening. Carer aged over 45 years

Level of support provided during the diagnosis stage.

- 3.18 The vast majority of participants with dementia and carers of people with dementia regarded the level of support provided during the diagnosis stage as inadequate. In general, participants recalled receiving the diagnosis and then leaving their GP / Consultant without any further information or a clear understanding of the implications of such a diagnosis.

- 3.19 Consequently, many participants were distressed and confused about what would happen next and how this diagnosis would affect the individual, the carer and the wider family circle.

- 3.20 Although it was recognised by participants that this disease had greatest impact on the individual who is diagnosed, it was raised that support is also important for carers, especially sole carers who may not have another individual they can turn to for help to deal with the substantial changes which will take place in their life.

I need someone to have a blooming good cry with – carers need someone to talk to especially in a husband and wife situation because your future is gone. Carer aged between 18 and 44 years

Yes you've got dementia. Take these tablets. There is the door. Person with early stage dementia

- 3.21 A number of participants received support during the diagnosis stage. This support was felt to be best delivered through either a Community Psychiatric Nurse (CPN) or a Social Worker. These health and social care professionals spent time with both the individual with dementia and the carer and provided them with the information they needed to know, at that point in time, and local services available. In addition, these individuals became a first point of contact when the person with dementia, or their carer, encountered problems or had queries.

My experience was completely different, I got great support and all the information I needed. I can't believe that we are all in the same geographical area and yet the services are so different. Carer aged between 18 and 44 years

My husband wouldn't accept help: it is difficult for the system to help where the sufferer doesn't want to be helped. Carer aged over 45 years

- 3.22 There is further discussion on the level of support received by people with dementia and their carers in the specific context of provision of information in the paragraphs that follow.

Provision of information

- 3.23 The majority of participants did not receive information on the day they / their relative was diagnosed. Information was subsequently provided, to some, through meetings with either the CPN or a Social Worker. For others it was not until they became involved with the Alzheimer's Society that they received information.

No explanation was given. Once you got your diagnosis you're expected to go out and find your own support. Person with early stage dementia

It was only through a chance conversation that I found out I didn't have to pay council tax. Person with early stage dementia

- 3.24 For many of these participants the level of information provided to them was cumbersome and difficult to sieve through to find the essential detail they required.

The social worker left me a pile of books with lots of information in them but I didn't know where to start. Carer aged between 18 and 44 years

I felt over-leafleted – the pile of papers just got bigger. What you really need is someone to sit down with you with a list of the practical things you need to know and action. Carer aged between 18 and 44 years

- 3.25 A few participants received the information they felt they required through their CPN who spent time highlighting the essential information and indicating who they should contact for further help and assistance. For these participants, this was regarded as the best approach to disseminating this information to people with dementia and their carers.

After my wife was diagnosed, the CPN wrote down the specific information and telephone numbers I needed – there were no leaflets. Carer aged between 18 and 44 years

- 3.26 Participants were asked to highlight what they regarded as essential information which should be provided at the diagnosis stage. The following information was regarded as being required:

- Practical advice about finances and entitlements;
- Information on how the disease will progress;
- Information about local services; and
- Information about services which are free and those that require a fee.

I've only been given information on finances etc because we went for independent financial advice. Person with early stage dementia

- 3.27 The Alzheimer's Society Booklet was viewed by participants as a very useful document which contained all the essential information for people diagnosed with dementia and carers. In general, participants received this booklet a few months after their diagnosis when they had already struggled to find out about benefits and service provision. Consequently, it was suggested that this booklet or a similar document would be much more beneficial if it was issued to the relevant individual on the day of their diagnosis.

Section summary

Diagnosis

- For the majority of participants the diagnosis period was a slow process. The GP was the first point of contact for all those with dementia, with referrals to specialist centres such as a Neuropsychological Centre or a Memory Clinic. For some of these participants they received scans and in some cases psychological testing.
- Prompt diagnoses were attributed to the proactive nature of their GP and their ability to schedule appointments with a specialist within a short timeframe.
- Diagnosis of dementia for younger people seemed particularly problematic.
- Carers strongly advocated the importance of their involvement throughout the diagnosis stage to provide the GP with invaluable information about the health of the person with dementia.
- The level of support provided during the diagnosis stage to those with dementia and carers, was considered to be inadequate. In addition to the provision of general dementia information, carers would like to receive individual support to help them, and in some cases their family, to come to terms with the diagnosis.

Information provision

- Where information was provided, it was mainly via a social worker, CPN or the Alzheimer's Society.
- The preferred method of receiving information was face-to-face discussions with a social worker or a CPN helping to discuss practical actions to be taken and key contact points for support and advice.
- The following areas were regarded as essential for receiving information on:
 - Practical advice about finances and entitlements; and
 - Information on how the disease will progress; about local services and about services which are free and those that require a fee.

4 Key findings – type of care received and carers' support

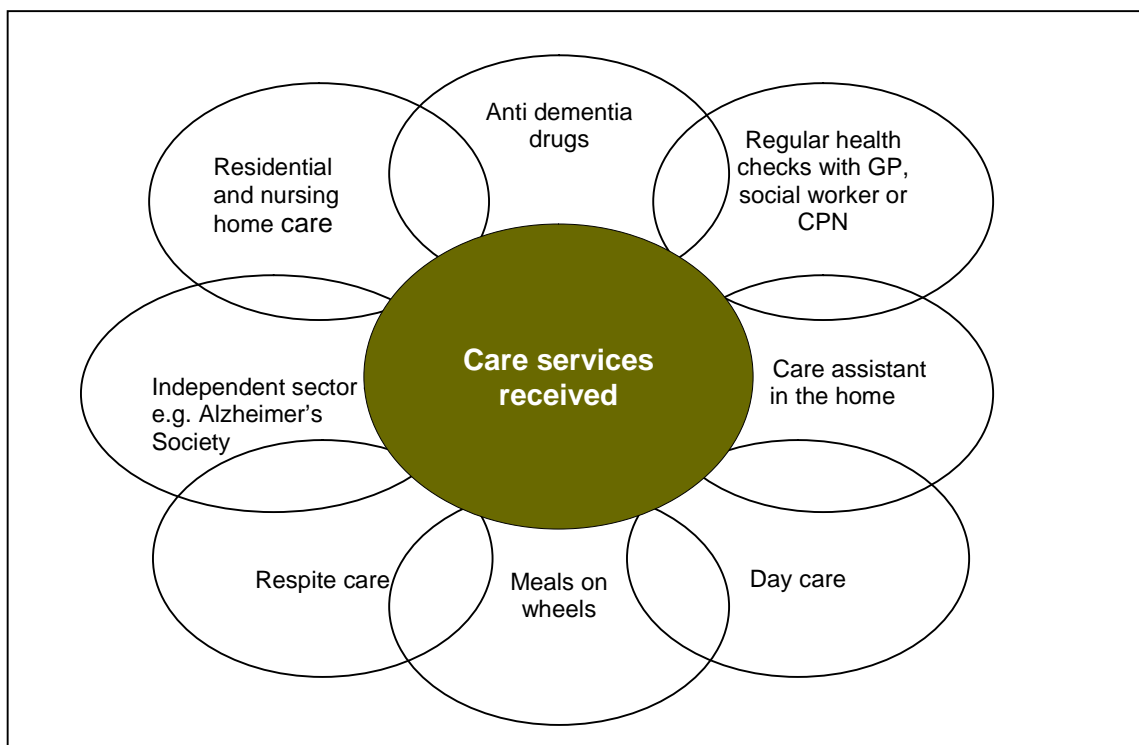
4.1 This section of the report provides detail on:

- The care services which group participants received; and
- The level of support provided to carers of people with dementia.

Care services received

4.2 A range of different care services were discussed, these are depicted in Figure 4.1 and then summarised in subsequent paragraphs. It is important to note that these snapshots of service provision are based on a small number of individual experiences within England.

Figure 4.1: Current care services



4.3 Focus group participants who were diagnosed with dementia, but still at the early stages of the condition, were not using a large number of services, instead they relied heavily on the support of their carer. All of these participants regularly received prescriptions for anti-dementia drugs and visited their GP and/or Consultant once or twice a year. These participants were also in regular contact with the Alzheimer's Society and frequented coffee mornings.

4.4 Participants who were carers of people with dementia identified a wider range of services being provided on a regular basis. These included: day centres / day hospital; care assistants

in the home; respite care; carer support groups; Alzheimer's café and meals on wheels.

Anti-dementia drugs

- 4.5 The supply of anti-dementia drugs to those diagnosed with dementia was regarded by many as a 'life line'. Generally, participants received a three month supply of their prescription drugs in the post. The provision of this medication was considered to be of utmost importance to each participant as they believed that this medication was prolonging the quality time which they could spend with their spouse or family.

It's a blessing for all those who are on medication now and we hope and we pray that it will be available for all those who are still waiting. Person with early stage dementia

- 4.6 Over the past few months, two carers had experienced the effect of their relative being taken off their prescribed drugs; these carers noted that this action resulted in a significant deterioration in the health of their relation.

My mum was on medication until a month ago – there has been such a big deterioration since she came off it. Carer aged between 18 and 44 years

- 4.7 All participants strongly voiced their concern in relation to the recent news that anti-dementia drugs may not be provided to patients who are at the early stages of dementia. For these participants, the early stage was the important period to receive such help as they believed it prolonged the time the individual could maintain and continue a 'normal' life.

Regular health checks with GP, social worker or CPN

- 4.8 All group participants stated that they or their relative had contact with health professionals at least once a year. The level of contact varied depending on the type and stage of the disease. For some participants they were in more regular contact with their Social Worker and/or CPN than their GP or Consultant.

I meet once a year with the Consultant. Every 3 months I get my Aricept prescription but apart from that I don't bother anyone. Person with early stage dementia

I only see one person a year. In and out in 10 minutes. Person with early stage dementia

Care assistant in the home

- 4.9 None of the participants in the focus group with early stage dementia had experience of using care assistants in their own home.
- 4.10 In total 4 carers stated that they were assisted, on a regular basis, by a care assistant in the home. These care workers provided one or more services such as the provision of medicine, washing of the person with dementia, assisting the individual into / out of bed, preparation of meals etc.

My wife was offered a carer who would come into the home to help, but she refused. In the end I insisted. Carer aged over 45 years

- 4.11 Although these carers were grateful for the help provided by care workers there were aspects of this service which they felt could be improved, such as:

- Increased dementia care training for care workers;

- Timing of visits scheduled to suit the needs of the individual and not when it suited the service provider;
- Minimisation of the number of different care workers attending. In certain cases, a lack of consistency in the continuity of care worker caused distress to some people with dementia and their carers;
- Limiting the use of temporary care workers. Although participants understood that in some cases resources are tight and temporary care workers are necessary, participants noted that there is often a lack of dementia care training for these workers. In addition, on some occasions, a few participants indicated poor attendance by such staff. Participants also identified that the majority of temporary workers do not speak fluent English. It was indicated that this could be both upsetting for the person with dementia but also frustrating for the carer because it can hamper communication with the care worker about the individual's needs; and
- In general, carers would welcome a smaller team of care workers who visit their home so that both the person with dementia and themselves can build relationships with the care worker.

A care worker comes three or four times a week to wash and get him ready for bed. Carer aged over 45 years

The lack of continuity in the care staff that visit my mum to give her medication confuses her. Carer aged between 18 and 44 years

Day care

- 4.12 Day care was regarded as important service provision for both the individual who had dementia and also for their carer.
- 4.13 In general, it was the focus group participant's mother or father who attended day care. A few participants had organised in the region of four days day care attendance for their relative whilst others were limited to either one or two days a week.
- 4.14 Provision tended to be either local health and social care services or the independent sector, with the Alzheimer's Society being most commonly identified as a key provider for the latter category.
- 4.15 Group participants were very positive towards the day care facilities provided by the Alzheimer's Society stating that their relative was involved in various activities such as gardening, painting and walking. These carers noted that their relative enjoyed doing these types of activities and was content to attend the day care centre on a regular basis.

I go and it's fantastic. I'm interested in gardening and I help others to do gardening at it. We all help each other. Person with early stage dementia

I got support for me and my mum from the day centre – it gives her a reason to get up in the morning. Carer aged between 18 and 44 years

Meeting others in my own area who also have dementia. A network of others. It's like going into the garden and someone has put a wonderful plant in. Person with early stage dementia

- 4.16 Participants were not as complementary of their experience of day care provision provided by

local health and social care services providers. This was indicated to be due to the lack of range of activities for service users to get involved with.

I know of a number of people who have stopped going to day care because they were getting depressed because all they did all day was sit in front of the TV. Person with early stage dementia

- 4.17 Two group participants noted the lack of suitable activities and companionship for younger people with dementia. These participants were carers to their husband both of whom were in their late fifties and they found that the day care focused on people aged 70 years and over.

Respite care

- 4.18 The provision of respite care was regarded as invaluable for a number of carers who provided full-time care to their spouse or relative. This service enabled them to rest and in some cases to spend valuable time with other family members such as their wife/husband and children.
- 4.19 Many of the carers felt that respite care should be more readily available and more flexible to suit their needs.

I get some private help at the weekend but this is an area, alongside respite care, that is lacking at present. Carer aged between 18 and 44 years

Meals on wheels

- 4.20 One participant organised 'meals on wheels' for their male relative and was very grateful for this service, as without it she believed he could not continue to live on his own.
- 4.21 However, this carer would have liked to see more flexibility in the times that meals were delivered. In her relative's situation, he was woken early for his breakfast, which was delivered at 6am, making it a very long day for him.

Yes, I told them that we needed help at breakfast time and they provided it, but I had to accept that it was at a time to suit them and not us (6am). Carer aged over 45 years

Independent sector e.g. Alzheimer's Society

- 4.22 The Alzheimer Society was regarded as an important support mechanism for both those with dementia and carers. It was recognised as the main source of information and for many their key point of contact to discuss problems or be signposted towards additional services which they were previously unaware of.
- 4.23 The day care facilities provided through the Society¹¹ were considered to be valuable in terms of maintaining a quality of life for people with dementia and also to provide a forum for them, and indeed their carers, as well as an opportunity to meet other people in a similar position. It was recognised that it is through these meetings that many individuals obtain essential information about the services available in the local area, benefits and financial planning for the future and how the disease progresses.

¹¹ The Society provides regular trips to sports centres where there are special activities, for the 60 plus age group, walking sessions, badminton and swimming are also arranged. In addition, day trips are organised to see steam trains and for foot massages and dancing classes.

The Alzheimer's Society provides discos, outings, dances, memory group meetings, Mencap discos, meals – we swap experiences; without them I would be lost. Carer aged over 45 years

The ladies at the Society are great, they provide me with respite beyond their 'working' hours – they took my mum for a pub lunch while I had a break one weekend. Carer aged between 18 and 44 years

Residential and nursing home care

4.24 Two participants in the group with carers over 45 years old indicated that their relatives received full-time care – one was in a residential home and one was in a nursing care home. Two participants in the young carers focus group also indicated that their relatives received full-time care – one was in a care home and one was in a nursing home.

4.25 One carer indicated that her greatest fear was that her relative be moved from the care home into an ordinary ward in a hospital setting. Another carer also expressed dissatisfaction at not having any input into the decision on which home their relative was placed in.

They don't feed them and let them lie because they don't know how to deal with them. Carer aged over 45

4.26 A focus group participant suggested that smaller care homes would provide a better service to people with dementia as in their view people with dementia could have a more personalised and dignified service.

Some people are in shared rooms because if they can't afford the fees for a full place, the residential home charges them half the fees and puts them in a shared room. Carer aged 18 to 44 years.

Carer input into the care provided for their relatives

4.27 Most carers regarded themselves as the co-ordinator of their relative's care provision. They liaised, where appropriate, with the Alzheimer's Society, NHS and social care to arrange the level of care required. In most instances, the level of care provided outside of their own role in their view was insufficient to suit the carer's individual needs and wider family commitments.

The carer is the co-ordinator – only I know what goes on each day. Carer aged between 18 and 44 years

4.28 On the basis of the participant's experiences, it was usually a Social Worker or CPN who directed the carer to the services available in their area and identified the person they should contact. This was often also supplemented by information from the Alzheimer's Society.

4.29 The provision of day care facilities, respite care and care workers in the home were regarded as essential for most carers, however, in many cases the carer did not have any input into when these services would be delivered to suit the needs of the person with dementia and themselves. It was felt that the provision of these services were not tailored to accommodate their or their relative's needs but instead to suit the provider of these services.

I didn't get to choose the home he went to – no input into it. Carer aged over 45 years

Carer support

- 4.30 The majority of carers stated that they were not fully involved during the diagnosis stage for dementia and also felt very excluded and alone when coming to terms with the diagnosis and initiating next steps to assist the person diagnosed with dementia.

If anything has happened to date, it is because I have pushed it, fought for it, found out about it. Carer aged between 18 and 44 years

There is no support for the carer – the emphasis is on the person you are looking after and you really feel forgotten about – except for the carers group. Carer aged over 45 years

When your husband is diagnosed so young (59), you suddenly realise that you've lost your future, you need support to come to terms with this. Carer aged between 18 and 44 years

- 4.31 A number of participants were members of a carer support group. All of these participants viewed this service as invaluable as it provided them with an opportunity to meet other carers and to use this forum as a source of information to discover other facilities and services available in their local area.

Carer's assessment

- 4.32 Only a small number of the carers of people with dementia, who we consulted, were aware of the availability of a carer's assessment of need. These participants had vague recollections about the process, and identified their Social Worker or the CPN as the professional who conducted the assessment.
- 4.33 In these few cases, it was indicated by the carer participants that the assessment did not improve the service provision they received due to a lack of resources in the local area. None of the carers indicated receiving a satisfactory outcome / follow-up subsequent to completing the carer assessment process.

The CPN sat down with me and worked through our requirements but she is struggling to find something suitable because the resources are just not there. Carer aged between 18 and 44 years

No, I feel that it's a 'cover your back' exercise. Carer aged between 18 and 44 years

Yes, but limited help was available. There are no resources for the needs identified. But it is still reassuring that someone else agrees that we need help – I thought I was going mad! Carer aged between 18 and 44 years

Section summary

Current care services used

- The current range of services used include: prescriptions for anti-dementia drugs; attending GP and/or Consultant once or twice a year; Alzheimer's Society events such as coffee mornings; day centres / day hospital; care assistants in the home; respite care; carer support groups and meals on wheels.
- All carers regarded themselves as the key co-ordinator of their relative's care provision. They would liaise with service providers to arrange the level of care required.
- The provision of day care facilities, respite care and care workers in the home were regarded as essential for most carers.

Carer input

- Carers would like more flexibility in relation to the delivery of services.

Carer support

- Generally, carers indicated wanting more involvement the diagnosis stage and consultation with healthcare professionals.

Carer's assessment

- Whilst there was some experience of the carer assessment process, none of the participants indicated receiving a satisfactory outcome/follow-up subsequent to completing the process. Participants believed that this was due to a lack of resources in their local area.

5 Key findings – main issues and future changes/improvements

5.1 This section of the report details:

- The issues that affect individuals with dementia and carers of people with dementia; and
- Views in relation to desired future changes to service provision.

Issues that face those with dementia and carers

5.2 Group participants were asked to identify and discuss the main issues for people with dementia and carers of people with dementia. Issues that were discussed are identified in Figure 5.1 and are then summarised in the subsequent paragraphs. It is worth noting that a number of the areas identified were highlighted by participants when they were talking about the range of services they received, as associated issues or concerns were often also discussed at this stage, and therefore some of the detail that follows is also reflected to varying degrees in the *Key findings – type of care received* section of this report.

Figure 5.1: Issues that face those with dementia and carers

How dementia affects families and friendships	Health professionals not involving the carer	Point of contact	Inconsistency of care workers in the home
Lack of understanding amongst the general public and health care professionals	Lack of respect for patients/service users	Anti-dementia drugs	Money – coping financially
Lack of awareness of services available	Monitoring of progress / health of person with dementia	Lack of specific training for staff to work with people who have dementia	Provision for young people with dementia

How dementia affects families and friendships

5.3 Participants with dementia recalled how subsequent to their diagnosis they experienced changes in the way some of their family members and friends treated them. This greatly affected their social life and resulted in instances of them, and their spouse, not being invited to certain occasions. For one participant, this resulted in not being able to go on holiday with a couple they regularly travelled with.

5.4 It was considered that this attitude was solely due to a lack of understanding and the stigma that many people have towards mental health conditions, such as dementia. Those with dementia noted that these attitudes were upsetting for both their spouse and themselves. This behaviour resulted in some of these participants feeling very alone and excluded from their previous lifestyle.

It affects your friends, family and others. Person with early stage dementia

The stress of the situation causes conflict in home and family life – I became confrontational with dad through frustration. Carer aged between 18 and 44 years

It causes stress on family life – friction between siblings: 'it's your turn to go and see mum/dad'. Carer aged between 18 and 44 years

- 5.5 In some situations participants with dementia were frustrated by the actions of their carer where they tried to act on the service user's behalf for example answering questions not directed towards them.

For people to realise that you're still a human being and you have rights. Also for the carers to stop being overpowering and overbearing to those with dementia. Person with early stage dementia

Lack of understanding amongst the general public and health care professionals

- 5.6 All participants had been frustrated at one point in time with the lack of understanding amongst the general public but also amongst health care professionals, in relation to the symptoms of dementia.

- 5.7 The individual with dementia, and indeed the carer, both identified this period as a very difficult time when they felt despair, isolation, and for the carer in some cases doubting their own sanity as they felt no-one was listening to their views.

One of the things we experience is people's disbelief that you have dementia because you're appearing normal. It's so frustrating. Person with early stage dementia

The local GP is the first point of contact with the system – they have to be the one who has the specialised knowledge first – if you can't convince him there's a problem, there is no chance of going any further. Carer aged between 18 and 44 years

Lack of awareness of services available

- 5.8 Poor awareness of the services available in the local area was considered to be an issue, with a large proportion of those with dementia and carers alike not aware of all of the services available.

- 5.9 This appeared to be a greater issue for those who had early stage dementia. Although these individuals felt at the current point in time that they did not necessarily require any further services, they were concerned about their future and the options that may be available to them and especially if their carer was not able to look after them.

Health professionals not involving the carer

- 5.10 A further issue for most carers was their lack of involvement with health and social care professionals, in particular check-up meetings with GPs and Consultants. In general, they perceived their role as sole carer essential to fully inform the relevant professional about their relative and current progression of their dementia.

- 5.11 In addition, carer involvement within the diagnosis stage and the provision of care services was highlighted to be important to ensure that carers were fully aware of their relative's condition and associated needs.

Lack of respect for patients/service users

- 5.12 This was an issue mainly for the carers consulted within the focus groups. These participants were of the opinion that, in certain instances, the health and social care professional staff their relative encountered treated them with little respect and sympathy.
- 5.13 A number of participants could recall their relative's diagnosis and the blunt approach which was taken by professional staff when delivering this diagnosis. These participants felt that health and social care professionals should be more sympathetic in the delivery of such news as the diagnosis has serious implications for future lifestyles, choices and relationships.

When we went to get the test results, the Professor at the hospital said to my husband, 'I'm afraid Charles, you have lost your marbles'. Carer aged over 45 years

They speak to him like a child: he's not a child! He has a condition. Carer aged over 45 years

All our relations are 'jobs' – we are the only people who actually provide 'care' for them. Carer aged over 45 years

Monitoring of progress / health of person with dementia

- 5.14 The lack of formalised monitoring of people with dementia in day hospitals, nursing and residential homes and when in respite care was an issue that many carers would have liked to have seen addressed. For those carers whose relative used these services, they would have liked to have received more information from staff to allay fears of their relative not eating their meals or refusing to be washed or changed. Group participants noted that this level of monitoring would alleviate many of their concerns, and for some carers, would encourage them to use for example respite care provision more often.

I would like to see rosters of his treatment, so that I know when he has been fed, when he has been changed – it would be really reassuring. Carer aged over 45 years

Point of contact

- 5.15 In many instances carers felt very alone and confused as to who they should contact to source further information and/or care services. A number of carers had already successfully established a single point of contact, this tended to be either a social worker or a CPN. These individuals found this support invaluable towards enabling them to cope with the responsibilities and pressures of being a full-time carer.
- 5.16 Those carers who had currently not established such links felt isolated and poorly informed about the service provision both for their relative and themselves.

Lots of times you are floundering – you don't know who to talk to. Carer aged over 45 years

Anti-dementia drugs

- 5.17 Group participants, who were diagnosed with dementia, were at an early stage of this disease and believed that anti-dementia drugs were slowing the progression of their disease and improving their current quality of life.
- 5.18 Many participants were concerned about the recent guidelines from NICE that the NHS should not fund prescription drugs for those with early stage and mild forms of dementia. This decision was regarded as unfair by all participants, who felt it should be reconsidered in terms of the implications for the quality of life for many people with dementia.

Lack of specific training for staff to work with people who have dementia

- 5.19 Some participants highlighted the lack of trained staff with the skill and knowledge of how to care for those with dementia. This issue was felt to be particularly acute with temporary care workers in the home and health professionals within NHS hospital wards.

If my uncle wouldn't take his food, then they ticked that box, rather than working with him to encourage him to eat. Carer aged over 45 years

- 5.20 Personal experiences within general hospital wards led participants to believe that the quality of care provided to those with dementia was at times not to the standard required and should be redressed through dementia care training for staff.

Medical and nursing staff from 'ordinary' wards do not understand – my biggest fear is that they (relative with dementia) will be taken from the care home and end up in a normal ward, where the staff don't know how to provide the level of care that they need. Carer aged over 45 years

Catch the students early who are going to deal with people with dementia and train them specifically about this. Person with early stage dementia

Some professionals have the attitude that dementia is 'just memory loss and just forgetting things'. But there is a behavioural side of things too – they need a specialised knowledge and understanding for this. Carer aged between 18 and 44 years

- 5.21 In addition, a number of participants highlighted long waiting times for doctor appointments as an issue as waiting can agitate many dementia service users and can cause considerable unrest and upset.

Alzheimer's sufferers cannot sit for a long time, they get agitated – hospital staff do not consider this when we have to wait for a long time in waiting areas before appointments. Carer aged over 45 years

Inconsistency of care workers in the home

- 5.22 Participants had encountered on occasions a constant influx of care workers as they were temporary staff, and this lack of continuity in care provision was often indicated to be distressing. Problems around communication where English was not the primary language of care workers was also highlighted.

I get care workers who do not turn up when they are meant to and who then ask me to sign that they have attended regularly – I have signed on occasions because I have been scared. Carer aged over 45 years

Money – coping financially

- 5.23 The financial constraint of being a full-time carer to a close relative, who has been diagnosed with dementia, was identified as a major issue particularly by younger carers. These individuals often found themselves in a situation where they had to leave their job and sacrifice their pension and job security to look after their spouse or parent.

- 5.24 For many of these individuals who had other family responsibilities, this left them in a stressful and uncertain position, as well as worrying about their future financial situation.

We had to give up our home, car, job etc because we still had 10 years to pay on our mortgage and he couldn't work. Carer aged between 18 and 44 years

We worked all our lives and now we are on benefits - you lay your whole life bare – you become completely vulnerable. Carer aged between 18 and 44 years

I feel like a second class citizen now that I have to live on benefits. Carer aged between 18 and 44 years

It's an illness like cancer – why do people have to pay? They are ill. Carer aged over 45 years

Provision for young people with dementia

5.25 The lack of provision for people with dementia who are aged between late forties and late fifties was a big issue for their carers. In these instances, carers indicated feeling guilty for organising for their spouse to attend a day care facility which was predominantly used by dementia service users aged 70 years and over.

My wife said to me, 'Why am I going out with very old people?'. Carer aged between 18 and 44 years

Prioritising issues

5.26 As part of the focus groups that were undertaken, participants were asked not only to identify issues but also to prioritise them. The most commonly identified issues for priority action, by type of focus group undertaken, were:

People with early diagnosis dementia

- The length of time taken for a correct diagnosis to be given and providing appropriate treatment as soon thereafter; and
- Ensuring, where possible, that the care provided enhanced the ability of the person with dementia to maintain a level of independence.

Carers

- The lack of support experienced throughout the diagnosis stage including interaction with healthcare professionals;
- The financial constraints of caring and being prepared for coping with the effect that providing full-time care can have on a marriage and family relationships;
- The lack of a single point of contact to discuss problems and source further information; and
- Carers of those with dementia, who were now cared for in a residential or nursing home or a hospital environment, also highlighted the lack of specific dementia care training for a number of staff in these organisations.

Future Improvements

- 5.27 Participants with early stage dementia were asked to describe their ideal care service. The response included a service which provided a prompt diagnosis and listened to people with dementia and put them at the centre of the care.

There is a lot of talk about “patient-centred care”. It’s about making that real, putting the person at the centre and making them feel valued, loved and living their life as independently as possible. Person with early stage dementia

The biggest service the NHS could do is to listen to people with dementia. Person with early stage dementia

- 5.28 In addition, participants identified an ideal service as helping the person with dementia to plan for the future when their health does deteriorate.

Aware of what would be there for you in the future which would kick in when you need it. Something flexible.... need a system which copes with a range of needs rather than fitting you into a box which suits them. Person with early stage dementia

We all want independence. We want to lay the foundations so when it comes that we can’t cope the services can come in. Until we need that we remain independent. Person with early stage dementia

- 5.29 All participants (i.e. both people with early stage dementia and carers) were asked to identify changes that they would like to see in the way services were provided in the future. The following areas for improvement were suggested:

- Improvement in the length of time until diagnosis;
- Information provision, however not information overload;
- Both those with dementia and carers would like to have a single point of contact. This person should be fully trained to deal with people with dementia and their role should involve providing advice, support and information about the services that may be required in the future once the condition progresses;
- Increased Government funding. All participants would like to see increased funding for mental health services in the future. They would like to see the funding targeted towards the recruitment of more staff, dementia care training and increased number of staff on wards, care homes and at day centres;
- Staffing - all participants would like to see more staff at day centres, care homes, respite care and on general wards and with appropriate training and experience in dementia. More male CPNs were also identified as being required.
- Joined up approach of service provision – single point of contact for carer;
- Improved flexibility in the delivery of care;
- Increased availability of respite care;
- Continued provision of anti-dementia drugs;
- Improved consistency in the care workers providing services and also smaller care wards

and single occupancy in care home rooms;

- Provision of tailored services for younger people with dementia; and
- Easy to complete application forms for applying for services / benefits; and
- Increased knowledge and awareness of dementia amongst the general public.

Carers

5.30 The following carer specific improvements were raised:

- Increased carer allowance;
- Provision of training for carers to help them deal with their new role e.g. a training day. This training may cover areas such as anger management; and
- Carer support group.

New services

5.31 Participants were asked to identify two new services / support that they would like to receive, the following suggestions were made:

- A free telephone number to call; 24 hour point of contact, operated by an experienced dementia nurse;
- A tailored care provision for younger people with dementia;
- Carer support groups through health and social services;
- One point of contact for all those with dementia and their carer;
- Non-profit making care homes;
- CCTV cameras in care homes;
- Tagging of people with dementia; and
- Representation of someone with early stage dementia at all policy meetings.

Provision of support services out of hours. Carer aged between 18 and 44 years

It would have been nice to have had someone at the end of the doctor's consultation where diagnosis was given to provide further information and continue the discussion about what it means to the individual. Person with early stage dementia

Section summary

Issues facing those with dementia and carers for people with dementia

- Early diagnosis, continued treatment and independence were the top priorities for those participants who had dementia.
- Carers for people with more developed forms of dementia prioritised the lack of professionals trained properly to deal with dementia as a key issue.
- The provision of carer support through organised support groups was also advocated by the majority of carer participants. In addition, carers identified the need for them to have more input with the GP / Consultant and to the service provision for their relative.
- The top two issues identified by young carers were the financial constraints of caring and more support in preparing for and dealing with the effect a caring role can have on other family members and relationships.
- For older carers whose relative lived at home with them, their main issue was the lack of a single point of contact to discuss problems and source information. Carers, for those who were in a care home or hospital environment, would like staff in these organisations to receive more dementia care training in line with their roles and responsibilities.

Future improvements

- A range of improvements were identified, many of which reflected addressing the issues that had been identified by focus group participants, for example:
 - a quicker diagnosis for people with dementia;
 - a single point of contact for all dementia service users and their carers;
 - increased Government funding for additional staffing and development of further services;
 - sufficient dementia care training for all healthcare staff; and
 - formal carer support groups.

6 Initial recommendations for discussion and further consideration

- 6.1 Based on our research findings we would propose consideration be given to the recommendations listed below. It should be noted that these are based on a small number of views and should therefore also be considered in light of the findings from the additional aspects of work being undertaken by the NAO into services for older people.
- 6.2 Whilst the information gleaned from the participants in the focus groups undertaken is useful in providing very powerful and important instances of practical experiences of service provision and dealing with the effect of a dementia diagnosis on an individual and their close relatives, they are examples of a number of individual experiences. Without wider research and further discussion these findings and resultant recommendations should not be interpreted as being necessarily representative of all service user and carer experiences in relation to dementia service provision in England.

Recommendations:

- Promotion of a timely diagnosis process with specific training to assist GPs in achieving a correct diagnosis as early as possible;
- Specific dementia care training for health and social care staff in line with their roles and responsibilities;
- Consider providing each individual with dementia with a single point of contact (this person would provide support and information to both the person with dementia and their carer);
- Information should be easily accessible through most health and social care professionals and available as soon as diagnosis has occurred. In particular, clear information should be provided in relation to the following areas as soon as possible after diagnosis:
 - Managing finances;
 - Preparation of wills;
 - Practical advice about finances and entitlements;
 - Information on how the disease will progress;
 - Information about local services; and
 - Information about services which are free and those that require a fee.
- Consider implementing local networks to enable carers to share their experiences, this could be through formalised carer support groups being in place;
- Provide tailored and flexible care services, in particular, to suit the needs of those aged 50 to 60 years who have dementia;
- Improve co-ordination and integration between service providers and the promotion of increased interaction between such providers and carers for individuals with dementia;
- Improved focus and support for the carer assessment process including the actual implementation of identified support to meet carer needs, for example phone support,

respite care, talking therapies etc;

- At Governmental level maintain an ongoing review of funding and latest research into the provision of dementia services;
- Review existing documentation and forms to apply for services and benefits to determine if simplification and further assistance in their completion can be provided; and
- Introduction of a programme to inform and improve the general public's understanding of the impact and effects of dementia.

