

Support. Stay. Save.

Care and support of
people with dementia
in their own homes

January 2011

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Foreword



My mum was well known for her bright and fiercely independent nature. This was something I had always admired and something, which even following a diagnosis of Alzheimer's disease was something I passionately wanted to help her preserve. Dementia is a cruel condition but I have seen for myself that it needn't be something which deprives a person of their quality of life. My mum was lucky. She had excellent support from some wonderful health specialists and a family who were more than happy to help. She was able to stay at home for much longer than would have been possible had she been forced to fend for herself.

As this report shows, my mum is not alone in valuing her independence. She is also not alone in having her quality of life vastly improved thanks to the help of others – paid and unpaid. However, what we are also seeing here is that this is not a universal picture. There are hundreds of thousands of people receiving insufficient support and this is having serious repercussions. Many people are having their health put at risk and being forced into hospital or care homes against their will. This is not only a personal travesty it also represents a huge financial burden which society cannot afford to take on, especially in these economic times.

Reassuringly, this report also demonstrates that there is a care workforce out there which really wants to do everything it can to help vulnerable people such as those with dementia. However, they need more training and more time and we need to mend the crumbling system within which they operate.

In this time of pressure on services and reduced budgets, there is a need to use money as effectively and efficiently as possible. Supporting more people with dementia to live independently in their own homes will achieve this. It will also help fulfil the aspirations of independence this report demonstrates many people with dementia hold very dearly. Alzheimer's Society has an invaluable role to play in highlighting the ways we can improve the lives of people with dementia.

I am honoured to be supporting this report and look forward to seeing the changes it will inevitably help bring about.

A handwritten signature in blue ink, reading 'Kevin Whately'.

Kevin Whately, Alzheimer's Society Ambassador

Executive summary

1 Summary

There are 750,000 people living with dementia in the UK, two-thirds of whom live in their own homes in the community, while one-third live in care homes. Dementia costs the UK £20 billion a year and these costs will rise as the number of people living with dementia increases.

The health and social care response to dementia has been inadequate and has not delivered good quality care. Dementia therefore provides a key opportunity for improving outcomes and value for money from spending. However, this will only be achieved if significant focus is given to supporting people with dementia to remain at home for longer and out of long-term and acute care.

Maintaining independence and quality of life are of key importance to people with dementia. Support and care received by people with dementia and their carers must be focused on empowering people with dementia to achieve these aspirations.

Half of people with dementia and carers who responded to an Alzheimer's Society questionnaire reported that the person with dementia is not receiving sufficient support and care. Over half of carers are not getting enough support to carry out their caring role.

There are significant perceived negative repercussions when people with dementia and carers do not receive enough support. Insufficient support is thought to lead to an exacerbation of needs and is frequently believed to result in avoidable admission to hospital and early admission to long-term care.

There are significant perceived benefits when people with dementia and carers do receive sufficient support. Sufficient support is thought to delay admission to long-term care and has benefits for physical and mental health.

People with dementia and carers access a range of services, but there is little evidence of expansion in use of these services compared to 2008. Access to support and care services needs to be expanded to enable people with dementia to maintain their independence and a good quality of life.

The need to make financial savings also presents an opportunity for service reform and redesign. However, co-ordination of care of people with dementia and carers remains variable and there are concerns about the impact of cuts on the provision of dementia care.

Home care workers who responded to the questionnaire recognise that people with dementia can have a good quality of life. However, many care workers say they need further training and support.

2 Purpose of the report

This report provides evidence from over 2,000 carers, people with dementia and home care workers on the aspirations, experiences and outcomes of providing dementia care in the community in England, Wales and Northern Ireland. The evidence and recommendations are for commissioners and service providers and are intended to support good practice in meeting the needs of people with dementia living in their own homes.

3 Methodology

Alzheimer's Society collected quantitative and qualitative evidence via questionnaires to the following groups:

- people with dementia and carers – 1,436 responses received, 48 from people with dementia
- home care workers – 989 responses received.

The Society conducted small group discussions and one-to-one interviews with people with dementia and carers. Interviews with commissioners, social workers and Alzheimer's Society service managers were also conducted to inform the report.

4 Key findings

4.1 Aspirations for support and care

- 83% of carers and people with dementia who responded to the questionnaire said being able to live in their own home was very important to the person with dementia.

- 59% of carers and people with dementia who responded believe being active in the community is very important to people with dementia.
- People with dementia and carers who responded to the questionnaire and participated in interviews and group discussions rate maintaining independence, along with remaining active and engaged as being key desired outcomes of services.
- There is significant variety in people's responses about the type of services people with dementia and carers think could most help people with dementia.

4.2 Outcomes for people with dementia and carers

- 50% of carers and people with dementia who responded to the questionnaire say the person with dementia is not receiving sufficient support and care to meet their needs.
- There are significant perceived repercussions for both the carer and the person with dementia from not receiving sufficient support and care, including early admission to long-term care and avoidable admission to hospital.
- 52% of respondents report the carer is not getting sufficient support to enable them to carry out their caring role. There are significant repercussions, especially for carers' physical and mental health, resulting from them not receiving enough support.
- Where respondents report the person with dementia receives sufficient support, there are significant perceived benefits, including benefits for mental and physical health and delayed admission to long-term care.
- There are close correlations between whether the person with dementia has received enough support and care and a range of other results including co-ordination of services, whether the person with dementia has received enough support from the NHS and whether carers are getting enough support to carry out their caring role.
- Access to diagnosis and assessment can be barriers which prevent people with dementia and carers receiving sufficient support and care.

4.3 Services used by people with dementia and carers

- People with dementia and carers are receiving support and care from a range of services, however there is little evidence of expansion in service provision compared to 2008.

- Satisfaction with services received by people with dementia and carers is generally high. However, expansion in access to services is needed, especially for carers.
- Home care workers responding recognise that people with dementia can have a good quality of life, but find working with people with dementia quite challenging.
- Home care workers who spend more time providing care to people with dementia than other home care workers are more likely to say this is enough time to provide good quality care.
- Home care workers recognise the importance of training to providing good dementia care, but many feel they need more training on dementia care, especially around recognising pain in dementia and responding to challenging symptoms.
- There remains a need to expand access to personal budgets among people with dementia.
- Co-ordination of care is still perceived to be an issue for many respondents.

Recommendations

Recommendation 1. There must be an urgent and concerted effort to support people with dementia to live independently in their own homes and avoid early and unnecessary admission to long-term care.

People with dementia and carers responding to the Alzheimer's Society questionnaire report that supporting people with dementia to remain independent at home should be the critical aspiration for the services they receive. 83% of respondents said being able to live at home was very important to the person with dementia and 59% say being part of the community is very important to people with dementia.

- Outcomes frameworks in health and social care must be considered in the context of dementia. Frameworks must consider the desired aspirations and outcomes of people with dementia, rather than simply looking at care and support needs in their narrowest sense.
- People with dementia should have holistic, personalised support plans, covering health, social services and aspirations identified in needs assessments. Support plans must be reviewed regularly and must adapt to changing aspirations of people with dementia.

- People with dementia and carers should have access to a range of different types of services, including prevention, early intervention, reablement and intermediate care services. Wherever feasible, those referring or signposting people with dementia towards other services should consider how to facilitate giving them a choice of services. This should include the use of independent advocacy services.
- Barriers to people with dementia accessing mainstream health and social care services, such as restrictive eligibility criteria, should be removed and professionals in social care should not make assumptions about what services people with dementia and carers may benefit from.
- Commissioners and those managing individual's support plans must seek to scope the support and care services that exist in their area and to which people with dementia could be signposted or referred. The results of these scopes should inform referral and signposting decisions.
- Dementia represents the biggest challenge to aspirations and targets for expansion of access to personal budgets. Commissioners should consider commissioning brokerage and advocacy services to facilitate and empower access to personal budgets among people with dementia. Staff training should challenge preconceptions that people with dementia cannot use or benefit from personal budgets.

Recommendation 2. Commissioners should recognise the considerable resources already being spent across health and social care on dementia and the opportunity to use them more effectively.

There are 750,000 people living with dementia in the UK, with a total cost to the economy of over £20 billion. Current hospital and long-term care costs resulting from dementia are unsustainable and represent a significant opportunity for resources to be used more effectively while achieving better outcomes.

- Because of the challenge dementia represents, health and social care commissioners should prioritise significant spending on community dementia services, especially early intervention and reablement. In England a significant proportion of the additional £2 billion funding allocated to social care needs to be spent on dementia to deliver better outcomes.
- There is an urgent need to review whole system costs for dementia to assess how resources are being spent and where they could be used more effectively.

- Commissioners should consider the financial and social benefits of providing support for people with dementia and carers, including savings from reductions in pressure on long-term care and acute services. In England, the opportunity improving dementia services represents must be considered as part of the Quality, Innovation, Productivity and Prevention (QIPP) workstreams.

Recommendation 3. Carers must be supported to carry out their caring role.

Only 37% of respondents report that carers have had an assessment of need and 52% of carers are not getting sufficient support to enable them to carry out their caring role.

- Implementation of carer's strategies must be prioritised, as outlined in national policies such as the National Dementia Strategy for England and Welsh Assembly Government Action Plans.
- Appropriate staff working in the NHS and social services who come into contact with carers must provide information on their right to ask for a separate carer's assessment.

Recommendation 4. Joined-up working across health and social care must become the norm if people with dementia are to be supported to remain independent in their own homes.

Only 26% of respondents said they thought services worked well together. Those responding who said support was insufficient and did not meet needs reported negative repercussions on the person with dementia and carer's physical and mental health.

- Joined-up diagnosis and assessment services must be put in place to ensure early detection and intervention, which can be crucial in enabling people with dementia to remain at home for longer.
- NHS and social care should look at ways of promoting joint working above and beyond commissioning, including joint training and multi-disciplinary team working.
- Local joint dementia strategy implementation plans or joint dementia action plans should be produced by health and social care commissioning bodies in England, Wales and Northern Ireland. These should be made publicly available and accessible so local communities can hold local authorities and NHS commissioners to account.

Recommendation 5. Variable experiences of care and support should be tackled through expanded sharing of good practice.

Whether respondents feel care and support is sufficient is closely related to: support for carers, support from the NHS, provision of information and support and whether respondents think services are joined-up.

- Mechanisms for sharing best practice in providing good quality dementia care have to be expanded and exploited. Levers for encouraging use of existing mechanisms for sharing best practice, such as the Social Care Institute for Excellence (SCIE) Dementia Gateway, should be explored.
- People with dementia and carers should be involved in monitoring quality of care and support services. Where possible, such monitoring should involve more in-depth forms of feedback to ensure issues and criticisms are identified and the opinions of those with more advanced dementia are not excluded.

Recommendation 6. Home care workers must be supported to provide good care to people with dementia in their own homes.

Dementia is core business of home care agencies and a core responsibility of home care workers. 82% of care workers believe people with dementia can have a good quality of life, however care workers report they still need more training on providing good dementia care.

- All home care workers should receive comprehensive training on dementia care which allows them to provide care that meets the needs and aspirations of people with dementia.
- The amount of time home care workers spend with people with dementia should be based on whether it is sufficient to meet needs and aspirations, not on rigid time or task-based schedules. Contracts, commissioning and practice should be designed to achieve this.
- Providers of training for home care workers should consider the results of this survey in the development of new or existing training courses. Dementia specific training courses, such as those developed by Skills for Care, should be promoted.
- Home care workers should be supported through close working with other health and social care professionals. They should be represented in discussions about people with dementia's support plans and their opinions on what is an appropriate amount of time to spend providing care to an individual should feed into decision making.

1 Introduction

1.1 Aim of the report

With two-thirds of people with dementia living in the community, the provision of appropriate support and care to people in their own homes is fundamental in order to meet the challenge of dementia. Good care in the community is better value for money than poor care, which often leads to expensive avoidable admissions to long-term and acute care.

However, the findings of this report demonstrate that many people with dementia and their family carers do not have access to sufficient care and support to meet their needs. These findings show that insufficient support and care often results in significant negative consequences for individuals, but also to substantial avoidable costs across the health and social care system.

With the current emphasis on reducing spending and shifting responsibility towards local leadership, accountability and delivery, this report is aimed at local commissioners and managers of service providers. It seeks to:

- provide evidence for commissioners and providers about the aspirations of people with dementia and their carers for care at home
- give an indicator about service use, satisfaction and staff understanding of dementia to inform future service development
- provide clear evidence regarding whether the needs of people with dementia and their carers are currently being met by the support and care they receive, in order to act as a catalyst for improvement and expansion.

The report also presents evidence that significant savings could be found across budgets by provision of better support of people with dementia at home. This is especially pertinent in the current climate of reducing costs and releasing savings across the NHS and social care.

It is also hoped this report will inform and energise the scope of public and political consideration of people with dementia among opinion formers, and help shift the public debate towards how we can best enable people with dementia to live good quality independent lives.

1.2 The current context of dementia

There are 750,000 people living with dementia in the UK at a total cost to the UK economy of £20 billion per year. The number of people living with dementia and the total cost are set to rise rapidly as the population ages.

Dementia is a progressive disease, however people with dementia can live for many years in their own homes after developing their condition. How long people have lived at home with dementia may impact on the support and care they need and also what services they have accessed.

Dementia has now been identified as a priority in England, Wales and Northern Ireland through the development and publication (or forthcoming publication) of strategies and action plans. In February 2009, the Department of Health in England published *Living well with dementia: a national dementia strategy for England (NDSE)*. In Wales, dementia action plans were published by the Assembly Government in May 2010 and in Northern Ireland a dementia strategy is expected to be published soon, following consultation on a draft strategy during summer 2010. These plans recognise the major societal challenge that dementia poses, and that services which do exist are often available too late, can be of poor quality and do not meet people with dementia's needs.

In England, the establishment of Dementia Action Alliance (DAA) has demonstrated commitment to improving the outcomes of people with dementia. The Alliance is made up of over 40 organisations which have signed the National Dementia Declaration and committed through the publication of action plans to improving the outcomes of people with dementia (DAA, 2010).

Across community and acute sectors, recent reports have highlighted the continuing significant challenge of dementia.

- Updated figures from Alzheimer's Society's 2007 Dementia UK report show that there are now 750,000 people in the UK with dementia and numbers are projected to rise to 940,000 by 2021 and over 1.7 million by 2051 (Alzheimer's Society, 2010a). Dementia UK also outlines that the financial impact of dementia is considerable, with current total UK costs of £20 billion per year (Alzheimer's Society, 2010a). The King's Fund has estimated the financial cost of dementia per year in England alone was £15 billion in 2008 and this was set to rise to £23 billion by 2018 if nothing was done to improve the cost-effectiveness of dementia services (King's Fund, 2008).

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- In 2007, the National Audit Office (NAO) report, *Improving services and support for people with dementia*, confirmed that dementia care services in England can lead to poor outcomes for people with dementia. The NAO also found that much of substantial government spending on dementia is focused on people in the later stages of the condition and does not represent value for money. The NAO stated that the provision of better quality dementia care represented an opportunity for releasing significant investment (NAO, 2007).
 - Alzheimer's Society's 2008 *Dementia tax* report found many people with dementia and carers were paying substantial amounts for care and few felt their needs were being met by social services support (Alzheimer's Society, 2008a).
 - Alzheimer's Society's 2008 *Home from home* report found many care homes were not providing good dementia care, with key problems including the provision of activities, treating residents with dementia with dignity and respect and the relationship between the care home and relatives/friends (Alzheimer's Society, 2008b).
 - The Commission for Social Care Inspection (CSCI) report, *See me, not just the dementia*, which was based on observation studies of people with dementia in care homes, found that even homes rated good or excellent were not often not providing good dementia care. The findings support the need for well-trained and committed staff providing person centred care in care homes (CSCI, 2008).
 - The All Party Parliamentary Group (APPG) on Dementia's 2009 report *Prepared to care*, outlined evidence that, as a whole, the social care workforce had a very limited knowledge of dementia and was not in a position to provide high quality dementia care (APPG on Dementia, 2009).
 - Alzheimer's Society's *Counting the cost* report found unacceptable variation in the quality of dementia care on general hospital wards. *Counting the cost* found people with dementia were staying in hospital longer than expected and reducing their length of stay through better quality care could yield hundreds of millions of pounds in savings (Alzheimer's Society, 2009a).
 - The All Party Parliamentary Group on Dementia report, *Always a last resort*, found that at least 100,000 people with dementia inappropriately prescribed antipsychotic medication (All-Party Parliamentary Group on Dementia, 2008).

- Professor Sube Banerjee's report on antipsychotic medication for the Department of Health, found only a quarter of those on antipsychotic medication benefited and laid out recommendations for a reduction in the prescription of antipsychotic medication by two-thirds (Department of Health, 2009). The government has committed to reducing prescription of antipsychotic drugs by two-thirds by April 2011.

The publication of strategies and plans is an important first step towards meeting the challenge of dementia that are outlined in these reports. However, the challenge will only be met through a rigorous approach to implementation, which evidence from England suggests this will be difficult.

- An NAO follow-up assessing progress towards implementing the NDSE found progress had been patchy and was slow to start. The NAO found a lack of leadership in dementia and insufficient system levers to increasing quality (NAO, 2010).
- The APPG on Dementia report, *A missed opportunity*, found many primary care trusts (PCTs) in England could not account for how they had spent their proportion of the £150 million earmarked to support implementation of the strategy. Furthermore, many PCTs had not produced joint plans with local authorities for implementing the NDSE despite a March 2010 deadline for doing so (APPG on Dementia, 2010).

1.3 Dementia in the context of support at home

The support available to people with dementia at home is broad, encompassing home (or domiciliary) care services (where carers provide support in people's homes), information and support services as well as NHS services and support.

There remains significant need for further development of community support and care services. Service provision is patchy with people with dementia and family carers often living with significant unmet needs, leading to avoidable crisis situations and costly admission to long-term care and hospital. This is despite increasing evidence about the benefit of earlier intervention in supporting people with dementia and carers to live well (Banerjee, 2008).

In recent years care services have been developing a new focus of supporting people to retain their independence in their own homes, with an emphasis on outcomes as opposed to prescriptive and task-orientated models of care provision.

This can be seen in the 2007 Putting people first concordat (HM Government, 2007), the Welsh Assembly Government's (WAG) social care strategy Fulfilled lives, supportive communities (Welsh Assembly Government, 2007a) and more recently in the Coalition Government's social care strategy Capable communities and active citizens (Department of Health, 2010a) and adult social care next steps agreement; Think local, act personal (Department of Health, 2010b).

There is clear evidence that this shift towards a more personalised approach is in line with the aspirations of people with dementia, who want to remain independent and engaged in their communities for longer (Department of Health, 2009; Alzheimer's Society, 2010b; Gutteridge, 2000).

There have been several reports in recent years highlighting the current state of support at home and outlining key challenges. Most of these reports have focused on home care services provided by home care workers, rather than more broadly at support at home in general.

- The CSCI report on home care, Time to care, found that home care services faced a significant challenge due to increasing restriction of provision for those with highest needs, difficulties recruiting and retaining skilled staff and increasing demands from service users around choice and control (CSCI, 2006).
- The Picker Institute report, Measuring dignity in care, written for Help the Aged, outlined key indicators of dignity in care but found limited evidence of existing indicators of dignity relating to home care (Help the Aged, 2008).
- The London Assembly Health and Public Services Committee report Home truths, found that older people in London often had to wait long periods to have their needs assessed and often lacked the information and advice they needed to guide them through the home care system. The Committee also found that growing pressure on budgets had restricted provision towards those with the highest needs (London Assembly, 2010).
- The Care Quality Commission (CQC) 2010 technical report on the adult social care market in England reported that there are over 5,500 home care agencies in England, of which 73% are privately run. The report outlined that on average, agencies met 87% of CQC standards in 2010 (CQC, 2010a).
- The CQC technical report on services purchased by local councils in England outlined that in 2008/9 £1 in every £4 spent by councils on social services for adults was spent on home care and that four out of five recipients of home care were over the age 65 (CQC, 2010b).

- The Care Council for Wales (CCW) 2010 report Care at home looked broadly at support at home in Wales. It outlined key challenges of supporting people at home: supporting the workforce, meeting aspirations for independence and choice, joint working across service boundaries, supporting carers and focusing on outcomes (CCW, 2010).

While there is some evidence of improvement in home care services, these reports show that the quality of these services is variable and patchy. They indicate a continuing lack of evidence about the experiences of people with dementia in relation to home care and support at home more generally.

Increasingly, there is work ongoing to improve the quality and experiences of support at home, through tackling existing challenges, developing the workforce and promoting joint working.

- The Dignity in Care Campaign, which works to end the tolerance of care services that do not respect the dignity of those using them.
- Skills for Care dementia care qualifications, which are part of Health and Social Care Diplomas in England and give care workers skills to provide good quality dementia care (Skills for care, 2010).
- The Department for Work and Pensions Link Age Plus pilots. These have demonstrated co-ordinated working across statutory agencies, voluntary and community groups, and that local and national government can provide accessible joined-up services for older people. Positive outcomes for individuals from pilots include tackling social exclusion and discrimination and benefits in terms of physical and mental health of older people.
- Partnership in Older People's Projects. These Department of Health funded projects aimed to develop services for older people that promote their health, well-being and independence and delay the need for institutionalised or higher intensity care. Evaluation of the projects showed benefits for older people's quality of life, considerable savings and better local working relationships.

The report presents findings on the aspirations of people with dementia and carers of the support they receive at home. It provides evidence on the services people with dementia use, their outcomes and the perceived repercussions of access to support and care.

The report also sets out evidence from home care workers about their experiences providing care to people with dementia and the training and support they receive.

It is hoped this report and its recommendations will inform future practice in the commissioning and provision of support at home for people with dementia, and help identify where money could be better spent in a time of financial constraint.

1.4 What will Alzheimer's Society do to improve quality of life for people living with dementia?

This report sets out evidence about the experience of people with dementia and their carers living at home. It also explains some recommendations for change which describe what needs to happen in order to improve people's quality of life and use resources more effectively.

As well as calling on NHS, local authorities and others to act, Alzheimer's Society will be working hard to ensure that it helps to deliver the improvements it is calling for.

In particular it will:

- inform the work of the Dilnott Commission on funding of care and campaign for a new funding system that recognises the needs of people with dementia and carers for access to good quality services
- continue to develop quality information and support services for people with dementia, their carers and families through local information and support services, the Society's website and helplines
- use evidence from the demonstrator sites on dementia advisers and peer support networks to develop more and better services for people with dementia and their carers
- improve the skills of the dementia care workforce by developing and delivering high quality education programmes to staff across a range of dementia care settings and through the use of our approved trainer scheme
- work with a range of partners to develop evidence about cost effective interventions for people with dementia and their carers
- work with partners in the Dementia Action Alliance to develop and publish evidence about dementia supportive communities.

Further information on how the Society is improving the support of people with dementia at home is presented in Appendix 1 of this report.

1.5 Financial context

The increasing importance of dementia and growing commitment to improving services comes with a backdrop of significant restraint in public spending and when there is already an insufficient resource available in social care. The Coalition Government has committed to abolishing the budget deficit by 2015, leading to significant cuts to local authority budgets and the budgets of devolved administrations in Wales and Northern Ireland (HM Treasury, 2010).

The Government has pledged funding to help avoid cuts to adult social care services and has committed to introducing legislation to provide a long-term solution to the social care funding shortfall. This has included an extra £1 billion for reablement by 2014 and £1 billion of NHS funding to support social care.

It will be important to monitor the impact of any cuts both locally and nationally. Cuts that delay intervention or reduce choice available to people with dementia and family carers are likely to increase the numbers of people with dementia going into costly acute and long-term care. It is important, therefore that local authorities consider carefully their dementia care provision and avoid making cuts that result in a false economy, saving money at one point, but costing the system more overall. Efforts must be made to redesign services so that they meet people's needs and to ensure better access to mainstream support services.

1.6 Research methodology

This report is based on quantitative and qualitative evidence from people with dementia and family carers and care workers providing support in people's own homes. This information was collected via two questionnaires; one to people with dementia and family carers and a second to home care workers. The findings of these two questionnaires are referred to throughout this report as DEMHOM.

The questionnaire for people with dementia and carers was piloted with members of Alzheimer's Society's Living With Dementia group (a group of people with dementia who contribute to the work of the Society), people with dementia and carers from the Society's online discussion forum Talking Point and Alzheimer's Society service users in Birmingham. Experts within the Society also provided advice on the questionnaire.

The questionnaire for home care workers was developed in conjunction with experts at Alzheimer's Society and following discussions with the United Kingdom Home Care Association, which represents home care organisations.

Responses from our questionnaire of home care workers are dealt with in chapter 4, section 4.3.

Alzheimer's Society also conducted qualitative interviews with commissioners, people with dementia and Society service managers.

1.6.1 DEMHOM people with dementia and family carer questionnaire

The questionnaire was sent to 21,000 Alzheimer's Society members via a monthly newsletter. It was also distributed through some Alzheimer's Society services and campaigning groups and was available to download from the Society's website. The Society received a high number of responses, with 1,436 received in total. However, because the questionnaire was open access, it is not possible to calculate an accurate response rate.

The questionnaire asked about services and experiences of both the person with dementia and their family carer. Because those responding have had some contact with Society, this may have impacted their experiences of care and support. Likewise, respondents were self-selecting and this may have influenced the results.

3% (48) of these responses were from people with dementia and 96% (1377) were from carers. The evidence from this aspect of our research is therefore dominated by carers' views. However, the Society held discussion meetings and interviews with people with dementia to help gather primary evidence from people with dementia themselves. The report is also informed by a review of research and policy documents and evidence from Alzheimer's Society services on people with dementia's experiences of support and care.

The majority of respondents were from England (91% or 1,308 respondents), with 6% (85) from Wales and 2% (34) from Northern Ireland. This is broadly in line with the proportion of populations across the nations.

1.6.2 DEMHOM home care worker questionnaire

Alzheimer's Society sent copies of the home care worker questionnaire to a sample of half the registered home care agencies in England, Wales and Northern Ireland. Lists of registered agencies were obtained through the three regulators; the CQC in England, the Care and Social Services Inspectorate (CSSIW) in Wales and the Regulation and Quality Improvement Authority (RQIA) in Northern Ireland.

Recipient agencies were asked to distribute the questionnaires to frontline home care workers. This process was reliant firstly on managers of care agencies distributing the questionnaires and secondly on home care workers responding. Therefore responses are self-selected and this may have impacted on results.

The Society received 989 responses to our care worker questionnaire. 91 % (902) of the responses were from England, 6 % (56) were from Wales and 3 % (30) were from Northern Ireland, broadly in line with the proportion of populations across the nations.

1.6.3 Other research

In addition to the questionnaires, the Society held qualitative interviews and discussions with people with dementia and family carers, commissioners of care and Alzheimer's Society service improvement managers. This aspect of the research was designed to broaden the evidence base for this report and provide qualitative evidence and examples of good practice.

Interviews with people with dementia and family carers took place at a dementia café in southern England and at a small group discussion in northern England. Commissioners who participated in interviews were recruited through Alzheimer's Society services staff, and so may be more knowledgeable or sympathetic to dementia issues than other commissioners with whom the Society may not have such relationships.

1.7 Structure of the report

The body of the report is set out over three subsequent chapters.

Chapter 2 sets out the results from the questionnaire, referred to as DEMHOM, on the demographic information on the people with dementia and carers who responded and their aspirations for care and support.

Chapter 3 sets out results from the survey about outcomes and impact of the services and support respondents received and evidence around access to diagnosis and assessment.

Chapter 4 sets out the results from DEMHOM about people with dementia and family carers' use of, and satisfaction with, services. It also outlines DEMHOM findings from home care workers about their experiences of providing care to people with dementia and what training they receive.

Recommendations are made throughout the report.

2 Aspirations for support and care

Summary

- 49% of questionnaire (DEMHOM) respondents report that the person with dementia is over the age of 80.
- 79% of respondents reported the person with dementia lived with a carer and 90% reported the person with dementia lived in a regular house or flat.
- A third of respondents report the person with dementia has lived at home with dementia for more than seven years.
- 83% of respondents said being able to live at home was very important to the person with dementia.
- 59% of respondents said being active in the community was very important to people with dementia.
- Respondents and people with dementia and carers who were interviewed highlighted independence, being active and engaged, and socialising as of key importance to people with dementia.
- 82% DEMHOM respondents said services were vital to supporting the person with dementia in their own home.
- Respondents gave a large variety of answers when asked what services or support they thought could most enable the person with dementia to remain independent and active in the community.
- Respondents want services to enable and empower people with dementia, rather than simply address specific care needs.

2.1 Introduction

A key focus of DEMHOM was to identify the aspirations of respondents for the care and support available and provided to people with dementia. The questionnaire also asked how important respondents felt being independent and active in the community was to people with dementia.

By understanding what people with dementia and their carers aspire to in terms of outcomes, it is then possible to benchmark the support and care respondents report they receive.

2.2 Age and where people with dementia live

Where people with dementia live, who they live with and the age of people with dementia and their family carers can all impact on their experiences of care. Likewise, the length of time people with dementia have lived at home with dementia will impact on what services and support they receive.

2.2.1 Age and relationships

Respondents to DEMHOM reported that almost half (49%) of people with dementia were over the age of 80. Respondents reported that 50% of family carers were over the age of 70, which means many are likely to be frail or have health problems themselves.

The age of people with dementia according to DEMHOM respondents is as follows:

- Nearly half (49%) of people with dementia were over the age of 80.
- Over a third (34%) of people with dementia were aged 70-79.
- 8% of people with dementia were aged 65-69.
- 8% of people with dementia were aged 40-64.

The age of family carers according to DEMHOM respondents is as follows:

- 21% of family carers were aged over the age of 80.
- 29% of family carers were aged 70-79.
- 12% of family carers were aged 65-69.
- A third (33%) of family carers were aged 41-64.
- 2% family carers were 40 or under.

It is difficult to compare the above findings directly with evidence on the age of people with dementia and family carers, although they do seem broadly in line with existing research. Alzheimer's Society's Dementia UK report (Alzheimer's Society, 2010a) found that, among people with dementia living in the community there were nearly five times as many people over the age of 75 (352,932 people) as those aged 65-74 (71,446 people).

Most family carers (68%) responding to DEMHOM were the spouse of the person with dementia, with just under a quarter of family carers (23%) the son or daughter of the person with dementia. However, among carers aged 41-64, 32% were the spouse of the person with dementia and 57% were their son or daughter.

2.2.2 Where carers and people with dementia live

79% (1,139) of DEMHOM respondents said the person with dementia lived with a carer. 11% (151) reported that the person with dementia lived in their own home, but with the support of a carer who lived elsewhere and 5% (68) replied the person with dementia lived alone. The predominance in carers responding to DEMHOM may be a factor in explaining why so many respondents report the person with dementia lived with their carer.

Other studies show higher numbers of people with dementia living alone. Studies suggest around a third of people with dementia live alone, either with the support of a carer who lives elsewhere or without any identified carer (Miranda-Costillo, 2010). Those living alone have more unmet care needs than people with dementia living with carers and may receive different packages of care (Miranda-Costillo, 2010).

Whether living alone or with a carer, most people with dementia live in a regular house or flat. However, there is increasing interest in new forms of housing for older people, where support and care is readily available on-site allowing older people to remain independent for longer ('extra-care housing' or 'housing with care'). Alongside extra-care housing, many older people live in more traditional sheltered accommodation; flats with wardens, but no on site additional care services.

DEMOM found the vast majority of people with dementia (90%) lived in a regular flat or house. 5% lived in sheltered housing with a warden and only 1% lived in extra-care housing, where support and care is offered on site. DEMOM data does not indicate whether this is by choice or due to a lack of availability of different housing options.

2.2.3 How long people with dementia have lived at home with dementia

DEMOM respondents reported people with dementia had generally lived at home for a number of years, with a third (33%) reporting that the person with dementia had been living with dementia for more than seven years.

- 2% of people with dementia have lived at home with dementia for under one year.

- 26% of people with dementia have lived at home for 1-3 years.
- 37% of people with dementia have lived at home for 4-6 years.
- 19% of people with dementia have lived at home for 7-9 years.
- 14% of people with dementia have lived at home for 10 or more years.

2.3 Desired outcomes for support and care

‘It’s much better to have care and support at home rather than having to go into residential care’ – carer of person with dementia

A primary goal of the DEMHOM research was to identify key outcomes that people with dementia wanted from the services and support they received. DEMHOM found that respondents believed overwhelmingly that being able to live in their own homes was very important to the person with dementia, with 83% (1,195) responding to that effect.

Remaining as part of the community was also seen as very important by the majority of DEMHOM respondents. 59% (843) responded that being part of the community was very important to people with dementia and a further 28% (407) said it was quite important.

These findings clearly demonstrate the high importance of being independent, active in the community and remaining at home to DEMHOM respondents. This is further evidenced by information collected during interviews and small group discussions.

‘Its good to be independent’ – person with dementia

‘I would like to stay in my house as long as I can’ – person with dementia

‘Come and go when you want. Freedom in your own house’ – person with dementia

‘The most important thing is that he’s able to do as much as possible’ – carer of person with dementia

Commissioners and social workers interviewed for the research strongly support the approach of supporting people with dementia to remain independent in their own homes.

‘We are committed to supporting people in their own homes for as long as possible’ – commissioner of dementia services

‘[Our] aim is to keep people independent for as long as possible in their homes of choice’ – social worker working with people with dementia.

Responses to an open question on what outcomes care and support should aim to achieve further support the importance of independence to people with dementia. Set out below are free-text responses given by DEMHOM respondents which have been coded into categories

Table 1

DEMHOM respondents’ aspirations for care and support of people with dementia

% respondents who gave answer	What outcomes do you think care and support should aim to achieve?
22 %	Enabling people with dementia to live an active and engaged life
22 %	Help to live/remain in their own home for as long as possible
16 %	Help to live as near normal life as possible
14 %	Support in socialising/meeting people/contact with the outside world
11 %	Support groups/respite for carers on regular basis
11 %	Supporting people to remain involved in their community

These six categories in table 1 are the most common responses given by DEMHOM respondents. All focus around enabling people with dementia to live an independent, good quality life. This clearly demonstrates that DEMHOM respondents want services to enable and empower people with dementia, rather than simply addressing specific care needs.

These findings on aspirations for outcomes of services and support are broadly in line with other research carried out by Alzheimer’s Society. The Society’s report *My name is not dementia* found the ten key indicators of quality of life perceived by people with dementia which included: relationships and someone to talk to, independence and ability or opportunity to engage in activities (Alzheimer’s Society, 2010b). *My name is not dementia* also found maintaining a person with dementia’s quality of life is perfectly possible.

The Department of Health, in its revised implementation plan for the National dementia strategy for England (NDSE) has set out key statements about the care of people with dementia it believes should be achieved (Department of Health, 2010c).

- I understand, so I make good decisions and provide for future decision making.
- I get the treatment and support which are best for my dementia, and my life.
- Those around me and looking after me are well supported.
- I am treated with dignity and respect.
- I know what I can do to help myself and who else can help me.
- I can enjoy life.
- I feel part of the community and I'm inspired to give something back.
- I am confident my end of life wishes will be respected. I can expect a good death.

Work with people with dementia and family carers to inform the National Dementia Declaration outlined seven key outcomes, which overlap with the above statements (Dementia Action Alliance, 2010)

- I have personal choice and control or influence over decisions about me.
- I know that services are designed around me and my needs.
- I have support that helps me live my life.
- I have the knowledge and know-how to get what I need.
- I live in an enabling and supportive environment where I feel valued and understood.
- I have a sense of belonging and of being a valued part of family, community and civic life.
- I know there is research going on which delivers a better life for me now and hope for the future.

Ensuring services are tailored to individual's needs is highlighted in the National Institute for Health and Clinical Excellence (NICE) Quality standards on dementia (NICE, 2010). Principles around person-centred care underpin the 2006 Clinical guideline for dementia, published by NICE and the Clinical Excellence and the Social Care Institute for Excellence (NICE/SCIE, 2006).

Evidence from DEMHOM and other research demonstrates that maintaining independence, being part of the community and remaining active are seen as very important to people with dementia. It must be recognised that with sufficient support and care it is perfectly possible to support people with dementia to fulfil these aspirations.

2.4 The role that support and care can play

‘[There is a] challenge for the nation to realise people with dementia should choose how people with dementia wish to be supported and where...menus of services that they can choose from: I would like to be supported on this day in this way’ – Alzheimer’s Society service improvement manager

Services have a vital role to play in supporting people with dementia and their carers to meet the quality of life outcomes set out above. Early intervention and support for people with dementia can help support them in the community (Banerjee, 2008) and can help meet their needs for remaining independent and part of the community (Nicholson, 2005; Gutteridge, 2000; Department of Health, 2009).

Respondents to DEMHOM overwhelmingly stated that services have a vital role to play supporting people with dementia to maintain their independence. 82% (1,179) of respondents said services were vital to supporting people with dementia to maintain their independence.

DEMHOM found that, unlike with aspirations for outcomes of services, respondents views on what single thing could help people with dementia remain more independent and play an active role in the community varied considerably. Set out below are responses given by DEMHOM respondents which have been coded into categories:

- 17% of respondents – access to day centres/special groups/socialising with others.
- 13% – having a companion/dedicated friend or relative/carer 24-7.
- 9% – having support/support for both carer and person with dementia/support from professionals.
- 7% – for the general public to be more aware/understanding of the effects of dementia.
- 5% – being able to remain at home/be supported at home/home help.

- Several other types of support and care services were outlined by small numbers of respondents and 16% of respondents outlined other services which we were unable to code due to their variability.
- 21% of respondents did not answer.

These findings suggest a wide variety of forms of support and care are needed to meet the aspirations of people with dementia and carers. This is supported by evidence from professionals and people with dementia and carers.

‘Looking at more low-key community services and things already going on. Get away from statutory provision. Just because people with dementia have that label it doesn’t mean they can’t go to local dances or teas’ – social worker working with people with dementia

‘Lots of going out; I really enjoy activities. Helps you remain independent and gets things circling’ – person with dementia

These findings show that quality of life is defined primarily by the person, not by the fact that they have dementia. The wide range of services respondents think could most help the person with dementia remain independent suggests a need for personalised services, tailored to individual need. This is in line with the government’s agenda for health and social care services (Department of Health, 2010a and b). An aspect of achieving this could be personal budgets and these are discussed in section 4.5 below.

Recommendation 1

There must be an urgent and concerted effort to support people with dementia to live independently in their own homes and avoid early and unnecessary admission to long-term care.

People with dementia and carers responding to the Alzheimer’s Society questionnaire report that supporting people with dementia to remain independent at home should be the critical aspiration for the services they receive. 83% of respondents said being able to live at home was very important to the person with dementia and 59% say being part of the community is very important to people with dementia.

- Outcomes frameworks in health and social care must be considered in the context of dementia. Frameworks must consider the desired aspirations and outcomes of people with dementia, rather than simply looking at care and support needs in their narrowest sense.

- People with dementia should have holistic, personalised support plans, covering health, social services and aspirations identified in needs assessments. Support plans must be reviewed regularly and must adapt to changing aspirations of people with dementia.
- People with dementia and carers should have access to a range of different types of services, including prevention, early intervention, reablement and intermediate care services. Wherever feasible, those referring or signposting people with dementia towards other services should consider how to facilitate giving them a choice of services. This should include the use of independent advocacy services.
- Barriers to people with dementia accessing mainstream health and social care services, such as restrictive eligibility criteria, should be removed and professionals in social care should not make assumptions about what services people with dementia and carers may benefit from.
- Commissioners and those managing individual's support plans must seek to scope the support and care services that exist in their area and to which people with dementia could be signposted or referred. The results of these scopes should inform referral and signposting decisions.
- Dementia represents the biggest challenge to aspirations and targets for expansion of access to personal budgets. Commissioners should consider commissioning brokerage and advocacy services to facilitate and empower access to personal budgets among people with dementia. Staff training should challenge preconceptions that people with dementia cannot use or benefit from personal budgets.

Recommendation 2

Commissioners should recognise the considerable resources already being spent across health and social care on dementia and the opportunity to use them more effectively.

There are 750,000 people living with dementia in the UK, with a total cost to the economy of over £20 billion. Current hospital and long-term care costs resulting from dementia are unsustainable and represent a significant opportunity for resources to be used more effectively while achieving better outcomes.

- Because of the challenge dementia represents, health and social care commissioners should prioritise significant spending on community

dementia services, especially early intervention and reablement. In England a significant proportion of the additional £2 billion funding allocated to social care needs to be spent on dementia to deliver better outcomes.

- There is an urgent need to review whole system costs for dementia to assess how resources are being spent and where they could be used more effectively.
- Commissioners should consider the financial and social benefits of providing support for people with dementia and carers, including savings from reductions in pressure on long-term care and acute services. In England, the opportunity improving dementia services represents must be considered as part of the Quality, Innovation, Productivity and Prevention (QIPP) workstreams.

3 The impact of care on individuals and society

Summary

- Half (50%) of the questionnaire (DEMHOM) respondents report the person with dementia is not getting the support and care they need.
- Those not getting sufficient support report significant negative repercussions for the mental and physical health of the carer, the person with dementia's general health and their symptoms of dementia.
- One in five of those reporting they are not getting sufficient support and care believe the person with dementia was admitted to long-term care earlier than expected and a similar proportion believe the person with dementia was admitted unnecessarily to hospital.
- Early admission to long-term care and unnecessary admission to acute care have significant financial impacts for health, social care services and individuals.
- Over half (52%) of the questionnaire respondents report the carer is not getting enough support to carry out their caring role, resulting in frequent perceived negative repercussions, especially for carers' mental and physical health.
- When people with dementia receive sufficient support there are clear benefits, both for individuals and also the wider social care system.
- Provision of sufficient support and care can result in benefits for carer physical and mental health, the person with dementia's symptoms of dementia and their general health. The provision of good quality support and care is also often perceived by respondents to delay admission to long-term care.
- There are a range of factors related to whether DEMHOM respondents believe they are getting the support and care they need. These include provision of NHS support, whether services are considered co-ordinated and whether they have been signposted to sufficient sources of free information and support.
- Problems with access to diagnosis and assessment inhibit the support people with dementia receive.

3.1 Introduction

Chapter 2 set out the aspirations of people with dementia. This chapter will outline DEMHOM respondents' perceptions of whether people with dementia and carers receive enough support and the repercussions of this. It shows stark division in DEMHOM respondents' views on the care they received and its impact.

Sufficient support is perceived to enable people with dementia to maintain a good quality of life and remain independent in their own homes, and help ensure the aspirations outlined by DEMHOM respondents in chapter 2 are met.

However, DEMHOM shows that where respondents perceive there is insufficient support there appear to be negative consequences for people with dementia and family carers.

Respondents perceive that insufficient support results in the exacerbation of the needs of people with dementia and carers, with reported worsening physical and mental health needs. As a result, people with dementia are more likely to be admitted earlier to long-term care and unavoidably admitted to hospital. These results have considerable cost to quality of life and the aspirations of people with dementia and carers, alongside considerable financial costs to the NHS, social services and individuals.

3.2 The provision of sufficient support

Half of the DEMHOM respondents (50% or 712) report the person with dementia is not getting the support and care they need, with only 44% (625) reporting that they are getting the support and care they need. These results demonstrate the aspirations of people with dementia and carers highlighted in chapter 2 are not consistently being met by the services and support available.

Respondents to DEMHOM also felt people with dementia generally were being excluded from the community. 67% (963) felt that people with dementia were sometimes excluded from the community, with 11% (156) responding they believed people with dementia were always excluded from the community. Only 13% (184) thought people with dementia were not excluded from the community.

DEMHOM also outlines the perceived repercussions of people with dementia and carers getting or not getting all the support and care they need. These findings show significant perceived negative repercussions for not receiving sufficient support to meet their needs and extensive benefits for those receiving enough support.

3.2.1 The repercussions of insufficient support

DEMHOM findings show that respondents those who perceive the person with dementia is not receiving sufficient support report substantial perceived negative repercussions, which are likely to exacerbate existing needs and result in significant additional costs to the NHS, social care and individuals. The 50% or 712 respondents who reported the person with dementia was not getting the care and support they needed highlighted the following negative impacts:

- 63% (452) said it had a negative impact on the carer's general health.
- 57% (406) said it had a negative impact on the carer's mental health.
- 46% (326) said it had a negative impact on the person with dementia's symptoms of dementia.
- 42% (300) said it had a negative impact on the person with dementia's general health.
- 21% (149) said the person with dementia was admitted to long-term care sooner than the respondent expected.
- 19% (133) said the person with dementia was admitted to hospital when they thought it could have been avoided.
- 14% (100) reported other impacts.
- Only 2% (14) did not highlight any of the above negative impacts.

It is clear that, where people with dementia are not getting the support and care they need, there are serious and extensive negative repercussions. These negative repercussions are likely to exacerbate people with dementia's needs and impact on carers who are often elderly themselves. Among these DEMHOM respondents, aspirations for independence, involvement in the community and good quality of life set out in chapter 2 are not being met.

Around a fifth of DEMHOM respondents perceive admission to hospital was a consequence of insufficient support and care and therefore could have been avoided. A similar proportion believed earlier than expected admission of the person with dementia to long-term care was a consequence of receiving insufficient support and care.

Admission to acute care is highly expensive, especially in emergency circumstances. Once in hospital, people with dementia often spend much longer on wards than people without dementia admitted for the same reason, with one in four staying much longer. The result of this is significant financial costs (Alzheimer's Society, 2009a). Similarly, in most cases, care in care homes

is substantially more expensive than caring for someone in their own home (Alzheimer's Society, 2007; Banerjee, 2008).

3.2.2 Enabling carers to carry out their caring role

DEMHOM found over half of carers (52% or 745 respondents) were perceived by respondents to be getting insufficient support to enable them to carry out their caring role. Less than two in five (39%) respondents said they thought the carer was getting sufficient support to carry out their caring role.

There are an estimated 600,000 carers of people with dementia in the UK who provide the vast majority of the care of people with dementia in the community; over £6 billion of care (Alzheimer's Society, 2007). There are clear and well documented impacts of carers not getting the support they need (Schoenmakers, 2010; Charlesworth, 2006), these include stress, depression, mental health problems, impact on the person with dementia and physical health problems for the carer.

Carers of people with dementia report higher levels of burden and stress than carers of people with other conditions (Moise, Schwarzingler and Um, 2004). When carers are well supported they provide better care to the person they care for (Ablitt, Jones and Muers, 2009) and report better well-being outcomes themselves (Schoenmakers, 2010).

DEMHOM respondents perceived extensive repercussions of carers receiving insufficient support. The 52% (745) of respondents saying they believed carers were receiving insufficient support to enable them to carry out their caring role highlighted the following repercussions:

- 83% (613) said there was a negative impact on the carer's mental or physical health.
- 36% (268) said there was a negative impact on the person with dementia's symptoms of dementia.
- 30% (222) said there was a negative impact on the person with dementia's general health.
- 22% (146) said the person with dementia entered long-term care sooner than anticipated.
- 10% (71) said there was another impact.
- Only 4% (28) did not state that there was an impact from the carer not receiving the support they needed to carry out their caring role.

Negative impacts on carers' mental or physical health are likely to inhibit them from caring. The very high proportion of respondents reporting this (83 %) strongly suggests many carers are experiencing significant detrimental impact because the support available to them is insufficient.

Respondents to DEMHOM also report perceived negative repercussions for people with dementia due to carers not receiving enough support to carry out their caring role. This is likely to exacerbate needs, leading to greater necessity for intervention and greater burden on NHS, social services and individuals as carers and people with dementia reach crisis point. This underlines the need for support for carers to be seen as fundamental to enabling people with dementia to remain independent and in their own homes.

3.2.3 The benefits of receiving sufficient support

DEMHOM findings show there are significant perceived positive outcomes when people with dementia get the support and care they need. The 44 % (625) of respondents who reported the person with dementia received all the support and care they needed highlighted the following positive impacts:

- 56 % (349) said the person with dementia remained at home longer than expected.
- 52 % (324) said there was a positive impact on the carer's mental or physical health.
- 48 % (302) said there was a positive impact on the person with dementia's general health.
- 35 % (219) said there was a positive impact on the person with dementia's symptoms of dementia.
- 13 % (80) said there was another impact.
- Only 7 % did not highlight any of the above positive impacts.

These clear benefits for the person with dementia and their carer are in stark contrast to the outcomes in section 3.3. Over half (52 %) of respondents who reported that care and support needs are being met say this had a positive impact on carer mental or physical health. This in turn is likely to have supported them to continue in their caring role (Ablitt, 2009).

The high proportion of respondents reporting benefits in terms of the person with dementia's physical health or symptoms of dementia clearly demonstrate the perceived benefits to people with dementia themselves of good quality support and care.

56% of DEMHOM respondents reporting the person with dementia and family carer are getting sufficient support say they believe this has enabled the person with dementia to remain at home longer than expected. This is meeting the aspirations of people with dementia and carers around independence and remaining at home, as outlined in chapter 2, and is also likely to be a cost saving.

Overall, these results are a clear indication that good quality care is perceived by respondents as having demonstrable benefits to people with dementia and carers, supporting them in meeting aspirations to remain independent at home. Moreover, meeting the care and support needs of people with dementia and carers is likely to result in significant cost savings.

There is an urgent need for best practice examples of care and support to be shared more widely so more people with dementia and carers can experience the benefits these DEMHOM respondents report. Use of existing mechanisms of sharing best practice, such as the Social Care Institute for Excellence (SCIE) Dementia Gateway needs to be encouraged

3.2.4 The cost of insufficient support for people with dementia in the community

There is likely to be a significant financial cost borne by individuals, social services and the NHS if the support and care needs of people with dementia and carers living in the community are not met.

DEMHOM found many respondents perceive sufficient care can enable people with dementia to remain at home longer and insufficient care can lead to early admission to long-term care. Professor Banerjee's economic metric outlined that significant savings could be made from better community care and corresponding reduction in admission to long-term care.

The metric outlined that improved diagnosis and support services which reduce admissions to long-term care by 20% would result in an overall societal cost saving. Services which reduce admission by 10% would almost be an overall societal cost saving (Banerjee, 2008). Findings from DEMHOM support the argument that significant savings can be achieved, with respondents perceiving there is substantial opportunity for reductions in admission to long-term care by the provision of sufficient care and support.

DEMHOM also found that many respondents perceived admission to acute care was a consequence of insufficient care in the community. The Nuffield Trust's review of emergency admission rates found older people are much more likely to have an emergency admission to hospital (Nuffield Trust, 2010).

Evaluation of Partnership for Older People Projects has demonstrated these saved an estimated £1.20 in cost of bed days for every £1 spent (Personal Social Sciences Research Unit, 2010). Looking at the DEMHOM findings in the light of this evidence, it suggests there is significant potential for substantial resources to be saved in acute care by providing sufficient and support of people with dementia in their own homes.

3.3 Factors related to whether there is sufficient support

Comparison across results from DEMHOM allows a more in-depth picture of the impact of provision of care and support to be developed. It is clear from this comparison that there are numerous factors related to whether care and support is considered sufficient. The results of this comparison are shown in tables 2-6.

It is impossible to make statements about causality based on these results. However, it is clear that numerous factors are related to whether respondents perceive they are getting the support and care they need. These relationships underline the need for holistic care, with good quality joined-up services for the person with dementia and carer and sufficient information provision.

Taken as a whole, this analysis supports and supplements findings in section 3.2 above. Where care and support is good, it is generally good across the board and there are clear benefits. However, where care is poor, it is often universally poor and has substantial perceived negative repercussions. This suggests a sharply divided system of dementia care, with some people receiving excellent care and others receiving poor care and experiencing detrimental and negative repercussions.

3.3.1 NHS services

Table 2

Sufficient support from NHS services against sufficient support and care overall

	Person with dementia is getting enough support from NHS services (456)	Person with dementia is getting some support, but not enough support from NHS services (756)	Person with dementia doesn't get any support from NHS services (164)
Person with dementia is getting all the support they need (625)	80% (365)	28% (209)	18% (30)
Person with dementia is not getting all the support they need (712)	16% (71)	67% (503)	73% (120)

Table 2 shows the relationship between support from NHS services and whether people with dementia are getting sufficient support and care.

Overall, DEMHOM respondents felt they did not receive sufficient support from NHS services. Less than a third (32% or 456 respondents) reported they received sufficient support from NHS Services, while over a half (53% or 756 respondents) reported they received some support, but not enough and 11% (164) said they did not receive any support.

In terms of specific NHS services, DEMHOM asked whether respondents received visits from community psychiatric nurses (CPNs). CPNs form an important part of community mental health teams, often acting as key workers for people with mental health problems. 441 (31%) respondents reported the person with dementia is has received visits from a CPN.

Expansion of access to NHS services, including CPNs, is an important aspect to ensuring people with dementia receive the support from NHS services.

3.3.2 Support for carers to carry out their caring role

Table 3

Support for carers to care against sufficient support and care overall

	The carer is getting enough support to enable them to carry out their caring role (560)	The carer needs more help to enable them to carry out the caring role (745)
Person with dementia is getting all the support they need (625)	82% (460)	17% (129)
Person with dementia is not getting all the support they need (712)	14% (79)	80% (593)

Table 3 demonstrates the very close relationship between supporting carers to carry out their caring role and whether people with dementia are getting sufficient support and care.

Further information on the services DEMHOM respondents report carers receive can be found in chapter 4.

3.3.3 Information on free sources of advice and support

Table 4

Sufficient information against sufficient support and care overall

	Person with dementia and carer are getting enough information on sources of free information and support (584)	Person with dementia and carer are getting information on sources of free information and support, but not enough (474)	Person with dementia and carer are not getting enough information on sources of free information and support (285)
Person with dementia is getting all the support they need (625)	68% (400)	30% (144)	16% (45)
Person with dementia is not getting all the support they need (712)	26% (151)	63% (299)	78% (223)

Table 4 shows the relationship between signposting to free information and support and whether people with dementia are getting sufficient support and care. This relationship clearly demonstrates the importance of information and advice as part of comprehensive care of people with dementia at home.

3.3.4 Information on benefits and allowances

Table 5

Information on benefits against sufficient support and care overall

	Person with dementia and their carer have received enough information on benefits and allowances (950)	Person with dementia and their carer have not received enough information on benefits and allowances (298)
Person with dementia is getting all the support they need (625)	53 % (508)	25 % (68)
Person with dementia is not getting all the support they need (712)	41 % (394)	72 % (215)

Table 5 shows the relationship between providing information on benefits and allowances and whether people with dementia are getting sufficient support and care.

Previous surveys have identified that benefits, especially attendance allowance, are greatly valued by people with dementia and carers (Alzheimer's Society, 2008a; Alzheimer's Society, 2009b; Alzheimer's Society, 2010c) and are primarily used to fund care costs (66%) and general household costs (48%) (Alzheimer's Society, 2008a). DEMHOM respondents placed great emphasis on the importance of benefits.

- 51% of respondents believe benefits are of vital importance.
- 29% said benefits were of some importance.
- Only 4% respondents believe benefits are of no importance or have no impact.

78% of DEMHOM respondents reported the person with dementia received attendance allowance, which is similar to findings from previous surveys (Alzheimer's Society, 2008a; Alzheimer's Society, 2009b).

3.3.5 Services working well together

Table 6

Services working well together against sufficient support and care overall

	Services the person with dementia receives work well together (368)	Services the person with dementia receives work okay together, but there are some problems (362)	Services the person with dementia receives do not work well together (306)
Person with dementia is getting all the support they need (625)	78% (288)	44% (158)	18% (55)
Person with dementia is not getting all the support they need (712)	19% (70)	54% (195)	78% (239)

Table 6 shows the relationship between how well services work together and whether people with dementia are getting the support and care that meets their needs.

This shows starkly that when services are perceived to work poorly together, people with dementia are more likely to feel they are not getting the support and care they need. Conversely, where services are thought to work well together, perceived outcomes are also better.

3.4 The diagnosis gap

A key aspect of accessing services and support is diagnosis. However, with only a third of people with dementia receiving a formal diagnosis, many are likely to have limited or no access to formal or even informal care and support services (Department of Health, 2008a; National Audit Office, 2007). When diagnosis does occur, it is often late, and frequently only resulting from a crisis

situation, thus limiting the options for care available to people with dementia and their carers (Banerjee, 2008).

DEMHOM did not ask a question on diagnosis, since all respondents would have had contact with the Society and it is likely the proportion reporting they have had a formal diagnosis would have been disproportionately high. Access to diagnosis is, however, identified in policy documents and by professionals spoken to in research as fundamental to the provision of good quality care and support.

‘Raising awareness and promoting early diagnosis are big things at the moment’ – commissioner of dementia services

‘Access to services is a grey area until [they] get that formal diagnosis’ – commissioner of dementia services

‘Half of our clientele in some areas don’t have access to a diagnosis’ – Alzheimer’s Society service improvement manager

Without diagnosis, people with dementia are often unable to access formal and informal support and care services. Failure to raise rates of diagnosis will continue to result in substantial numbers of people with dementia and their carers living with significant unmet needs, denying them their aspirations of independence and leading to avoidable and costly admissions to long-term care and acute care.

Professor Sube Banerjee has outlined a clear economic case that early diagnosis and intervention in dementia is cost efficient, reducing the numbers of people going into long-term care (Banerjee, 2008). Diagnosis and early intervention could potentially also help reduce avoidable emergency admissions to hospital, again potentially yielding significant savings (Personal Social Sciences Research Unit, 2010).

3.5 Access to assessment

High quality assessment of need is an essential component of accessing appropriate care and support systems. Without assessment of need, people with dementia will be unable to access social services support and are less likely to be signposted to voluntary support and care services.

Respondents to DEMHOM reported that 61 % (878) of people with dementia had been assessed and receive social services support. 17 % (247) of respondents reported the person with dementia had not received an assessment and 15 % (215) reported they had received an assessment but not been deemed eligible to receive services.

Of the 17% (247) who had not received an assessment, just under a quarter (24% 60 respondents) reported this was because they were not aware they were entitled to an assessment. 45% (110) reported they don't need any help as the support is provided by their carer.

Of the 15% (215 respondents) who were assessed but were not deemed eligible to receive services:

- 62% (134) said this was because they had too much money. This is a concern since it could indicate means testing in determining assessment of eligibility. Revised Fair Access to Care Services (FACS) guidance clearly state that any assessment of financial circumstances should only take place subsequent to a proper needs assessment and that financial circumstances 'should have no bearing on the decision to carry out a community care assessment' (Department of Health, 2010d).
- 17% (36) said the person with dementia did not meet the local authority criteria for support.

All people with dementia and carers Alzheimer's Society spoke to in small group discussions and one-to-one interviews had received a needs assessment. This is unsurprising as these individuals were recruited through Society's services and so are likely to have gone through the assessment process to access these services.

Overall, people with dementia and carers we talked to in our interviews and group discussions were generally positive about their experience of the assessment process. However, several reported problems getting an assessment in the first instance.

'I happen to know someone who was in the OT department, rang her up and she said "Oh, there's a number in _____ you can ring" and as soon as I rang that number it was all put into place' – carer of person with dementia

'There are a lot of people who don't know how to get information. I've had problems previously, so I've had a good idea what doors to knock on' – person with dementia

These results demonstrate that access to social services needs assessment remains an issue for some people with dementia and carers.

3.5.1 Carer assessment

Carers of people with dementia have the right for a separate assessment of their own needs and local authorities have a responsibility to provide services to meet identified needs. There is low awareness of this right among carers themselves and also among social care professionals, contributing to low levels of assessment and consequently often poor access to support.

The DEMHOM responses support evidence that uptake of carers assessments are poor. Only 37% (535) carers report they have had an assessment and receive social service support. Over a third (34% or 485 respondents) report the carer was either not aware they were entitled to an assessment or were deemed ineligible to receive support. A further 15% (216) reported they didn't want or need an assessment.

Without an accurate needs assessment, carers of people with dementia are likely to have significant unmet care and support needs. Findings from the DEMHOM research outlined earlier in this chapter clearly show this is the case and there are significant perceived negative repercussions.

Recommendation 3

Carers must be supported to carry out their caring role.

Only 37% of respondents report that carers have had an assessment of need and 52% of carers are not getting sufficient support to enable them to carry out their caring role.

- Implementation of carer's strategies must be prioritised, as outlined in national policies such as the National Dementia Strategy for England and Welsh Assembly Government Action Plans.
- Appropriate staff working in the NHS and social services who come into contact with carers must provide information on their right to ask for a separate carer's assessment.

Recommendation 4

Joined-up working across health and social care must become the norm if people with dementia are to be supported to remain independent in their own homes.

Only 26% of respondents said they thought services worked well together. Those responding who said support was insufficient and did not meet needs

reported negative repercussions on the person with dementia and carer's physical and mental health.

- Joined-up diagnosis and assessment services must be put in place to ensure early detection and intervention, which can be crucial in enabling people with dementia to remain at home for longer.
- NHS and social care should look at ways of promoting joint working above and beyond commissioning, including joint training and multi-disciplinary team working.
- Local joint dementia strategy implementation plans or joint dementia action plans should be produced by health and social care commissioning bodies in England, Wales and Northern Ireland. These should be made publicly available and accessible so local communities can hold local authorities and NHS commissioners to account.

Recommendation 5

Variable experiences of care and support should be tackled through expanded sharing of good practice.

Whether respondents feel care and support is sufficient is closely related to: support for carers, support from the NHS, provision of information and support and whether respondents think services are joined up.

- Mechanisms for sharing best practice in providing good quality dementia care have to be expanded and exploited. Levers for encouraging use of existing mechanisms for sharing best practice, such as the Social Care Institute for Excellence (SCIE) Dementia Gateway, should be explored.
- People with dementia and carers should be involved in monitoring quality of care and support services. Where possible, such monitoring should involve more in-depth forms of feedback to ensure issues and criticisms are identified and the opinions of those with more advanced dementia are not excluded.

4 Support and care services received by people with dementia and carers

Summary

- The questionnaire (DEMHOM) results show people with dementia and family carers are accessing a range of care and support services. DEMHOM respondents' satisfaction with individual services received by people with dementia and carers is generally good.
- Most common services received by people with dementia are day centres, home care workers and adaptations to people's homes.
- There is little evidence of substantial expansion in access to support and care from DEMHOM results when compared to Alzheimer's Society's 2008 Dementia tax report.
- Home care workers frequently work with people with dementia, with 98% of those responding saying they at least sometimes work with people with dementia.
- Home care workers responding believed people with dementia could remain independent, however, home care workers had mixed views on whether people with dementia can remain active and engaged in the community. Home care workers report they need more training on dementia.
- The more time home care workers can spend providing care to people with dementia, the more likely they are to believe they are providing good quality care.
- DEMHOM respondents believe benefits are a key component of support for people with dementia and nearly four fifths (78%) report the person with dementia is receiving attendance allowance.
- A minority of DEMHOM respondents receive or were offered personal budgets (23%), but 60% were not informed about personal budgets, indicating dementia will be a key challenge of the Coalition Government's universal personal budget target.

- DEMHOM respondents are critical of overall support and care the person with dementia received, especially around availability of support early following a diagnosis.

4.1 Introduction

Access to comprehensive packages of care at home are a fundamental component of the National dementia strategy for England (NDSE), Welsh Action plans and the draft Northern Ireland dementia strategy (Department of Health, 2009; Welsh Assembly Government, 2010; Northern Ireland Department of Health, Social Services and Public Safety, 2010). The NDSE talks about a range of services including home care, assisted technology, peer support and day centres, forming a comprehensive personal support service (Department of Health, 2009).

DEMHOM provides evidence on what services and support people with dementia access while living in their own home and also how satisfied or dissatisfied they were with these services. This chapter looks across all these services, but particularly focuses on home care services, outlining results from the survey of 989 home care workers.

4.2 Services used by people with dementia

The DEMHOM survey asked respondents to highlight whether the person with dementia had received the following identified services. It should be highlighted, that respondents would have come into some contact with the Society and this may have skewed the results for service use. The wider population of people with dementia may well have lower levels of access to support and services than DEMHOM findings below would indicate.

Table 7

Services DEMHOM respondents report people with dementia receive

What types of support and care does the person with dementia receive while living in their own home?	% respondents reporting use	% using very satisfied	% using satisfied	% using dissatisfied	% using very dissatisfied
Attends a day centre	42% (609)	49% (297)	31% (186)	8% (46)	10% (58)
Adaptations have been made to their home to support them to live independently	40% (576)	42% (244)	37% (213)	8% (44)	9% (49)
Care assistants visit to help with personal care (such as washing or getting dressed)	37% (535)	34% (182)	37% (196)	13% (71)	12% (66)
Receives visits from a community psychiatric nurse	31% (446)	40% (176)	29% (131)	11% (49)	16% (69)
Receives visits from a care manager (social worker)	30% (427)	32% (138)	38% (163)	16% (68)	9% (40)
Attends a support group for people with dementia	26% (373)	46% (172)	32% (121)	7% (25)	11% (41)
Care worker provides support in the home during the day, night or overnight	22% (313)	35% (111)	35% (110)	10% (32)	15% (46)

Table 7 (continued)

Services DEMHOM respondents report people with dementia receive

What types of support and care does the person with dementia receive while living in their own home?	% respondents reporting use	% using very satisfied	% using satisfied	% using dissatisfied	% using very dissatisfied
Receives help with household tasks such as cleaning, gardening or shopping	22% (313)	34% (105)	35% (108)	11% (35)	17% (52)
Receives support worker from a occupational therapist	18% (263)	38% (99)	34% (89)	11% (28)	15% (39)
Receives support from a dementia adviser	18% (261)	46% (119)	24% (63)	7% (18)	18% (46)
Has a support (personal assistant) other than those described above	13% (193)	47% (91)	23% (44)	5% (10)	18% (35)
Receives support from a physiotherapist	9% (136)	42% (57)	19% (26)	12% (16)	24% (33)
Other services	26% (343)	52% (178)	22% (75)	6% (22)	7% (23)
Not stated	3% (44)	N/A	N/A	N/A	N/A
The person with dementia has not received any services while living in their own home	15% (209)	N/A	N/A	N/A	N/A

Table 7 demonstrates the range of services people with dementia are receiving. The table also demonstrates that satisfaction with services is generally positive.

4.2.1 How length of time living with dementia affects services used

Analysis of DEMHOM results suggests those who have lived with dementia at home for longer are more likely to use services.

Table 8

Services DEMHOM respondents report they receive against time living at home with dementia

What types of support and care does the person with dementia receive while living in their own home?	% of respondents reporting use				
	All 1,435 respondents	Person lived at home with dementia for 1–3 years – 378)	Person lived at home with dementia for 4–6 years – 531)	Person lived at home with dementia for 7–9 years – 279)	Person lived at home with dementia for more than 10 years – 194)
Attends a day centre	42% (609)	35% (134)	44% (234)	49% (138)	42% (82)
Adaptations have been made to their home to support them to live independently	40% (576)	33% (125)	38% (204)	48% (133)	48% (93)
Care assistants visit to help with personal care (such as washing or getting dressed)	37% (535)	31% (118)	33% (175)	46% (127)	49% (96)
Receives visits from a community psychiatric nurse	31% (446)	31% (117)	32% (171)	30% (84)	31% (61)

Table 8 (continued)

Services DEMHOM respondents report they receive against time living at home with dementia

What types of support and care does the person with dementia receive while living in their own home?	% of respondents reporting use				
	All 1,435 respondents	Person lived at home with dementia for 1–3 years – 378)	Person lived at home with dementia for 4–6 years – 531)	Person lived at home with dementia for 7–9 years – 279)	Person lived at home with dementia for more than 10 years – 194)
Receives visits from a care manager (social worker)	30% (427)	22% (82)	31% (166)	35% (98)	35% (68)
Attends a support group for people with dementia	26% (373)	24% (92)	29% (155)	21% (59)	27% (53)
Care worker provides support in the home during the day, night or overnight	22% (313)	19% (70)	20% (105)	25% (69)	28% (54)
Receives help with household tasks such as cleaning, gardening or shopping	22% (313)	20% (77)	21% (110)	21% (59)	25% (48)
Receives support from a occupational therapist	18% (263)	14% (53)	20% (107)	19% (54)	21% (41)
Receives support from a dementia adviser	18% (261)	15% (57)	19% (103)	29% (52)	20% (38)

Table 8 (continued)

Services DEMHOM respondents report they receive against time living at home with dementia

What types of support and care does the person with dementia receive while living in their own home?	% of respondents reporting use				
	All 1,435 respondents	Person lived at home with dementia for 1–3 years – 378)	Person lived at home with dementia for 4–6 years – 531)	Person lived at home with dementia for 7–9 years – 279)	Person lived at home with dementia for more than 10 years – 194)
Has a support worker (personal assistant) other than those described above	13% (193)	10% (39)	13% (71)	14% (38)	18% (35)
Receives support from a physiotherapist	9% (136)	7% (25)	9% (48)	11% (31)	13% (26)
Other services	26% (343)	19% (71)	24% (126)	28% (77)	32% (62)
Not stated	3% (44)	4% (14)	2% (9)	4% (10)	3% (5)
The person with dementia has not received any services while living in their own home	15% (209)	18% (69)	16% (83)	8% (23)	11% (21)

This pattern demonstrates a clear need for those newly diagnosed or entering the care system to have access to more services and support.

4.2.2 Changing patterns of service use

It is possible to roughly compare results from DEMHOM with results from Alzheimer's Society's 2008 Dementia tax report (Alzheimer's Society, 2008a) to suggest changing patterns of service use. Since both surveys were sent to the Society's membership, these two surveys may be roughly the same sample.

When respondents not receiving any services are excluded, comparison between DEMHOM and the Dementia tax report suggests a reduction in the reported percentage of people with dementia accessing the following services:

- Attendance at day centres seems to have declined from 57 % (525) Dementia tax respondents to 52 % (609) DEMHOM respondents.
- Help with personal care at home seems to have declined from 51 % (473) Dementia tax respondents to 45 % (535) DEMHOM respondents.
- Receiving visits from care managers (social workers) seems to have declined from 43 % (410) Dementia tax respondents to 36 % (427) DEMHOM respondents.

This comparison also suggests an increase in the percentage of people with dementia attending support groups (32 % of those responding to DEMHOM compared to 19 % of those responding to Dementia tax, excluding those not accessing services or support) and small increases in use of other services and support such as occupational therapists or community psychiatric nurses.

Interpreting these indications of changes in service use is difficult. The decrease in percentage of people with dementia accessing care at home could signal a restriction of access to these services, but could also be a factor of greater numbers of people with low level needs responding. Likewise, the decrease in the percentage of people with dementia attending day centres could either be a concerning indication of reduction of access to low level services, or a result of apparent increase in access to dementia support groups, which may well be more appropriate to people with dementia's needs.

What is of clear concern is the noticeably smaller percentage of respondents reporting they received social worker visits compared to Dementia tax. Visits from social workers are fundamental to accurate assessment of need and signposting to other services and sources of support.

4.2.3 Satisfaction with support and care

While satisfaction levels with services could and should be better, they do not point to significant problems or failings with any of the services people with dementia receive. However, high satisfaction with services is not an uncommon finding of this form of research (Commission for Social Care Inspection, 2006) and it should be borne in mind that most respondents to DEMHOM are carers and their satisfaction with services may differ from those of the person with dementia.

Commissioners interviewed in this research identified several mechanisms by which service quality was being improved.

‘We are reviewing services involving people with dementia’ – commissioner of dementia services

‘We use surveys and then fine tune the results through our stakeholder group’ – commissioner of dementia services

It is important that satisfaction with services is monitored, especially at a time of constraint in spending. People with dementia should be involved in this process.

4.3 Home care services

Home care is one of the primary services that supports people with dementia to live independently in their own homes. Home care is provided to a range of people with a range of social care needs, but the majority of recipients are older people. A Care Quality Commission (CQC) analysis of home care provided in England in the last week of March 2009, found 358,000 people received home care, 80% of whom were over 65 (CQC, 2010a).

Home care workers provide a range of often essential care and support for people with dementia living in their own homes, including support with personal care, support with household tasks or general support, for example overnight (CSCI, 2006).

The provision of good quality home care is an essential component of supporting people with dementia to remain at home and a major area of spending area for local authorities. The CQC found in the financial year 2008/9 that one quarter of adult social services spend was on home care and this represented half of all net spending on community services (CQC, 2010b).

In England, Wales and Northern Ireland, home care providers are regulated and have to comply with minimum standards set out by the regulators; CQC in England, the Care and Social Service Inspectorate Wales and the Regulation and Quality Improvement Authority in Northern Ireland.

Home care providers in England show good compliance with minimum standards. The CQC found 92% of recipients of home care in England were receiving care from an agency rated excellent or good, but this figure varied significantly across England (CQC, 2010a). In Wales, the Care Council for Wales (CCW) report; Care at home stated regulations and national minimum standards for home care were firmly embedded in practice with over 90% of

providers having appropriate quality assurance mechanisms in place (CCW, 2010).

In recent years, there has been an intensification of home care provision, with fewer recipients receiving more hours of care and a concurrent tightening of access criteria reducing support for people with lower level needs (CSCI, 2006). This has been substantial criticism of this practice as being counter to aims of early intervention (CSCI, 2006; Department of Health, 2010d).

Concerns have also been voiced about the sustainability of the home care sector (CSCI, 2006). CSCI and the Care Council for Wales have highlighted barriers to provision of good quality care at home, including inconsistencies in commissioning, fragmented provision and lack of career development for staff (CCW, 2010; CSCI, 2006). The lack of career progression amongst home and care home carers was also expressed strongly in the All Party Parliamentary Group (APPG) on Dementia's report, Prepared to care, which called for a career structure to be established (APPG on Dementia, 2009).

4.3.1 People with dementia receiving home care

Findings from DEMHOM indicate that people with dementia are often recipients of home care while living in their own home.

- 37% (535) DEMHOM respondents receive personal care support in their home.
- 22% (313) of respondents reported people with dementia had access to care workers during the day.
- 22% (313) reported support with household tasks.

DEMHOM respondents report people with dementia living alone were more likely to receive home care in their own homes, which is in keeping with other research (Miranda-Costillo, 2010). However, the percentage of home care recipients who live with a carer was higher in DEMHOM than other research, indicating higher home care use amongst DEMHOM respondents living with a carer.

The level of satisfaction with home care services was generally in line with respondents' views on other services. Just over quarter of recipients of each the different forms of home care report that they were either dissatisfied or very dissatisfied with the quality of services and around 70% reported they were satisfied or very satisfied. Participants in small group discussions and one-to-one interviews carried out to inform this report were generally very complimentary of the home care they received.

‘He [my husband] just comes alive’ – carer of person with dementia

‘I would love to do something back to them, its incredible what they do’ – person with dementia

However, an issue with timing was raised by some respondents.

‘I have carers coming in morning and night. But it’s difficult to set any times. In the afternoons it’s any time between four and half past seven. In the mornings it might be half past seven or ten o’clock’ – person with dementia

While DEMHOM does not provide evidence of the kinds of issues that exist with home care services, they are referred to in research and policy evidence. Issues such as continuity of care, flexibility, staff training and the time staff can spend with the person with dementia are frequently mentioned in literature (Rothera, 2008; CSCI, 2006; Heiser, 2002; Venables et al, 2006; CCW, 2010; Miranda-Costillo, 2010). CSCI noted that more in-depth interviews with service users about home care services often uncovered significant problems (CSCI, 2006; Heiser, 2002).

The NDSE highlighted that home care provided to people with dementia is often task orientated and problems often arise from inconsistency of home care workers and timings, which can be confusing and distressing to people with dementia (Department of Health, 2009). It highlights a study by Rothera, which found specialised home care for people with dementia resulted in better outcomes than access to generalised home care services (Department of Health, 2009; Rothera, 2008). However, other studies have found no benefit from specialist domiciliary care services over generalist services (Venables et al, 2006).

Several commissioners who were interviewed for the research highlight issues and problems with home care in their areas.

‘Domiciliary care is not able to provide a consistent approach in our area’ – commissioner of dementia services

Other commissioners talk about mechanisms for improving the quality of home care services, including using user feedback and forums of carers and care recipients.

‘[We are] looking at service user groups involved in evaluation of domiciliary care services’ – commissioner of dementia services

4.3.2 Home care workers caring for people with dementia

DEMHOM findings from care workers shed further light on the home care services in England, Wales and Northern Ireland and provide an invaluable insight into the views and experiences of frontline staff.

Care workers responding to DEMHOM reported they regularly worked with people with dementia.

- 30% (194) of care workers reported they always worked with people with dementia.
- 44% (440) reported they often worked with people with dementia.
- 24% (234) reported they sometimes worked with people with dementia.
- 2% (17) reported they did not work with people with dementia.

These results shows 98% of home care workers report they always, often or sometimes work with someone with dementia.

Table 9

Proportion of people with dementia that care workers report they work with

Proportion of people with dementia care workers report they work with	Percentage of respondents reporting
All people I work with have dementia	7% (69)
1 in 3	27% (267)
1 in 4	20% (201)
1 in 5	23% (230)
1 in 10	18% (174)
Other	2% (24)
Not stated	2% (24)

Table 9 shows the median proportion of people with dementia home care workers report they work with is one in four.

These results demonstrate caring for people with dementia is a fundamental aspect of home care workers' roles. This underlines the importance of appropriate training and support on dementia for home care workers. As highlighted in the introduction, it should be borne in mind that home care workers who work regularly with people with dementia may have been more likely to respond to DEMHOM and this may have skewed the results.

4.3.3 The care provided by home care workers

Most home care workers reported they had worked in the care profession for seven or more years and only a small percentage reported they had worked in the profession for less than one year.

- 59% (583) of home care workers had worked in the caring profession for more than 7 years.
- 16% (154) of home care workers had worked in the caring profession for 4–6 years.
- 18% (181) of home care workers had worked in the caring profession for 1–3 years.
- 7% (67) of respondents had worked in the caring profession for less than a year.

These results indicate that home care workers responding to our survey had generally worked in the profession for a considerable length of time.

Home care workers provided a range of types of care, but the vast majority (91%) of respondents provided personal care, such as help washing or getting dressed. This broadly correlates with responses from people with dementia and their carers, where personal care was the most frequently received form of care.

- 91% of home care workers provided help with personal care, such as washing or getting dressed.
- 66% provided help with household tasks such as cleaning, gardening or shopping.
- 38% provided care in the home during the night or overnight.
- 25% provided some other form of care.

On the whole home care workers report they find caring for people with significant memory problems as quite challenging.

- 58% (572) of home care workers report they find caring for people with significant memory problems as quite challenging.
- 18% (176) report they find caring for people with significant memory problems very challenging
- 17% (172) report they find that caring for people with dementia is not very challenging

- 4% (44) report they don't find it challenging at all.

These results demonstrate the importance of training and supporting home care workers to provide good care for people with dementia.

4.3.4 Support needed by home care workers

Given that home care staff work with a high proportion of people with dementia, it is vital that they receive appropriate support to carry out their caring role. Home care workers responding to DEMHOM report that they could benefit from a range of types of help.

Table 10

Types of support that care workers report they need

Would the following help you to care for people with dementia in their own homes?	Not helpful at all	Of little help	Quite a lot of help	Very helpful
Training on working with people with dementia	3% (34)	9% (92)	24% (241)	57% (567)
More help and advice from experts whenever you need it	1% (13)	8% (77)	28% (278)	58% (572)
More time to spend with the person with dementia on each visit	5% (47)	18% (179)	27% (269)	43% (429)
To be able to care for the same person with dementia over a long period of time	3% (29)	11% (105)	25% (249)	55% (543)
More choice over what care you provide to the person with dementia when you visit	6% (59)	18% (178)	31% (305)	35% (342)

Table 10 clearly shows that home care workers believe they could benefit from a range of types of help to enable them to carry out their caring role. Over half of home care workers report training, help and advice from experts and caring for the same person, rather than seeing different people over the time would be very helpful. These results tie in with DEMHOM findings from research literature and people with dementia and carers set out in 4.2.

Given care workers are clearly identifying these forms of support as very helpful, agencies and commissioners of care must look at how they can provide for this need among the home care workforce.

4.3.5 Time spent providing care

DEMHOM found that the vast majority of home care workers report they spend less than an hour with the person with dementia.

- 54% (530) report they spend 0–1 hours providing care.
- 18% (179) report they spend 1–2 hours providing care.
- 11% (105) report they spend 2–4 hours providing care.
- 10% (98) report they spend more than four hours providing care.

When asked if this is enough time to provide good quality care that meets the needs of people with dementia, less than a half (45%, or 447 respondents) reported that it was. A third (34%, 332 respondents) of home care workers report that it is not enough time, 14% (135) care workers didn't know and 7% (74) did not answer.

However, among those care workers reporting they only spend 0–1 hours providing care (total of 530 respondents), only 37% (196) report this is enough time to provide good quality care and 44% (233) report that it is not enough time.

This contrasts strongly with those providing more than one hour of care (the total of all those reporting 1-2 hours, 2-4 hours and more than four hours; 382 respondents). Among these home care workers, 57% (178) report this is enough time to provide good quality care and only 23% (89) report it is not enough time.

This demonstrates that where care workers are given more time, they are more likely to report the time they are given is sufficient to provide good quality care that meets people with dementia's needs. Those given only limited time are more likely to report this is not enough time.

It is therefore heartening that DEMHOM results provide some indication that the time home care workers are able to spend with people with dementia has, in some instances, expanded over the last year.

- 57% (545) of home care workers report there had been no change in the amount of time they can spend caring for people with dementia in the last year.

- 12% (119) report that, over the last year, they can spend less time providing care.
- 23% (217) report that, over the last year, they can spend more time providing care.

Given the vital role that care workers provide supporting people with dementia, it is hoped that this suggested small increase in the time they can spend caring continues, despite reductions in local authority funding allocations.

4.3.6 Home care meeting the aspirations of people with dementia

With home care workers reporting they work frequently with people with dementia, their understanding of people with dementia's aspirations and needs is essential.

It is encouraging therefore that over 82% (815) of home care workers responding to DEMHOM believe people with dementia can have a good quality of life. 14% (143) reported people with dementia can only have a limited quality of life and only 2 (less than 1%) of home care workers responding said people with dementia can't have a good quality of life.

These results clearly indicate that home care workers understand that people with dementia can maintain a good quality of life, and so should be empowered to provide care which enables this.

However, home care workers were more sceptical about whether people with dementia could remain independent and active in the community.

- 44% (430) reported people with dementia can remain independent and active in the community.
- 11% (107) reported they could only to a limited extent.
- 38% (375) reported they could only to a limited extent and with the support of a family member or another carer.
- 1% (6) said they couldn't.

Carers and people with dementia responding to DEMHOM highlighted that remaining independent, being active in the community and involved in activities are their primary aspirations of the services they receive. However, the above results demonstrate that the majority of home care workers responding do not believe people with dementia can achieve these aspirations.

It is unclear whether these results indicate home care workers hold this view because they do not think people with dementia can remain independent, or whether they do not think enough support is available to people with dementia to enable their independence. However, it is vital that home care services support people with dementia in achieving their outcomes of independence and quality of life.

4.3.7 Dementia training for home care workers

DEMHOM asked a series of questions about the attitudes of care workers towards training, what training they had received and whether they had any unmet training needs. Given the importance to people with dementia of independence and maintaining a good quality of life, it is vital that care workers are trained to meet this need. As highlighted above, there is substantial evidence that appropriate training is a major issue for home care workers (CSCI, 2006; Rothera, 2008; CCW, 2010).

Specific qualifications in dementia care have been developed by Skills for Care as part of health and social care diplomas. Courses are now in place for both dementia awareness and dementia care and cover a wide range of areas including person-centred care, communication and enabling choice (Skills for Care, 2010).

DEMHOM found the majority of home care workers understand that people with dementia have special needs and their needs are not the same as those of other older people.

- 72% (707) of home care workers replied people with dementia had special needs.
- 19% (185) said people with dementia's needs are the same as those of other older people.
- 10% (96) either did not answer or didn't know.

These are encouraging findings and suggest a widespread acceptance that working with people with dementia requires specialist training and support.

Home care workers responding to DEMHOM identified training as being of key importance to providing care to people with dementia. 79% (786) of home care workers said training was vital to providing care to people with dementia and 19% (191) said it was important. Only 3 of the 989 home care workers who responded said that training was not very important. This is a clear indication that home care workers identify training as essential to caring for people with dementia.

Over half the respondents (56 %; 556 respondents) reported that they had received as much training from their current employer as they needed. However, nearly a third of care workers (32 %; 313 respondents) reported they had some training, but not enough and 11 % (110) reported they had not received any training. These results may be skewed in favour of home care workers who have more experience and training on dementia, since these home care workers may have been more likely to respond.

These results clearly indicate that, while many home care workers report that their employers have provided enough training, still over two in five report they have not been given enough training on how to provide care to people with dementia. Given how highly home care workers responding to DEMHOM rate training it is imperative home care agencies and commissioners ensure sufficient training is available to staff.

Home care workers report that the training they have received is generally reasonably comprehensive, although with some degree of variation.

Table 11

According to care workers' responses, how comprehensive was the training they received?

Training topic	Not covered/ covered a little	Covered a lot/ covered in full
Recognising symptoms of dementia	23% (224)	69% (684)
Communicating with the person with dementia	20% (195)	73% (717)
Responding to challenging symptoms of dementia	29% (282)	64% (621)
Providing care focused on the individual's needs	20% (201)	72% (711)
Dignity and respect while providing care	10% (98)	82% (808)
Recognising pain in people with dementia	36% (360)	55% (545)
Understanding the difficulties that people with dementia may have with eating and drinking	27% (268)	65% (644)
Moving and handling people with dementia	27% (267)	65% (645)
Continence needs	25% (248)	68% (667)
Suspected abuse of the person with dementia	25% (250)	67% (661)
Emergency first aid training	37% (363)	54% (543)
Personal safety and working alone with people with dementia	32% (318)	60% (589)

Care workers seem to be suggesting that they have received less comprehensive training on more specific issues, such as personal safety, recognising pain or emergency first aid training. They report they have received more comprehensive training on broader concepts of care, such as such as dignity and respect, communicating with the person with dementia and providing care focused on needs.

To some extent, this is mirrored in home care workers' responses relating to areas where they feel they need more training.

Table 12

Areas in which care workers report they need more training

Training topic	Need a lot more training	Need more training	Need only a little training	Don't need any training
Recognising symptoms of dementia	15 % (152)	23 % (224)	31 % (303)	26 % (253)
Communicating with the person with dementia	14 % (142)	23 % (230)	30 % (292)	27 % (269)
Responding to challenging symptoms of dementia	18 % (182)	27 % (269)	29 % (286)	20 % (197)
Providing care focussed on the individual's needs	13 % (130)	23 % (223)	31 % (309)	27 % (267)
Dignity and respect while providing care	11 % (104)	16 % (154)	26 % (253)	42 % (415)
Recognising pain in people with dementia	19 % (186)	29 % (289)	29 % (286)	18 % (174)
Understanding the difficulties that people with dementia may have with eating and drinking	16 % (156)	23 % (223)	32 % (314)	24 % (236)
Moving and handling people with dementia	14 % (141)	23 % (232)	29 % (289)	27 % (269)
Continence needs	11 % (111)	20 % (194)	29 % (289)	33 % (330)
Suspected abuse of the person with dementia	15 % (147)	24 % (239)	29 % (289)	25 % (250)
Emergency first aid training	18 % (178)	21 % (207)	28 % (275)	26 % (254)
Personal safety and working alone with people with dementia	16 % (163)	23 % (229)	27 % (266)	25 % (251)

Table 12 demonstrates that a sizeable proportion of home care workers responding to DEMHOM feel they need more training on a range of areas, with only dignity and respect in care reported as an area where care workers strongly report they feel they don't need more training.

Specifically recognising pain in people with dementia and responding to challenging symptoms are identified by home care workers as areas where they need more training. These two aspects are closely linked; without care workers receiving appropriate training on understanding signs of pain in people with dementia, many people with dementia they care for will continue to display challenging symptoms. Review and provision of training must be prioritised.

4.4 Other care and support services

Alongside home care services, DEMHOM respondents report they are accessing a range of other services, as highlighted in Table 7 above. These services are vital in order to support people with dementia to live independently at home.

4.4.1 Support and information in the community

A key component to supporting people with dementia in the community is access to support services, which can help maintain people's quality of life and independence. Such services are varied, some being focused on information and advice provision and others supporting people with dementia to remain involved and engaged. They have been considered as a group here, since the routes people with dementia take into these services is often similar.

Support services in the community are strongly advocated for in the NDSE, the NICE Quality standards on dementia and Fair access to care services (FACS) eligibility guidance, which outlines that such services are an important part in 'ensuring people feel supported, included and able to participate in the community in which they live'. While the FACS guidance states such services may not be funded through social care, it outlines that councils should signpost individuals to these services and consider investing in voluntary organisations who might be able to provide them.

Findings from DEMHOM suggest variable access to support services in the community. 42% (609) of DEMHOM respondents attend a day centre, 26% (373) attend a support group for people with dementia and 18% (261) have access to a dementia adviser. Qualitative evidence from people with dementia and carers who took part in interviews and small group discussions suggests strong support for such services from those who receive them.

'The café is also a very good place to come to get information' – carer of person with dementia

‘I find it very useful to talk to people who have been through similar experiences. I don’t find it depressing at all but everyone is different’ – person with dementia commenting on dementia café

Models of low level intervention based around peer support and dementia advisers are currently being piloted across England at demonstrator sites. The results of these pilots will be crucial to informing future commissioning. However, in the interim NHS and local authority commissioners must seek to develop a market of support services for people with dementia, looking always at how services can ensure people with dementia can remain active and involved and retain their independence.

Information can play a vital role supporting people with dementia and their carers to understand their condition, its impact and how to cope. Provision of information and advice is a key priority of the NDSE, draft Northern Ireland draft dementia strategy and the Welsh Assembly Government action plans (Department of Health, 2009; Northern Ireland Department of Health, Social Services and Public Safety, 2010; Welsh Assembly Government, 2010). It is also one of the NICE Quality Standards on Dementia, which outline good quality dementia care (NICE, 2010).

Only 41 % (585) of DEMHOM respondents said that they had been given enough information on free information and support. A third (33 % or 475 respondents) said that they had been given information, but not enough and 20 % (286) reported that they had not received enough information. These findings indicate considerable variation in the provision of free information and support for people with dementia and their carers.

People with dementia and carers spoken to in interviews and group discussions highlighted varied experiences related to accessing information.

‘I have all the information I need. I know what’s going on, but sometimes you just need to phone somebody’ – carer of person with dementia

‘Alzheimer’s [Society] do put anything in your way. They’re very good for passing on information’ – person with dementia

‘You do have to go out of your way to find information about what help is available, but if you’ve got a good GP they will help. We have been very lucky’ – carer of person with dementia

Commissioners interviewed as part of research reported support for community and services and information and advice provision.

‘We signpost people with dementia towards the third sector and have wellbeing directories of services’ – commissioner of dementia services

‘Our project workers are looking at what is available in the community and have developed a directory of services and activities in the community’ – social worker working with people with dementia

However, one commissioner reported that such services were often inaccessible once people’s care needs reached the point where more formal services were required.

‘Befriending has to stop when they reach need for personal care. This is double loss for the person with dementia and the carer’ – commissioner of dementia services

4.5 Services for family carers

‘We see carer as person in their own right. Often cared for aren’t aware of their carer’s needs’ – social worker working with people with dementia

The NDSE states carers are the most valuable resource in supporting people with dementia to remain at home (Department of Health, 2009). Dementia action plans in Wales and the Northern Ireland draft dementia strategy also clearly outline the vital role that carers play (Welsh Assembly Government, 2010; Northern Ireland Department of Health, Social Services and Public Safety, 2010).

4.5.1 What services do carers receive?

The Carers strategy, Welsh carers strategy, the NDSE and the Northern Ireland draft dementia strategy all highlight the need for carers to have access to a range of flexible services to support them to carry out their caring role (Department of Health, 2008b; Welsh Assembly Government, 2007b; Department of Health, 2009; Northern Ireland Department of Health, Social Services and Public Safety, 2010). DEMHOM findings suggest that there remains limited access to carer support services, with nearly a third of carers (31 %) not receiving any services.

Table 13

Services DEMHOM respondents report the carer of the person with dementia has received

What services does the carer of the person with dementia receive?	% respondents reporting use	% using satisfied/very satisfied	% using dissatisfied/very dissatisfied
Carer support groups	39 % (566)	80 % (451)	16 % (93)
Short break services (respite) where the person with dementia stays in a care home for a short while	25 % (356)	68 % (241)	27 % (95)
Short break services (respite) in the home, such as day or night care	20 % (285)	74 % (211)	20 % (56)
Carer training courses	18 % (260)	77 % (201)	17 % (43)
Psychological therapy or counselling	8 % (115)	56 % (64)	41 % (47)
Services where the carer received one-to-one support and advice from another carer	6 % (92)	59 % (54)	36 % (33)
Other services	11 % (157)	75 % (118)	8 % (12)
Not stated	7 % (99)	N/A	N/A
The carer has not received any services	31 % (438)	N/A	N/A

These findings strongly suggest that there is still a need for increased access to, and a wider range of, services for carers of people with dementia. Support for carers can play a crucial role in ensuring that people with dementia can remain active and involved in the community and it is clear from other findings in chapter 3 that failing to support carers has significant repercussions for both the carer and the person with dementia.

The need for expansion of services for carers was recognised by some of commissioners interviewed as part of research, with one reporting forthcoming budget cuts provided an incentive to reform support for carers in their area:

‘Currently we have high intensity support for a small number of carers. [budget cuts] provide an opportunity to support more carers more effectively’ – commissioner of dementia services

4.5.2 How satisfied were carers with their services?

DEMHOM findings show that carers were generally satisfied with services, although it should be noted that with the exception of carer support groups, training courses and respite care, results are based on relatively small numbers of respondents.

DEMHOM respondents reported high levels of satisfaction with carer support groups and respite in people's own home, indicating these services are clearly valued by carers. Both psychological training/counselling and peer support services recorded sizeable levels of dissatisfaction among the small numbers of carers using them.

It is notable that 11 % of respondents report using other services and satisfaction with such services is very high (75 % satisfied or very satisfied). This suggests carers are accessing a varied range of services and value these forms of support.

4.6 Personal budgets

Service users can receive a personal budget with which to buy support and care, rather than using traditionally commissioned services. Personal budgets potentially provide service users with more flexibility and choice about what forms of support and care they use, however, support has to still be agreed in their support plan. Budgets can either be managed by the local authority (a managed budget) or money can be given directly to the individual (a direct payment).

There has been substantial political support for expanding personal budgets for people receiving social care services. Improving access to personal budgets is a clear priority of Capable communities and active citizens, the recently published adult social services strategy and was also a priority of Putting people first, the previous government's public services strategy (Department of Health, 2010a; HM Government, 2007).

However, previous research has found little evidence of people with dementia using personal budgets or direct payments. A survey by Davey et al found only 0.1 % of those receiving direct payments had mild to moderate dementia (Davey et al, 2007).

DEMHOM findings show that a significant minority of people with dementia were accessing personal budgets, or had been offered one. However the majority of respondents reported that people with dementia had not been offered a personal budget.

- 14% (204) respondents said that they are using a personal budget or direct payment to purchase services and care.
- A further 9% (130) said they had been offered a personal budget, but had declined.
- 60% (855) reported that they had not been offered a personal budget.

Some of the people with dementia and carers talked to in small discussions or interviews reported that they were using a personal budget. One carer reported she greatly valued receiving direct payments to pay for her husband's care, but highlighted that the money provided was insufficient.

'It's only £10.72 an hour and it's very difficult to get a carer for £10.72 an hour, so I just fudge it' – carer of person with dementia

Commissioners interviewed as part of this research reported both anxiety and optimism about personal budgets and dementia.

'We are making significant progress on direct payments using brokerage services....[but] have struggled to get people with memory problems to think about choice and its hard to find people who can advocate on behalf of those with dementia and get families involved' – commissioner of dementia services

'There's lots of anxiety about self-directed support. But it's particularly good for young onset [dementia]; lots on personal budgets. Quite a lot of people with young onset choosing to go down that route instead of respite' – commissioner of dementia services

DEMHOM clearly shows sizeable numbers of people with dementia are using personal budgets and this is to be welcomed. The figure of 14% receiving personal budgets is more or less in line with the estimated average across social care of 13% (Demos, 2010). However, the proportion of DEMHOM respondents receiving personal budgets may not be reflective of the wider population of people with dementia, especially as a higher proportion of DEMHOM respondents than expected are living with a carer, who may be able to manage the budget on their behalf.

There are widely reported issues relating to personal budgets/direct payments and people with dementia and older people more generally. Evidence suggests older people are often uncertain about personal budgets (Individual Budgets Evaluation Network, 2008) and can find the system onerous and confusing (National Audit Office, 2007). Likewise, there is evidence that older people do not benefit as much as others from personal budgets, reporting lower levels of psychosocial well-being (Individual Budgets Evaluation Network, 2008).

Demos' ongoing study of attitudes to personal budgets found older and people with mental health needs were most likely not to want to change anything about their support as a result of receiving a personal budget (Demos, 2010). These studies may explain the 9% of DEMHOM respondents reporting offers of personal budgets were turned down.

However, these findings do not explain why so many respondents to DEMHOM report they have not been offered the option of a personal budget. Evidence collected by the Audit Commission suggests that the greatest challenge for increasing uptake is cultural change, both among service users, but also among social care workers, provider and finance staff (Audit Commission, 2010).

Fundamentally, this cultural shift needs to take place if the Coalition Government's target of all eligible people to have a personal budget by April 2013 is to be met.

4.7 Co-ordination of care

Alongside satisfaction with individual services, which as demonstrated in table 7 was generally good, DEMHOM sought the views of respondents on their opinions of the services they have received overall.

Table 14

DEMHOM respondents' views on services and support overall

Thinking about all the services the person with dementia and their carer receives, how would you score them on:	% respondents reporting mostly very poor	% respondents reporting mostly unsatisfactory	% respondents reporting mostly satisfactory	% respondents reporting mostly very good
Availability of support early following diagnosis – 100% (1,434)	27% (383)	20% (291)	26% (376)	16% (229)
Whether services focused on meeting the person with dementia's needs – 100% (1,433)	17% (244)	25% (357)	28% (408)	13% (185)
Staff understanding of dementia – 100% (1,433)	14% (198)	19% (267)	32% (454)	19% (269)
Continuity of staff – 100% (1,433)	20% (291)	19% (269)	28% (405)	20% (287)
Time staff can spend with the person with dementia – 100% (1,432)	20% (284)	23% (323)	26% (369)	11% (161)
Flexibility of services – 100% (1,432)	19% (275)	22% (320)	23% (326)	8% (112)
Ability of services to react to a crisis – 100% (1,432)	16% (235)	12% (171)	17% (246)	12% (171)

Nearly half (47%) of the respondents rated services overall as mostly very poor or unsatisfactory for their availability soon after a diagnosis. Likewise, high proportions of respondents rated services overall as mostly unsatisfactory or very poor in terms of the amount of time staff can spend with people with

dementia (43%), flexibility (41%), focus on needs (42%) and continuity of staff (39%). It is noted and welcome that the most positive response was around staff understanding of dementia, where over half of respondents (51%) said services were overall mostly satisfactory or mostly very good.

The above negative responses are further supported by DEMHOM respondents' views on whether the services they received worked well together, set out in section 3.3.5. Only just over a quarter (26%) of DEMHOM respondents reported that services worked well together. 25% reported services worked okay together but there were some problems and 21% reported services did not work well together.

Poor co-ordination of care was a key finding of the NAO 2007 report on dementia in England, which found health and social care services in England were spending significantly on dementia, but this spending was poorly co-ordinated and often too late (NAO, 2007). The APPG report, A missed opportunity, found that many primary care trusts in England missed the March 2010 deadline for having joint strategies in place with local authorities, also indicating variable progress on joint working. Similar problems with co-ordination of dementia services are known to exist in Wales and Northern Ireland.

These results suggest not all health and social services are providing joined up support and care to people with dementia. This is in spite of the guidance on publishing joint commissioning strategies in England, integrated health and social care commissioning in Northern Ireland and duties on integrated working in Wales.

However, evidence from commissioners interviewed during this research suggested clear progress on joint working, with many commissioners reporting joint strategies and commissioning was taking place.

‘We have joint planning and commissioning teams, with a mixture of separate and joint contracts for providers’ – commissioner of dementia services

One of the social workers who was interviewed highlighted on-the-ground joint working.

‘There is a single point of discussion which meets once per week to discuss new referrals. This initial discussion provides insight into situation and background, even where people don't receive services. This process also promotes good communication and information sharing’ – social worker working with people with dementia

However, the same social worker went on to highlight conflict between health and social care.

‘Our health colleagues still see social services as a panacea to all ills’ – social worker working with people with dementia

These findings suggest that, while there is some evidence for co-ordinated commissioning and working, this is not working its way down to the experiences of many people with dementia and carers.

4.8 The impact of funding cuts

‘Looking at providing the same services with less money. Will also look at remodelling’ – commissioner of dementia services

Local authorities face significant cuts to budgets in coming years. Although funding has been announced to mitigate the impact of this on adult social services, there are concerns that cuts may impact on the services people with dementia and carers use. Similarly, the NHS, while protected against cuts, is facing both significant reform and a continuous drive to make efficiency savings. It is against this backdrop that the aspirations of people with dementia to remain independent and active in their communities have to be met.

4.8.1 Cuts already taking place

Results from DEMHOM suggest that cuts to services for people with dementia may already have been taking place at the time the survey was carried out in September and October 2010.

- 14% (203) of DEMHOM respondents report that services have been reduced or withdrawn recently.
- 48% (693) report there has been no change recently.
- 8% (115) report services have expanded recently.
- 29% (421) didn't know or didn't answer.

These results are of concern given this survey was carried out at a time when the impact of local government budget cuts had yet to materialise.

While commissioners and Society service managers who were interviewed all recognised the challenge of spending cuts, there was a sense of inevitability.

‘We are already talking with commissioners about cuts’ – Alzheimer’s Society service manager

‘There have always been these challenges, always been these cuts. Just a part of working in the third sector’ – Alzheimer’s Society service manager.

Well, we’re not going to have any more money’ – commissioner of dementia services

However, cuts were seen by most of the commissioners and Society service managers as both a challenge and an opportunity for remodelling of services and support.

‘People instantly think you need more money to do things. My view is that you can do some things better with the money you have. Services have gone on much the same for lots of years and no one has looked as to whether to change them.’ – commissioner of dementia services

‘We’re cutting things where it will have least impact and targeting more effectively...we’re also doing equalities impact assessments when we do cuts; not just slashing budgets’ – commissioner of dementia services

‘Cuts also provide the opportunity to remodel and re-position our services and reduce waste’ – Alzheimer’s Society service manager

It is important to reiterate that all the commissioners who were interviewed had good relationships with Alzheimer’s Society services staff and so may have better understanding of dementia. However, these results do indicate that some commissioners are preparing to meet the challenge of improving outcomes of people with dementia while managing reductions in budgets.

It is important that commissioners and those managing individual’s care monitor closely the impact of cuts locally. Commissioners must seek consultation with local populations and service users before making cuts which may impact on people with dementia and carers’ access to support and care.

4.8.2 The future funding of care

Current funding of social care is inadequate to provide sufficient services and support for service users, often resulting in greater pressure on acute NHS services, which are free at the point of use and funded from general taxation. Because the social care system is means tested, people with dementia and their families have had to pay substantial amounts for the care they receive.

This report has not dealt with the amount paid for services, as it deals with services from NHS, social services and wider support. Nevertheless, implementation of its recommendations on improving access to mainstream services and close working with the NHS will help alleviate pressure on social care budgets.

Fundamentally, however, a fairer funding solution is needed for social care which both reduces the substantial costs incurred by people with dementia and their families (Alzheimer's Society, 2008a) and also increases resources available in the system.

Recommendation 6

Home care workers must be supported to provide good care to people with dementia in their own homes.

Dementia is core business of home care agencies and a core responsibility of home care workers. 82% of care workers believe people with dementia can have a good quality of life, however care workers report they still need more training on providing good dementia care.

- All home care workers should receive comprehensive training on dementia care which allows them to provide care that meets the needs and aspirations of people with dementia.
- The amount of time home care workers spend with people with dementia should be based on whether it is sufficient to meet needs and aspirations, not on rigid time or task-based schedules. Contracts, commissioning and practice should be designed to achieve this.
- Providers of training for home care workers should consider the results of this survey in the development of new or existing training courses. Dementia specific training courses, such as those developed by Skills for Care, should be promoted.
- Home care workers should be supported through close working with other health and social care professionals. They should be represented in discussions about people with dementia's support plans and their opinions on what is an appropriate amount of time to spend providing care to an individual should feed into decision making.

Appendix 1

Alzheimer's Society's role in supporting people living in their own homes

This appendix outlines some of the ways the Society is taking to ensure services the Society offers support people with dementia to remain independent at home. This is not intended as an extensive summary of the Society's services and wider work. For further information on the work of the Society supporting people with dementia living in their own homes, please see the Society's website: alzheimers.org.uk

1 Overview

The Society has over 2,000 services in England, Wales and Northern Ireland which support people with dementia living in their own homes. These include home support through our dementia support worker service, day care services as well as support and befriending services to help support partners and families.

Alzheimer's Society's core services are focused around information, education, care and support. These include leisure and well-being services to promote maintenance of good quality of life, information services, such as the Society's helpline, website and online forum Talking Point, and support services such as day centres and peer support. Alongside these services the Society operates several care services, including a number of registered home care services.

The Society's wider work influencing practice, campaigning and raising the profile of dementia also plays a central role helping improve the support of people with dementia in their own homes.

2 Ensuring services meet needs

New referrals to Society services undergo an individual personalised assessment involving, where appropriate, their carer. Society staff work with the person with dementia or carer to identify their personal desired goals and

outcomes. This assessment looks at how individuals are affected by dementia, their physical needs, the activities and hobbies they like, and their practical and information needs .

Subsequent to assessment, support plans are developed with the person with dementia or carer, outlining desired outcomes, support required and additional services they may wish to access. Support plans are reviewed regularly.

3 Consistency in services

The Society has introduced service specifications for all of the services it provides. These clearly and consistently define services according to set standards, with defined outcomes and ways of delivering services.

The specifications themselves are based on national regulations and guidance and will be accompanied by service templates, which will provide information on policies and procedures. Service specifications and templates enable the Society to provide more comprehensive and consistent support of people with dementia living in their own homes.

The Society has also recently reorganised its services to meet the growing challenge of dementia and react to the growing public priority which is being given to dementia. This reorganisation will allow the Society reach out to substantially more people and ensure quality and consistency in all services. The Society will be providing all of its services to people with personal budgets in 2011.

4 Maintaining and improving quality

Alzheimer's Society has robust internal mechanisms in place to ensure services are high quality. Services are reviewed by Society Service Improvement Managers and will be monitored against service specifications. Services also seek regular feedback from service users to maintain and ensure quality. Where services are not of high enough quality, steps will be taken to improve their quality.

Services the Society runs which are registered with regulators are also externally assessed and rated, for example, through Care Quality Commission (CQC) inspections and star ratings.

5 Training

Alzheimer's Society's education and training aims to transform the culture of dementia care and change lives through the development of an informed and effective workforce. The Society runs foundation, intermediate and advanced courses on a range of aspects of working with people with dementia. These courses are available to be commissioned by local health and social care organisations.

The Society also strives to ensure its own workforce is trained in understanding dementia. Society staff have access to a range of free training courses on working with people with dementia.

6 Wider work of the Society

The wider work of the Society influencing standards, policy and practice has significant potential to improve the support of people with dementia living in their own homes. Campaigning and research work undertaken by the Society also play a role enabling better support of people with dementia in their own homes.

6.1 Dementia Action Alliance

In October 2010, Alzheimer's Society, the Department of Health and over 40 other national organisations launched the Dementia Action Alliance. The Alliance members have signed the National Dementia Declaration and committed through the publication of action plans to improve outcomes for people with dementia.

6.2 Worried about your memory?

The Society is actively encouraging the early detection of dementia through the Worried about your memory? campaign. This campaign aims to inform people about memory loss and encourage them to seek medical advice if they have concerns.

6.3 Research

The Society's research programme includes a focus on ensuring research is translated into the best possible care, thus improving quality of life for people with dementia and their carers. This includes developing the best training for

care staff, supporting GPs with tools to enable earlier and simpler diagnosis and the design of innovative technologies and facilities for care and support.

A key element of the Society's research strategy is to ensure our research informs and supports our service delivery. As a first step towards this, the Society is currently developing infrastructure to support the translation of discoveries from research into services. Several initial projects are already being explored, focusing around online information and support.

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