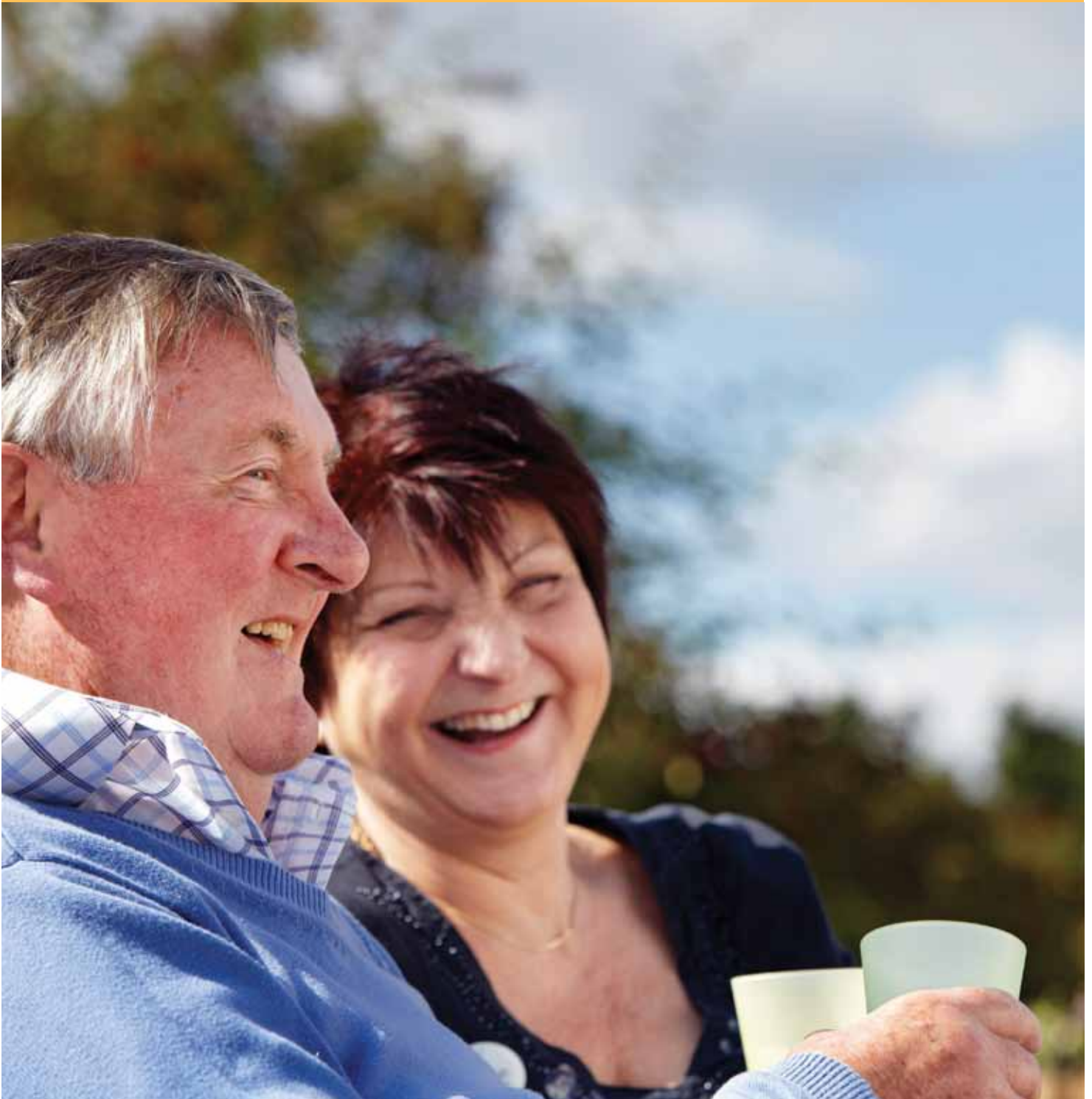


Dementia 2012: A national challenge



Document purpose	Dementia 2012 describes how well people are living with dementia in 2012 in England, Wales and Northern Ireland. Alzheimer's Society will provide an annual report on how well people are living with dementia to help chart progress and opportunities for action, year on year.
Title	Dementia 2012: A national challenge
Publication date	March 2012
Target audience	Dementia 2012 is intended for a wide range of organisations and people who can improve quality of life for people with dementia. This includes partners from business, the public sector, civic organisations, the government, NHS and local authorities.
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Foreword

It is said that having dementia is like standing in a busy airport. Everything speeds up around you while you stay still. Only things are not getting faster. Your brain is slowly shutting down. Gradually a person with dementia will lose the ability to walk, talk, eat, dress or even go to the toilet unaided. Standing alone in that airport must be the scariest moment in your life. It was for my father.

Between these pages Alzheimer's Society presents the dementia problem and its solution. The problem is clear. There are rising numbers of people with dementia; spiralling costs; low levels of public and professional understanding. Too often people with dementia are living a poor quality of life, often cut off from their community and even losing friends. Almost two thirds say they are suffering from feelings of depression, loneliness or anxiety. Economically it exposes the UK to a £23 billion dementia black hole.

Dementia 2012 provides a compelling vision for change. People living with dementia want to remain independent for as long as possible, and they want choice and control over their lives. With an early diagnosis and the right support they can.

Yet this is far from reality for most people. My father faced a battle for a diagnosis and support from the health and social care system. Everyday things – getting to the shops, spending time with friends, getting money from the bank, even going on holiday – were made unnecessarily difficult by a lack of understanding of dementia. I hate to think how things would have been without his excellent carers.

This year every village, town and city should work towards becoming a dementia friendly community. A community that gives people the independence and dignity they need to live their lives to the full. From bank managers to bus drivers we must work in partnership to ensure people with dementia are supported to live well wherever they are.

Imagine changing that 'airport' experience forever. Imagine giving support, information and quality care that enables people to enjoy a life in control. If you can socialise, keep hobbies, make choices and stay with your family then your reasons for being afraid greatly diminish. How different would the journey be for the 800, 000 people living with dementia today and the millions in future? The answer is important for all of us. As the number of people with dementia grows, all our lives will undoubtedly be affected. One in three people over 65 will develop dementia.

To change this experience we need to radically rethink how we treat people with dementia in the UK. By reading this report you are one step closer to changing the way we, as a nation, deal with dementia. Read on and become part of the solution. Just one change could make a huge difference to the life of someone you know and hundreds of thousands more.

Rosie Boycott

Rosie Boycott
Alzheimer's Society Ambassador



Executive summary

1 Summary

There are now 800,000 people with dementia in the UK and there are estimated to be 670,000 family and friends acting as primary carers. The current financial cost of dementia is £23 billion a year to the NHS, local authorities and families and the cost will grow to £27 billion by 2018. Yet this significant spend is often not being deployed effectively and is not delivering good outcomes for people with dementia and carers.

Given the numbers of people with dementia and the rising costs, it is vital that we understand how well people are living with the condition. This must be based on the outcomes that are important to them, to help chart progress and the opportunity for action.

Dementia 2012, the first in a series of annual reports, describes how well people are living with dementia in 2012 in England, Wales and Northern Ireland. Living well is assessed by exploring the seven outcomes that people with dementia and carers have told us are important to them as described in the Dementia Action Alliance National Dementia Declaration for England. These outcomes take into account public services that must form part of the approach, but also wider issues such as family and community.

It is acknowledged that there is work being undertaken to improve quality of life for people with dementia and their carers, and much has been achieved. Three years on from publication of the National Dementia Strategy for England, and following plans in Wales and Northern Ireland, much is being done within health and social care to improve support and services for people with dementia and their carers. In addition, a range of organisations have committed to acting on dementia, including members of the Dementia Action Alliance.

However, Dementia 2012 shows that at the current time people are still not living well with the condition. For many people with dementia and their carers, quality of life remains extremely varied. Not only do people face potential battles for a diagnosis and support from the health and social care system, but everyday things we all take for granted – having control over daily life, spending time with friends and family, socialising and enjoying hobbies – are made difficult by a lack of understanding of dementia in our communities.

Alzheimer's Society believes that dementia must be recognised as a challenge for society. Given the breadth of the quality of life issues that must be addressed to ensure that people live well with the condition, and the size of the dementia challenge, good quality of life for people with dementia and their carers cannot be achieved in isolation or by a few. We must work in partnership to improve quality of life, focusing on all outcomes that are important to people living with dementia, including developing dementia friendly communities. This partnership must have people with dementia and carers at the heart and must include a range of partners from business, the public sector, civic and voluntary organisations, as well as the government, NHS and local authorities.

We must see a major shift in societal awareness and understanding about dementia, and a move towards the development of dementia friendly communities. While recognising the difficulty and urgency of the challenge, the potential for progress if we work together is huge.

2 Methodology

Dementia 2012 presents new evidence from people with dementia in the early stages of the condition and living in their own homes. A survey was distributed to people with dementia via Alzheimer's Society dementia support workers and dementia advisers in England, Wales and Northern Ireland.

The report also draws on existing research and current work. For example a range of public policy documents, research literature, learning from good practice and existing indicators.

YouGov also completed a poll of the UK adults for Alzheimer's Society in December 2011. 2,070 individuals were asked about both their own quality of life and their perceptions of how well people are able to live with dementia.

3 Key findings

Key findings of the report are based on an Alzheimer's Society survey completed by people living with dementia and a YouGov poll of the general public.

3.1 How well are people living with dementia?

People are not living well with dementia. Dementia 2012 found that:

- 17% of people with dementia responding to the survey said that they are not living well with dementia at all, 55% said they are living quite well with dementia and only 22% said that they are living very well with dementia.
- In addition, a YouGov poll of 2,070 members of the general public found that respondents perceive people with dementia to have either a fairly bad quality of life in the UK (39%) or a very bad quality of life in the UK (19%). Only 1% thought that people with dementia have a very good quality of life, while 6% thought they had a fairly good quality of life.

Issues that contribute to how well people are living with dementia are explored in the report by focusing on the outcomes important to people with dementia and carers, as described in the Dementia Action Alliance National Dementia Declaration. Key findings are as described below.

3.2 Choice and control over decisions

The National Dementia Declaration identifies having personal choice and control or influence over decisions as a key outcome for people with dementia. This section in the full report explores how much control people living with dementia feel they have over their day to day lives, experiences of getting a diagnosis, financial issues, opportunities to plan for the future and end of life care. Key findings from the survey of people with dementia include:

- 14% of respondents felt that they were not able to make choices about their day to day life and 37% of respondents felt that they were only sometimes able to make these choices.
 - For someone with dementia one of the foundation stones for being able to make choices is receiving a timely diagnosis. However, the survey for this report found that many respondents struggled to receive a diagnosis:
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- One third (31%) of people with dementia said that they struggled to get a diagnosis. (It is important to note that respondents to the survey are in touch with Alzheimer's Society and therefore more likely to have received a diagnosis and to be receiving support.)
- 68% of respondents had a gap of longer than a year between noticing their symptoms and getting a diagnosis. 8% of respondents had to wait five years or over for a diagnosis.
- Other data shows that only 43% of people with dementia have been formally identified in the UK.
- In addition, the YouGov public poll found that 30% of the general public thought they would struggle to get a diagnosis if they had dementia.

3.3 Services that are designed around individual need

The National Dementia Declaration identifies having services and support that meet their individual needs as a key outcome for people with dementia. This section of the report explores issues such as whether services are designed around need, individuals feel supported by their GP, people are able to access a range of good quality services, people living with dementia feel that their care is delivered by well trained professionals and their carers are supported in their role. Key findings from the survey of people with dementia include:

- 34% of people with dementia responding to the survey said that the support services that they receive only sometimes (25%) or do not (9%) help them to live as independently as they need to.
 - Respondents want services that are better designed around their needs. 44% of respondents said that professionals either only sometimes (28%) or do not (16%) involve them in decisions about their care and support. In addition, 46% of respondents said either that they only sometimes (25%) or never (21%) have a choice over the support services they receive.
 - 47% of respondents felt that their carer is only sometimes (30%) or is not (17%) getting the support that they need to carry out their caring role.
 - 83% of respondents said that research into improving care for people now was important; 83% said that research into the cause was important and 87% said that research into the cure was important. 82% of respondents also felt that there should be more funding for dementia research.
 - The YouGov public poll asked people how good or bad access to services was for people with dementia. Nearly half (48%) of respondents said it was bad, while only 9% rated access to services as good.
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3.4 Support and knowledge to help people live well with dementia

The National Dementia Declaration identified that people need the right support and knowledge to help them live their lives. This section of the report particularly focuses on the social networks that people living with dementia have and the importance of peer support. It also looks into their information needs now and in the future. Key findings from the survey of people with dementia include:

- When asked if they lost friends after their diagnosis of dementia 12% of respondents said yes, most of them, 28% said yes, some of them, and 47% said no. 4% of respondents reported that they haven't told their friends.
 - 49% of people with dementia responding to the survey said that they sometimes have opportunities to meet and talk to other people with dementia and 18% reported that they never have opportunities (67% in total).
 - When asked if they ever felt lonely, 61% of people with dementia reported that they felt lonely always (6%) or some of the time (55%). When asked if they ever felt anxious or depressed, 77% also reported that they felt anxious or depressed always (9%) or some of the time (68%).
 - 48% of respondents reported that they felt like a burden to their family and 19% of people felt that they were a burden to friends.
 - In addition, 40% of respondents to the YouGov poll of the general public felt that having dementia would mean they would be lonely and 57% felt that having dementia would mean that they would feel anxious.
 - 32% of surveyed respondents reported that they were receiving some but not enough information about their condition and 6% reported that they had not received any information. 27% of respondents also reported that they had received some but not enough information to plan for the future and 19% said that they had not received enough.
 - 75% of respondents thought that it was either very or quite important to hear about research into dementia and 64% indicated that being asked to take part in dementia research was important for them.
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3.5 Living in an enabling and supportive community

The National Dementia Declaration identified two outcomes that are strongly related to how people live in the community. This section of the report has a particular focus on exploring the evidence from people with dementia and carers on whether they feel part of their community, the work that is already being undertaken to make communities dementia friendly and what needs to happen next. Key findings include:

- 22% of respondents to the survey of people with dementia said that they did not feel part of their community and 38% said that they felt part of their community only sometimes.
 - 61% of respondents think that their community doesn't understand at all (25%) or has only a little understanding (36%) of how to help them live well. 71% would like their community to understand how to help them live well a lot (57%) or a little (14%) and 67% think that this understanding would make their life a lot (45%) or a little (22%) better.
 - In addition, the YouGov poll of the general public asked whether they felt people with dementia were included in their community. 60% rated the inclusion of people with dementia in their community as bad (38% as fairly bad and 23% as very bad).
 - The poll also asked the public if society is geared up to deal with people who have dementia. Only 5% said that this was true and 75% said that this was false (while 20% did not know).
 - There are possible negative outcomes for people with dementia if they are not supported to live well within their community. For example, some survey respondents feel that they are a burden to health and social care professionals (10%) and people in the wider community – neighbours (8%); people working in banks/post offices/shops (9%) and the police (4%).
 - Respondents also reported that they perceived that they very often do not have a voice in their community. Only 12% of survey respondents said that they always have a voice, 31% only sometimes and 41% never.
 - The top five solutions that people with dementia report could be done in their community to make it easier for them to live life the way they want are:
 - Better understanding of dementia and less social stigma attached (25%). People with dementia would like the following to have more of an understanding of dementia: family (54%), friends (58%), neighbours (51%), health and social care professionals 58%), people working in banks, post offices and shops (62%), the police (54%).
 - More public awareness of the condition (17%).
 - More local activities and opportunities to socialise (13%).
 - More tolerance and patience from others (7%).
 - More community spirit (7%).
-

4 Recommendations

Recommendations for action are outlined in detail at the end of each section of the report. For easy reference, in the Executive summary the recommendations have been grouped into five key areas where action is required if the dementia challenge is to be met. These are topline recommendations only and further details on the action required are at the end of each section.

1 Improve awareness and understanding

- Rates of diagnosis must be increased to two-thirds by 2015 and three-quarters by 2017.
- A major shift in public awareness and understanding of dementia is required to reduce stigma and encourage people to visit their GP with problems about their memory. This should combine large-scale public campaigns with targeted work to increase understanding of dementia among a range of individuals and organisations, such as the police, banks and retail outlets.
- All health and social care staff should have access to dementia care training that is consistent with their role and responsibilities and access to expert advice. In particular, key stakeholders such as Royal Colleges, university deaneries, local education and training boards, and workforce advisory groups must prioritise action on dementia.
- The Mental Capacity Act 2005 must be comprehensively implemented. Analysis of the emerging evidence on how the Act is being applied, and further evidence on this, is vital.

2 Improve health and social care systems

- The government should put forward plans to implement the recommendations from the Dilnot Commission on Funding of Care and Support (2011).
 - It must also be recognised that implementing the Dilnot recommendations will not go far enough to reform the social care system. Extra funding is needed to ensure that people with dementia and carers can access better quality as well as more care. We must consider as a society where this money can come from.
 - Resources should be shifted from inappropriate acute and residential care for people with dementia into the community setting. This would help ensure that the right support is available for people with dementia and carers such as early intervention and prevention services, and respite care services. Commissioners in Wales, England and Northern Ireland should also prioritise the integration of health and social services in dementia.
 - It must be ensured that people with dementia and carers are fully involved in the personal budgets agenda.
 - The inappropriate prescription of antipsychotic drugs should be reduced.
 - People with dementia should be provided with good quality end of life care that meets their needs.
 - Robust data across health and social care to support delivery on dementia is required.
 - Dementia clinical networks should be created by the NHS Commissioning Board to ensure effective use of clinical expertise to improve services for people with dementia and carers.
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3 Ensure that people living with dementia have appropriate information and support

- Every person diagnosed with dementia and their carers must be able to access peer support (such as Dementia Cafés) that is delivered in the most appropriate way for them.
- Local authorities should have responsibility for ensuring that there is independent provision of information about local services across the spectrum of the statutory, voluntary and independent sectors. This information should be presented in a format which is accessible to people with dementia and carers.
- Organisations providing written information should consider how they could enhance these services by providing follow-up assistance for people with dementia, supporting them to understand and act on information.
- Local authorities should ensure that people with dementia have access to a named contact throughout their life with dementia.

4 Ensure that people with dementia are recognised as active citizens with the potential to live well in the community

- Work must be undertaken to understand what makes a dementia friendly community and how communities can best support people with dementia and carers to live well.
- Communities must be enabled to understand how to help people with dementia and carers live well within the community. Support should be provided to community agencies, for example, shops, businesses, the public sector and churches, as they contribute to developing dementia friendly communities.
- People with dementia and carers must be at the heart of the dementia friendly communities work. They should be key partners, speaking out about their experiences of living well with dementia and the solutions they would like to see.
- There should be particular work to apply the thinking and practice of dementia friendly communities to health and social care services to ensure that social networks are maintained and developed.

5 Research

- The government should signal commitment to dementia research by significantly increasing its investment: a target of £100 million would be appropriate and ambitious.
 - Information about research, and opportunities to participate in research, should be considered as part of the overall package of information to individuals.
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5 What is Alzheimer's Society doing to meet the dementia challenge?

Alzheimer's Society will be working with a range of partners and organisations to meet the dementia challenge. In particular the Society will:

- Continue to work with the Dementia Action Alliance and fulfil the outcomes committed to in the Society's action plan.
 - Lead work in the area of dementia friendly communities, as committed to in the Society's Dementia Action Alliance action plan and the Society's five year strategy, Delivering on dementia (2012–2017). The strategy includes a key ambition to work with people affected by dementia, partners from business, the public sector and civic organisations, to define and develop dementia friendly communities.
 - Continue to increase awareness and understanding of dementia, for example through campaigning to improve early diagnosis and the Worried About Your Memory? project.
 - Provide a range of information services, resources and training for health and care professionals who work with people with dementia.
 - Provide local information and services across England, Wales and Northern Ireland to people affected by dementia in their communities.
 - Continue to provide a unique research programme funding research into the cause, cure, care and prevention of dementia to improve treatment for people today and to search for a cure for tomorrow.
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1 Introduction

1.1 Introduction to the report

This report describes how well people are living with dementia in 2012 in England, Wales and Northern Ireland.¹ It creates a snapshot of the current situation by presenting new research among people with dementia (particularly those in the early stages and living in their own home) and their carers, as well as collating existing evidence such as research literature, national indicators and key public policy.

It measures how well people are living with dementia against seven outcomes that people with dementia and carers have told us are important to them in the Dementia Action Alliance National Dementia Declaration (Dementia Action Alliance, 2010). There is much overlap between these outcomes and other research into quality of life for people with dementia and older people. For example, My name is not dementia (Alzheimer's Society, 2010a), Quality outcomes for people with dementia (Department of Health, 2010a) and the Joseph Rowntree Foundation work programme A better life (2009–2013). The body of research shows that many issues influence quality of life for people with dementia, from health and social care, to social relationships and engagement in activities.

Dementia 2012 is published at a vital moment. Now that dementia is firmly on the public and political agenda, there is a unique opportunity to change quality of life on a wider scale for people living with the condition. Dementia 2012 therefore explores how well people are living with dementia in relation to the seven outcomes and explains the further work that is required. From now on, Alzheimer's Society intends to provide an annual report like this one. We will show how well people are living with dementia based on the outcomes that are important to them and chart progress and opportunities for action, year on year.

This first report acknowledges that three years on from the National Dementia Strategy for England, and following plans in Wales and Northern Ireland, much is being done in health and social care to improve dementia care. It also explores current work being undertaken into wider issues related to quality of life. For example, work to make sure that communities where people live are appropriate for older people.

However, the report shows that quality of life for many people with dementia and their carers remains extremely varied. The survey for this first report suggests the majority of people with dementia in the early stages of the condition and living in their own homes do not feel they are living well with dementia:

- 17% of respondents said they are not living well with dementia at all; 55% of respondents said they are living quite well and only 22% said very well.
- 65% of respondents said having dementia changes the way they live their life a lot and 24% said it changes the way they live their life a little. Only 7% said having dementia didn't change their life at all.

¹ Alzheimer's Society operates in England, Wales and Northern Ireland, not Scotland, which is represented by Alzheimer Scotland.

- In addition, the YouGov poll of 2,070 members of the general public found that respondents perceive people with dementia in the UK to have either a fairly bad quality of life (39%) or a very bad quality of life (19%). Only 1% thought that people with dementia have a very good quality of life, while 6% thought they had a fairly good quality of life (17% thought that it was neither good nor bad).

This report explores the challenge of dementia – the numbers of people with the condition and the wide range of issues that must be addressed to improve quality of life. It asserts that based on the scale of the issue, dementia must be viewed as a challenge for society. Good quality of life for people with dementia cannot be achieved in isolation or by a few. We must work in partnership, focusing on all outcomes that are important to people with dementia, including health and social care but also developing dementia friendly communities. These partnerships must have people with dementia and carers at their heart, and include a variety of organisations that can make a difference. This approach is being modelled by the Dementia Action Alliance (DAA)², where each member has committed to an action plan to improve quality of life for people living with dementia.

Dementia 2012 is aimed at many different organisations and people who are in a position to improve quality of life for people with dementia. The evidence presented here should support work already being undertaken, while encouraging others to act. We must expand the pool of stakeholders, both nationally and locally, who are supporting people with dementia to live well. Organisations, professionals, people with dementia and carers – anyone who can help develop a society where people can live well with their dementia – should be invited to join in discussions across the country.

Furthermore, the report will support and shape work on dementia friendly communities. As a member of the Dementia Action Alliance, Alzheimer's Society has committed to leading work in this area. The Society's five year strategy, *Delivering on dementia* (2012–2017), includes a key ambition to work with people affected by dementia, and partners from business, the public sector and civic organisations, to define and develop dementia friendly communities. Dementia 2012 is a starting point for this work, assessing the efforts already underway, adding to the evidence available and recommending new actions.

1.2 Methodology

1.2.1 Survey and respondents

Dementia 2012 presents new evidence from people with dementia in the early stages of the condition and living in their own homes. A survey was distributed to people with dementia via Alzheimer's Society dementia support workers and dementia advisers in England, Wales and Northern Ireland.

The total number of respondents to the survey was 306. The majority of respondents (77%) were people with dementia, either filling in the survey alone or with support. The number of carer respondents was 26% (some respondents ticked two options). In addition:

- The majority of respondents were aged 65 and over: 8% were under 65 years; 75% were 65–85 years and 17% were 85+.

² www.dementiaaction.org.uk

- Many people had been living with dementia for several years: 9% had been living with the condition for under a year; 36% for 1–3 years; 33% for 4–6 years; and 7% for over 10 years.
- 58% of respondents were male and 42% were female.
- When asked where they live, 16% of respondents said on their own; 71% said with a carer; 3% with someone who is not a carer; and 9% said other.

This is a significant number of people with dementia and it provides an important evidence base on how well people are living with the condition. However, there are limitations to the sampling on which it is based. This is a self-selecting survey and the sample is comprised of people already in touch with Alzheimer's Society and therefore accessing support. It must be acknowledged that the majority of respondents will have had a diagnosis of dementia. The evidence therefore provides a snapshot of how well people in the early stages of the condition are living in their own homes, rather than a definitive evaluation covering all stages of living with dementia. Future reports will develop and extend the methodology to reach a wider sample, including people in the later stages of dementia and people living in residential care.

1.2.2 Existing data and reports

The report draws on existing research and current work to provide further information, including on the experiences of people with dementia who are not represented by the survey sample. For example:

- Public policy documents: these include Alzheimer's Society reports and key national documents such as the dementia strategies.
- Research literature: the British Medical Association completed a search of the Medline database for Alzheimer's Society, collating research related to quality of life in the context of dementia. Other key literature was also identified from various sources.
- Learning from good practice: current work to improve quality of life for people with dementia is included, particularly that which relates to people living within communities.
- Existing indicators: data that illustrates how well people are living with dementia has been included. For example, data from the Quality and outcomes framework (QoF) and the NHS Atlas of variation.

1.2.3 Public poll

- YouGov completed a poll of the UK adults for Alzheimer's Society in December 2011. 2,070 individuals were asked about both their own quality of life and their perceptions of how well people are able to live with dementia. The findings are discussed throughout the report.
 - Data has also been included from the Office for National Statistics' (ONS) opinions survey on subjective well-being, published in 2011.
-

1.3 Introduction to dementia

There are now 800,000 people with dementia in the UK. Over 17,000 younger people (65 years of age or below) have dementia (Alzheimer's Society, 2007, updated to reflect 2012 figures), and an estimated 11,000 people from black and minority ethnic groups have the condition (Alzheimer's Society, 2007).

The term 'dementia' describes a set of symptoms which include loss of memory, mood changes, and problems with communication and reasoning. These symptoms occur when the brain is damaged by certain diseases, including Alzheimer's disease and damage caused by a series of small strokes. It is progressive, which means the symptoms will gradually get worse.

Because the size of the population is growing and people are living longer, by 2021 there will be over 1 million people living with dementia in the UK. This currently costs the NHS, local authorities and families £23 billion a year (Alzheimer's Society, 2007, updated to reflect 2012 figures), and this will grow to £27 billion by 2018 (King's Fund, 2008).

Two-thirds of people with dementia live in the community (Alzheimer's Society, 2007). There are estimated to be 670,000 people in the UK acting as primary carers for people with dementia, which saves the state £8 billion per year (Alzheimer's Society, 2007, updated to reflect 2012 figures). It is important to recognise that one-third of all people with dementia in the UK live alone in their own homes.

As the symptoms of dementia progress, people need increasing amounts of care. Once the symptoms of dementia become severe it is often appropriate for an individual to live in a care home. One-third of people with dementia live in a care home and at least two-thirds of care home residents in the UK have dementia (Alzheimer's Society, 2007). People with the condition are also core users of NHS care – a quarter of hospital beds are occupied by people with dementia over 65 at any one time.

Despite the number of people living with dementia, and the associated costs, numerous reports from the National Audit Office (NAO) (2007; 2010), Public Accounts Committee, regulators, NHS Atlas of variation (NHS Right Care, 2011) and Alzheimer's Society show that many people with dementia are being let down. Despite the significant spend on dementia, this is not being developed effectively and too many people are not provided with good quality care and support that meets their needs and aspirations. Furthermore, the quality of care varies considerably across geographical areas.

However, dementia is now a public and political priority in a way that it has never been before. All four nations of the UK have developed dementia plans which set out an aspiration to help people live well with dementia. It is now three years since the National Dementia Strategy was published in England (Department of Health, February 2009). The NAO found the following year that implementation had been slow, but there is continued commitment to dementia as a high priority, with levers in place to drive change (NAO, 2010).

For example, the revised NHS Operating framework for 2012/13 in England identifies dementia as a high-level priority for action. There will be a new Commissioning for Quality and Innovation (CQUIN) target on improving diagnosis of dementia in hospitals (Department of Health, 2011). And the Department of Health has committed to having a dementia-related indicator in the NHS outcomes framework (which sets out the outcomes and corresponding indicators that will be used to hold the NHS Commissioning Board to account for the outcomes and services it commissions from 2012/13).

1.4 What quality of life outcomes and aspirations are important to older people and people living with dementia?

Because national dementia plans and strategies are led by governments, naturally they focus on improving the accessibility and quality of public services for people with dementia and carers. Public services must indeed play a role in helping people live well with dementia. However, the outcomes that we know matter to people with dementia and carers make clear that living well with dementia must involve wider approaches – for example, by taking families and communities into account.

Recent work has begun to identify the quality of life outcomes and aspirations that are important to people with dementia. This includes My name is not dementia (Alzheimer's Society, 2010a), Quality outcomes for people with dementia (Department of Health, 2010a), the Dementia Action Alliance's National Dementia Declaration (2010) and Support. Stay. Save. (Alzheimer's Society, 2011a). While it is important to acknowledge that each individual will have personal aspirations, the research highlights some common outcomes that can guide our understanding of how well people are living.

In 2010, Alzheimer's Society worked with partner organisations to launch a National Dementia Declaration for England. This was developed by the Dementia Action Alliance (DAA), which brought together different organisations interested in delivering change. In the Declaration for England, people with dementia and carers described seven outcomes that are most important to their quality of life. These are:

- 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 now and hope for the future.

The Support. Stay. Save. report (Alzheimer's Society, 2011a) surveyed carers about the aspirations and needs of people living with dementia in the community. They reported that people with dementia want to remain independent and engaged in their communities. Key factors that were highlighted included independence, being active and engaged, and socialising. 83% of respondents said that being able to live at home was very important to people with dementia. 59% said being active in the community was very important to the person. The report also showed the importance of services in enabling people with dementia to remain independent: 82% of respondents said services were vital to supporting people with dementia to live in their own home. Respondents said they wanted services to enable and empower people with dementia, rather than simply address specific care needs.

In *My name is not dementia* (Alzheimer's Society, 2010a), people with dementia stated that their lives are not defined by having the condition. The report identified a series of factors that are important in delivering quality of life for people living with dementia. The primary concern that people described was the importance of social relationships and networks in helping them maintain well-being and independence. The key factors were:

- relationships or someone to talk to
- environment
- physical health
- sense of humour
- independence
- ability to communicate
- sense of personal identity
- ability or opportunity to engage in activities
- ability to practise faith or religion
- experience of stigma.

Other work has recently highlighted the outcomes and aspirations that matter to older people. For example, the three-year project *Shaping our age* (a collaboration led by WRVS) aims to provide new insight into issues related to ageing. Phase one of the project, *Voices on well-being* (WRVS, 2011), explores how people aged 65+ understand and define their well-being.

Participants defined well-being as feeling healthy, free from pain and able to lead a positive life. By far the most frequently mentioned things that contributed to well-being were relationships and social contacts with family, friends and neighbours. These were said to provide fun, support and feelings of belonging and being valued. Many participants also placed high value on getting out and having a range of enjoyable interests and activities to 'fill the day', such as groups and clubs. These were said to provide structure to people's lives and 'something to look forward to'. The report also discusses the positive impact of services on well-being.

Research findings therefore suggest that numerous factors contribute to quality of life and general well-being. People need health and social care services of the right type and quality. However, this is only part of the picture. The growing research shows that an emphasis on social interactions, relationships and community is increasingly essential.

The seven National Dementia Declaration outcomes cover the key aspects that are important for quality of life for people with the condition. These outcomes are used in this report to analyse how well people with dementia are living. The report is set out as follows:

- Outcome one: I have personal choice and control or influence over decisions about me
- Outcome two: I know that services are designed around me and my needs
- Outcomes three and four: I have support that helps me live my life and I have the knowledge and know-how to get what I need
- Outcomes five and six: I live in an enabling and supportive environment where I feel valued and understood, and I have a sense of belonging and of being a valued part of family, community and civic life

Outcome seven (I know there is research going on which delivers a better life for me now and hope for the future) relates to quality of life in a number of areas covered in the report and has therefore been incorporated into sections 3 and 4.

2 Outcome one: I have personal choice and control or influence over decisions about me

2.1 Introduction

Research to inform the Dementia Action Alliance's National Dementia Declaration found that a key outcome for people with dementia was having personal choice, control or influence over decisions. To describe this outcome in more detail, the declaration includes a range of statements by people with dementia and carers. These are:

- I have control over my life and support to do the things that matter to me
- I have received an early diagnosis, which was sensitively communicated
- I have access to adequate resources (private and public) that enable me to choose where and how I live
- I can make decisions now about the care I want in my later life
- I will die free from pain and fear, and with dignity, cared for by people who are trained and supported in high quality palliative care.

This section will assess the extent to which people living with dementia have personal choice and control in England, Wales and Northern Ireland, using some of the above statements as a basis.

2.2 I have control over my life and support to do the things that matter to me

Being able to make decisions about what happens to you has long been understood as a key part of well-being for us all. Every day people exercise choice over what they eat, how they dress, where they live, how they spend their time and countless other things. People with dementia have said that being able to make decisions about their own lives and having support to do the things that matter to them is very important. These could be decisions from choosing what to eat and drink, to having an early say over what happens in their treatment and care as their condition advances.

However, the symptoms of dementia affect decision-making, particularly as the disease progresses. Because of this, it can be all too easy to assume that someone with dementia is unable to make a decision about anything in their daily life. But this is not the case. With the right support, many people who have dementia can continue to have choice and control over some areas of their lives.

In the survey for this report, over half of respondents reported that they either felt unable to make choices about their day-to-day life, or only sometimes felt able to make them.

- 14% of people with dementia responding to the survey felt that they were not able to make choices about their day-to-day life, while 37% of respondents felt that they were only sometimes able to make these choices.
- 44% of people with dementia responding to the survey said that they were able to make choices about their day-to-day life.

As this exact question has never been put to the general public, no direct comparison can be made with national statistics. When the ONS asked the general public how much control they had over important areas of their life, however, less than 1% (0.9%) said they had no control (ONS, 2011a). Moreover, the public poll conducted for this report found that nearly a third of people (30%) were afraid of not being able to make choices about their day-to-day lives.

The finding from the survey that over half of respondents reported that they either felt unable to make choices about their day-to-day life, or only sometimes felt able to make them, can partly be explained by the condition. However, it can also be explained by a lack of support to enable people to make those decisions. People should be supported to make their own decisions about their care and everyday life for as long as possible. All practical steps must be taken to help an individual participate in decision-making. Even if a person with dementia can no longer make complex decisions, such as where to live, it is likely that with support they may still be able to make everyday decisions, such as what they would like to eat or drink. Along with being supported to make decisions for as long as possible, these choices must be respected and implemented when appropriate – the ability to choose is not meaningful if it cannot be acted upon.

In England and Wales, when someone loses the ability to make a particular decision, the principles of the Mental Capacity Act 2005 must be followed. The act has provisions for the person to appoint specific people to make decisions on their behalf. It also has provisions for someone to plan in advance if there is any medical treatment they do not wish to have and would like to refuse. In Northern Ireland, there is no formal legal framework for making decisions on behalf of someone who lacks mental capacity although the principle of making a decision in someone's best interest exists as a result of legal test cases. A bill on mental capacity is expected to come to the Northern Ireland executive in 2012/13.

While the Mental Capacity Act provides a working framework for making decisions when someone lacks capacity, good decision-making on someone's behalf is dependent on it being applied properly. As the act only came into force in 2007, evidence of how it is being applied is only now beginning to emerge. A study by the Mental Health Foundation found a worrying level of misunderstanding over the reasons for assessing mental capacity in the first place, and a significant amount of practice which appeared to contradict the fundamental principles of the act (Mental Health Foundation, 2010). Analysis of this emerging evidence, along with further research into how the act is being applied, would be welcome.

2.3 I have received an early diagnosis, which was sensitively communicated

For someone with dementia, one of the foundation stones for being able to make choices is receiving a timely diagnosis. Not only does this allow access to services and medication that will support someone to remain in control of their life for longer, it will also allow them to plan for the future. For example, by putting their finances in order, or considering areas of their personal or health care which they might like to provide instructions about.

Early diagnosis also makes financial sense for the NHS. A 2009 paper found that investing in services for the early diagnosis of dementia can be cost-effective. Increasing diagnosis rates can potentially mean that people receive more early stage care, which could sometimes delay entry into a care home. The report found that delaying admissions to residential care by 20% over a six year period would be cost-effective (Banerjee and Wittenberg, 2009).

Case study

Personal experience of early diagnosis

'I was diagnosed with dementia six years ago at the age of 50. Although I struggled for three years to get my diagnosis because of my young age, I was still able to receive my diagnosis while in the early stages. I first noticed symptoms 10 years ago when I started to struggle in my job as a teacher – I was forgetting things and struggling to organise classes. I also lost my mathematical ability.

I was put on Aricept straight after my diagnosis, which made a huge positive difference to my quality of life. Life doesn't have to end after receiving a diagnosis; you just have to start making choices. I have a very positive outlook and think it is extremely beneficial to have an early diagnosis as it enables you to make important choices and decisions that can help you live life well. I still enjoy playing tennis and regularly go on holiday.'

Person with dementia

However, often a diagnosis can come too late for someone to get the most from services or properly plan for the future. The survey for this report found that many respondents struggled to receive a diagnosis.

- 31% of people with dementia said they had struggled to get a diagnosis. (It is important to note that the survey respondents are in touch with Alzheimer's Society and therefore more likely to have received a diagnosis and to be receiving support).
- 68% of respondents had a gap of longer than a year between noticing their symptoms and getting a diagnosis. 8% of respondents had to wait five years or over for a diagnosis (see Table 1).
- In addition, the YouGov public poll for this report found that 30% of the general public have the perception that they would struggle to get a diagnosis if they had dementia.

Table 1 Length of time taken to receive a diagnosis of dementia

Up to 12 months	22%
1–2 years	37%
3–4 years	23%
5–6 years	5%
Over 6 years	3%
Don't know	5%

Other data shows that only 43% of people with dementia in the UK have been formally identified³ (Alzheimer's Society, 2011b). This is a proxy measure sourced from the best evidence available. It is based on a comparison between dementia prevalence rates and the number of people with dementia on GP registers (from the 2010 NHS QoF indicator number DEM1) used as a proxy measure of how many people have been formally identified as having dementia. The data also shows an extreme variation across the nations: 70% of people with dementia in Belfast can expect a diagnosis, while only 26.5% of people with dementia in Dorset can (Alzheimer's Society, 2011b).

Such a low rate of diagnosis overall shows that many people with dementia are not able to make the crucial first step to accessing services that will support them in their choices. One main recommendation of this report is therefore to increase the rate of dementia diagnoses. While the diagnosis of dementia has been broadly emphasised in public policy, for example, the NICE-SCIE Guideline on dementia (2006) and objectives set by the dementia strategies, little practical progress has been made so far. There may be numerous reasons for this lack of progress. Firstly, the QoF is part of the General Practitioner (GP) contract, and financially

³ For the three countries, the diagnosis rate is 41% in England, 37.4% in Wales and 61.5% in Northern Ireland.

incentivises GP practices to produce a register of their patients who have dementia. The payment is not sensitive to the needs of the population served by that GP practice nor to how prevalent dementia is in that area. There is no scrutiny of the diagnostic process, such as whether people with dementia who report their symptoms do get a diagnosis.

For example, a GP practice that has special responsibility for a care home, where there may be many people with dementia, would be paid the same amount to incentivise the treatment of dementia as a practice that mainly deals with a much younger population and may only have one or two people with dementia on their register. At worst, the QoF can be seen as a disincentive to diagnosis: for every person with dementia that is diagnosed and placed on the register, there are additional criteria that need to be met, such as health checks. Therefore GPs with fewer people on their register will need to do fewer additional interventions while still receiving the payment (for more information on the QoF see section 3.3).

In addition, there are further problems, described below.

- There are some widely recognised problems with the process of diagnosis. Despite growing public awareness of dementia, many people are still reluctant to visit their GP if they have memory problems. They may not want to think about problems with their memory; may not notice it themselves; or dismiss it as a normal part of ageing. There are also harder to reach communities where the stigma of mental health problems remains exceptionally strong and deters people from seeking medical help. The public poll to inform this report found that 12% of the general public felt it was true that there was no benefit in getting a diagnosis of dementia. But encouragingly, two-thirds (66%) of people thought this statement was false.
- There is a lack of training for GPs in diagnosing dementia and it can often be misdiagnosed. Alzheimer's Society hears from many people with dementia who are initially diagnosed with depression or another illness, which causes long delays before getting the right diagnosis. There are also reports of carers not being taken seriously if they approach the person's GP with their own concerns. Increased training would equip GPs with greater skills in detecting dementia and working sensitively with people.
- Some GPs may also be reluctant to diagnose dementia, for example if it is perceived that there is little in the way of support available for people with dementia.
- There is no consistency in memory services, the secondary care clinics to which people are referred for a diagnosis. An audit of memory services by the NHS Information Centre found that, while 94% of primary care trusts (PCTs) and health boards said they commission memory services, less than 32% of them were nationally accredited, and over a quarter lacked some of the recommended features of a memory service (NHS Information Centre, 2011a). In addition, 20% of PCTs and health boards did not respond to the call for information about memory services.

Alzheimer's Society would like to see reform of the QoF to incentivise diagnosis in primary care. The Society also believes greater public awareness of dementia would encourage

people to visit the GP if they have memory problems. Dementia training for GPs would also help improve rates of diagnosis. It is important that different parts of the health and social care system work together, ensuring that there is adequate support during and following the diagnosis. In its inquiry, The £20 billion question (APPG, 2011), the All-Party Parliamentary Group on Dementia found that a whole system approach was a key factor in making dementia services effective. This means there is not only timely diagnosis, but also enough services in an area to support people thereafter. The group's 2012 inquiry is exploring evidence on barriers to diagnosis.

The need for adequate support following diagnosis, and the role of GPs, is further explored in section 3.3.

2.4 I have access to adequate resources (private and public) that enable me to choose where and how I live

In the survey for this report, people were asked an open question about what one thing could be done to make their care and support more focused on what they want. 9% of comments were about financial support or financial advice (in the top four answers to this question – the top answer to this question was the need for more information on the help available and is discussed in section 4.3). Comments included people saying they wanted:

‘Financial advice, allowances advice, knowledge about what help is out there.’

‘Slightly better income.’

Finances can substantially influence the choices of a person with dementia, just as they can for everyone. Yet people with dementia can be disproportionately hit financially by their condition, paying for the cost of their own care, whereas people with other health conditions often get more help. This is because much of the essential care required by people with dementia, such as assistance with washing or eating, is provided by local authorities. These costs are not met by the NHS. Instead they are means tested, which can result in some people paying vast sums for their care.

The cost of dementia can directly affect someone's income, meaning they are less well-off than people with other conditions. The majority of people with dementia are over 65 and therefore receive Attendance Allowance, which is lower than the equivalent paid to those under 65, the Disability Living Allowance (DLA).⁴ Being older also means that the person is more likely to be retired and on a lower income than those who are under 65. If someone with dementia is under 65, dementia can significantly affect their ability to maintain employment, particularly as the condition progresses.

The ability to make decisions over financial matters is also affected by a person's diminishing capacity. In a survey for Short changed (Alzheimer's Society, 2011c), more than three-quarters (77%) of people with dementia agreed that it was important to make plans about how to manage their money in the future. Over four-fifths (82%) had made a will setting out how their money would be spent after they die. This makes public awareness of dementia and early diagnosis even more important; people must be able to plan how their money should be spent when they lack capacity to make major decisions.

In July 2010, the government asked Andrew Dilnot to head the Commission on Funding of Care and Support. In July 2011, the Commission made the following recommendations

⁴ Disability Living Allowance will be replaced by Personal Independence Payments (PIP) in the future.

(Commission on Funding of Care and Support, 2011):

- A cap on the amount any one individual would have to pay for their care. A cap of £35,000 was suggested.
- Raising the asset threshold above which people are liable for the full cost of their care from £23,250 to £100,000.
- National eligibility criteria and portable assessments.

Alzheimer's Society believes that implementing this system would make the funding of care fairer for people with dementia and would allow everyone to plan much better for their later years. It would also enable people to plan financially for the future, including a possible future with dementia, throughout their lives. It would encourage greater responsibility, providing greater certainty in the cost of care, which people could then plan for accordingly. However, Alzheimer's Society believes that implementing the Dilnot proposals alone will not do enough to ensure people with dementia and carers receive increased quality and quantity of care. A Dilnot-plus model is needed to deal with unmet need, postcode lotteries and poor quality care and support. This will require further funding.

2.5 I can make decisions now about the care I want in my later life

Alzheimer's Society argues strongly that people with dementia should be helped to plan ahead because doing so enables them to have a say in their future care and treatment, as well as other personal matters, even when they may lose the capacity to make that decision in the future. In particular, an impaired ability to communicate their wishes as dementia progresses can mean that the person is not able to state what they would like. Advance planning means that someone with dementia can have a say over care and treatment options they may want or not want in the future, and how their money is managed when they are no longer able to do this themselves. Advanced planning must be underpinned by the principles of the Mental Capacity Act 2005, as described in section 2.2. The provision of information is also key in enabling people to make decisions for the future (for more on this also see section 4.3).

2.6 I will die free from pain and fear, and with dignity, cared for by people who are trained and supported in high quality palliative care

The ONS found that Alzheimer's disease and dementia is the third leading underlying cause of death in women, and seventh in men (ONS, 2011b). It is likely that one in three people over 65 will end their lives with some form of dementia, even if a concurrent illness is their underlying cause of death (Brayne et al, 2006).

Despite this, poor quality end of life care for people with dementia is common. The symptoms of dementia themselves make end of life care more difficult. As dementia progresses, the person is less able to make decisions, including those relating to their care. As someone loses the ability to communicate, it becomes more difficult to detect and address even basic needs such as thirst and pain. There are also problems with dignity and quality of care for people with dementia in hospital and care home settings. Taken together, these factors can make the end of life for some people with dementia a harrowing experience.

Many specialist palliative care services are designed around the needs of people with cancer, and are either not accessible to people with dementia, or poorly placed to meet the

differing needs of people in the final stages of the condition. Medical professionals find it difficult to assess the length of time someone with dementia has left to live. This can mean that people with dementia are often rushed to hospital in the final stages of their illness for treatment which they may not have wanted.

However, there are some examples of excellent practice across England, Wales and Northern Ireland. The end of life care strategy in 2008 placed some emphasis on this crucial area, and academic research on end of life care for dementia is growing (Department of Health, 2008). Furthermore, in England, the Quality, innovation, productivity and prevention (QIPP) programme included end of life care as a national workstream. This has meant that some primary care trusts have made this a priority and increased the quality of care.

Alzheimer's Society would like to see the variability in end of life care for people with dementia addressed. In particular, the draft NHS Outcomes framework contains an indicator based on bereaved carers' experiences of the end of life care received by the person they cared for. This should be broken down by condition to show whether people with dementia are experiencing the same level of care as people with other conditions. Measures such as increased dementia training for general and palliative care staff, and greater public awareness that everyone should plan their end of life, are still required. These will help ensure that people with dementia receive as high a standard of care at the end of their lives as people with other diseases.

2.7 Recommendations

People with dementia must be supported to make choices by those working with and caring for them, and be enabled to act on these choices. This would allow people with dementia to lead a fuller life, participate in the activities they enjoy for longer and plan for the future.

In particular:

- 1 Rates of diagnosis must be increased to two-thirds by 2015 and three-quarters by 2017. In particular, Alzheimer's Society would like to see:
 - Develop the Quality and outcomes framework to incentivise diagnosis in primary care.
 - Greater public awareness of dementia to reduce stigma and encourage people to visit their GP with problems about their memory.
 - Greater training for health and social care professionals to recognise the symptoms of dementia and understand the condition.
 - Improvements in the type and supply of services and support that are available to people with dementia and carers following a diagnosis, particularly early intervention and prevention services. Commissioners should recognise the considerable resources already being spent across health and social care and be given the opportunity to spend resources more effectively to provide quality care of the appropriate type.
 - 2 The government should put forward plans to implement the recommendations from the Dilnot Commission on Funding of Care and Support to prevent people with dementia and their families being financially penalised by very high care costs.
 - 3 It must also be recognised that implementing the Dilnot recommendations will not go far enough to reform the social care system. Extra funding is needed to ensure that
-

people with dementia and carers can access better quality as well as more care. We must consider as a society where this money can come from.

4 The Mental Capacity Act 2005 must be comprehensively implemented. Analysis of the emerging evidence on how the Act is being applied, and further evidence on this is vital. In addition:

- full training in the act is required for the health and social care workforce in all care settings
- the Care Quality Commission should establish a monitoring framework to improve understanding of how the act is being implemented
- public awareness raising would ensure that people are fully informed about the status of Lasting Powers of Attorney, and advance statements and decisions
- a bill creating mental capacity legislation in Northern Ireland should also be brought forward and acted on.

5 People with dementia should be provided with good quality end of life care that meets their needs. The data from the NHS Outcomes framework indicator for end of life care should be broken down by condition to fully understand the variations in quality of care.

3 Outcome two: I know that services are designed around me and my needs

3.1 Introduction

Research for the Dementia Action Alliance's National Dementia Declaration identified that people with dementia wanted access to services that are designed around them and their needs. To describe this outcome in more detail, a range of statements by people with dementia and carers are included alongside it in the declaration. They are:

- I feel supported and understood by my GP and get a physical checkup regularly without asking for it
- There are a range of services that support me with any aspect of daily living and enable me to stay at home and in my community, enjoying the best quality of life for as long as possible
- I am treated with dignity and respect whenever I need support from services
- I only go into hospital when I need to, and when I get there staff understand how I can receive the best treatment so that I can leave as soon as possible
- care home staff understand a lot about me and my disability – they know what helps me cope and enjoy the best quality of life every day
- my carer can access respite care if and when they want it, along with other services that can help support them in their role.

Using some of the above statements as a basis, the following section will assess the extent to which people living with dementia have personalised services in England, Wales and Northern Ireland. It will also assess whether carers are able to access the support they need as individuals.

3.2 I know that services are designed around me and my needs

The survey to inform this report found that a significant number of people with dementia did not always receive help to live as independently as they needed to. Respondents also reported that professionals do not always involve people with dementia in decisions about their care and support.

- Over a third of respondents (34%) said that the support services they receive only sometimes (25%) or don't (9%) help them to live as independently as they need to. However, 50% of respondents said that the support services they receive do help them to live as independently as they need to.
- Over a third of respondents (44%) said that professionals either only sometimes (28%) involve them in decisions about their care and support, or do not (16%) involve them. 43% said that professionals do involve them in such decisions.

When asked what more could be done to make sure that care and support were more focused on what they wanted, several respondents said they wanted services better designed around their needs. One respondent reported:

'[I want] a complete change in the way social services are run and a change in its focus. One size does not fit all and the forcing of clients into residential care is not the only solution. They did not listen to us and also wasted public money insisting on putting into place things that would never work for us. They were told not to do it but went ahead and these have proved a complete waste of money. A meeting with social services is a box-ticking exercise.'

Person with dementia

In addition, respondents were asked about the importance to them of research into improving care for people with dementia now. More than three-quarters (83%) said this was important, indicating that people with dementia feel more could be done to improve the care they are being offered.

Existing evidence reflects the survey findings for this report, with many people with dementia not supported with services that enable them to live as independently as possible. This is despite a public policy context that emphasises the importance of empowering service users with greater choice and control over their care and support. In the NHS in England, this can be seen in the current emphasis on No decision about me without me, which the government has said underpins the current NHS reforms (Department of Health, 2010b).

Personalisation is also prioritised in social care services, with emphasis across England, Wales and Northern Ireland on greater choice and control over support (Department of Health, 2010c; Welsh Government, 2011b). All three countries advocate the use of personal budgets. These are a particular priority in England, where the government has committed to providing a personal budget to everyone who receives publicly funded social services. These budgets will ideally be distributed through direct payments (Department of Health, 2010c).

Alongside the shift towards personalisation, government and stakeholder policy also advocates the supporting of people in their own homes in the community. For example, the NHS Operating framework for 2012/13 in England emphasises the need to reduce unnecessary hospital admissions for people with dementia through greater provision of care and support in the community. It also reiterates that local dementia plans need to be publicly available and should reference local and national targets (Department of Health, 2011). The importance of supporting people in their own homes is also prioritised in dementia strategies in England and Northern Ireland, and the dementia vision and action plans in Wales. In addition, ensuring quality care for those living in care homes is central to improving services for people with dementia; recognised in dementia policy and strategy across England, Wales and Northern Ireland (Department of Health, 2009; Department for Health Social Services and Public Safety, 2011a; Welsh Government, 2010, 2011a).

3.3 I feel supported and understood by my GP and get a physical check-up regularly without asking for it

GPs are crucial for people with dementia, both for obtaining a diagnosis and accessing ongoing support and care. As highlighted in section 2.3, it is estimated that less than half (43%) of people with dementia in the UK have been diagnosed and that this figure varies considerably nationwide.

In recent years there has been evidence of improving understanding of dementia by GPs. Surveys by the NAO in England found evidence of a positive shift in GP understanding, but with significant further improvement still needed (NAO, 2010) (see Table 2).

Table 2 Change in GPs' opinions on the benefits of a diagnosis of dementia between 2006 and 2009

	Percentage of GPs agreeing in 2006	Percentage of GPs agreeing in 2009
It is beneficial to make an early diagnosis of dementia	68%	77%
Families would rather be told about their relatives' dementia as early as possible.	68%	73%
Providing a patient with a diagnosis is usually more helpful than harmful	51%	58%

(NAO, 2010)

The diagnosis of dementia by GPs and evidence from the Quality and outcomes framework (QoF) is discussed in section 2.3. In addition, data from the QoF can provide evidence on the care management for people with dementia in general practice. This shows only limited evidence of improvement in ongoing management of people with dementia. For instance, only 78.9% of people with dementia on registers in England had a review in 2008/9. This rose to 79.3% in 2009/10, but fell to 79.2% in 2010/11 (NHS Information Centre, 2011b). In Wales, 78.9% of those on dementia registers had a review in 2010/11 (NHS Wales, 2011).

However, the QoF awards full marks to practices that review 60% of people with dementia on registers. As a result, the overall point scores for this indicator are above 98% in England, Wales and Northern Ireland (NHS Information Centre, 2011b; NHS Wales, 2011; DHSSPS, 2011b).

Polling of GPs suggests broadly similar levels of care management for people with dementia. 86% of GPs polled as part of a Doctors.net.uk survey in November 2011 said that they undertook a medicines review of their patients with dementia at least once a year (Doctors.net.uk, 2011).

Even after diagnosis, people with dementia are likely to be in regular contact with their GP because of other health needs and co-morbidities. So there is significant potential for primary care to help support people with dementia and respond appropriately to their wider health needs.

To achieve this, surgery times and procedures must be appropriate for the ongoing management of people with dementia. For instance, longer appointment times for people with dementia and carers should be considered. While people with dementia may struggle to communicate health problems and concerns, GPs and practice staff should not rely solely on carers. Instead they should try to communicate directly with the person with dementia alongside their carer.

3.4 There are a range of services that support me with any aspect of daily living and enable me to stay at home and in my community, enjoying the best quality of life for as long as possible

There was a clear perception among people with dementia responding to the survey that it is hard for them to exercise choice over their support services, or to influence decisions about their treatment and care.

Respondents were asked if they have had a choice over the support services that they could receive:

- 46% of survey respondents said either that they only sometimes (25%) have a choice over the support services they receive or never (21%) have a choice. 34% of respondents said that they always have a choice.
-

The evidence suggests ongoing problems accessing services and support, which may be reducing choice over the services people can receive. While there is evidence of a range of services that could support people with dementia, in many areas these are not available. The current funding system for social care severely limits access to services, and people often cannot access support until their needs reach crisis point (Alzheimer's Society, 2008a). This problem is exacerbated by the economic climate, in which local government finances are severely restricted. In England, the government has tried to minimise the impact of austerity by allocating health funding to support social care. However, evidence suggests that access to support is still worsening.

Age UK recently predicted that the funding gap for social care will widen in 2012. They calculated that councils should be spending £7.8 billion this year to maintain 2010 levels of social care provision. Instead, reductions in central government funding mean councils have only budgeted £7.3 billion, leaving a £500 million shortfall. This is equivalent to a 4.5% cut (Age UK, 2012).

A survey by the United Kingdom Home Care Association (UKHCA) of its members found widespread evidence that councils reduced the number and length of visits to service users (UKHCA, 2011). Meanwhile, last year Support. Stay. Save. (Alzheimer's Society, 2011a) found little evidence that access to services had expanded since the publication of The dementia tax (Alzheimer's Society, 2008a). This view is supported by evidence that eligibility for adult social care is continually being restricted. More than three-quarters (78%) of councils now only provide support to people with substantial needs and 4% only provide support to those with critical needs (ADASS, 2011).

Support. Stay. Save. (Alzheimer's Society, 2011a) found that half of the carer respondents said the person with dementia was not getting enough support to meet their needs. These respondents reported that the lack of support had negative repercussions for the person with dementia and their carer.

There is also widespread belief among the general public that people with dementia have poor access to services. The YouGov poll for this report asked people how good or bad access to services was for people with dementia. Nearly half (48%) of respondents said it was fairly or very bad, while only 9% rated access to services as good or very good.

There are also challenges in terms of quality with those services that are available. An Equality and Human Rights Commission inquiry into home care (EHRC, 2011), for example, found significant evidence that older people receiving such services sometimes had their human rights breached. The inquiry concluded that a significant factor was insufficient promotion of human rights in the commissioning of home care. There is a widespread belief among the general public that services for people with dementia are poor. The YouGov public poll for this report asked members of the general public how good or bad the quality of care is for people with dementia. More than half (51%) said the quality was bad, while only 9% said it was good.

3.4.1 Personal budgets

Personal budgets are an important tool. But they must not be seen as the solution to increasing the range of services for people with dementia. Getting personal? (Alzheimer's Society, 2011d) shows that people with dementia, who are eligible for support, face barriers to accessing personal budgets. The report found that less than a quarter (23%) of people receiving social services support as a result of an assessment were receiving a personal

budget. A further 15% reported having been offered a direct payment or personal budget but turned it down.

Getting personal? (Alzheimer's Society, 2011d) concluded that the system of personal budget options has not yet adapted to the needs of people with dementia. It highlighted a lack of understanding of the system among people with dementia, carers, and health and social care professionals. It reported that other problems, such as insufficient funding for social care (see section 2.4) and strict eligibility criteria, were also slowing up progress. However, those using personal budgets did say they got support earlier and reported higher satisfaction levels with particular services.

To make personal budgets work properly for people with dementia and carers, a market for dementia services must be developed. In turn, local authorities should review their systems to ensure people with dementia are supported to use the range of personal budget options.

3.4.2 Dementia as a public health issue

When considering the provision of services and support to enable people to live well, dementia as a public health priority must also be addressed. Dementia is a major public health challenge on the scale of cancer, stroke or heart disease. However, it is often neglected by comparison with these other illnesses. It remains poorly understood, and research into the condition is underfunded. There is still not enough focus on dementia in public health messaging.

Existing public health resources should consider dementia as a priority. Information on dementia, both signs and symptoms and risk factors, should be included in current public health messaging. The Public health outcomes framework in England includes a placeholder on dementia, clearly recognising the potential role that public health can play in supporting people with dementia (Department of Health, 2012). Furthermore, dementia must now be emphasised as a key issue by Public Health England, the new central public health body.

Greater investment in research is needed to better understand the factors associated with dementia. A ministerial taskforce is exploring ways of increasing funding for dementia research; a National Institute for Health Research call on dementia has been a welcome first step. However, UK government and private investment in dementia research remains only a fraction of the money invested in cancer research.

The survey for this report reveals how important research into dementia is for people living with the condition.

- When asked how important dementia research is to them, over three-quarters (83%) of respondents said that research into improving care for people now was important; the same proportion said research into the cause was important; and 87% said research into the cure was important.
 - Respondents were also asked if they thought that a cure for dementia could be found. Nearly half (47%) said yes, 9% said no, and 38% didn't know.
 - Over three-quarters (82%) of respondents felt there should be more funding for dementia research.
-

3.5 I only go into hospital when I need to and when I get there staff understand how I can receive the best treatment so that I can leave as soon as possible

People with dementia are core users of health care. At any one time, a quarter of hospital beds are occupied by people with dementia aged over 65. Yet widespread evidence suggests there are ongoing problems with the quality of care for people with dementia in hospitals, and with the number of avoidable admissions.

For example, the Royal College of Psychiatry Audit of dementia care in general hospitals found that significant improvement was needed. Only a third (32%) of staff reported feeling that training and development on dementia were sufficient. Half reported they had received insufficient training on how to communicate with people with dementia. And more than half (54%) said they had not received enough training on responding to challenging symptoms of dementia (Royal College of Psychiatrists, 2011). The report follows a paper by the Care Quality Commission (CQC) in 2011 showing many hospitals were not meeting basic care standards on nutrition or dignity (CQC, 2011a).

Furthermore, around one in 10 respondents to Support. Stay. Save. (Alzheimer's Society, 2011a) suggested the person with dementia was admitted to hospital unnecessarily because of insufficient care and support in their own home. This is underscored by data from the NHS Atlas of variation showing that many areas are still struggling to provide enough support in the community to ensure that people with dementia are not admitted to hospital unduly. The Atlas showed a 4.1-fold variation in admission rates to hospital for people over 74 with a secondary diagnosis of dementia.⁵ Admission rates for people in residential or nursing care showed even greater variation, with a 767-fold variation across PCTs in England. Even excluding the top and bottom five PCTs, variation was still 69-fold (NHS Right Care, 2011).

These findings support the conclusions of Counting the cost (Alzheimer's Society, 2009), which found unacceptable variation in quality of care for people with dementia on general hospital wards. The report's research found nearly half (54%) of carer respondents felt the person's dementia symptoms worsened as a result of their time in hospital. Nearly half (47%) reported that the person's general health deteriorated. Individuals were staying in hospital longer than other people who were admitted for the same reason but did not also have dementia. Around one in three people with dementia who went into hospital from their own home was discharged into a care home.

The NHS Atlas findings illustrate the significant challenges facing the NHS in supporting people with dementia to leave hospital sooner. Total bed days for people with a secondary diagnosis of dementia varied 4.8-fold across the UK (NHS Right Care, 2011). In short, many hospitals are struggling to ensure that people with dementia are discharged as soon as possible.

However, there are examples that show that it is possible to reduce the number of bed days for people with dementia. The Liaison psychiatry service offered in Leeds is a multidisciplinary mental health team offering support to a number of hospitals. It is made up of psychiatrists, psychiatric nurses, an occupational therapist and health support workers. The service has reduced the average length of stay for people with dementia by 54%, from 30 to 13.9 days. This is the equivalent of 1,056 bed days per year (APPG, 2011).

⁵ 4.1 fold variation means the rates of admission to hospital in the PCT with the highest rates of admission were 4.1 times higher than the rates of admission in the PCT with the lowest rates of admission.

In addition, in 2007 the NAO highlighted a case study from Lincolnshire of successful reallocation of resources from acute to community services. A bed usage survey identified that most people with dementia on acute wards no longer needed to be there. Resources were successfully reallocated to home-based services and improving early diagnosis, potentially benefiting 500 people a year and using at least £6.5m more effectively (NAO, 2007).

Overall the evidence suggests that many hospitals are struggling to provide care for people with dementia. However, there is growing recognition of the need to improve care. In England, the 2012/13 Operating framework identifies care of people with dementia in hospital as a priority. The framework also sets out a new Commissioning for Quality and Innovation (CQUIN) target on improving diagnosis of dementia in hospitals (Department of Health, 2011).

3.6 Care home staff understand a lot about me and my disability and know what helps me cope and enjoy the best quality of life every day

In 2008, the Commission for Social Care Inspection (who have since been replaced by the CQC) reported that even good or excellent homes were often not delivering good quality dementia care (CSCI; 2008). In the same year, Home from home (Alzheimer's Society, 2008b) similarly found many care homes falling down on dementia care. Particular problems cited by respondents included a lack of activities and opportunities for social interaction.

In 2011, the CQC found that while the majority of care homes inspected were compliant with standards on care and welfare, a significant minority caused moderate or major concern (CQC, 2011b). This was especially true in nursing homes, where moderate or major concerns were identified in 27% of cases. They also found moderate or major concerns in 16% of care homes without nursing that they inspected. In England, regulation is now shifting towards an emphasis on compliance with essential standards, with the CQC no longer taking an active role in promotion of quality.

A key issue is a lack of training for staff. A report by Laing and Buisson (Mitchell, 2009) found one-third of dementia specialist residential care homes did not offer their staff specific dementia training. The report found dementia-specific training was ad hoc and fragmented, ranging from informal training to fully accredited courses. Laing and Buisson stated that co-ordinated and systematic arrangements for training were lacking. They also noted that government objectives for basic training and continuous professional and vocational development were some way off being realised.

Many care home operators are under financial pressure. Local authorities are restricting the amount they are willing to pay for care home places. The high profile collapse of Southern Cross demonstrated the fragility of both the operator's business model and the wider care home market.

With increasing emphasis on personalisation, care homes should be providing personalised care and promoting quality of life for residents that is based on their experiences and aspirations. There must be sufficient funding available to achieve this. The regulatory system must ensure robust and regular inspection which places the experiences of residents with dementia at the centre of assessment. Lay involvement in regulation to improve quality and prevent abuse in care homes should be considered as having an important role to play, perhaps adopting the model of Independent Monitoring Boards currently used by the prison system. New evidence on the care experiences of people with dementia in care homes is also needed.

3.7 I am treated with dignity and respect whenever I need support from services

Across all care settings, people with dementia need to be treated with dignity and respect by health and social care professionals. Failing to promote dignity and treat people with dementia respectfully risks breaching their human rights and leads to inappropriate care. Many health and social care services struggle to treat people with dementia with dignity and respect. As highlighted in section 3.4, the EHRC report on home care found provision for older people often breached their human rights. CQC inspections of hospitals have also found frequent cases where patient dignity has not been respected.

The need for more dignity and respect was highlighted by some respondents to the survey for this report. When asked what one thing could help make the support and care they receive more focused on their needs, one respondent said:

‘[I want] social services/doctors to be more sympathetic and provide more information to patients and carers. They conceal the rights and what is available for carers and patients. Social services don’t return phone calls – no one. Even the duty officer is not available.’

Person with dementia

One major area where dignity and respect are currently being compromised is the inappropriate use of antipsychotic drugs. These are often prescribed as an initial response to behavioural and psychological symptoms of dementia (BPSD), despite limited evidence of their efficacy. An estimated two-thirds of antipsychotics prescriptions for people with dementia are inappropriate. The drugs cause around 1,800 deaths a year.

The Dementia Action Alliance has a call to action focused on ensuring all people with dementia on antipsychotics have their treatment reviewed by 31 March 2012. There is now evidence from audits of antipsychotic use that some progress is being made to reduce their inappropriate usage. But further efforts are needed. These must include training and support to staff about antipsychotics. Staff should also be supported to use non-pharmaceutical interventions for the behavioural and psychological symptoms of dementia.

Appropriate training for staff is a key aspect of ensuring dignity and respect. Nearly two-thirds (62%) of people responding to the YouGov poll felt that health and social care workers need to improve their understanding of dementia. Systemic prioritisation of training is needed across the health and social care system, including pre-registration and post-registration training.

3.8 My carer can access respite care if and when they want it, along with other services that can help support them in their role

The vast majority of care for people with dementia is provided by family carers. There are an estimated 670,000 carers of people with dementia in the UK, many of whom have unmet care needs. Many carers report personal satisfaction from their caring role. Significant distress, however, is a reality for many. Unpaid caring has a considerable impact on a carer's health and well-being. Depression, emotional and physical exhaustion, and general poor health are common. Research shows that carers of people with dementia experience greater strain and distress than carers of other older people (Moise, Schwarzinger and Um, 2004). But 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.

There is public policy on improving support for carers. In November 2010, the government published *Recognised, valued and supported: Next steps for the carers' strategy* (Department of Health, 2010d). The Wales carers strategy (Welsh Assembly Government, 2000) is due to be refreshed this year, while an independent review of respite care in Wales was published in 2010 and consulted on in 2011 (LE Wales, 2010). The Carers strategies (Wales) measures will start being implemented this year. In Northern Ireland, trusts are already obliged to inform carers of their entitlement to have their own needs assessed (DHSSPS, 2006).

Despite recognition of the importance of supporting carers, a survey carried out by the Princess Royal Trust for Carers and Crossroads identified that much of the funding allocated for carers' services has not been spent on carers (Princess Royal Trust for Carers and Crossroads Care, 2009). The NHS Operating framework in 2012/13 states that PCTs in England will now have to publish their spending on services for carers (Department of Health, 2011).

The survey for this report found that almost half (47%) of respondents felt their carer (family or friend) is not, or is only sometimes, getting the support they need in their caring role. 17% felt that their carer was not supported, and 30% said their carer was only sometimes supported (see Table 3).

Table 3 How well people with dementia believe their carer is supported

If you have a carer (family or friend) are they supported to care for you?	
Always	40%
Sometimes	30%
No	17%
Don't know	3%
Don't have a carer	8%
Not stated	3%

This is consistent with findings from Support. Stay. Save. (Alzheimer's Society, 2011a). In that report, over half (52%) of carers said they were not getting sufficient support to carry out their caring role. Where respondents reported carers were insufficiently supported, they identified a significant negative impact on that carer's mental and physical health. Furthermore, a significant minority in these cases also reported negative repercussions for the person with dementia. These included an increase in the person's dementia symptoms, a decline in their general health and the person with dementia entering long-term care earlier than anticipated.

These findings reinforce previous research by Alzheimer's Society into different aspects of carers' needs.

- **Assessment of needs** Carers need clear assessment of their needs, with a single point of contact to help them navigate the system. But often carers do not have an assessment of their needs, cannot access support to meet this need, or are unaware that they are entitled to an assessment. Alzheimer's Society (2011a) found that only 37% of carers reported receiving social services following an assessment. However, 18% said they had been assessed but deemed ineligible to receive support and 16% said they had not had an assessment because they didn't know they were entitled to one. A further 15% said they hadn't had an assessment because they didn't want or need one (and 14% didn't answer the question).
 - **Information for carers** Information about caring is essential for carers to manage their role. It helps them maintain quality of life and provide good care. However, information provision for carers remains inadequate. In *The dementia tax* (Alzheimer's Society, 2008a), nearly a third (31%) of carers said they had not received enough information about services. The Alzheimer's Society Carer's Information Programme found that, following sessions that provide information about dementia, legal and money matters, ways of coping day to day and getting help from local services, 81% of carers were able to identify services that would help them support the person they care for.
 - **Peer support for carers** Peer support is a source of valuable emotional support for carers as well as people with dementia. Alzheimer's Society currently runs 266 Dementia Cafés across the country. These forums help carers escape the social isolation faced by many. The internet has also revolutionised people's ability to access peer support. In 2004, Alzheimer's Society launched Talking Point, an online chat forum for carers of people with dementia. This now has over 14,000 active members. The key benefit of Talking Point is that it is accessible 24/7, which means people can seek help and advice whenever they need it. The forum is particularly helpful for people who do not want to call a telephone helpline. Over three-quarters (78%) of users agreed or strongly agreed that Talking Point helped them feel less isolated. For information on peer support for people with dementia see section 4.2.
 - **Access to respite care and breaks** Carers can benefit significantly from services that allow them time for their own needs. Indeed, without them many carers would be unable to continue caring. Respite care and breaks are short-term care arrangements that provide temporary alternatives to a person's usual care. Despite their great potential to help carers, respite services are not always available or of high quality. In some areas, respite is only available in emergencies. In others, there is no respite at all. The challenges involved in providing respite are demonstrated by this survey respondent:
-

‘Make it easier to obtain respite care. Also not a minimum of two weeks, so that my carers can have short breaks and feel refreshed, or have someone stay in the house overnight or for a day or two.’

Person with dementia

3.9 Recommendations

- 1 Resources should be shifted from inappropriate acute and residential care for people with dementia into the community setting. This would help ensure that the right community support for people with dementia and carers is available, including respite care services.
 - 2 Commissioners in Wales, England and Northern Ireland should prioritise integration in health and social care services for dementia. In England, health and well-being boards should recognise that dementia represents a key opportunity for integration of care and support.
 - 3 All health and social care staff should have access to dementia care training that is consistent with their role and responsibilities, as recommended in the NICE guideline, and access to expert advice. In particular, key stakeholders such as Royal Colleges, university deaneries, local education and training boards and workforce advisory groups should prioritise action on dementia.
 - All hospitals should appoint a lead senior clinician responsible for improving quality of care for people with dementia. Social care providers should appoint senior and frontline staff with responsibility for dementia.
 - Health and social care practitioners must understand the important role of unpaid carers. They must treat them as equal partners in the professional teams that support people with dementia. To ensure this, information about the role of carers should be part of professional training and development.
 - 4 Antipsychotics prescriptions should be reduced, and replaced with appropriate management of behavioural and psychological symptoms of dementia. Training and support to staff about antipsychotics and alternatives and support to use non-pharmaceutical interventions are essential.
 - 5 Robust data across health and social care to support delivery on dementia is required. For example, the Quality and outcomes framework measure on dementia should be reformed to encourage more regular management of people with dementia in primary care. This could include increasing the threshold at which practices are awarded full points.
 - 6 Hospitals and care home inspections should gather evidence from people with dementia and their carers about their experiences of care.
 - 7 It must be ensured that people with dementia and carers are fully involved in the personal budgets agenda.
-

- The system must be adapted to meet the particular needs of people with dementia and carers, including commissioning of support brokerage services to facilitate access.
 - Timely and appropriate information for people with dementia and carers must be provided.
- 8** The government should signal commitment to dementia research by significantly increasing its investment: a target of £100 million would be appropriate. The amount spent on research per person with dementia would then equal the amount spent per person with cancer.
- 9** In line with the NHS Operating framework 2012/13, commissioners in England, as well as those in Wales and Northern Ireland, should ensure that dementia plans are publicly available.
- 10** Dementia clinical networks should be created by the NHS Commissioning Board to ensure effective use of clinical expertise to deliver better services for people with dementia and carers.
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4 Outcomes three and four: I have support that helps me live my life and I have the knowledge and know-how to get what I need

4.1 Introduction

Research for the Dementia Action Alliance's National Dementia Declaration identified that people need the right support and knowledge to help them live their lives. To describe these outcomes in more detail, a range of statements by people with dementia and carers are included alongside the outcomes in the declaration.

Statements describing outcome three – I have support that helps me live my life – are:

- I can choose what support suits me best, so that I don't feel like a burden
- I can access a wide range of options and opportunities for support that suit me and my needs
- I know how to get this support and I am confident it will help me
- I have information and support and I can have fun with a network of others, including people in a similar position to me
- my carer also has their own support network that suits their own needs.

Statements describing outcome four – I have the knowledge and know-how to get what I need – are:

- it's not a problem getting information and advice, including information about the range of benefits I can access to help me afford and cope with living at home
 - I know where I can get the information I need, when I need it, and I can digest and re-digest it in a way that suits me
 - I have enough information and advice to make decisions about managing, now and in the future, as my dementia progresses
 - my carer has access to further information relevant to them and understands which benefits they are also entitled to.
-

Given the overlap with other areas in the report, this section focuses on:

- for outcome three: social networks for people with dementia, with a discussion of peer support services
- for outcome four: information provision now and for future planning.

4.2 Social networks and peer support for people with dementia

Like anyone, people with dementia have a clear need for regular social interaction, which significantly improves their quality of life and social inclusion. However, the survey findings for this report suggest that people with dementia can find themselves with reduced opportunities for social interaction. This is partly because their peer group may diminish.

The survey shows that respondents reported losing friends after their diagnosis or being unable to tell them. Nearly half (44%) of respondents said they had either lost most of their friends, some of their friends, or hadn't been able to tell them.

- **When asked if they lost friends after their diagnosis of dementia 12% of respondents said yes, most of them, 28% said yes, some of them, and 47% said no.**
- **4% of respondents reported that they haven't told their friends and 5% didn't know.**

The survey also shows that some people with dementia can feel a burden to family and friends.

- **48% reported feeling like a burden to their family.**
- **19% felt they were a burden to friends.**

The survey also shows that some people with dementia can experience feelings of loneliness, anxiety and depression.

- When asked if they ever felt lonely, 61% of people with dementia reported that they felt lonely always (6%) or some of the time (55%).
- When asked if they ever felt anxious or depressed, 77% also reported that they felt anxious or depressed – always (9%) or some of the time (68%).

The finding that 61% of people with dementia report feeling lonely always or some of the time is comparable to the ONS finding that 66.5% of the general population said they feel lonely in their daily life (ONS, 2011a). In terms of anxiety, 77% of people with dementia reported that they often felt anxious or depressed. By comparison, the ONS survey found that 75% of the general population said they felt anxious yesterday (ONS, 2011a). Comparing these findings suggests there are similar perceptions of loneliness and anxiety within the general population. However, the respondents to the survey were all in contact with Alzheimer's Society and in the earlier stages of dementia. The sample may therefore feel more supported, and less lonely or anxious, than those who, for example, are not accessing support, are living alone, or are in the later stages of dementia. The numbers of people with dementia feeling lonely, anxious or depressed are therefore likely to be much higher.

Among the general public, there is a perception that loneliness and anxiety are consequences of having dementia. Over a third (40%) of respondents to the YouGov public poll for this report felt that having dementia would mean they would be lonely. More than half (57%) felt that having dementia would mean that they would feel anxious, which again suggests that this area must be addressed.

According to the Campaign to End Loneliness⁶, a partnership between charities to tackle loneliness in later life, research over recent decades has consistently shown 10% of older people are always or very lonely. Recent estimates place the number of people aged over 65 who are often or always lonely at over 1 million (Age Concern and Help the Aged, 2009).

These results can be explained in part by a lack of social interaction and connectedness. Older people and people with dementia tend to report a poorer sense of belonging, and participate less than some other groups in society (Berry, 2008). For example, a lack of social connectedness among disabled people, including those with memory impairment, is suggested by the Life opportunities survey, published in December 2011, (Office for Disability Issues, 2011). The survey compares how disabled people (based on the Equality Act definition) and non-disabled people participate in society in a number of areas. Exploring social interaction, the survey found that non-disabled adults were more likely than disabled adults to report they could 'count on' at least six other people (64% and 54% respectively). In addition, a higher proportion of disabled adults had just one or two close contacts compared with non-disabled adults (12% and 8% respectively).

⁶ www.campaigntoendloneliness.org.uk/information-on-loneliness/loneliness-research/ (accessed on 06 February 2012)

To complement the Life opportunities survey, the ONS and Office for Disability Issues (ODI) commissioned qualitative research among people with severe learning, memory or neuro-diversity impairments who could not complete the survey (Office for Disability Issues, 2010). This revealed factors that either prevented or enabled the maintenance of personal relationships and social contacts. These included:

- contact with voluntary organisations provided participants with opportunities to meet people on a regular basis and make friends
- lack of suitable public transport prevented some participants from visiting family and friends, particularly those who lived further away.

4.2.1 Peer support services

As identified by the ODI (2010) research above, voluntary organisations can be vital in helping people make social contacts. This is partly because they provide services, such as peer support for people with dementia, which create opportunities for social interaction (peer support for carers is discussed in section 3.8). For people with dementia, one of the greatest sources of support is having access to other people with dementia following diagnosis (Alzheimer's Society, 2010a). The reported benefits of such peer relationships include emotional support, information, advice and practical tips about how to cope day to day, and reduced social isolation.

Peer support helps to reassure individuals with dementia that they are not alone in coping with the disease. It provides interaction with others who know, as far as is possible, what they are going through. It can also give people an understanding of how other people with dementia perceive and cope with their illness, and the problems they may encounter every day.

However, the survey for this report found that 67% of respondents either only sometimes or never have opportunities to interact with other people with dementia.

- **Nearly half (49%) of people with dementia responding to the survey said they sometimes have opportunities to meet and talk to other people with dementia, and 18% said they never have opportunities.**
- **26% of respondents said that they always have opportunities to meet and talk to other people with dementia.**

Case study

An evaluation of Alzheimer's Society's peer support services

In 2011, Alzheimer's Society evaluated three of its 568 peer support group services from a user's perspective. The review focused on several key areas, such as the provision of information and advice.

The three groups all follow the same model and include people with dementia and carers. Upon arrival all members meet together and have coffee. Carers then split off from people with dementia and have a session with a facilitator. This includes information provided by the facilitator along a theme, and the sharing of information and experiences between participants. During this time, people with dementia participate in activities with volunteers. At the end of the session, everyone comes back together to chat over a light lunch.

Participants in a focus group of 12 people with dementia described them as friendly and fun. One commented that the group is the most people they see all week. Another explained how talking to someone who is not a stranger makes life acceptable when you have dementia. One of the key reasons they felt the groups reduced the sense of isolation was because they involved contact with people in a similar situation. Many participants described the groups as places to share information and ideas of how to deal with dementia, and to unburden themselves. One person with dementia explained that attending a group had meant they were not left fending for themselves following diagnosis. Some added that the group gave them hope and optimism, while reducing their sense of stigma. Several participants mentioned the importance of humour in dealing with their situation. The companionship allowed them to have a laugh, which lightened the seriousness of dementia.

'I get a chance to meet and talk with people who are sympathetic, experienced and have cared for individuals with dementia. This is now one of my main sources of social contact as many of my previous friends are too embarrassed and do not know how to deal with me and have gradually stopped meeting me.'

Person with dementia, Cumbria

A small number of people with dementia were 'not sure' whether they enjoyed talking to other people with dementia. This may reflect the difficulty some service users face looking into the perceived 'future' of their dementia progression. However, most respondents felt that attending the peer support group was important to them. The majority described their attendance as frequent, though some respondents said they did not attend as many meetings as they would like to.

4.3 I have enough information and advice to make decisions about managing, now and in the future, as my dementia progresses.

Previous research by Alzheimer's Society has demonstrated the importance of information in accessing personalised care and support. For example:

- timely and appropriate information is key to enabling people with dementia to access the various personal budget options available (Alzheimer's Society, 2011d).
- where the person with dementia and carer felt they were sufficiently informed about sources of free information and support, they were more likely to say that the person with dementia was getting the support they need (Alzheimer's Society, 2011a)
- having the right information is an important tool to help people adjust to a diagnosis of dementia (Alzheimer's Society, 2008c).

The importance of information provision for people with dementia has been recognised in the dementia strategies in England, Northern Ireland and Wales. The National Institute for Health and Clinical Excellence and Social Care Institute for Excellence guidelines on dementia care (NICE-SCIE, 2006) and NICE Dementia quality standard (2010) both recommend that, following a diagnosis of dementia, people should receive written information about their condition, treatment and the support options in their local area.

However, over a third of respondents to the survey for this report believed they had not received enough information about their condition:

- **32% of respondents reported that they were receiving some but not enough information about their condition and 6% reported not receiving any information. 53% of respondents said they had all the information they needed.**

The survey also asked people if they had received enough information to plan for the future:

- **27% of respondents reported that they had received some but not enough information to plan for the future and 19% said that they had not received enough information. 40% of respondents said they had enough.**

When asked about the one thing that would make care and support services more focused on what people want, information was the topic most commonly raised. Nearly a fifth (17%) of respondents mentioned wanting changes to the amount of information they are given, particularly on the help and support available, and the ways they receive it.

These findings suggest that some people with dementia feel they have not received enough information about their dementia and about planning for the future. Indeed, information provision appears to vary considerably. This was reflected in the responses received to free text questions in the survey. Some people felt well-informed, and needed no further information:

‘I have only recently been diagnosed but feel I can get very good help and information from my Alzheimer’s group.’

Person with dementia

‘Have enough information to access help and support when needed so far.’

Person with dementia

However, others needed more information. Some respondents wanted:

‘...to be made aware of help and services through doctors, social workers and medical staff, without having to seek it.’

Person with dementia

‘...more information as to what help or support is available.’

Person with dementia

Furthermore, in a public poll conducted for Alzheimer’s Society in July 2010, almost a third (31%) of respondents said they would not know how to get information and support if they received a diagnosis of dementia. This reinforces previous Alzheimer’s Society research. For example:

- Support. Stay. Save. (Alzheimer’s Society, 2011a) found less than half (41%) of respondents had been given enough advice on how to access free sources of information about dementia and support services. One-third said they’d been given information but not enough; 20% said they didn’t have enough information.
 - The dementia tax (Alzheimer’s Society, 2008a) found that 47% of people thought they had enough information about local services to support people with dementia, whereas 34% thought they did not.
 - 27% of people with dementia and carers report that getting the information they needed was either quite difficult or very difficult. This proportion may be higher among people who are not in touch with Alzheimer’s Society (Alzheimer’s Society, 2010b).
-

A key problem is that people have to ask for information, rather than it being provided proactively (Alzheimer's Society 2010b; Picker Institute, 2007). One of the challenges here is that, while certain core issues are important for nearly everyone, individuals will also have personal preferences about how, when and what quantity of information they receive. Needs will also vary according to the form of dementia an individual has, the particular way that their dementia affects them, and the individual's background and identity (for example, their particular cultural needs). The result is that individuals have very different information needs. This may mean that the same information may be sufficient for one individual but not another. The survey data suggest this is an ongoing challenge. Further research is needed to understand the numerous factors that affect whether people with dementia and carers receive the information they need. Research is also needed into ways of avoiding gaps or unhelpful duplication in information provision.

To improve information provision for people with dementia and carers, it would be helpful to know the topics on which people want more resources, where people would access these, and the preferred formats and delivery channels. While recent research (Alzheimer's Society, 2010b) partially answers these questions, further work is needed on the gaps in current information provision.

4.3.1 Information about research

The survey asked how important it was to people with dementia to hear about research into dementia. Three-quarters (75%) of respondents thought it was either very or quite important, suggesting this is an area of information provision that is valued by people with dementia. Research may be outside the usual range of topics that people with dementia and carers would be given information about. Respondents to Alzheimer's Society's survey were also asked how important being asked to take part in dementia research was for them. Nearly two-thirds (64%) indicated that this was important. Alzheimer's Society (2010b) found that participation in research studies for memory loss was one of the 10 most important issues for people with dementia to receive information about. (It was rated less important by carers, however.) It is therefore vital that information about research, and opportunities to participate in research, are considered as part of the overall package of information to individuals.

4.3.2 Support alongside information provision

Alzheimer's Society's research (2010b) has found that organisations that provide information and support, such as charities, emphasise the value of providing additional support alongside written information. This could be in the form of emotional support for people living with dementia to help them cope with the written information they receive. Combining support with information is likely to become increasingly important as a person's dementia progresses and their ability to access or understand information becomes reduced. This support is often provided by family carers, but people may require a dementia adviser or in some cases an advocate. Further research to understand what additional support is required alongside information provision as a person's dementia advances would be helpful. This work would contribute to the goal of supporting people with dementia to make informed choices about their lives for as long as they are able and help others to ensure that a person's views and wishes are represented.

4.4 Recommendations

- 1 Every person diagnosed with dementia must be able to access peer support that is delivered in the most appropriate way for them. Local commissioners and the voluntary sector should work with local groups to develop a range of peer support networks.
 - 2 Local authorities should have responsibility for ensuring that there is independent provision of information about local services across the spectrum of the statutory, voluntary and independent sectors. This information should then be presented in a format that is accessible to people with dementia and carers. The information should be provided on a proactive basis.
 - 3 Organisations providing written information should consider how they could enhance these services by providing follow-up assistance for people with dementia, supporting them to understand and act on information.
 - 4 Local authorities should ensure that people with dementia have access to a named contact throughout their life with dementia.
 - 5 Information about research, and opportunities to participate in research, should be considered as part of the overall package of information to individuals.
-

5 Outcomes five and six: I live in an enabling and supportive environment, and I have a sense of belonging and of being a valued part of family, community and civic life

5.1 Introduction

Research to inform the Dementia Action Alliance's National Dementia Declaration identified two outcomes that are strongly related to how people live in the community. These are I live in an enabling and supportive environment where I feel valued and understood and I have a sense of belonging and of being a valued part of family, community and civic life.

To describe these outcomes in more detail, a range of statements by people with dementia and carers are included alongside the outcomes in the National Dementia Declaration. The complete list is as follows:

- I had a diagnosis very early on and, if I work, I have an understanding employer which means I can still work and stay connected to people in my life
 - I am making a contribution that makes me feel valued and valuable
 - my neighbours, friends, family and GP keep in touch and are pleased to see me
 - I am listened to and have my views considered, and have been from the point I was first worried about my memory
 - the importance of helping me to sustain relationships with others is well recognised
 - if I develop behaviour that challenges others, people will take time to understand why I am acting in this way and help me try to avoid it
 - my carer's role is respected and supported; they also feel valued and valuable, and neither of us feel alone
 - I feel safe and supported in my home and in my community, which includes shops and pubs, sporting and cultural opportunities
 - neither I nor my family feel ashamed or discriminated against because I have dementia – people with whom we come into contact are helpful and supportive
-

- my carer and I continue to have the opportunity to develop new interests and new social networks
- it is easy for me to continue to live in my own home and I and my carer will both have the support needed for me to do this.

There is some overlap between these statements and the quality of life outcomes covered in prior sections of this report. Therefore this section will particularly focus on exploring the evidence from people with dementia and carers on whether they feel part of their community. In addition, it will consider current work to make communities dementia friendly, and suggest what needs to happen next.

5.2 I live in an enabling and supportive environment where I feel valued and understood and I have a sense of belonging and of being a valued part of family, community and civic life

The survey for this report asked people living with dementia for their perceptions on the community they live in. When asked whether they felt part of their community, nearly two-thirds of people living with dementia said this was not always the case.

In addition, the YouGov poll for this report asked 2,070 members of the general public whether they felt people with dementia were included in their community. Nearly two-thirds (60%) rated the inclusion of people with dementia in their community as bad (38% as fairly bad and 23% as very bad). Only 1% rated it as good and 5% as fairly good (14% rated the inclusion of people with dementia as neither good nor bad).

- **22% of respondents said that they did not feel part of their community, while 38% said that they felt part of their community only sometimes.**
- **30% of respondents said they always felt a part of their community.**

People with dementia and carers were also asked whether they think their community understands how to help them live well with dementia; whether they would like their community to understand how to help them to do so; and how much better life would be if this was the case. The findings show that people with dementia do not feel that their communities understand how to support people with dementia, but that they also perceive benefits to communities being 'dementia friendly'.

The tables below (Tables 4, 5 and 6) highlight that nearly two-thirds (61%) of people with dementia in Alzheimer’s Society’s survey thought their community either doesn’t understand at all, or has only limited understanding, of how to help them live well. Furthermore, 71% of respondents would like their community to understand how to help them live well, while over two-thirds (67%) think this understanding would make their life a lot or a little better.

Table 4 How well people with dementia think their community understands how to help them live with dementia

Yes, very well	12%
A little	36%
No	25%
Don’t know	22%

Table 5 How much people with dementia would like their community to understand how to help them live well with dementia

Yes, a lot	57%
Yes, a little	14%
No	8%
Don’t know	12%

Table 6 How much better people with dementia think their life would be if their community understood how to help them live well with dementia

A lot	45%
A little	22%
None	7%
Don’t know	19%

The YouGov poll of the general public also asked if society is geared up to deal with people who have dementia. Only 5% felt this was true, while three-quarters (75%) said it was false (20% did not know).

The general public were also asked if they felt that the statement ‘the government has responded well to the challenge of dementia’ was true or false. More than half (59%) said this was false and 7% said that this was true (34% did not know). Respondents were also

asked how prepared or unprepared they felt UK society is for dealing with people with particular conditions: dementia, breast cancer, diabetes and asthma. Overwhelmingly, the public believes that UK society is least prepared to deal with dementia (see Table 7).

Table 7 How prepared the general public feels UK society is for dealing with people with dementia, breast cancer, diabetes and asthma

Dementia	
Very prepared	2%
Fairly prepared	15%
Neither prepared nor unprepared	15%
Fairly unprepared	34%
Very unprepared	26%
Don't know	8%
Breast cancer	
Very prepared	10%
Fairly prepared	51%
Neither prepared nor unprepared	16%
Fairly unprepared	11%
Very unprepared	5%
Don't know	8%
Diabetes	
Very prepared	12%
Fairly prepared	46%
Neither prepared nor unprepared	14%
Fairly unprepared	15%
Very unprepared	5%
Don't know	8%

Asthma

Very prepared	14%
Fairly prepared	47%
Neither prepared nor unprepared	16%
Fairly unprepared	10%
Very unprepared	5%
Don't know	9%

Number of responses: 2,070

The findings outlined in this section show that many people with dementia feel they are living in a community that does not understand how to help them live well. Furthermore, the general public agree that communities are unprepared to support people with dementia. This suggests a need to provide support for communities, enabling them to understand how to help people with dementia live well in the community.

Case study

Personal experience

B is 72 and is in the early stages of Alzheimer's. His wife, C, is 60 and cares for him at home. But B is still fairly independent.

Dementia has changed B's life in that he finds it difficult to find words. He has to be very patient, concentrate and make an effort. He is no longer able to do cryptic crosswords which he previously enjoyed as a hobby.

B feels that dementia has also changed the way he is viewed by other people. He thinks that this is inevitable.

However, B tends to let people know about his condition because he feels there is nothing to be gained by hiding it and has found that others are often genuinely interested. He hasn't lost any friends since his diagnosis and has found them all to be supportive.

B says he finds it easy to be part of the community. He doesn't feel excluded and still regularly goes to the gym and plays tennis. He feels that it is important to keep busy. However, he does occasionally feel anxious and lonely.

B hasn't yet had the opportunity to meet any other people with dementia, except at the memory clinic. B's wife, C, said she was recently given a leaflet about her local Alzheimer's Society by the Carers' Association. She is hoping to get a volunteer who can come in every other week or so to support her, and to give B some company other than her.

C said that being a carer is very difficult. Her family help and B is not yet at the stage where he needs carers to come in and help him to wash and eat, for example. She sometimes gets down and it's often B that lifts her mood. She feels guilty leaving him at night to go out with her friends. C feels that B has difficulty using the remote control and making meals – he can only really make a sandwich. She also feels that he used to be very sociable. For example, he often went for a pint at the pub and rarely does this now.

Case study

Personal experience

R's wife, S, has advanced Alzheimer's disease. She is nearly 80 years old and has had the disease for 12 years. She also has sub-cortical vascular dementia and is now in a nursing home. R is 70 and has been told that it is likely he has the beginnings of multi-infarct dementia.

S did not accept that she had dementia (although she did know that she had the disease) and she would make excuses for the things she did. Dementia changed S's life – she wouldn't settle in their new home after moving house and she was aggressive when first diagnosed. Now that she's in a residential home it has changed both their lives. After being 'joined at the hip' since he was 20, R now visits her every day in a home 2.5 miles away. She was always very particular about her appearance, but isn't anymore. She is now wheelchair-bound and doubly incontinent.

R said they lost a number of friends after S's diagnosis. He thinks it is through embarrassment, fear, lack of understanding; or perhaps they are frightened themselves. He has lost contact with a lot of people.

In terms of the community, S would often wander up the road and knock on neighbour's doors. R had to warn them not to let her in because of her incontinence, among other things. Often she would be found and he'd go to collect her. He thinks she was often, and still is anxious, lonely and agitated.

S is in a home and her floor is made up entirely of people with dementia, which R thinks is a good thing. There are two dozen other patients with dementia in all stages. She has the opportunity to meet others with the condition. He attends Dementia Cafés and services in Ashford and Weybridge.

R said he found it hard to access information and support in North Yorkshire, but when he moved back down to Surrey it was fairly easy because of the local Alzheimer's Society.

R said he is offered all sorts of care for himself but he is not interested: 'I am strong enough and alert enough to look after myself.' His focus has always been on his wife. He is dedicated to S and her well-being is the most important thing to him.

5.2.1 Possible outcomes for people with dementia if their community is not supported to understand how to help them live well

The survey results suggest some of the possible negative outcomes for people with dementia if their community does not understand how to help them live well.

For example, while more than half (58%) of respondents report that they feel safe in their communities, nearly a third (27%) only feel safe sometimes and 6% never feel safe. This is one of the statements used to assess outcomes five and six (I feel safe and supported

in my home and in my community, which includes shops and pubs, sporting and cultural opportunities) and is therefore of importance to people living with dementia.

A lack of understanding about how to help people with dementia live well may also lead individuals to feel they are a burden to others. As discussed in section 4.2, nearly half (48%) of people with dementia reported that they feel a burden to family and 19% felt they are a burden to friends. Furthermore, some respondents also feel they are a burden to health and social care professionals (10%) and people in the wider community: to neighbours (8%); people working in banks/post offices/shops (9%) and the police (4%).

Respondents also reported feeling that they very often do not have a voice in their community. Only 12% said that they always have a voice, while nearly a third (31%) said only sometimes, and approaching half (41%) felt that they never had a voice. This is one of the statements used to assess outcomes five and six (I am listened to and have my views considered, from the point I was first worried about my memory) and also underpins other outcomes such as having choice and control.

In addition, as discussed in section 4.2, survey respondents reported losing friends after their diagnosis or being unable to tell them. Nearly half (44%) of respondents said they had either lost most of their friends, some of their friends, or hadn't been able to tell them. People with dementia also reported feelings of loneliness (61% said they sometimes or always feel lonely), as well as anxiety or depression (77% said they sometimes or always feel anxious or depressed).

5.2.2 Why might communities not be able to support people with dementia?

There are many factors that can contribute to a community not being ready or able to support people with dementia to live well. These need further exploration and understanding. However, some of the key factors to emerge from the survey for this report, and previous research and reports, include:

5.2.2.1 A lack of focus on social connectedness within communities

A lack of social connectedness, for example, lack of access to peer support groups and losing friends once a person has been diagnosed with dementia, has been highlighted in this report (see section 4.2 in particular).

In 2009, the RSA (Royal Society for the Encouragement of Arts, Manufactures and Commerce) launched Connected Communities, a five-year project looking in detail at social networks, their affect on well-being, and how to develop them. The project is gathering evidence from communities in seven diverse locations. A report on early findings suggests that traditional approaches to community regeneration, which define communities in solely geographic terms, have severe limitations. Such approaches have failed to deliver on key areas such as improving trust between residents or fostering a greater sense of belonging. The report proposes instead an approach based on an understanding of the importance of social networks, helping local communities and public sector workers to understand communities as a complex series of relationships (Rowson et al, 2010).

As part of the Connected Communities project, a separate report was published exploring the current health system reforms in the context of social isolation (Morris and Gilchrist,

2011). The paper concluded that the reforms will create impersonal relationships between users and providers of public services, and will not build or sustain the social networks that are vital for people's physical and mental health. Furthermore, it highlights the valuable role that local people and community groups have to play in preventive or support services. For example, through volunteering, peer support and befriending.

The report makes recommendations for government and healthcare bodies to develop social networks rather than reduce them, including:

- Commissioners of public services, such as GP consortia or local authorities in charge of public health spending, should ensure that public services do not reinforce isolation or loneliness, but instead aim to build people's social networks.
- Commissioners should protect, build on and utilise those things in the community that currently contribute positively to people's mental and physical health. These 'assets' could be well-connected people, buildings, associations, organisations or cultural assets.
- Engaging the community with public services should be done in a way that encourages people to make connections with others in their community that they would not normally come into contact with.

The Health Empowerment Leverage Project (HELP) also explores the role of communities in health. HELP was commissioned by the Department of Health in 2011 to demonstrate the business case for wider use of community-based methods of health improvement. Programmes such as Connected Communities and HELP demonstrate practical ways that services can work with communities, helping them use their existing assets to promote inclusion.

For example, one asset in any community is the potential for people of different generations to work together for mutual outcomes. This is known as intergenerational practice. The University of Central Lancashire, commissioned by Alzheimer's Society to explore social inclusion for people with dementia, described in a report how an intergenerational focus may help break down generational barriers by improving social relationships and enabling the person with dementia to feel both valued and a part of the community (Coupe and Morris, 2011, unpublished).

5.2.2.2 Stigma and lack of understanding of dementia

There has been much work to raise awareness and understanding of dementia, both among health and social care professionals and the general population. However, existing evidence and research highlights a very real need to raise understanding within communities. For example, in a poll of the general public conducted in 2010, over half (52%) of respondents said they did not know enough about dementia to be able to help someone with the condition (Department of Health public poll, 2010).

The YouGov public poll for this report found overwhelmingly that people rate the UK public's understanding of dementia as bad or very bad. Only 9% of respondents rated the UK public's dementia understanding as good or very good, while nearly two-thirds (63%) said it was fairly bad or very bad (15% rated it as neither good nor bad and 13% didn't know). The poll also uncovered negative perceptions of what people think would happen if they developed dementia, showing that stigma is still prevalent (see Table 8).

Table 8 Opinions from the general public on what they think would happen if they developed dementia

I would feel anxious	57%
I would feel lonely	40%
I wouldn't know where to get help or the services available to me	39%
I would lose friends	31%
I would struggle to get a diagnosis from a GP or professional	30%
None of these	4%
Don't know	20%
Prefer not to say	1%

Part of the solution here must be to increase the focus on social connectedness, as described in the section above. Stigma and social networks are inextricably linked. Stigma and discrimination in communities can break many of the relationships that people with dementia previously held. By focusing on social networks, it may be possible to reduce the effects of stigma by introducing new connections and relationships, and strengthening existing ones.

In the same way, working to reduce stigma directly may prevent the initial breakdown of relationships. To this end, there is a case for targeting specific groups of people to increase their understanding of dementia. The survey for this report found that people with dementia feel it is important for a range of people to have a better understanding of dementia (see Table 9).

Table 9 Who people with dementia would like to have more of an understanding of dementia

Family	Yes 54%	No 26%	Don't know 5%	NS* 16%
Friends	Yes 58%	No 20%	Don't know 9%	NS 13%
Neighbours	Yes 51%	No 20%	Don't know 12%	NS 17%
Health and social care professionals	Yes 58%	No 18%	Don't know 9%	NS 14%
People working in banks/shops	Yes 62%	No 14%	Don't know 10%	NS 14%
Police	Yes 54%	No 10%	Don't know 18%	NS 18%

*Please note that not all respondents to this particular question answered each part of the question. Therefore a percentage of respondents are shown as not stating (NS) a preference to each part.

In the YouGov poll conducted for this report, the general public did recognise a need for different groups of people to improve their understanding of dementia. They were asked which, if any, of the following groups need to improve their general understanding of the condition. The results were as follows:

Table 10 Which groups according to the general public need to improve their general understanding of dementia?

Health and social care workers	62%
Family of people with dementia	56%
Friends of people with dementia	56%
Neighbours of people with dementia	56%
MPs and parliamentarians	56%
People working in banks, post offices and shops	54%
The police	44%
None of these	1%
Don't know	16%

5.2.2.3 Influencing and being involved in shaping own community/having a voice

As described in section 5.2.1, people with dementia surveyed for the report felt they do not always have the opportunity to make their voice heard in the community. Yet it is vital that people with dementia and their carers are supported to influence and shape both the health and social care services they use, and their communities.

For example, the Dementia Engagement and Empowerment Project (DEEP) is collecting information about all the important and inspiring activities, groups and projects around the UK that actively involve people living with dementia influencing services and policies that affect them and others. The project has recently completed a survey to collect this information and the findings will be available at a later stage. The results will help to build a picture of groups and projects that are led or actively involve people with dementia influencing services and policies. An overview of some of the project is available on the DEEP website.⁷ The results will provide good practice examples on how people with dementia can be engaged and involved.

5.3 How can communities begin to be prepared to support people to live well with dementia?

5.3.1 What solutions do people with dementia want to see?

The survey evidence from this report strengthens the case for ensuring that communities are prepared to support people who have dementia to live well. People with dementia were asked what could be done in their community to help them live life the way they want. This was an open question in the survey and respondents gave written answers that were also analysed to provide statistics. The statistics are as follows and illustrative quotes have been included (see Table 11).

⁷ www.mentalhealth.org.uk/deep

Table 11 What could be done in your community to help you live the life you want?

Better understanding of dementia/less social stigma	25%
Publicity/more public awareness of the condition	17%
‘More understanding that dementia has different effects on those with it and that life can continue very much as normal with support.’	
‘Education about dementia for members of community that I am likely to come into contact with.’	
‘More security, neighbourly support and understanding and acceptance by the authorities, eg police.’	
‘More people to understand the symptoms. Get out more and talk and have a laugh with old and young people.’	
‘For people to understand, have patience and be prepared to help.’	
‘If people understood why I behaved the way I do sometimes, my husband and family might not have to explain or get embarrassed.’	
‘People just don’t understand the difficulties there are if you have dementia. Younger people don’t even know what it is.’	
‘I just want to be accepted just as I am without any fuss.’	
Local activities/opportunity to socialise	13%
More day trips out	3%
‘More visits and opportunities to socialise – a best friend.’	
More tolerance/patience from others	7%
Community spirit/watch out for each other/more caring/helpful	7%
‘Get back more of a community spirit. People watching out for each other more.’	
‘More community spirit, ie, neighbours calling round to see if I’m ok.’	
‘People knowing how to treat people with dementia, eg person in paper shop could help if his customer was confused or lost if he understood the customer had dementia.’	

Provide more information	5%
Training for professionals/support workers	5%
Improve bus services/cheaper forms of transport	4%
Increased/better funding	4%
Communication	4%
Respite care	3%
Education of young people	2%
To be treated as an individual	2%
More help/one-to-one help	2%

These findings add to previous research among people with dementia and carers that explored how they felt communities could help people to live well with the condition (Innovations in Dementia, 2011). In this research, people thought communities could become more dementia-capable by:

- increasing their awareness of dementia
- supporting local groups for people with dementia and carers
- providing more information, and more accessible information, about local services and facilities
- thinking about how local mainstream services and facilities can be made more accessible for people with dementia.

To achieve this, people with dementia and carers said that communities needed knowledgeable input, including from people with dementia. They said more funding was needed to support those living with dementia. Furthermore, they added that continued media attention and public awareness campaigns on dementia are needed.

5.3.2 What work is already being undertaken within communities?

Understanding the role of communities in delivering better quality of life for older people and people with dementia is the subject of a range of ongoing work programmes and research.

Since 2000, the World Health Organisation's (WHO) Age-Friendly Cities programme⁸ has led an international effort to understand and promote the environmental and social factors

⁸ www.who.int/ageing/age_friendly_cities/en/index

that contribute to active and healthy ageing in societies. WHO defines an age friendly city as an inclusive and accessible urban environment that promotes active ageing. Such cities tackle the issue by considering all aspects of neighbourhoods, from the physical design to their services and opportunities.

In the UK, Manchester has committed itself to being an age friendly community. In 2010, Manchester became a member of WHO's global network of age friendly cities.

Case study

Manchester – age friendly city

The **Valuing Older People team** (VOP), which is part of Public Health Manchester at Manchester City Council, is leading the age friendly city programme. VOP has high-level commitment to the work programme from councillors and chief officers, and is developing its UK networks further. The programme is shaped around:

- people – giving older residents the opportunity to get involved and influence the city's plans
- places – working in neighbourhoods, responding to local need to create new opportunities that ensure Manchester's diverse neighbourhoods become 'age friendly' and are considered as good places to grow older
- projects – practical, whole-systems pieces of work that improve services and help learning
- partnerships – practical collaborations to deliver plans locally and attract resources and investment to the city
- policy – influencing policy and embedding age friendly principles in other areas of city strategy.

Project example

The VOP work involves linking with many different sectors. Several projects are being developed with the cultural sector, for example one project involves linking older people from deprived neighbourhoods to cultural facilities in Manchester, such as museums and art galleries. Around 40 'culture champions' from within communities are being recruited from all over Manchester. They will be immersed in artistic and cultural experiences, for example, backstage tours and rehearsal viewings. They will then will go back to their communities and act as passionate advocates of these cultural opportunities.

Particular work is taking place with the Manchester Camerata orchestra. Funding for three years has been obtained for a music therapist to work with groups of people with dementia and carers, in care homes and in other settings such as Dementia Cafés. Musicians from Camerata will come along to help people create music.⁹

⁹ www.manchester.gov.uk/vop

There is also dementia-specific work taking place. In 2012, Alzheimer's Disease International intend to use the 'dementia friendly communities' theme for World Alzheimer's Day on 21 September. Projects in a number of countries have looked at the question of how to develop dementia friendly communities. For example, a variety of projects in Europe are encouraging good practice to help people with dementia and their carers live well in their local community. In January 2012, the King Baudouin Foundation presented awards to 10 projects led by community-based organisations from eight European countries, including Belgium, Germany, Austria and Portugal. The awards recognise and encourage the dissemination of good practices that help people with dementia and their families to live well, and to participate actively in their local community.¹⁰

In the UK, there has been a range of initiatives and events related to dementia friendly communities. For example, Plymouth and York are exploring how they might become dementia friendly communities.

¹⁰ www.kbs-frb.be

Case study

Dementia friendly communities in urban and rural settings – Plymouth

1 Dementia friendly city

The University of Plymouth's Dementia Research team (PDRT) worked with the City of Plymouth and Alzheimer's Society to develop a Plymouth Dementia Action Alliance (PDAA). The PDAA is committed to becoming a Dementia friendly city by November 2012. To achieve this, over 30 organisations are continually assessing and improving their understanding of the needs of individuals with dementia and carers, with the aim of transforming quality of life. Membership of the PDAA also ensures that the organisations have:

- connection to a network of dementia experts, including senior officials in health and social care, researchers from the University of Plymouth and people from the voluntary sector working in the field of dementia
- receipt of the latest news and material on relevant dementia projects
- meetings and events throughout the year organised by the PDAA
- guidance on developing and implementing dementia friendly city approaches
- participation in discussions of best practices for building a dementia friendly city
- facilitation of partnerships or collaborative activities between other cities.

2 Dementia friendly rural parishes

As part of this work, a pilot project to help people with dementia and carers in rural communities to access support and services is being completed.

The steering group includes representatives from five parish councils, Alzheimer's Society, Plymouth University Dementia Research team and others. The group has created a job description and person specification for a community development project worker. This person will raise awareness about dementia in the community, particularly with local businesses and organisations.

The aim will be to develop an inclusive community approach in the villages for people with dementia and their carers. This includes liaison with GPs and other health and social care professionals to develop individual services and opportunities, which will be done in consultation with people with dementia and carers from the community. The PDRT will evaluate this innovative pilot project, with a view to using the model in other rural communities.

Case study

A dementia friendly city – York

In York, the Joseph Rowntree Foundation is funding a year-long project exploring how local partners, including people who are living with dementia and their families, can make the City of York work better for local people who are living with the condition. The Dementia Without Walls project will use the experiences of people with dementia, and those who support and care for them, to consider how life can be lived to the full.

Also drawing on examples of current best practice locally, nationally and internationally, the project will challenge people to think afresh, not only about health and social care services, but housing, shopping, leisure and transport. In other words, the everyday amenities that most people take for granted, but which can create enormous challenges for people with dementia. A core aim will be creating opportunities for people with dementia to experience different kinds of services. This will be done through ‘seeing is believing’ visits (to see different places and services where innovative approaches are being tried) and by sharing their experiences with other service users.

In addition, the Local Government Group (LGG) has completed a work programme to help councils develop good places in which to grow old.¹¹ The programme recognised that if a council is truly preparing for an ageing society, it will need to take action in relation to people with dementia. The LGG states that creating dementia friendly communities is likely to require:

- work with existing local services, including emergency services
- work with existing community networks such as women’s groups, youth groups, faith groups, local Age UK groups and Neighbourhood Watch
- intergenerational work
- involving members of the public who might want to participate in local activities, from holding awareness raising events to becoming ‘neighbourhood friends’.
- engagement of commercial sectors, including retail – for example, to educate and train their staff to a deliver dementia friendly service
- community and citizen empowerment – developing resilient communities, local decision-making and shaping own communities through inclusion of people with dementia and their families/carers

¹¹ www.local.gov.uk/topic-ageing-well

- involving other council services, eg leisure, transport, libraries and housing with support and other healthy activities such as healthy ageing, yoga, cycling, swimming, walking and community activities that help maintain independence and well-being.

At the time of writing, the outcome of the programme will be a guide for local authorities about how they can create a dementia friendly community. There are also plans for a website containing the guide, along with insights and case studies from the project.

5.4 Recommendations

Alzheimer's Society believes that there must be a shift in societal awareness and understanding about dementia. People living with dementia and carers must be recognised as active citizens with the potential to live well in the community.

In particular:

- 1 Work must be undertaken to understand what makes a dementia friendly community and how communities can best support people with dementia and carers to live well. Alzheimer's Society has committed to leading this work in its Dementia Action Alliance action plan, in partnership with other organisations and stakeholders.
 - As a starting point, local and national-level discussions with key stakeholders are needed to define what a dementia friendly community is, and to understand what the opportunities are.
 - 2 Communities must be enabled to understand how to help people with dementia and carers live well within the community.
 - A starting point must be a reduction in stigma. The government, Alzheimer's Society and others have invested in work programmes to move this forward. However, a major shift in societal awareness and understanding is still required. This should combine large-scale public campaigns with targeted work to increase understanding of dementia in a range of individuals and organisations, such as the police, banks and retail outlets.
 - Support should be provided to community agencies, for example, shops, businesses, the public sector and churches, as they contribute to developing dementia friendly communities. The shape of this support will partly depend on the discussions that are to be held, and from learning from dementia friendly communities already underway.
 - 3 People with dementia and carers must be at the heart of the dementia friendly communities work. They should be key partners, speaking out about their experiences of living well with dementia and the solutions they would like to see.
 - 4 There should be particular work to apply the thinking and practice of dementia friendly communities to health and social care services to ensure that social networks are maintained and developed. In particular, commissioners should understand the needs of people with dementia and carers in the context of living within a community.
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Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers. We provide information and support to people with any form of dementia and their carers through our publications, National Dementia Helpline, website, and more than 2,000 local services. We campaign for better quality of life for people with dementia and greater understanding of dementia. We also fund an innovative programme of medical and social research into the cause, cure and prevention of dementia and the care people receive.

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