

Dementia 2013: The hidden voice of loneliness



Document purpose	Dementia 2013 describes how well people are living with dementia in 2013 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. Dementia 2013 focuses on one aspect of quality of life for people with dementia – loneliness.
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Target audience	Dementia 2013 is intended for a wide range of organisations and people who can improve quality of life for people with dementia. This includes partners from the public sector, local authorities, commissioners of health-care, civic organisations and government.
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Foreword

I did everything I could to care for my dad when we discovered he had dementia. Unfortunately, the efforts of one person – or even a family – aren't always enough. It soon became clear to me that while I could keep Dad safe when I was by his side, I couldn't be there every minute of every day.

My dad was living on his own when he developed dementia at the age of 77. I loved the fact that he lived close by, and he loved living in London. Over time, however, his wandering and getting lost became worryingly frequent. In the end, to help him navigate his way home, I ensured every one of his coat pockets contained his address and my phone number. The police kindly helped him find his way home a few times. I was so grateful to know that people had stepped in when he needed help.

I found windows of time where I could drop in on him between choreographing in the West End and caring for my young family. I would dash across London between rehearsals to have a meal with him. My sister was living miles away in Leeds, so it was hard for her to visit as often as she wanted to.

I'm glad that I was able to help my dad stay in his own flat after he was diagnosed. It was right for him, but it was a struggle.

This is why I am pleased to support the work of Alzheimer's Society. Two-thirds of people with dementia live in the community – a significant and increasing number of them on their own. When someone has dementia, they find it difficult to do the things they used to love. They find it hard to keep in touch with people. They become isolated, and feel lonely.

My mum passed away aged 43 and it was heartbreaking for my dad, with three young teenagers to care for. When we left home, I was worried about him being lonely, especially in his later years as the dementia developed. This report shows people with dementia are more likely to be isolated, and are particularly at risk of loneliness if they live alone. Nearly half of people with dementia questioned by Alzheimer's Society said they felt lonely. Almost two-thirds said they felt anxious or depressed.

I know my dad was grateful to have me nearby in London. Similarly, this report found that where people with dementia have family members or friends nearby, they rely on and value this support and contact. My whole family were very supportive of Daddy, but some people don't have this support network. It would help to know that neighbours and people in the local community were happy to look out for people with dementia.

While 2012 marked a big change in dementia policy in the UK, what matters is the day-to-day experience of people with dementia. There are still substantial barriers to people with dementia doing the normal things they used to do that keep their quality of life at an acceptable level. For my dad this meant gardening, going into town in search of a new book, or a trip to the ballet. I wish I could have helped him continue to do these things independently, while knowing that people would be aware of dementia and willing to help if he became confused.

Caring for someone with dementia is not an easy thing to do. You watch someone you love slowly lose the power to remember, and how to say and do things they once knew. Changes in personality often occur that one needs infinite patience to deal with. We all need to be aware of how kind we need to be to help and support those with dementia.

Prime Minister David Cameron said of dementia: 'It is as though we've been in collective denial.' I hope people soon start to realise it is essential that people with dementia have the same rights as other citizens, and don't become prisoners in the place that they live.



Arlene Phillips

Arlene Phillips CBE
Alzheimer's Society Ambassador

Executive summary

Dementia 2013: The hidden voice of loneliness is Alzheimer's Society's second annual report looking at the quality of life for people with dementia in England, Wales and Northern Ireland. Like Dementia 2012: A national challenge, it provides a snapshot of how well people are living with dementia, what support they are receiving, and what barriers they face to living well.

The evidence presented in Dementia 2013 shows that some progress has been made towards improving the quality of life for people with dementia and carers. Dementia has become a policy priority in England following the launch of the Prime Minister's challenge on dementia (Department of Health 2012) and has increased in prominence in Wales and Northern Ireland. Since launching last year, the ambitious challenge is beginning to see developments in the health and care field in England, while providing additional funding for research.

However, Dementia 2013 acknowledges that progress has been slow, and there is still much to be done to ensure that the policy is reflected in the experiences of people with dementia in all care settings. While 61% of people with dementia surveyed said that they are living well with the condition, the report reveals that quality of life remains extremely varied for substantial numbers of people.

Dementia 2013 highlights that health and care for people with dementia still needs improving. Key findings include that a lack of diagnosis continues to be an issue for many people, with less than half (44%) of people with dementia in England, Wales and Northern Ireland currently receiving a diagnosis. This is a very small increase since 2012 – only 3% – and it still means that most people cannot access appropriate information or support, or make informed decisions about their future.

Good health and social care for people with dementia – from before diagnosis until end of life – remains an essential aspect of good quality of life. Momentum must be maintained on improvements. To achieve this, actions must include a well-funded social care system offering high quality, appropriate services that drive up quality of life for people with dementia.

Dementia 2013 also focuses on the impact of loneliness and social isolation on people living with the condition, particularly for those living alone. Nearly two-thirds (63%) of people with dementia surveyed said they felt anxious or depressed. A third of people with dementia said they had lost friends and 5% said they have not told their friends about their diagnosis. This is actually a slight increase from 2012 when 4% of people said they had not told their friends about their diagnosis. Of those living alone, nearly two-thirds (62%) of people with dementia reported feeling lonely.

With more than two-thirds of people with dementia living in the community (Alzheimer's Society, 2007) **and a significant proportion of them living on their own, addressing health and care alone is not enough.** Throughout England, Wales and Northern Ireland, there is now a focus on equipping communities to deal with dementia. The Dementia-friendly Communities programmes in England and Northern Ireland and the Dementia-supportive Communities programme in Wales have made promising beginnings. It is essential that resources, programmes and interventions are developed to help communities meet the needs of people with dementia.

Given the breadth of quality of life issues that must be addressed to ensure that people live well with the condition, we must all continue to work together to improve quality of life for people with dementia. This report is aimed at anyone who has a role to play in improving quality of life for people with dementia, from central governments to service commissioners, voluntary agencies and community groups. It makes the case to keep up momentum on improving quality of life for people with dementia, particularly those who live in the community or on their own.

Key findings

- Only 44% of people with dementia in England, Wales and Northern Ireland have a diagnosis. This has increased just 3% from last year.
 - In England, the mandate from the government to the NHS Commissioning Board includes an objective to make measurable progress on improving the rates of timely diagnosis.
 - The number of inappropriate prescriptions for antipsychotic medication to people with dementia had been reduced by 52% between 2008 and 2011.
 - In England in 2013, there are 64 Dementia Adviser services. In 2012, there were 35.
 - Approaching two-thirds (61%) of people in England, Wales and Northern Ireland say they are living well with dementia. However, 17% said that they are not living well with dementia – the same number as chose this option last year.
 - A third (33%) of people with dementia said they lost friends following a diagnosis. In 2012, 40% of people with dementia said they lost friends. While this is a reduction, there has been an increase in people not telling their friends about their diagnosis.
 - More than a third (39%) of people with dementia responding to the survey said they felt lonely. Only a quarter (24%) of over 55s in the general public said they have felt lonely in the last month.
 - Nearly two-thirds (62%) of people with dementia who live on their own said they felt lonely. Difficulties in maintaining social relationships and other features of dementia contributed to this.
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Priorities for attention

While health and social care services play a role in improving the lives of people with dementia, momentum needs to be kept up to build communities that support people with dementia – communities where stigma is reduced and isolation can be tackled.

The findings of this report are based on an Alzheimer's Society survey completed by people living with dementia, a YouGov poll of the general public and publicly available statistics. Based on the findings of this report, the following areas should be a priority for governments, statutory bodies, local authorities, Alzheimer's Society and others. The priorities are discussed in context within the body of the report.

Improve health and care for people with dementia

- National governments in England, Wales and Northern Ireland must urgently take measures to address the underfunding of the social care system. Adequate resources must be made available to fund the social care system and secure its future.
 - National governments in England, Wales and Northern Ireland must also address the unfair system of charging for care, which leaves people with dementia facing disproportionately high care costs. A cap on care costs must benefit as many people as possible, rather than only a few.
 - National governments in England, Wales and Northern Ireland should take steps to ensure that regulators, such as the Care Quality Commission, monitor the quality of social care, including care in care homes. They should also ensure that people with dementia are treated with dignity and respect at all times.
 - National governments in England, Wales and Northern Ireland should ensure that there is continued momentum on the national dementia strategies. This must include appropriate funding to ensure that they can be implemented in a way that will make a difference to people with dementia.
 - In England, advantage should be taken of new clinical structures to embed dementia and the Prime Minister's Challenge. Areas where improvement could be made include:
 - As part of strategic clinical planning undertaken by Health and Wellbeing Boards, the public health, NHS and social care needs of an area should be assessed and services commissioned to meet these needs. This should have particular attention on preventing crises and enabling people with dementia to remain independent.
 - Acute trusts should sign up to the Dementia Action Alliance call to action on creating dementia-friendly hospitals.
 - Clinical Commissioning Groups and Academic Health Science Networks should each appoint a dementia lead.
 - Residential care providers should sign the Dementia Care and Support Compact.
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- In Wales, Local Health Boards should demonstrate their commitment to the Dementia Vision for Wales by:
 - Commissioning services with a focus on preventing crises and enabling people with dementia to remain independent.
 - Commissioning adequate memory assessment service provision to allow for a substantial increase for the number of people with dementia with a diagnosis in Wales.
- In Northern Ireland:
 - Transforming Your Care, a review of health and social care in Northern Ireland, envisages a shift from acute care to providing care and support in a range of community settings, through Integrated Care Partnerships.
 - The Who Cares? consultation on the future of adult care and support in Northern Ireland is set to develop adult care and support services along those lines. Commissioning should follow these principles in order to improve quality of life for people with dementia and their carers.
 - Health and care services should be commissioned with a focus on preventing crises and enabling people with dementia to remain independent.

Make choice and control a reality for people with dementia

- Commissioners and GPs should set out clear plans and maintain impetus behind initiatives to improve the diagnosis of dementia, particularly in areas where the diagnosis rate is low.
 - Health and care services should encourage planning around future care with people with dementia and carers who have recently been diagnosed by providing post-diagnosis information packs and referring the person with dementia to a Dementia Adviser service.
 - The Ministry of Justice in England and the Department for Health and Social Care in Wales should improve monitoring of the Mental Capacity Act. In Northern Ireland, formal mental capacity legislation should be introduced without delay.
 - Services providing information should ensure that it is not just available digitally, but is accessible and useful to people with dementia, recognising the potential exclusion of a 'digital by default' policy.
 - Healthwatch in England and other health consumer champions in Wales and Northern Ireland should publish clear plans to ensure the involvement of people with dementia and their carers.
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Improve quality of life for people with dementia by reducing loneliness

- Local authorities and other commissioners should understand the needs of people with dementia in the context of living within the community, and work together to commission a wide range of services to ensure that they are not socially isolated or lonely. Examples include:
 - social groups, such as dementia cafés
 - services suitable for younger people with dementia, such as walking groups
 - befriending services that allow people with dementia living alone to have regular contact with a person they trust – who can also offer support with daily tasks such as shopping
 - accessible transport to allow people with dementia to attend social clubs or other services.
 - Dementia-friendly communities are an important vehicle for reducing social isolation and loneliness. Work undertaken has already begun to identify what it means to be dementia friendly; more now needs to be done to raise awareness of what it means and encourage businesses, organisations and communities to commit to becoming dementia friendly.
 - In England, the government and local authorities should commit to sustained support for the Dementia-friendly Communities strand of the Prime Minister’s dementia challenge to ensure its various initiatives make a difference to the day-to-day lives of people with dementia.
 - The Welsh Government should sustain its commitment to implementation of the National Dementia Vision for Wales and create dementia-supportive communities through the Ageing Well in Wales programme, endorsed by the First Minister and delivered through collaboration between the Older People’s Commissioner and Alzheimer’s Society.
 - The Northern Ireland Assembly Executive should sustain its commitment to timely implementation of the Northern Ireland dementia strategy, along with encouraging other public bodies to work with Alzheimer’s Society to further develop the Dementia-friendly Communities programme.
 - The public, including friends and family members of people with dementia, should sign up to the Dementia Friends programme. This can give them the confidence to engage more fully with people they know with dementia and people they meet who they may suspect have cognitive difficulties.
 - The recognition process for dementia-friendly communities which is currently being developed should be adopted by businesses, organisations and communities in order to show their commitment to becoming dementia friendly.
 - Alzheimer’s Society should lead in developing plans to ensure that the initiatives on dementia-friendly communities are maintained to ensure long term change.
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Format of the report

As in Dementia 2012, section 2, Progress since Dementia 2012, describes how well people are living with dementia in England, Wales and Northern Ireland in 2013. It reports on the outcomes identified by people with dementia as being important, and on progress made towards achieving these outcomes since the publication of Dementia 2012 in March 2012.

Section 3, Loneliness and people with dementia living alone, explores in-depth issues surrounding loneliness, social networks and formal support. This includes those that are particular to people with dementia living alone in the community. It presents new information from survey respondents with dementia who said they lived alone, along with material from individual interviews and focus groups with people with dementia who live by themselves.

Methodology

Dementia 2013 provides new evidence from a survey of more than 500 people with dementia, 50% more than completed last year's survey. The survey was distributed via Alzheimer's Society services, along with a direct mailing to participants from last year who were willing to be contacted again. It therefore only reaches out to people with dementia who are in touch with Alzheimer's Society services and are more likely to be living at home and to have a diagnosis.

The majority of respondents were aged 65 and over; 8% were under 65 years; 71% were 65–85 years; and 21% were 85 and over. When asked where they live, 16% lived on their own; 65% lived with a carer; 5% lived with somebody who is not their carer; 8% lived in a care home and 7% said other. The large majority (93%) of respondents were from England; 5% were from Wales and 1% from Northern Ireland.

The survey allowed Alzheimer's Society to reach out to a large number of people with dementia. It does not, however, provide detailed information into the experiences of people who live alone with dementia. To explore this, Alzheimer's Society conducted seven in-depth interviews with people with dementia living on their own, along with two focus groups.

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

Finally, YouGov completed a poll of UK adults for Alzheimer's Society in January 2013. The survey asked 2,287 individuals about their perceptions of dementia.

1 Introduction

Introduction to dementia

There are around 800,000 people in the UK who have dementia (Alzheimer's Society, 2012a). This includes 665,065 people in England, 44,598 in Wales and 18,862 in Northern Ireland (Alzheimer's Society, 2013a). Based on current projections, by 2021 there will be over 1 million people living with dementia in the UK (Alzheimer's Society, 2012a). Currently this costs the NHS, local authorities and families £23 billion a year (Alzheimer's Society 2007, updated to reflect 2012 figures). By 2018, this sum will grow to £27 billion (King's Fund, 2008).

The term dementia describes a set of symptoms that include loss of memory, mood changes and problems with communicating and reasoning. These symptoms occur when the brain is damaged by certain diseases, including Alzheimer's disease. Dementia is progressive, which means that people with dementia and their carers are coping with changing abilities over time. These changes include a reduction in the person's capacity to make decisions, both about major life events and circumstances as well as day-to-day situations. Eventually they will need help with all their daily activities and beyond.

Two-thirds of people with dementia live in the community (Alzheimer's Society, 2007). From this proportion, one-third live alone in their own homes (Mirando-Costillo, 2010). An estimated 670,000 people in the UK act as primary carers for people with dementia, saving the state £8 billion per year (Alzheimer's Society, 2012a).

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 care homes (Alzheimer's Society, 2007), and 80% or more of care home residents in the UK have dementia or significant memory problems (Alzheimer's Society, 2013b).

People with dementia are core users of the NHS. At any one time, up to a quarter of hospital beds are occupied by people with dementia (Alzheimer's Society, 2009). The national dementia strategies in England, Wales and Northern Ireland aim to ensure improvements in the quality of health and social care for people with dementia. The NICE-SCIE Guidelines aim to improve health and social care by supporting health and social care professionals in choosing appropriate treatments for people with dementia. But despite the number of people with dementia – and the associated costs – many living with the condition are being let down. Only 44% of people with dementia in the UK have a diagnosis (Alzheimer's Society, 2013a) meaning that many people who are undiagnosed never receive appropriate treatments and care.

Report methodology

Dementia 2013 examines the quality of life for people with dementia, with a particular focus on those living on their own. It presents fresh evidence from a survey of people with dementia, which was distributed through Alzheimer's Society services in England, Wales and Northern Ireland. Members of the Dementia Action Alliance also helped distribute surveys, as did people involved in dementia-friendly towns and cities. The survey was conducted at the same time of year as the Dementia 2012 survey the previous year. This year 510 people with dementia completed the survey – usually supported by someone else – and 70 of them were living alone. This is a significantly larger sample than last year, when 306 respondents completed the survey.

Here are some further details on the Dementia 2013 survey sample:

- The majority of respondents were aged 65 and over: 8% were under 65 years; 71% were 65–85 years and 21% were 85 and over.
- When asked where they live, 16% lived on their own; 65% lived with a carer; 5% lived with somebody who is not their carer; 8% lived in a care home and 7% said other.
- 93% of respondents were from England; 5% were from Wales and 1% from Northern Ireland.
- Most of the respondents were from urban areas: 67% were from towns or cities; 33% were from villages or the countryside.

Following feedback on last year's survey, some adaptations were made. These included simplifying the response scale to 'yes', 'no' and 'don't know'. Direct comparisons therefore cannot be made where questions are repeated from Dementia 2012. Furthermore, different people responded to the survey for Dementia 2013 than those who took part in Dementia 2012, producing additional variations in the responses.

It must be noted that the survey largely reached people with dementia in touch with Alzheimer's Society services. For this reason, it may not be representative of people with dementia generally. It does not represent people with dementia who have not been diagnosed, for example.

The survey allowed Alzheimer's Society to reach out to a large number of people with dementia, many more people than could be reached through interviews alone. However, it does not provide as detailed information into the experiences of people who live alone with dementia. To gain a more detailed picture, Alzheimer's Society spoke directly to people with dementia living alone.

In November 2012, Alzheimer's Society conducted in-depth interviews with seven people with dementia who live alone – either in private or supported accommodation – to understand how well these people are living with dementia. We were particularly interested to speak with people living alone as this group are especially likely to be socially isolated. The people with dementia who volunteered to be interviewed live in towns, cities and villages across England. To complement these interviews, we also spoke to the support staff and befrienders who work with the people with dementia.

In the same month, Alzheimer's Society ran two focus groups with people with dementia. It must be noted that these participants were in contact with the Society or using its services. Therefore, they were not totally isolated. Those people who are completely isolated do not receive any support from Alzheimer's Society or elsewhere, and have little or no contact with other people. This makes it very hard to reach this group.

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

Finally, Alzheimer's Society commissioned a YouGov poll of UK adults. In January 2013, 2,287 individuals were asked about their perceptions of dementia and people with dementia living alone.

What quality of life outcomes and aspirations are important to those living with dementia?

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, 2010), Quality outcomes for people with dementia (Department of Health, 2010), the Dementia Action Alliance's National Dementia Declaration (2010) and Support. Stay. Save. (Alzheimer's Society, 2011a). 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.

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, many of which echo common themes from other research.

These outcomes 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.

Dementia 2012 used the National Dementia Declaration outcomes as a framework to chart progress towards reaching the aspirations of people living with dementia. These outcomes are used again in this report to analyse how well people with dementia are living. Section 2 addresses each of the seven outcomes in turn, looking at evidence on whether these outcomes are now a reality for people with dementia. It discusses relevant policy from the last year, and looks at whether the recommendations of Dementia 2012 have been achieved. Section 3 puts a spotlight on the loneliness and social isolation experienced by many people with dementia. It explores the role that can be played by enabling and supportive environments and communities, when it comes to improving the lives of people with dementia.

2 Progress since Dementia 2012

Dementia in the UK in 2013

61% of people who responded to the survey said they were living well with dementia.

Despite increased attention on dementia in political, policy, and health and social care fields in the last year, we still have a mixed picture of quality of life for people with dementia. Statistics do not show that more people with dementia believe that they are living well. And while it seems that fewer people report feeling anxious or depressed, the number still remains high – and should be treated with caution.

63% of people with dementia who responded to the survey said they feel anxious or depressed. 37% said they never felt anxious or depressed (27%) or they didn't know (10%).

The survey conducted for this report found that 61% of people said that they were living well with dementia. Following feedback to the Dementia 2012 survey, we changed the questions slightly, which makes it difficult to directly compare the results. However, in both the Dementia 2012 and 2013 surveys, 17% said they were not living well with dementia at all.

Dementia 2012	Dementia 2013
17% of people said they were not living well with dementia at all	17% of people said they were not living well with dementia
77% of people said that they were living very well (22%) or quite well (55%). 5% said that they did not know	61% of people said that they were living well with dementia. 22% said they did not know

Further to this, the Dementia 2013 survey showed that nearly two-thirds (63%) of people with dementia said they felt anxious or depressed, while 10% said they did not know. Please note that respondents were people already in touch with Alzheimer's Society services or support. They therefore have more help with their condition and are likely to have better quality of life.

The public perception is that people with dementia have a poor quality of life. Results from the YouGov poll showed nearly two-fifths of people (39%) think the quality of life for people with dementia is fairly bad, and a further 15% rated it very bad.

According to a YouGov poll, 54% of people think that the quality of life for people with dementia is very bad (15%) or fairly bad (39%).

Dementia 2012	Dementia 2013
17% of people with dementia said that they did not feel anxious or depressed	27% of people said they never feel anxious or depressed
77% of people said they always (9%) or sometimes (68%) felt anxious or depressed	73% of people said that they feel anxious or depressed (63%) or they did not know (10%)

Dementia is now a public and political priority in a way that it has never been before. In England in 2012, the Prime Minister announced his personal dementia challenge. This builds on the National Dementia Strategy (Department of Health, 2009), focusing on improvements in health and care, creating dementia-friendly communities and improving research. Following this, the Secretary of State for Health, Jeremy Hunt, announced that dementia would be one of his four priorities. All nations of the UK now have national dementia plans to help people live well with dementia. The Dementia Vision for Wales (Welsh Assembly Government, 2011a) and Improving dementia services in Northern Ireland: a regional strategy (Department of Health, Social Services and Public Safety 2011) have both been published for more than a year, and numerous policy initiatives have been announced. Other relevant policy developments throughout the UK since Dementia 2012 will be discussed in relevant sections in this report.

Some progress has been made. But clearly, policy initiatives are taking time to filter into the lives of people with dementia. We are seeing improvements in the system. But in too many cases people with dementia are still not diagnosed – and too many are going without with good quality care and support that meets their needs and aspirations. Meanwhile, the quality of available care varies considerably across geographical areas. This can have an impact on the public perception of policy initiatives. A YouGov poll of the public found that 60% of people do not think that the government has responded well to the challenge of dementia. So it is essential that the momentum behind policy initiatives – in all nations – continues, so that they start to really make a difference in the everyday lives of people with dementia.

In a YouGov poll, 60% of people don't think that the government has responded well to the challenge of dementia.

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

Introduction

Having personal choice, control or influence over decisions was identified in the National Dementia Declaration as a key outcome for people with dementia. 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 with dignity cared for by people who are trained and supported in high quality palliative care.

Using these statements as a basis, this section assesses progress since Dementia 2012 towards achieving greater choice and control for people with dementia.

Dementia, choice and control

Being able to make decisions and exert control over your life is a key factor influencing well-being. However, the symptoms of dementia impair a person's cognitive ability, which over time will affect their capacity to make different decisions. It is important to stress that dementia does not mean the person immediately loses all ability to make all decisions; but they may be less able to make certain decisions over time. Even if a person can no longer make complex decisions – such as difficult financial ones – it is likely they will continue being able to make decisions about their daily life for a long period. For example, choosing what they would like to eat or drink.

65% of people with dementia who responded to the survey said they were able to make choices about their day-to-day life. 35% said they were not able to make choices about their day-to-day life (28%) or they did not know (7%).

Dementia 2012

81% of people said they were always (44%) or sometimes (37%) able to make choices about their day-to-day lives

16% of people said they were not able to make choices about their day-to-day life (14%) or they did not know (2%)

Dementia 2013

65% of people said they were able to make choices about their day-to-day lives

35% of people said they were not able to make choices about their day-to-day lives (28%) or they did not know (7%)

Given these facts, the snapshot provided by the Dementia 2013 survey is worrying. More than a quarter (28%) of people with dementia who responded said they were not able to make choices about their day-to-day life, and a further 7% said that they did not know. By comparison, the previous year's survey found fewer people saying they were not able to make choices about their day-to-day life (16% said they were not able; 2% said they did not know). This may be accounted for by differences between the questions asked and the sample of the survey, as discussed in the Methodology section of this report. But nevertheless it clearly indicates that when it comes to supporting people with dementia to make decisions, there has been little change in the last year. One person in a focus group for this research said: 'I don't feel I have the choice to go out as much. You lose choice as you get older.'

Despite the current agenda of personalisation, the above findings suggest that a lack of awareness of dementia sustains an assumption that some people with dementia do not have the capacity to make decisions about their day-to-day life. But the fact is that people with dementia should be supported to make as many decisions about their life as possible.

Naturally there are limits to the number of options from which a person can choose, and the scope for control is also not boundless. But choice and control would be improved by supporting people with dementia to make decisions, and by respecting and implementing these choices when they are made. These principles are contained within the Mental Capacity Act. Examples of good practice do exist. But the picture of whether people with dementia are able to exercise choice and control is still poor – and certainly more should be done to improve the scope for both. Dementia 2012 made recommendations regarding the implementation and monitoring of the Mental Capacity Act in England and Wales. It also recommended that capacity legislation be brought forward in Northern Ireland. Such legislation would determine when an individual with limited capacity in some areas still has choice over the things that matter to them. To date, however, Northern Ireland has yet to improve, or establish, these national level frameworks.

Case study: R

R is a younger person with dementia who lives alone in a rural community. There are no services for younger people with dementia in his area, but due to his condition he is unable to go out alone. He feels limited because he doesn't want to use services which are designed for much older people. He values being active and being able to do the things that he used to do. So, a member of Alzheimer's Society staff arranges events, such as bowling, for younger people with dementia in the area. This is not a regular meeting, however, and it's dependent on staff from Alzheimer's Society having time to organise the get-together. But given a choice, R would have regular occasions to meet up with other people of his own age and share common interests.

Diagnosis

‘For a long time we were in limbo, not really knowing what was going on. I had my suspicions, but it was very difficult to accept when we did not know what was going on. Since the diagnosis we have felt more comfortable with everything, and we can plan. It has been a lot better.’

Evidence from a carer who gave evidence to the All-Party Parliamentary Group on Dementia 2012 inquiry, Unlocking diagnosis

Receiving a diagnosis is essential for allowing people to make choices about their lives. This includes decisions they want to make now for a future time when they may have lost the necessary capacity. It also means choosing the most appropriate support and services. The recommendation in Dementia 2012 was that diagnosis rates must be increased to two-thirds by 2015 and three-quarters by 2017, to be achieved by developing the Quality and Outcomes Framework, increased public awareness and dementia training for all health and social care staff.

While steps are being taken to improve this picture, the latest figures covering the financial year 2011/12 show that less than half (44%) of people with dementia in the UK have a diagnosis. This comprises 44% of people with dementia in England, 39% in Wales and 63% in Northern Ireland (Alzheimer’s Society, 2013a). There is also strong geographical variation within the nations. For example, less than a third (32%) of people with dementia in the East Riding area of Yorkshire have a diagnosis. The London Borough of Islington, by contrast, has diagnosed three-quarters (75%) of residents who have dementia.

Dementia 2012 (figures from 2010/11)	Dementia 2013 (figures from 2011/12)
41.1% of people with dementia in England have a diagnosis	44.2% of people with dementia in England have a diagnosis
37.4% of people with dementia in Wales have a diagnosis	38.5% of people with dementia in Wales have a diagnosis
61.5% of people with dementia in Northern Ireland have a diagnosis	63% of people with dementia in Northern Ireland have a diagnosis

Despite improvements in recent years, it is still alarming that more than half of people with dementia are currently undiagnosed. During 2012, the All-Party Parliamentary Group on Dementia launched an inquiry into dementia diagnosis. Its findings suggested that diagnosis rates did not need to be so low, and the report made several recommendations to help all parts of the UK lift diagnosis rates (All-Party Parliamentary Group on Dementia, 2012). The inquiry also heard good practice examples from Scotland and Northern Ireland.

It is likely that progress which has been made has been boosted by an increased policy focus on diagnosing dementia. Each of the dementia strategies in England, Wales and Northern Ireland mentions early diagnosis. In Northern Ireland, diagnosis rates are comparatively high, and Belfast has the highest diagnosis rates anywhere in the UK. However, the rates have remained stable over recent years in Northern Ireland. It is possible that different initiatives may be needed to reach the remaining 30–40% of people who remain undiagnosed.

In 2012 in England, early diagnosis became a key area of the health and care strand of the Prime Minister's dementia challenge (Department of Health, 2012a), and prompted a national awareness campaign. Following on from this, the mandate from the government to the NHS Commissioning Board includes an objective to make measurable progress on improving the rates of timely diagnosis (Department of Health, 2012b). Meanwhile, it has been suggested that the NHS Commissioning Board will run a consultation into rewarding GP practices that proactively find cases of people with dementia through the Quality and Outcomes Framework (Department of Health, 2012c), a reward system for good practice.

In Wales, there has been growing awareness of the low diagnosis rate and the need to tackle this. The recent National Assembly Wales report into residential care for older people concluded that early diagnosis of dementia can help people to better plan for the future (National Assembly for Wales, 2012). The Society would like to see policy commitments to change the situation.

Across England, Wales and Northern Ireland, we would expect to see current and future policy commitments having an impact on diagnosis rates in coming years. However, clear next steps are required to monitor progress and develop initiatives if those suggested do not seem to be working – particularly where it concerns pushing diagnosis rates above 70%.

Financial concerns

While there has been public discussion of changes to universal benefits for pensioners – such as state pension and winter fuel allowance – this has yet come into effect. The public funds available for people with dementia and their carers have changed little since the publication of Dementia 2012. Meanwhile people's private resources in this time of financial instability may remain uncertain. While significant changes have been made to the benefits system throughout the UK, these have mainly targeted working age people. Such changes could touch people with dementia below 65, but leave the majority of people with dementia unaffected. Carers allowance remains the same. However, strained personal finances and rising prices can directly impact the choices it is possible for a person with dementia to make.

In March 2013, the UK government announced plans to introduce a cap on social care costs to £72,000. In February 2013, they announced to raise the means test threshold from £23,250 to £123,000. By raising the means test threshold, many people will be spared the strain of paying for care. However, Alzheimer's Society believes the cap on care costs is too high. Furthermore, the government is still to address the issue of paying for the social care system, which remains seriously underfunded.

Planning and end of life care

'I think, at the end, it wants to be so the person is least stressed or upset or in [as little] pain as possible, so they can be calm and go with dignity.'

Carer of a person with dementia (taken from the report, My life until the end)

Dementia 2012 recommended that people with dementia should be provided with good quality end of life care that meets their needs. This issue is now more pressing than ever. The Office of National Statistics death certificate data released in 2012 indicated that dementia is now the fifth leading cause of death in men, and second in women: nearly 37,000 death certificates listed it as a cause (Office of National Statistics, 2012a). It is also likely that the number of people who have dementia in their last months and weeks is even higher: as many as one in three people have dementia when they die (Brayne et al, 2006). This means that approximately 160,000 people who die per year have dementia – either as a cause of death, or as an illness that may complicate the end of life care they receive for a different condition.

In 2012, Alzheimer's Society extensively explored end of life care for people with dementia in My life until the end: dying well with dementia (Alzheimer's Society, 2012b). This report found that while there were some examples of excellent practice, many people with dementia still end their lives in pain and without dignity. It recommended increased public awareness, emphasised the importance of advance planning, and explored the different challenges faced in different settings.

As indicated previously, the situation across the UK is broadly one of under-diagnosis and late diagnosis. As death is considered a taboo subject not to be talked about, this means the majority of people with dementia often have little opportunity to put plans in place for future and end of life care. While policy encourages planning, it will take time to address the double stigma that surrounds dementia and death.

Despite this, numerous initiatives to improve the final period of life for people with dementia have been developed and are ongoing since Dementia 2012. The Prime Minister's dementia challenge Health and Care Champion Group are addressing end of life care. Plus, the National End of Life Care Programme has overseen the piloting of electronic palliative care registers. The registers help co-ordinate care for patients who are nearing death, and ensure that all professionals caring for them are aware of their care plans (Department of Health, 2012e).

In Wales, the recent consultation Together for health – delivering end of life care: a delivery plan up to 2016 for NHS Wales (Welsh Government, 2012a) heavily emphasised a healthy, realistic approach towards dying which involves planning. In Northern Ireland, the Transforming your care (Health and Social Care Board, 2012) consultation also addresses end of life care, and may encourage improvements in this area.

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

Introduction

People with dementia want access to services that are designed around them and their needs. This was one of the key outcomes for people with dementia identified by the National Dementia Declaration. To describe this outcome in more detail, the declaration includes a range of statements by people with dementia and carers. These are:

- I feel supported and understood by my GP and get a physical check up 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 to 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 these statements as a basis, this section will assess the progress since Dementia 2012 towards achieving services designed around the person with dementia and their needs.

Community-based care

‘I wouldn’t want to put her into a care home. I want to stay with her for as long as possible. To part with her: I couldn’t do that. Unless it came to something serious and I couldn’t look after her.’

Carer of a person with dementia (Taken from the report, Home from home, Alzheimer’s Society, 2008)

A YouGov poll showed that 49% of the public think that the quality of care provided for people with dementia is very bad (13%) or fairly bad (36%).

Care delivered in the community and closer to people’s homes is generally accepted by health and social care systems to be better for the person with dementia, as well as potentially providing savings to the health service. The Dementia 2012 report recommended shifting resources from inappropriate acute and residential care into community settings. In policy terms, this seems to have been accepted and acted upon. In England, the Health and Social Care Act 2012 came into force in April 2013. Whether it will be successful remains to be seen. But the newly-introduced Health and Wellbeing Boards, and the emphasis on dementia in *Everyone counts: planning for patients 2013/14* (NHS Commissioning Board, 2012), share the aim of improving care for people with dementia. The focus in each case is delivering care that suits the person’s needs, and preventing unnecessary hospital admissions. Dementia 2012 also recommended nationwide dementia clinical networks, which were established in the new NHS in England. For more information on the achievements of the Health and Care Champion Group, see the Prime Minister’s dementia challenge progress report (Department of Health, 2012e).

In Northern Ireland, the proposals contained in *Transforming your care: vision to action* (Health and Social Care Board, 2012) would transfer focus onto community-based care and preventing hospital admissions through integrated care partnerships and re-ablement. If implemented and appropriately funded, these could go some way towards achieving the outcomes that are important to people with dementia. The report *Who cares?: the future of adult care and support in Northern Ireland* (DHSSPS, 2012) also explores ideas for how adult social care might be provided in the future. It is similarly inclined towards investing in preventing ill health, promoting early intervention, and supporting well-being and independence.

However, cuts to social care budgets have made it less likely that people with dementia who need low levels of social care at home will actually receive it. Indeed, eight out of 10 councils will now only provide services to people assessed as having substantial or critical needs. But without investment in this key area of prevention, it is unlikely that hospital admissions can be prevented. The UK Homecare Association (UKHCA, 2012) found that almost three-quarters (74%) of providers said the councils they traded with had become more interested in securing a low price than in the quality of service they were procuring. More than a third (34%) of providers were concerned that their councils required them to provide personal care in such short visit times, and that this risked undermining the

dignity of service users. This was particularly striking in Northern Ireland, where more than four-fifths (87%) felt there was a risk to dignity. Furthermore, a report from the Care Quality Commission in February 2012 found that a quarter of home care providers are not meeting all five standards of quality and safety. Alzheimer's Society believes that good quality home care is essential to preventing hospital admissions and early entry into care homes.

In addition, the existing evidence on management of the health of people with dementia in primary care remains broadly the same. GPs are crucial players in the community support of people with dementia, and they are rewarded for undertaking annual reviews of people with dementia. But uptake of this has remained mostly static in recent years. In 2011/12, 79.3% of people with dementia on GP registers in England had a review of their care – a fraction different from 79.2% in 2010/11. In Wales over the same period, 78.1% of people with dementia on GP registers had a review – a slight decline from 78.9% last year (Welsh Government, 2012b). Alzheimer's Society believes that GPs must do more to drive improvements in managing the health of people with dementia. GPs should also take responsibility for ensuring that people with dementia maintain good physical health, and can remain active for as long as possible.

Dementia 2012 (figures from 2010/11)	Dementia 2013 (figures from 2011/12)
79.2% of people with dementia on GP registers in England had a review of their care	79.3% of people with dementia on GP registers in England had a review of their care
78.9% of people with dementia on GP registers in Wales had a review of their care	78.1% of people with dementia on GP registers in Wales had a review of their care

The rhetoric suggests that community care will be strengthened. But lack of funding for home-based social care services, and little movement in the general community healthcare of people with dementia, suggests more work is needed to turn the policy into a reality for people with dementia.

Hospital care

While much policy is focused on treating people with dementia in the community, it is still estimated people with dementia occupy up to one in four hospital beds (Alzheimer's Society, 2009). Many people with dementia stay in hospital longer and are more likely to be discharged into a care home, rather than their own home, than people without dementia. Dementia 2012 made several recommendations to improve quality of care. Since then, numerous initiatives to improve hospital care for people with dementia have been announced.

In England the Dementia Action Alliance launched a call to action to improve the care of people with dementia in acute hospitals. The goal was that by March 2013 every acute hospital will have committed to becoming dementia friendly. This is in addition to the existing call to action on antipsychotics, which last year reported that the number of inappropriate prescriptions of antipsychotic medication for people with dementia had been reduced by 52% between 2008 and 2011. This is a positive result, but there are still major regional variations (NHS Information Centre, 2012). Meanwhile, the Secretary of State for Health committed £50 million to make the built environment in hospitals better suited to people with dementia. And the Prime Minister committed to creating dementia champions on every NHS ward.

In Wales, a purpose-built centre caring for up to 60 people with dementia was opened in 2012. The centre was built using the latest evidence to create an ideal environment for older people with dementia needing hospital care.

However, there are still too many people with dementia being admitted to hospital, and staying too long. While Alzheimer's Society is pleased that half of hospitals have committed to becoming dementia friendly, action is needed to ensure that people with dementia have a positive experience in hospital. People with dementia are currently seeing little change in their experience on acute care wards, where care and dignity can frequently be poor. Alzheimer's Society supports recommendations in the recent Francis Report which call for staff to be held accountable for poor care and for the creation of a culture of honesty. The Society wants to see regulations which ensure that the voices of patients and families are better heard and acted upon.

Case study: P

P was admitted to hospital for physical health problems which were unrelated to dementia. When in hospital, he found it dirty and made a complaint to nursing staff. The staff did not clean up the mess on the ward and, as P has dementia, accused him of being confused. This made P feel that the failings in the quality of care were his fault. The situation made P even more distressed, which worsened his dementia.

In addition, Alzheimer's Society believes that health and social care services should be more closely integrated. People with dementia access services across health and social care. Proper co-ordination between professionals ensures efficient and timely interventions, which can prevent an issue from escalating. For example, once a person with dementia is discharged from hospital, a re-ablement programme should be drawn up with both health and social care professionals, so that the person is not readmitted to hospital.

Care homes

As stated previously, while the majority of people with dementia live in the community, one-third of people with dementia live in care homes. It is estimated that at least 80% of people in care homes have dementia or significant memory problems (Alzheimer's Society, 2013b). This means that dementia is core business for care homes; it is essential that they are able to provide services which meet the desired outcomes of people with dementia. Dementia 2012 recommended improvements to the data on monitoring and inspections of care homes.

Since Dementia 2012 there have been several high profile scandals concerning undignified treatment in care homes. For instance, a Panorama documentary in April 2012 exposed the treatment of someone with dementia in Ash Court Care Centre in Kentish Town, north London. In a recent Alzheimer's Society report (Alzheimer's Society, 2013b), more than two-thirds (70%) of the UK public said they would feel scared about moving into a care home in future. However, these cases of undignified treatment, while unacceptable, are not the norm. The same Alzheimer's Society report found nearly three-quarters (74%) of carers would recommend the care home the person with dementia was in. Over two-thirds (68%) said the quality of care in the home was good.

But it is worth noting that while care may be good, less than half (41%) of carers thought that the quality of life of the person with dementia living in the care home was good. This suggests more work is needed to promote and improve quality of life of people with dementia in care homes.

In policy terms, in England the Prime Minister's dementia challenge established the Dementia Care and Support Compact. This now has at least 79 signatories, including the majority of major care home chains in the UK (BUPA, Barchester Healthcare and Four Seasons Healthcare), and the bodies representing independent care providers, such as the English Community Care Association (ECCA) and organisations providing services in care homes. Co-ordinated by ECCA, the compact is a commitment from care home providers to focus on quality of life for people with dementia, and to set a benchmark for high-quality relationship-based care. However, there has been little reporting on how this is being implemented, and so far it is unclear whether quality of life is being enhanced for people with dementia living in care homes.

In Wales, the need to improve health and social care workforce understanding of dementia is recognised by the Welsh Government. Although there are limited government commitments to improving dementia care in care homes, a recent report of the Welsh Assembly Health and Social Care committee called for more dementia training in this setting (National Assembly for Wales, 2012).

In Northern Ireland, *Transforming your care: vision to action* (Health and Social Care Board, 2012) proposes substantially to reduce the number of people with dementia in care homes by improving access to care at home, and its quality. It also proposes to halve the number of statutory residential homes over the next three to five years. Northern Ireland has a higher proportion of people over 65 living in care homes compared with other parts of the UK (Alzheimer's Society, 2007). To achieve this outcome, it is essential that the correct care and support are in place to enable people with dementia to remain in their community. Meanwhile, adequate care home provision must be maintained for people who do require it.

Carers

Carers are entitled to have an assessment of their needs. Frequently this does not happen; or carers do not have a package of support in place to deliver on their assessed needs. Many are unaware they are entitled to an assessment in the first place. Carers need their needs clearly assessed, and a single point of contact to help them navigate the system. Alzheimer's Society believes carers should be supported with improved assessments – which take place alongside the assessment of the person for whom they are caring. Such assessments should aim to ensure that the impact of caring on the carer is manageable and sustainable. There are currently no plans to address these issues.

Dementia 2012 recommended that information and peer support should be available to carers as well as to people with dementia. The Prime Minister's challenge on dementia (Department of Health, 2012a) championed better support for carers, suggesting close working between the NHS and local organisations. It also highlighted the funding the government committed for carers respite in 2011. This money was not ring-fenced, however, and there has been no evidence to show if the quality of carers' respite has improved – or if the NHS and local organisations have been working together more closely.

There are suggestions that new indicators aimed at supporting carers will be added to the Quality and Outcomes Framework in 2014/15, which is used to incentivise GPs towards good practice (NICE, 2013). For example, GPs could be required to create and maintain a register of carers of people with dementia, and ensure that those carers are offered an assessment of their needs on an annual basis. NICE consulted on the new indicators early in 2013 and Alzheimer's Society showed its support for these developments.

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

Introduction

People with dementia need the right support and knowledge to help them live their lives. This was one of the key outcomes for people with dementia identified by the National Dementia Declaration. To describe these outcomes in more detail, the declaration includes a range of statements by people with dementia and carers.

For outcome three (on 'support') these 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 needs.

For outcome four (on 'knowledge') these 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 entitled to.

Using these statements as a basis, this section will assess the progress since Dementia 2012 towards achieving greater support and knowledge for people with dementia. Given the overlap with other sections of the report, this section focuses on support and networks, along with information and advice.

The public opinion is that people with dementia are not able to easily access services. The YouGov public poll for this report found that only 12% of people think that access to services for people with dementia is very good (2%) or fairly good (10%). Nearly a quarter (23%) of those polled think that access to services for people with dementia is neither good or bad, and the remaining 18% do not know.

Personal budgets

Recent years have seen increasing attention on personal budgets and the personalisation agenda. As discussed in outcome two above, ensuring people receive quality care and support that responds to their needs is essential for meeting the challenge of dementia. This chapter will not discuss formal care in detail, as this is discussed in the previous chapter.

While personalisation is increasing – with 432,349 adults directing their support in 2011/12 (ADASS, 2012) – dementia can pose a particular challenge to this. Indeed, take-up of personal budgets among people with dementia has been low (Alzheimer's Society, 2011b). Dementia 2012 recommended that people with dementia and carers were fully involved in the personal budgets agenda. The system is still not geared up to meet their needs, and the market for a range of dementia services remains underdeveloped. In October, the Care Services Minister, Norman Lamb, announced the government was scrapping the target of 100% of people who use social services managing this with a personal budget – reducing it instead to 70%. However, there is still significant variation across the country.

The use of personal budgets must be based on the needs of the person with dementia and their carers. While personal budgets are useful in some circumstances, the principle of self-directed support is key not only to the idea of personal budgets but also to their delivery.

Networks

75% of people with dementia who responded to the survey said they had enough people to count on for support. 15% said they did not have enough people to count on. 10% said they did not know.

Dementia 2012 recommended that every person with dementia should be able to access peer support. Beyond formal support for people with dementia, it is often a network of friends and family who provide day-to-day support – particularly when the person with dementia lives in the community. This support can be essential to ensuring a good quality of life. But due to several combined factors, people with dementia may not be as supported as people without dementia. These include issues which affect all older people, such as the increased likelihood of being widowed, or having a reduced social network. But in addition, the stigma surrounding dementia – and the discomfort which some people can feel when communicating with people with dementia – can contribute to a smaller social network.

People in some communities may face particular barriers to accessing support from their network of friends and family. For example, among minority ethnic groups there can be lower awareness, higher levels of stigma and different cultural understandings of dementia. This may result in members of these communities presenting to general dementia services later than their white counterparts.

33% of people with dementia who responded to the survey said they had lost friends after a diagnosis of dementia. 50% said that they had not lost friends. 18% said that they did not know (13%) or had not told them (5%).

Dementia 2012	Dementia 2013
44% of people with dementia said that they had lost some (28%) or all (12%) of their friends following their diagnosis, or they had not told them (4%).	38% of people with dementia said that they had lost friends after a diagnosis of dementia (35%) or they had not told them (5%).

It is concerning that, in 2013, more than one-third of people with dementia say they have lost friends or have not told them. These issues and the priorities for attention surrounding them – including the need for peer support – are discussed in more detail in section 3.

Information and advice

Information and advice for people with dementia is an essential component of enabling choice and providing the best care. The lack of information and support for people with dementia, particularly immediately after diagnosis, is a frequent complaint (All-Party Parliamentary Group on Dementia, 2012). Dementia 2012 recommended that organisations providing written information should consider ways to enhance these services. The report urged local authorities to ensure that independent information is available, as well as a named contact for support throughout a person's life with dementia. Encouragingly, steps have been taken since 2012 to improve the provision of information and advice for people with dementia.

As part of the Prime Minister's dementia challenge, the Our Health website was developed in south-west England. The site offers a comprehensive local service directory, along with performance indicators allowing comparisons between areas. While only available in the south at the time of writing, it should be available across England by April 2013.

Alzheimer's Society is working to develop a new information resource for people at the point of a dementia diagnosis and for their carers. It will help to build an understanding of dementia and present important steps that can be taken to live well after a diagnosis and plan ahead for the future. It will also signpost to services and support for both people with dementia and carers. It will be launched in the summer of 2013.

Alzheimer's Society was also able to commit funds to expanding its national helpline. This is now open seven days a week, and accessible by a single number from anywhere in England, Wales and Northern Ireland. As of December 2012 there were also 64 Dementia Adviser services across England – up from 35 in December 2011.

The Welsh Government has committed additional funding to the provision of information packs for people with dementia following diagnosis (Welsh Government, 2012c). The

packs, Living well with dementia after a diagnosis, contain basic information and are available in both English and Welsh. There is also a bilingual Wales Dementia Helpline, available 365 days a year.

It is clear, however, that a need for good quality accessible information remains. To ensure the information provided can be used, it is essential these resources are accessible to all people with dementia, and provide information which is useful to them.

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

Introduction

People with dementia want to live in an enabling and supportive environment where they feel valued and understood. Where they have a sense of belonging and of being a valued part of family, community and civic life. These were among the key outcomes for people with dementia identified as part of the National Dementia Declaration. To describe them in more detail, the declaration includes a range of statements by people with dementia and carers.

For Outcome five ('an enabling and supportive environment') these are:

- 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 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.

For Outcome six ('a sense of belonging and being valued') these are:

- 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.

Using these statements as a basis, this section will assess the progress since Dementia 2012 towards achieving more enabling and supportive environments for people with dementia where they are a valued part of the community. More detailed evidence on dementia-friendly communities will be published in another report in summer 2013.

Dementia-friendly and dementia-supportive communities

The public poll conducted by YouGov asked about the level of inclusion of people with dementia in their communities. When asked how good or bad they would rate the inclusion of people with dementia in the community, 59% of people think that it is very bad (12%) or fairly bad (47%).

Last year (2012) was a landmark year for developing dementia-friendly communities in England. The Prime Minister's dementia challenge stated an ambition to create dementia-friendly communities, and committed to engage 20 cities towns and villages – along with leading national organisations – in getting communities more geared towards supporting people with dementia. Progress is being made. Numerous initiatives are underway, including staff training, factsheets and education in schools. Meanwhile, groups in 20 locations have committed to working towards being dementia-friendly villages, towns and cities. As recommended in Dementia 2012, national level discussions with key stakeholders have been taking place – and people with dementia and carers have been at the heart of this work. For more information, see the update report of the Prime Minister's dementia challenge (Department of Health, 2012d).

Wales has also made progress towards dementia-friendly communities. Alzheimer's Society is co-ordinating activity with the Older People's Commissioner's Aging Well programme. The partnership also includes Age Cymru and the delivery board of the Welsh mental health strategy. The programme is planned to launch this spring.

In April 2013, Alzheimer's Society in Northern Ireland will initiate a four-year Dementia-friendly Communities project funded by The Atlantic Philanthropies. The programme will develop knowledge and skill in the population at large, so that everyone can contribute to supporting people with dementia in their community. Alzheimer's Society will work with the business, community and voluntary sectors to raise awareness of dementia and its effects on the person, to enhance understanding, and to change attitudes and behaviour towards people living with the condition.

The public poll conducted by YouGov for this report found that 76% of people agree it is important that everybody should be able to get out of their homes and feel comfortable in their local area.

Dementia 2012 recommended research into what makes a dementia-friendly community, and how communities can best support people with dementia to live well. Alzheimer's Society has been undertaking this work, which will be published this summer.

Outcome seven: I know there is research going on which delivers a better life for me now and hope for the future.

Introduction

People with dementia should know there is ongoing research into the condition. This was a key outcome identified for people with dementia as part of the National Dementia Declaration. To describe this outcome in more detail, the declaration includes a range of statements by people with dementia and carers. These are:

- I regularly read and hear about new developments in research
- I am confident that there is an increasing investment in dementia research in the UK.
- I understand the growing evidence about prevention and risk reduction of dementia.
- As a person living with dementia I am asked if I want to take part in suitable clinical trials or participate in research in other ways.
- I believe that more research will mean that my children and I can look forward to a range of treatments when I need it and there will be more treatments available for their generation.
- I know that with a diagnosis of dementia comes support to live well through assistive technologies as well as more traditional treatment types.

Using these statements as a basis, this section will assess the progress since Dementia 2012 towards achieving better dementia research in the UK.

The Prime Minister's challenge

The Dementia 2012 report called for significant commitment to dementia research. One of three strands of the Prime Minister's dementia challenge was 'Better research'. This committed to more than doubling overall funding for dementia research to over £66 million by 2015. Dementia research has historically been underfunded compared to the cost of dementia to health and social care. There was also a commitment to getting more people with dementia involved in research.

The government provided £9.6 million to enable the expansion of UK Biobank, particularly for investment in brain scanning, which will provide the platform for future dementia research. The Medical Research Council has provided 50% more funding for neurological research, expanding programmes looking at neurodegenerative diseases such as dementia. Another £36 million was also provided by government for a Translational Research Collaboration in dementia, working on new treatments and questions about early diagnosis. Significant extra funding has also been provided or committed to continue work on implementing research and the social science elements which may improve quality of life for people with dementia. For more information see the progress report from the Prime Minister's dementia challenge (Department of Health, 2012d).

Trials for new medications

There has been much activity in pharmaceutical research for new treatments for Alzheimer's disease since Dementia 2012. There are currently two main types of medication used to treat Alzheimer's disease: cholinesterase inhibitors (including the brand names Aricept and Exelon) and NMDA receptor antagonists (the brand name Ebixa). These are not effective for all people with Alzheimer's disease, nor do they work for people with other types of dementia.

In recent years, the pharmaceutical industry has developed some new potential treatments in the form of antibodies. While there have been disappointing phase 3 trials, one drug tested – solanezumab – seems to have a small benefit on slowing down the progression of Alzheimer's disease. It may also possibly boost quality of life, particularly in people who are in the milder stages of the disease. However, the data are complex and difficult to interpret: in places implying contradictory things. The drug company Eli Lilly, which owns solanezumab, will conduct a further phase 3 trial in early 2013.

Case study:

An initiative in research – DeNDRoN patient register

DeNDRoN are developing a public online service for patients to register their interest in research and receive information. They will then directly be sent information about opportunities to participate in research, rather than having to search numerous websites for details of different trials.

3 Loneliness and people with dementia living alone

Background

Research for Dementia 2012 (Alzheimer's Society, 2012a) revealed that people with dementia are often socially isolated and lonely. Nearly half of respondents to the 2012 survey reported losing most or some of their friends, or that they had been unable to tell friends about their dementia diagnosis. The survey also found that people with dementia can feel a burden to family and friends. In this year's survey, more than a third (38%) of the respondents said they feel lonely. Among the oldest group (over 55s) of the public who responded to the YouGov survey for this report, only a quarter (24%) said they had felt lonely in the past month.

The negative consequences of social isolation and loneliness are well-researched. For Dementia 2013, Alzheimer's Society wanted to examine these issues further with one particular group of people with dementia – those living alone – to see how well they are living with the condition. As previously stated, research shows a high proportion of people with dementia feel socially isolated – however, those who live alone are at even greater risk of loneliness, more so than people with dementia who do not live alone. Meanwhile, it is important to note that definitions of social isolation and loneliness make clear that these are two separate states.

50% of people who responded to the survey in 2013 said they are lonely (38%) or don't know if they are lonely (12%).

This section of the report also examines why people with dementia are more likely to be socially isolated and lonely. In particular, it explores the impact of dementia on people who live on their own in the community, covering issues including loneliness, social networks and formal support.

It presents new information from people with dementia responding to the survey who said they lived alone. Over 500 people with dementia completed the survey, usually supported by someone else, including 70 people who live alone. Through interviews and focus groups, Alzheimer's Society also spoke in-depth with individuals with dementia who live alone.

The report draws out areas that local authorities should prioritise. As the bodies responsible for commissioning services for people with dementia, the report urges them to enable individuals to live independently in their communities. Priorities for attention aimed at commissioners of healthcare services highlight that people with dementia need the right support to lead healthy and active lives for as long as possible. Other priorities for attention build on the Dementia-friendly Communities programme.

Definitions of isolation and loneliness

Isolation describes the absence of social contact, or contact with friends, family, community involvement or access to services (Campaign to End Loneliness, 2012). In other words, social isolation is an objective state, measurable by the number of contacts a person has.

Loneliness is different from social isolation: it is a subjective state. Different people experience loneliness in different ways. For example, some people may feel lonely even if they have regular contact with friends and family; others may have few contacts but not feel at all lonely. There are different types of loneliness: emotional and social (Weiss, 1973). Emotional loneliness is the absence of a significant other with whom a close emotional attachment is formed (Burholt, 2011). Social loneliness, on the other hand, is the lack of a social network or group of friends, neighbours or colleagues.

The social isolation and loneliness of people with dementia are both discussed in this report. The reasons why people with dementia have few social contacts are considered, along with the reasons why people with dementia can feel lonely.

Policy background

All nations in the UK now have a dementia strategy that aims to improve the quality of life of people with dementia. Progress is still needed to achieve the ambitions in these strategies. Nevertheless, Alzheimer's Society particularly welcomes recent measures in England, Wales and Northern Ireland to overcome social isolation.

England

The Adult Social Care Outcomes Framework (ASCOF) for England for 2013/14 (Department of Health, 2012f) includes – for the first time – a measure of social isolation. The ASCOF is split into four domains, against which local authority performance will be measured. Domain 1 is 'Enhancing quality of life for people with care and support needs'. The third outcome measure which supports Domain 1 states that people should be able to maintain a family and social life, contribute to community life and avoid loneliness or isolation. This will be measured in five ways, including by the proportion of people who use services, as well as their carers, who have as much social contact as they like. This outcome is shared with the Public Health Outcomes Framework.

In the ASCOF for 2013/14, the quality of life measure does not isolate the impact that care and support services have on these outcomes. Research has been commissioned to identify a way of generating a social care-related quality of life 'value added' measure. This would allow the impact of social care on people's quality of life to be identified.

The ASCOF for 2013/14 reflects the priorities for care and support in the White Paper published in July 2012. The Care and Support White Paper includes the promotion of integrated care and support and the need to tackle loneliness and social isolation.

The Care and Support White Paper reinforces the government's commitment to making dementia a priority in the Prime Minister's dementia challenge. The challenge states ambitions to go further and faster in driving improvements to health and care for people with dementia, building on progress made through the National Dementia Strategy for England. As a result, the 2013/14 ASCOF includes a placeholder measure on dementia. The placeholder indicates that the Department of Health intends to develop a measure on the effectiveness of post-diagnostic care and improvements in quality of life for people with dementia. This placeholder is shared with the NHS Outcomes Framework.

The White Paper includes plans for encouraging communities to reach out to those at risk of isolation.

This will be done in many different ways, including:

- Involving communities in decisions around health and care services through Local Healthwatch and health and well-being boards.
- Developing time banks to help people share their time and skills with others in their community.
- Establishing a £200 million care and support housing fund, which will support development of specialised housing for older and disabled people.

Wales

The Welsh Government published a National dementia vision for Wales in 2011. The long-term ambition is to create dementia-supportive communities where people with dementia – and those who care for them – are treated with the dignity and respect they deserve, and receive the help and support they need. The priorities are to develop closely integrated services, comprehensive programmes of care, and greater awareness and understanding of the needs of people with dementia.

Prior to its Dementia Vision, in 2003 the Welsh Government published its Strategy for older people. Phases one and two of the strategy, running from 2003 to 2013, focused on four strategic themes. One of these was promoting social inclusion for people over 50. The strategy recognises the importance of social inclusion to maintaining quality of life and well-being.

It includes policies for achieving social inclusion, which comprise:

- Creating a positive image of people over the age of 50.
- Producing guidance on meaningful and effective participation for older people.
- Improving access to public transport.
- Ensuring accessibility for all in the early design stages of new houses and town planning.

Social inclusion remains a key theme in the third phase of the Strategy for Older People for 2013–2023. The final strategy will be published at a later date.

Coming from this strategy is Sustainable social services for Wales: A framework for action (Welsh Assembly Government, 2011b) which sets out the priorities for action for the future of social services and social care in Wales. The framework recognises that low-level support services (such as gardening clubs, dial-a-ride or befriending) are vital, and reduce the need for more intrusive and costly solutions.

Northern Ireland

Improving dementia services in Northern Ireland: a regional strategy was published in 2011. The strategy aims to overcome social exclusion through supported housing schemes. These schemes reduce the stigma often associated with dementia by building partnerships with families, maintaining links with the local community, and fostering a more positive public perception of dementia.

In addition, there are conversations around the future of adult care and support. The discussion document, *Who cares?* (DHSSPS, 2012), recognises the importance of community support in enabling older people to remain independent. While this is still in the discussion stage, Alzheimer's Society supports the plan to build communities where everybody has a place and people look out for each other, and where accessible community transport is promoted to help overcome social isolation. Further, Alzheimer's Society believes there is a need to raise awareness of social care in Northern Ireland. At present, few people realise they may need support services at some point in the future.

Scale of loneliness among older people in the UK

34% of people who responded to a YouGov poll for this report said they had felt lonely in the last month. Among people over 55, 24% said that had felt lonely in the last month.

It is estimated that about 10% of the general population aged 65+ in the UK is lonely all or most of the time (Victor, 2011). According to research (Victor 2003), 17% of older people are in contact with family, friends and neighbours less than once a week – and 11% are in contact less than once a month. Research from Age UK (2013) has found that 12% of older people say they feel trapped in their own home, and 9% feel cut off from society. The same research found that 6% of older people leave their house once a week or less.

Loneliness and dementia

38% of people who responded to the survey said they feel lonely. 62% said they never felt lonely (50%) or they didn't know (12%).

Comparing the survey for this report with the YouGov public poll, it seems that people with dementia tend to be more lonely than the population as a whole. Among the oldest age group in the public poll – those over 55 – nearly a quarter (24%) said that had felt lonely in the last month. While most people with dementia are in much older age groups, this figure is the closest we can compare to people with dementia – of whom nearly 40% said they feel lonely. The nature of dementia can be a factor in determining loneliness. But there are other factors, which are applicable to many older people in general. More detail on the effects of dementia on social isolation and loneliness are considered later in this report. The impact of factors which affect older people in general are also discussed. All of them contribute to how well people live with dementia.

Loneliness is a difficulty for many people with dementia. In Dementia 2012, more than half (55%) of people with dementia reported feeling lonely some of the time. The survey results in this year's report provided a snapshot of people who were relatively well-connected; but a sizable proportion of people with dementia who responded to the survey still reported feeling lonely. It is also important to note that the respondents to the survey were all known to Alzheimer's Society, and were accessed through services. So it is likely to show a sample of better supported people with dementia, rather than a truly representative sample. Alzheimer's Society recognises that it is very difficult to gain views from people who are totally isolated, precisely because they may have very few social contacts and receive no support from services.

The risks of social isolation and loneliness are more profound in people with dementia. Studies have highlighted several personal characteristics which influence whether a person is lonely or not – many of which are common among people with dementia. Living alone (de Jong Gierveld et al, 2011) or living in residential care (The Residents and Relatives Association, 2010) are factors which are associated with loneliness. Poor health (Victor C et al, 2005), reduced mobility (Tijhuis MAR et al, 1999) and cognitive impairment (Victor C et al, 2005) all increase in line with an older person's chances of being lonely.

There is evidence which suggests that the risk of Alzheimer's disease more than doubles in older people experiencing loneliness (Wilson et al, 2007). However, this research concluded that while loneliness is associated with an increased risk of dementia in later life, it is not one of the leading causes. By contrast, another recent study (Holwerda et al, 2012) stated that the link between loneliness and dementia is tentative. This research suggested that loneliness could be considered a consequence of the deteriorating social skills that are part of the personality change as dementia progresses. Although this study could offer an explanation of why some people with dementia lose friends, Alzheimer's Society believes that a lot more research is needed in this area.

Evidence in the survey for Dementia 2013 suggests that the nature of dementia compounds loneliness, rather than loneliness being a cause of dementia. However, the report found a different reason to explain loneliness among people with dementia. Family members of people living with dementia, as well as dementia support workers with whom Alzheimer's Society had contact for this research, reported that people with dementia may have lots of visitors, but they do not remember that somebody has been to see them. As a result, they do not perceive the social contact and feel more lonely. Befriending managers and dementia support workers involved in this project explained that some people with dementia living alone have a whiteboard in their home where visitors can record that they have been. This provides an aide memoir to the person with dementia.

Social contact and dementia

Face-to-face contact

Nearly two-thirds (63%) of people with dementia who responded to the survey said they spoke to family or friends face-to-face every day. Nearly a quarter (24%) said they spoke to family or friends once a week. 13% said they spoke to family or friends face-to-face once a fortnight (2%), once a month (4%), less than once a month (5%) or that they did not know (2%).

More than one in 10 people said they spoke to friends or family face-to-face less than once a fortnight, or that they did not know how often they spoke with friends and family. Face-to-face contact is important for people with dementia: these conversations will contain visual and other sensory clues for the person. Such elements are an essential part of communication, particularly as dementia progresses.

People with dementia interviewed for this research did describe how they enjoyed visiting their family or friends for dinner or Sunday lunch. These occasions provide important social contact. For those who have family nearby, it is reassuring to know there is somebody who can check up on them regularly.

Case study: F

F lives alone, but near to his daughter. He uses a taxi card provided by his local council to visit his daughter every Sunday for lunch. His daughter calls him on the telephone every day, but when he goes round for Sunday lunch, he also sees his two grown-up grandsons. They enjoy having fun and sharing a joke together. As F lives alone, this is a weekly event that he can really look forward to.

As this case study shows, people with dementia like to have regular face-to-face contact with family or friends. In fact, dementia support workers involved in this research said the person with dementia they care for enjoyed being involved in this report, because they had somebody to talk to for an hour or so about their experiences of living with their condition. Alzheimer's Society strongly believes that face-to-face contact is a means of overcoming loneliness. Evidence from befriending services supports this fact.

Case study:

A befriending service

In September 2011, a befriending service was set up in Merseyside, West Lancashire and North and West Cheshire, in partnership with BBC Radio Merseyside. The service focuses on befriending people living with dementia at all stages in their journey. The service is free at point of use, with volunteer befrienders trained and supported by Alzheimer's Society. The number of referrals to the service has always far exceeded the number of volunteers, so the service has prioritised finding volunteer befrienders for people living alone. Two of the people living alone who currently have befriending visits have no next of kin.

Three people living alone have been enjoying regular visits from volunteer befrienders for over a year now. These visits have had a positive effect on their general well-being and self-esteem, and have eased their sense of isolation. One person noted how his mother, whose short-term memory is severely affected, is generally much more cheerful than she used to be. Volunteer befrienders also notice changes: a willingness to initiate conversation; laughter; offers to make cups of tea; new memories and new conversation points. One woman with dementia who lives alone rarely leaves her home now, but has had a befriender visiting her for about five months. She said how it's really good that people give up their time, it's lovely having someone to chat to, and that she and her befriender always have a good laugh. She thinks her befriender gets a lot out of the relationship, and that she's doing her volunteer a favour by being her friend, because everyone can get lonely. Another person living alone with dementia said how befriending is important because it enables 'someone just to acknowledge you as a human being'.

Telephone contact

25% of people with dementia who responded to the survey said they spoke to friends or family on the telephone every day. 38% said they spoke to friends or family on the telephone once a week (29%) or once a fortnight (9%). However, a third (33%) said they spoke to friends or family on the telephone less than once a month (21%), or that they did not know how often they spoke to friends and family on the telephone (12%).

The telephone is an important method of social contact. But it is one that can be difficult to maintain, particularly for someone in the later stages of dementia. The one-third (33%) of respondents who spoke to family or friends on the telephone less than once a month, or said they didn't know how often they did so, were often assisted in filling in the questionnaire. Alternatively someone completed the questionnaire on their behalf. In both cases it was indicated that speaking on the telephone was no longer possible for the person, or that they no longer owned a phone. Several respondents said the person with dementia they care for has difficulty with communication or following conversations, which would make using the telephone very hard. Nevertheless, when asked what can make you feel less lonely, some respondents said they do call people on the telephone.

Alzheimer's Society recognises that the telephone can be used by many people with dementia to overcome loneliness. However, the telephone should not be used as a replacement for face-to-face contact, for the reasons already discussed.

Electronic contact

87% of respondents to the survey did not use electronic communication or social networks to connect with people. 12% said that they did and 6% said that they did not know.

The survey asked whether people with dementia use electronic communication to maintain contact with friends and family. This is an increasingly important part of maintaining social contact between younger people, particularly across geographical distances. The Office of National Statistics reports that age has a sizeable effect on whether someone has ever used the internet. Whereas nearly all adults aged 16 to 24 years (99%) have used the internet, less than a third (30%) of those aged over 75 have done so (Office of National Statistics, 2012b). That means 3.24 million people over 75 years have never used the internet. As dementia affects predominantly an older age group, it is likely that connection with others via the internet will play a very small part in their lives. This may cause increased isolation from distant family and friends if those people routinely use electronic communication. It could also lead to isolation from information and services if they are provided as 'digital by default' (Cabinet Office, 2012). As anticipated, nearly nine-tenths (87%) of people with dementia did not use electronic communication to connect with friends and family. This figure is also likely to be inflated due to the questionnaire being available online as well as in paper format, and being promoted through the 'Living with dementia' section of the Talking Point forum. It was therefore easily accessible by the most active online community of people with dementia.

One person who responded to the survey said they never felt lonely. However, as the statistics show, this is an exceptional case rather than the norm. There is a danger that the government policy of ‘digital by default’ could exclude many people with dementia from participating fully in their communities. Alzheimer’s Society therefore recommends that information and services should be available not just electronically, but in a format accessible to people with dementia, according to the preferences of the individual. Families and friends should also remember to include people with dementia when sharing news or photographs, remembering that the person with dementia may not be able to access these electronically.

Neighbours

19% of people with dementia who responded to our survey said that they spoke to their neighbours less than once a month.

While it may be possible to keep in touch with friends and family via the telephone, relationships with neighbours are also important. Evidence suggests, however, that people with dementia do not have meaningful relationships with their neighbours. Some people we interviewed said they knew their neighbours by face, but said the conversation never develops beyond a friendly greeting. The reasons for this are manifold. Several people with dementia involved in the research explained that friendly neighbours had moved away, and one said her neighbours did not need to know she had dementia.

Well over a third (39%) of people who responded to the questionnaire said they spoke with their neighbours every day. However, a sizeable minority (19%) said they spoke to their neighbours less than once a month. This is concerning: while society may be moving away from close relationships with neighbours as a point of necessity, these relationships can be an important point of social contact for people with dementia.

The YouGov public survey for this report found that 35% of people would not feel comfortable having a conversation with a person with dementia (16%) or do not know if they would feel comfortable talking to somebody with dementia (19%).

At a focus group held at an Alzheimer’s Society dementia café, a wife of a person with dementia explained that neighbours often talk to her about her husband, rather than addressing him directly. The YouGov poll highlighted that the general public are not sure they could have a conversation with a person with dementia. Nearly a fifth of respondents (19%) to the YouGov poll said they do not know if they would feel comfortable talking to a person with dementia. This highlights the need to raise awareness of dementia, and to promote understanding of the condition so that people can feel confident talking to their neighbours with dementia. Awareness-raising initiatives, such as the Dementia Friends project, go some way to achieving this aim.

Activities and engagement

Nearly 50% of people with dementia only go out to do things in their local area once a week or less.

The YouGov survey for this report found that 40% of people think it is true that all people with dementia can take part in all activities they want to or enjoy.

There are factors specific to dementia that increase the likelihood of people with the condition having to stop doing things they used to enjoy. This can increase social isolation and loneliness. For example, from people with dementia who responded to the survey, more than two-thirds (70%) have stopped doing things they used to, due to a lack of confidence. (This figure is marginally higher among people with dementia who live alone.) Diminished confidence can lead to a loss of independence, as people with dementia may feel concerned about what could happen if they leave their home, or reactions from other people. They may feel they can no longer go out or take part in activities. This, in turn, leads to social isolation and loneliness. One woman interviewed for this research explained that she does not go out much because she does not like going out alone, and is afraid of the outside world. Research from the WRVS (2012a) found that once an older person loses their confidence, it is very difficult to regain. Alzheimer's Society believes it is important for people with dementia to retain their confidence, or have support that can help them rebuild it.

Losing confidence can be as a direct result of other attributes related to dementia. For example, more than two-thirds (68%) of all people with dementia have stopped doing things they used to do because they worry about becoming confused, and 60% worry about getting lost. Among the people with dementia that were interviewed, those who live in urban areas were more likely to worry about becoming confused or getting lost, especially when using public transport. Meanwhile, the public perception is that people with dementia cannot do everything they would like to do. In the YouGov public poll, less than half the respondents believed that all people with dementia can take part in activities they want to or enjoy.

70% of people with dementia have stopped doing things they used to due to a lack of confidence. 68% worry about becoming confused, and 60% worry about getting lost.

The YouGov poll of public opinion found that 51% of people think that people with dementia are hindered from participating more fully in the community because their symptoms keep them restricted to their own homes.

However, people with dementia may also have other difficulties related to age which prevent them from doing things they used to. For example, almost 60% of all people living with dementia have stopped doing things that they used because of mobility difficulties. Among people who live alone, this figure is just above 60%. People with dementia interviewed also said that physical impairments now prevented them from going out as much as they used to. For example, one person said she had been a keen tennis and cricket player, but her bad shoulder now means that she cannot play sports. Remaining active is important to maintaining a healthy lifestyle and preventing the development or progress of other age-related conditions.

Almost 60% of all people living with dementia have stopped doing things that they used to as a result of mobility difficulties.

In addition, several of the people with dementia interviewed said they have stopped doing things they used to because they have nobody to go with. One person said he would like to watch live football. Another said she misses watching cricket. Both these people said they would like to go and watch live sport if they had a companion.

Case study: R

R is in his late 50s. He is physically fit and enjoys walking and cycling, but he is unable to do these activities by himself because his dementia means that he gets easily lost and confused. He would like to go out for regular walks with people of a similar age, but he is reliant on staff and volunteers from Alzheimer's Society to take him out when it's possible.

Moreover, the survey results show that nearly one in five people with dementia find there is nothing available that they enjoy. Dementia support workers and befriending managers said this is particularly the case for younger people with dementia, who may still be physically able to enjoy getting out and about, but lack the confidence to do so. Indeed, anecdotes from people with early-onset dementia show that younger people do not want to join the same groups as people with dementia in their seventies or eighties.

53% of respondents to the YouGov poll thought that a lack of appropriate activities for people with dementia is a barrier to them participating more fully in their community.

In fact, respondents to the YouGov survey identified a lack of appropriate activities for people with dementia as a barrier to them participating more fully in their community. More than half (53%) of people believed this to be the case. The importance of personalisation is discussed later in this report.

Overcoming loneliness

This report has established that people with dementia are more likely to be lonely. As part of this research, Alzheimer's Society wanted to learn what people with dementia do, or would like to happen, to overcome their loneliness. When asked what would make them feel less lonely, respondents to the survey who live alone said that having somebody to talk to, receiving visitors, or being able to attend clubs or day centres, would help to alleviate loneliness. One person with dementia interviewed for the research said he does not have anybody to talk to unless he goes to the local Alzheimer's Society dementia café. In the survey, people with dementia were asked what things might help them feel less lonely. More than half of them (53%) mentioned face-to-face contact. This ranged from more contact with family and friends, to more services. One respondent commented:

'It's smashing coming to the gentlemen's Peer Support Group... I really enjoy talking to the other men. More contact with other human beings makes me feel less lonely.'

A toolkit from the Campaign to End Loneliness has identified a variety of services which help to reduce loneliness. These include befriending services, day centres, social clubs, community arts and crafts activities, walking groups and volunteering opportunities.

One person who responded to the survey provided a poignant answer to overcoming loneliness:

'Less stigma attached to dementia diagnosis so people don't feel scared to come and visit me.'

Nearly a quarter (24%) also mentioned getting out of the house more. The survey showed that people with dementia would appreciate spending time with like-minded people. As one respondent said:

'More contact with people outside of my home environment who have similar thoughts and discussions.'

These points reiterate Alzheimer's Society's concerns over a lack of opportunities for people with dementia to have social contact. For this reason, the Society recommends that local authorities commission appropriate services for people with dementia to ensure they are not socially isolated or lonely. However, there is also a need to promote an understanding of dementia and to help reduce stigma still associated with the condition.

People with dementia living alone

So far this report has concentrated on loneliness among people with dementia in general. Although a person living alone is not necessarily lonely, research shows that those who do live alone are more likely to be lonely (de Jong Gierveld et al, 2011). The YouGov public poll showed that more than half (52%) of the respondents who live alone said they felt lonely in the last month. This is compared with a third (34%) of all people who completed the YouGov survey. Alzheimer's Society therefore wanted to investigate whether people with dementia who live alone are even more likely to be lonely. Alzheimer's Society interviewed people with dementia to uncover the personal experiences behind this evidence. Again, it is important to note that the people interviewed have contact with Alzheimer's Society and are therefore not totally isolated. If it were possible to reach people who have no social contacts or access to any services, the stories could reveal a bleaker picture of loneliness and social isolation among people with dementia.

Loneliness and living alone among older people

In 2010, nearly half (49%) of people over 75 in the UK lived alone (Office for National Statistics, 2010). The Department for Communities and Local Government (2010) has predicted that between 2008 and 2033 there will be a 44% increase in the number of 65–74 year olds living alone. For those aged 75–85 there will be a 38% increase, and a 145% increase in those aged over 84. Given that dementia is most common in older people (Alzheimer's Society, 2012a), there is a high probability that many people with dementia currently live alone – and this number will increase in the future.

Loss of social contacts for people with dementia living alone

23% of people who responded to a YouGov poll think that it is possible for people with dementia to live alone.

Results from the survey found that over a third of people with dementia do feel lonely. However, for people with dementia who live alone, this figure rises to nearly two-thirds. This evidence is corroborated by the interviews with people with dementia living alone. All seven people interviewed described feeling lonely, although all of them said they try not to think about being lonely, try to carry on as normal, and find activities to keep them occupied. In contrast, less than a quarter of people (23%) who responded to the YouGov survey think it is possible for people with dementia to live alone. This could be due to a lack of understanding of dementia.

62% of people with dementia living alone who responded to the survey said they feel lonely. 38% of all people with dementia said they felt lonely.

People with dementia who live alone are more likely to be lonely. They are more socially isolated with less social contact, as they do not live with anybody to interact with. Furthermore, a key determining factor for increased social isolation among people with dementia who live alone is a loss of friends. Nearly a third of people with dementia living alone reported losing friends after a diagnosis of dementia, or that they have not told

their friends about their diagnosis. This figure is higher among people who do not live alone (at nearly 40%). But for people who live alone, the impact of losing friends is more profound. As the figures above suggest, people who live alone are almost twice as likely to be lonely as those who do not live alone.

Among people who live alone who responded to the survey, 49% said they have lost friends (18%), they haven't told their friends (14%) or they didn't know if they had lost friends (17%).

People with dementia interviewed for the research gave various reasons for losing friends. For example, some had lived in the same house or area for a long time. Often friends and neighbours had moved away as they had got older – to be nearer their children, or to move into sheltered accommodation or a care home. For some people with dementia, moving out of the area where they have lived for many years is unthinkable because they do not want to go to an unfamiliar place. This is directly related to dementia: the nature of the condition means that people can become confused in new environments.

For other people, the stigma surrounding dementia has led to a loss of friendships or has made it very difficult to form new ones. As one person interviewed explained:

'I wouldn't talk to people about having dementia. People have a thing about people with dementia. They think you are completely gaga.'

However, when asked if he would like to have more visitors, one person with dementia was stoical in his response:

'Yes, that would be nice, but at the same time people have their own lives to lead and I'm very much aware of that... I don't expect people to come and see me in the week, but it's different over the weekend.'

This perspective is confirmed by people who responded to the survey. Half of people living alone said they do not want to be a burden, and had stopped doing things they used to do because of these feelings.

In the survey, nearly 60% of respondents who live alone reported feeling anxious or depressed. (For people not living alone, this was just above 60%.) This survey of course does not tell us why people are anxious or depressed. But nevertheless, several of the people interviewed expressed their concerns about feeling unsafe in the house alone and being lonely. One person admitted that he does take medication for depression, and that his anxieties cause other health issues. In particular, the women who live alone who were interviewed for this research described feeling anxious about going out alone.

It is also important to note that not all people who are socially isolated are lonely. There are people who enjoy being by themselves and do not seek the company of others. So it is necessary to distinguish between a person's personality and the symptoms of their dementia. Above all, services for people with dementia must fit around individuals, recognising that not all people will want to join clubs and spend time talking within a group. Some people may prefer a walk outside with one or two other people. Alzheimer's Society is supportive of a social care system based on personalisation, and recommends that people with dementia are fully involved in planning their care. Personal budgets and direct payments, however, must not be seen as a solution to issues in the social care system. Any system based on personalisation must be adapted to meet the particular needs of people with dementia.

Case study: R

R is a younger person with dementia who lives alone in a rural community. He describes himself as a free spirit. He has a friendly neighbour, an older woman; he helps her and she looks out for him. He chats to staff in the local shop and a carer visits once a day. Living in rural area, he is reliant on other people to take him out – but this is only about once a week. He says he occasionally feels lonely and describes living alone as strange, but most of the time he enjoys his own company. He always has the radio on in the house and enjoys pottering around in his own space, doing things in his own time.

This research shows that people with dementia who live alone are both socially isolated and lonely. Many people with dementia who live alone have few social connections. In fact, most of the social contact that people who live alone have is with members of their family, carers or Alzheimer's Society staff. Few people living alone with dementia have meaningful friendships outside of their own family, which reinforces the feelings of loneliness. Research has suggested that loneliness can lead to early death (Holt-Lunstadt et al, 2010). The Holt-Lunstadt research found that loneliness is just as likely to increase the risk of mortality as smoking and alcohol consumption. Medical research has linked loneliness to heart disease and depression. Further health problems can add to the worries of a person with dementia, particularly if they live alone and are not able to share their concerns with another person they trust. In fact, one person with dementia who lives alone who was interviewed for the research explained that he has time to worry about having dementia, and that this has caused other health problems.

This reinforces Alzheimer's Society's belief that people with dementia who live alone need access to services which allow them to build trusted relationships and maintain social contacts. And that they need access to health services which encourage them to maintain an active and healthy lifestyle.

Support networks

Friends and family

59% of people with dementia living alone speak to friends or family in person every day. 46% of people with dementia living alone speak to family or friends on the telephone every day.

For many people with dementia who live alone, support from family and friends is vital. Well over half (59%) of people living alone who answered the survey said they speak to family or friends face-to-face every day. This is compared to nearly two-thirds (63%) of people with dementia who live in their own home, but not alone. It would be expected that all people who live with another person would speak to somebody else every day (in other words, they would speak to the person they live with on a daily basis). Although the survey does not reveal with whom the respondents are speaking, it is possible that the respondents have excluded the family member or carer they live with from their answer. Similarly the percentage of people living alone who speak to a friend or family member every day could be perceived as quite high. Again, it is impossible to know from the survey who the respondents are talking to on a daily basis. It could be that formal carers have been included. Equally, some of the people interviewed said they may greet an acquaintance, but not develop the conversation any further than this.

For some people with dementia, their friends or family live too far away to be able to visit regularly. For people living alone who may not have daily face-to-face contact with family or friends, the telephone is an important tool for maintaining social contact. Nearly half (46%) of people with dementia surveyed who live alone speak to friends or family on the telephone at least once a day. (This is compared to a quarter of all people with dementia.) Most interviewees described how they looked forward to a daily phone call from a friend or relative because it helped alleviate boredom and feelings of loneliness. One Alzheimer's Society befriending manager described a person with dementia in her care who often felt very lonely. She would call the Samaritans or the emergency services simply so that she could have somebody to talk to.

Case study: M

M lives by herself in a small town. She has twin sons, but one lives over 100 miles away and the other lives abroad. She has regular contact with her son abroad over the telephone. Despite living thousands of miles away, he takes responsibility for the care of his mother. After one visit to M, he decided she needed extra support and contacted the local Alzheimer's Society. M is now in contact with a dementia support worker, with whom the son also keeps in regular contact. He also takes responsibility for her financial affairs, although M has on occasions got into difficulties when her son has been away for work and not around to help.

Although the telephone is useful for keeping in touch, it is still not a substitute for face-to-face contact. All the people with dementia interviewed who lived far away from family reported often feeling lonely and missing having people to talk to. This is confirmed by recent evidence from the WRVS. The research found that older people who see their children once a month or less are twice as likely to feel lonely (WRVS, 2012b).

As this evidence and case study confirm, it is important that family maintain contact with a relative with dementia. Alzheimer's Society wants to encourage more distant relatives, such as grandchildren, nieces and nephews, to visit their family members with dementia – especially if other relatives live at a greater distance. Where this is not possible, local authorities should offer befriending services to reach out to those people with dementia who are truly isolated.

Neighbours

In the YouGov public poll for this report, 29% of people didn't think there were any barriers to having a conversation with people with dementia. 28% of people identified time as a barrier; 25% of people identified uncertainty about how the person would react; 21% identified concern that the person would get confused and not follow the conversation.

Furthermore, evidence from interviews found that neighbours may be unwilling to provide much active support to a person with dementia who lives alone. Given that people with dementia may be worried about dealing with difficult problems or emergency situations when family and friends live at a distance, this lack of neighbourly support could intensify feelings of isolation. There is a sense of fear among some people with dementia who live alone about what would happen in an emergency. One person interviewed explained that he is afraid of dying and nobody finding him for days or even weeks. As another person involved in the research said:

'I could lie on the floor and scream all day and all night and nobody would come because I don't know anybody.'

This reinforces the need for people to have the confidence to assist and talk to their neighbours with dementia.

Case study: P

P lives by himself in an urban area. He has a partner who lives over an hour away by public transport. They speak to each other every day on the telephone and P says he really looks forward to the calls. Sadly, one day P had a stroke while at home. He was unable to move for 45 minutes to get to the telephone and call an ambulance. When he could, he reached the telephone and called his partner who alerted the emergency services. P was very frightened by the experience and his neighbour now holds a key in case any similar incident should occur. However, the neighbour is reluctant to have any more responsibility than this.

Pets

The importance of pets as companions for people with dementia should not be underestimated. Although many may feel people with dementia could struggle to look after a pet properly, the pet owners involved in this research saw their pets as a companion. Pets also provide the person with dementia with a purpose. For example, dogs will always need walking, and all animals need to be fed. One woman living alone, when asked how she spends her day, explained that looking after the cats can take up a lot of her time. Another person described her cat as her best friend. Several respondents to the survey said that their pet helps them to overcome feelings of loneliness. As one person said:

‘My puppy helps me feel less lonely.’

Nevertheless, pets cannot offer the practical support that many people with dementia depend on.

Other support and coping mechanisms

Without a network of friends or family in their immediate area, people with dementia living alone are more reliant on support in other ways. This support is vital for all people with dementia, but especially so for people with dementia who live by themselves. The nature of dementia means that some people have difficulties with aspects of day-to-day life, such as personal care, planning and preparing meals, getting out to the shops, or attending medical appointments. For example, one person with dementia described that he had gone out on occasions and left the gas cooker on.

A wife, and carer, of one man with dementia said in a focus group discussion that often carers cover up for the problems that the person with dementia has carrying out every day tasks. So for those people with dementia who live alone, coping mechanisms and support from formal and informal carers are of utmost importance, to ensure that they can carry out essential daily activities.

For those people with dementia who live alone, there are other coping mechanisms to ensure they can remain independent and safe in their own home. Several people interviewed for the research had notes left in strategic positions around the home, reminding the person with dementia to turn off the cooker, take keys before going out, and to take medication. One person with dementia also kept a diary of what he had done during the day because he forgets what has happened. Other people use assistive technology, such as devices which shut off gas or electricity supplies automatically.

The majority of the people with dementia interviewed explained that they have support from a formal carer. The level of this support is variable according to the needs of the person. Some people have chosen to find their own care to help them feel prepared for the future; whereas others have reached a stage in their condition where support from a formal carer is a necessity. The carers support the people involved in this research with daily essential activities, such as getting washed and dressed, going food shopping, taking medication and reminding them to eat. Most of the people involved in the research have one carer a day, usually in the morning. One person had a carer three times

a day. One younger person with dementia lives in a village with little public transport. He explained that his carer takes him out shopping once a week. This person can look after himself and enjoys cooking, but without support he is not able to get to the shops and buy the food to cook.

Case study: A

A lives by himself in a city. He is finding it increasingly hard to look after himself. He does not really like the nearby supermarket, but his favourite food store is difficult for him to reach alone. He sometimes forgets to go shopping, and when he feels hungry in the evening he opens the fridge to find it empty – so he resorts to having some toast for dinner. He has a carer who comes in the mornings to remind him to take his medication and eat breakfast.

This makes it clear that people with dementia rely on other people for support, from both formal and informal carers. This support is necessary to help them with everyday activities, such as making breakfast, taking medication, housework and going shopping. Nevertheless, people with dementia do not always receive support to do other things they may want to do, like going to the theatre or visiting a social club. It is essential that people with dementia are offered support to live a fulfilling life, rather than merely existing.

Lack of support

A lack of support can prevent people with dementia from taking part in activities they enjoy. Many people with dementia who live alone said they have stopped doing things they used to enjoy. One quarter (24%) of all people with dementia who responded to the survey said they have stopped doing things because of a lack of support from services. This is higher among the people who live alone: more than a third (36%) said they have stopped doing things they used to for this reason.

Because of their condition, a lack of support from services can have a more profound impact on people living alone with dementia than on people with dementia who do not live alone. In addition, people with dementia living alone find it harder to access information about services and to obtain support. They may not have guidance from another person to help them through these processes. The people living alone with dementia involved in this research, who were also in receipt of support, had family members who helped them arrange care from Alzheimer's Society, their local authority, or privately.

As well as a lack of support, lack of confidence is an issue. Over two-thirds (71%) of people living alone reported in the survey that they have had to stop doing some things due to a lack of confidence. (Although, this figure is similar among all people living with dementia who responded to the survey.) This is an issue particular to people with dementia. People living alone interviewed confirmed this sentiment, but also provided more insight into the reason why they do not do the activities they used to as a direct

result of having dementia. Two of the people interviewed explained that because they live alone, they do not have anybody to prompt or encourage them to go out and be active. One person, who used to go swimming regularly, said:

‘Anything which needs initiative is now out of bounds. I used to do it a lot and I loved doing it. I used to go in the morning and have a swim but now I don’t do it.’

Another respondent to the survey said:

‘I can do things when I don’t forget. Need people to help organise.’

57% of the public polled by YouGov thought that a lack of formal or informal support from others to carry out the activity they want to was a barrier to people with dementia participating more fully in their community.

The public perception is that people with dementia lack support to do the things that they want to. The YouGov survey showed more than half (57%) of the public thought a lack of formal or informal support from others to carry out the activity they want to prevented people with dementia participating more fully in their community.

Case study: M

M described that she used to go to a group which she thoroughly enjoyed because it allowed her to talk with other people about a whole variety of issues. But she missed one session, got out of the habit of going, and then felt too much time had passed. She lacked the confidence to return. Following the interview with M, the dementia support worker with whom she has contact offered to reintroduce her to the group. M was very happy with this arrangement and felt as though she had something to look forward to again.

Lack of activities

A consequence of having dementia is that some people have to stop taking part in activities they used to enjoy. Some people may also lack the motivation to go out and do things. As a result, many people with dementia will stay at home to do things around the house, or go out for a walk alone, but few take part in activities or initiate contact with other people. One man said:

‘I walk into town and sit outside Marks and Spencer and watch the world go by.’

Case study: F

F lives in sheltered accommodation. He hates sitting in all day staring at the walls, so he goes for a walk into town every day. He says there is no point in looking at the clock – he has no need to know the time because he has nothing to do. He feels sad about this and often finds that the days just drag on.

Nevertheless, people interviewed also cited diverse interests, from carpentry to playing the guitar. The interviewees with these skills said they would like to share their interests with other people, but were unsure how to find people with similar hobbies. Of course, the nature of dementia means that people may find it increasingly difficult to do the things they enjoy. For example, one person interviewed for the research has an English literature degree and has always loved reading. But now he reads less because he has difficulties concentrating, and it takes him longer to grasp what he is reading.

Many people with dementia said they would like to be more active and involved in their community. In the survey, respondents who live alone offered a variety of activities they would like to be able to do in their area:

‘Going on shopping trips with someone, going to the cinema, out for a meal.’

‘Visiting the library and attending the church.’

The Campaign to End Loneliness has examined the role of the arts in tackling loneliness in older age. It found examples of many projects, such as touring theatre companies, poetry and creative arts. The Mental Health Foundation (2011) came to the conclusion that ‘participatory art can improve the wellbeing of older people and mediate against the negative effects of becoming older.’

Case study:**House of Memories, National Museums of Liverpool**

The House of Memories is a co-ordinated project with the National Museums of Liverpool and AFTA Thought, a training provider. Centred on the objects, archives and stories at the Museum of Liverpool, the House of Memories supports staff in home and residential settings to care for people living with dementia, including the use of the museum's collections and resources.

The value of being part of a community also cannot be disregarded. It is especially important to recognise that people with dementia can make a valuable contribution to the community. Likewise, communities can play a role in supporting people with dementia to remain independent in their own homes. Minister for Care Services, Norman Lamb MP, made his position clear in January 2013 when he said local councils need to build a resilience to prevent older people becoming lonely and isolated. Everybody has a part to play in supporting older people to live at home, he said, adding that this can ensure the social care system is sustainable. Action is now needed to make this a reality.

Nevertheless, barriers remain which prevent people with dementia from being able to do the things that they want to do. A lack of motivation and a lack of confidence have already been discussed. But there are also external factors which have an impact on the lives of people with dementia. In the survey there was an overwhelming feeling among people with dementia who live alone that a lack of transport prevents them from getting out and taking part in activities. One respondent explained that there are clubs and opportunities to socialise, but no way to travel to them. In fact, 92% of respondents who live alone said they rely on friends and family to take them out. From all the people with dementia who responded to the survey, almost the same percentage (88%) said they rely on family and friends for transport. Clearly transport is an issue for all people with dementia, and not just those who live alone. Although, for those living alone who are already isolated, this lack of transport can compound feelings of isolation.

88% of all people with dementia surveyed rely on family or friends for transport. Among people with dementia living alone this rose to 92%.

Alzheimer's Society strongly believes that local authorities have a responsibility to ensure that people with dementia can access appropriate activities. As has been shown, without the right support people with dementia lose motivation to be active in their community, and thus become more socially isolated and lonely.

4 Priorities for attention

While health and social care services play a role in improving the lives of people with dementia, momentum needs to be kept up to build communities that support people with dementia – communities where stigma is reduced and isolation can be tackled.

The findings of this report are based on an Alzheimer's Society survey completed by people living with dementia, a YouGov poll of the general public and publicly available statistics. Based on the findings of this report, the following areas should be a priority for governments, statutory bodies, local authorities, Alzheimer's Society and others. The priorities are discussed in context within the body of the report.

Improve health and care for people with dementia

- National governments in England, Wales and Northern Ireland must urgently take measures to address the underfunding of the social care system. Adequate resources must be made available to fund the social care system and secure its future.
 - National governments in England, Wales and Northern Ireland must also address the unfair system of charging for care, which leaves people with dementia facing disproportionately high care costs. A cap on care costs must benefit as many people as possible, rather than only a few.
 - National governments in England, Wales and Northern Ireland should take steps to ensure that regulators, such as the Care Quality Commission, monitor the quality of social care, including care in care homes. They should also ensure that people with dementia are treated with dignity and respect at all times.
 - National governments in England, Wales and Northern Ireland should ensure that there is continued momentum on the national dementia strategies. This must include appropriate funding to ensure that they can be implemented in a way that will make a difference to people with dementia.
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- In England, advantage should be taken of new clinical structures to embed dementia and the Prime Minister's Challenge. Areas where improvement could be made include:
 - As part of strategic clinical planning undertaken by Health and Wellbeing Boards, the public health, NHS and social care needs of an area should be assessed and services commissioned to meet these needs. This should have particular attention on preventing crises and enabling people with dementia to remain independent.
 - Acute trusts should sign up to the Dementia Action Alliance call to action on creating dementia-friendly hospitals.
 - Clinical Commissioning Groups and Academic Health Science Networks should each appoint a dementia lead.
 - Residential care providers should sign the Dementia Care and Support Compact.
 - In Wales, Local Health Boards should demonstrate their commitment to the Dementia Vision for Wales by:
 - Commissioning services with a focus on preventing crises and enabling people with dementia to remain independent.
 - Commissioning adequate memory assessment service provision to allow for a substantial increase for the number of people with dementia with a diagnosis in Wales.
 - In Northern Ireland:
 - Transforming Your Care, a review of health and social care in Northern Ireland, envisages a shift from acute care to providing care and support in a range of community settings, through Integrated Care Partnerships.
 - The Who Cares? consultation on the future of adult care and support in Northern Ireland is set to develop adult care and support services along those lines. Commissioning should follow these principles in order to improve quality of life for people with dementia and their carers.
 - Health and care services should be commissioned with a focus on preventing crises and enabling people with dementia to remain independent.
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Make choice and control a reality for people with dementia

- Commissioners and GPs should set out clear plans and maintain impetus behind initiatives to improve the diagnosis of dementia, particularly in areas where the diagnosis rate is low.
- Health and care services should encourage planning around future care with people with dementia and carers who have recently been diagnosed by providing post-diagnosis information packs and referring the person with dementia to a Dementia Adviser service.
- The Ministry of Justice in England and the Department for Health and Social Care in Wales should improve monitoring of the Mental Capacity Act. In Northern Ireland, formal mental capacity legislation should be introduced without delay.
- Services providing information should ensure that it is not just available digitally, but is accessible and useful to people with dementia, recognising the potential exclusion of a 'digital by default' policy.
- Healthwatch in England and other health consumer champions in Wales and Northern Ireland should publish clear plans to ensure the involvement of people with dementia and their carers.

Improve quality of life for people with dementia by reducing loneliness

- Local authorities and other commissioners should understand the needs of people with dementia in the context of living within the community, and work together to commission a wide range of services to ensure that they are not socially isolated or lonely. Examples include:
 - social groups, such as dementia cafés
 - services suitable for younger people with dementia, such as walking groups
 - befriending services that allow people with dementia living alone to have regular contact with a person they trust – who can also offer support with daily tasks such as shopping
 - accessible transport to allow people with dementia to attend social clubs or other services.
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- Dementia-friendly communities are an important vehicle for reducing social isolation and loneliness. Work undertaken has already begun to identify what it means to be dementia friendly; more now needs to be done to raise awareness of what it means and encourage businesses, organisations and communities to commit to becoming dementia friendly.
 - In England, the government and local authorities should commit to sustained support for the Dementia-friendly Communities strand of the Prime Minister's dementia challenge to ensure its various initiatives make a difference to the day-to-day lives of people with dementia.
 - The Welsh Government should sustain its commitment to implementation of the National Dementia Vision for Wales and create dementia-supportive communities through the Ageing Well in Wales programme, endorsed by the First Minister and delivered through collaboration between the Older People's Commissioner and Alzheimer's Society.
 - The Northern Ireland Assembly Executive should sustain its commitment to timely implementation of the Northern Ireland Dementia strategy, along with encouraging other public bodies to work with Alzheimer's Society to further develop the Dementia-friendly Communities programme.
 - The public, including friends and family members of people with dementia, should sign up to the Dementia Friends programme. This can give them the confidence to engage more fully with people they know with dementia and people they meet who they may suspect have cognitive difficulties.
 - The recognition process for Dementia-friendly Communities which is currently being developed should be adopted by businesses, organisations and communities in order to show their commitment to becoming dementia friendly.
 - Alzheimer's Society should lead in developing plans to ensure that the initiatives on dementia-friendly communities are maintained to ensure long term change.
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5 Conclusion

While some progress has been made, it is clearly taking time for policy initiatives to filter into the lives of people with dementia. The clearest example of this concerns diagnosis. Gradually more and more people with dementia are getting diagnosed, but half of all people with the condition are still denied what treatment and support is available to them.

It is therefore essential to maintain momentum behind the respective dementia strategies in England, Wales and Northern Ireland. And that communities, businesses, researchers and the health and care sector pull together in improving the lives of people with dementia.

Although Alzheimer's Society believes that communities should be more supportive of people with dementia, this should not be seen as a replacement for good quality social care services. Local authorities and healthcare commissioners must meet their obligations to ensure that people with dementia are able to remain independent in their community for as long as possible.

Current policies and plans in England, Wales and Northern Ireland have the potential to make positive steps in the direction of preventing social isolation and loneliness. However, there is still a need to provide suitable services and support for people with dementia, to raise public awareness that breaks down the stigma of dementia, and to encourage communities and neighbourhoods to support people with dementia in their local area.

6 References

ADASS (2012). Personal budgets survey March 2012. [online] Available at: www.thinklocalactpersonal.org.uk/_library/PersonalBudgets/PersonalBudgetsSurveyMarch2012.pdf [Accessed 4 January 2013].

Age UK (2013). Later life in the United Kingdom. [online] Available at: www.ageuk.org.uk/Documents/EN-GB/Factsheets/Later_Life_UK_factsheet.pdf?dtrk=true [Accessed 28 December 2012].

All-Party Parliamentary Group on Dementia (2012). Unlocking diagnosis. London: Alzheimer's Society.

Alzheimer's Society (2007). Dementia UK. London: Alzheimer's Society.

Alzheimer's Society (2008). Home from home. London: Alzheimer's Society.

Alzheimer's Society (2009). Counting the cost. London: Alzheimer's Society.

Alzheimer's Society (2010). My name is not dementia. London: Alzheimer's Society.

Alzheimer's Society (2011a). Support. Stay. Save. London: Alzheimer's Society.

Alzheimer's Society (2011b). Getting personal? London: Alzheimer's Society.

Alzheimer's Society (2012a). Dementia 2012: A national challenge. London: Alzheimer's Society.

Alzheimer's Society (2012b). My life until the end: dying well with dementia. London: Alzheimer's Society.

Alzheimer's Society (2013a). Mapping the dementia gap. London: Alzheimer's Society.

Alzheimer's Society (2013b). Low expectations. London: Alzheimer's Society.

Brayne, C, Gao, L, Dewey, M and Matthews, FE (2006). Dementia before death in ageing societies: The promise of prevention and the reality. *PLoS Med*3(10):e397.

Burholt, V (2011). Loneliness of older men and women in rural areas of the UK in Safeguarding the Convoy – A Call to Action, Campaign to End Loneliness. Abingdon: Age UK.

Cabinet Office (2012). Government Digital Strategy. [online] Available at: <http://publications.cabinetoffice.gov.uk/digital/strategy/#initial-outline-of-proposed-digital-by-default-transactional-service-standard> [Accessed 4 January 2013].

Campaign to End Loneliness (2012). Loneliness – the state we’re in. Campaign to End Loneliness. Abingdon: Age UK.

de Jong Gierveld, J et al (2011). Alleviating loneliness among older adults in Safeguarding the Convoy – A Call to Action, Campaign to End Loneliness. Abingdon: Age UK.

Department for Communities and Local Government (2010). Household Projections 2008 to 2033, England. London: Department for Communities and Local Government.

Department of Health (2009). Living well with dementia: A national dementia strategy for England. London: Department of Health.

Department of Health (2010). Quality outcomes for people with dementia: building on the work of the national dementia strategy. London: Department of Health.

Department of Health (2012a). Prime Minister’s challenge on dementia: delivering major improvements in dementia care and research by 2015. London: Department of Health.

Department of Health (2012b). The mandate: A mandate from the Government to the NHS Commissioning Board: April 2013 to March 2015. London: Department of Health.

Department of Health (2012c). Letter to Dr Laurence Buckman, Chairman of General Practitioners Council, BMA. [online] Available at www.wp.dh.gov.uk/publications/files/2012/12/GMS-Contract-letter.pdf [Accessed 4 January 2013].

Department of Health (2012d). Prime Minister’s challenge on dementia: delivering major improvements in dementia care and research by 2015: A report on progress. London: Department of Health.

Department of Health (2012e). End of life care strategy: Fourth annual report. London: Department of Health.

Department of Health (2012f). The Adult Social Care Outcomes Framework 2013/14. London: Department of Health.

Department of Health, Social Services and Public Safety (2012). Who cares? The future of adult care and support in Northern Ireland: a discussion document. Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2011). Improving dementia services in Northern Ireland: a regional strategy. Belfast: DHSSPS.

Health and Social Care Board (2012). Transforming your care: vision to action. A consultation document 9 October 2012 – 15 January 2013. Belfast: Health and Social Care Board.

Holt-Lunstad et al (2010). Social relationships and mortality risk: A meta-analytical review. Utah: Brigham Young University.

- Holwerda et al (2012). Feelings of loneliness, but not social isolation predict dementia onset: results from the Amsterdam Study of the Elderly (AMSTEL). *Journal of Neurology, Neurosurgery and Psychiatry* 2012 (0) 1-8.
- Kings Fund (2008). *Paying the price: The cost of mental health care in England to 2026*. London: The Kings Fund.
- Mental Health Foundation (2011). *An evidence review of the impact of participatory arts on older people*. London: Mental Health Foundation.
- Mirando-Costillo et al (2010). People with dementia living alone: what are their needs and what kind of support are they receiving? *International Psychogeriatrics*, 22(4) 607-617.
- National Assembly for Wales (2012). *Health and Social Care committee inquiry into residential care for older people in Wales*. Cardiff: National Assembly for Wales.
- NHS Commissioning Board (2012). *Everyone counts: planning for patients 2013/14*. London: NHS Commissioning Board.
- NHS Information Centre (2012). *National Dementia and Antipsychotic Prescribing Audit* [online] Available at: www.ic.nhs.uk/Article/1806 [Accessed 7 January 2013].
- NICE (2013). *Consultation on potential new indicators for the 2014/15 Quality and Outcomes Framework*. [online] Available at: http://www.nice.org.uk/media/00D/29/NICE_QOF_Indicator_Consultation_Document_final.pdf [Accessed 7 January 2013].
- Office of National Statistics (2010). *General lifestyle survey 2010*. [online] Available at: www.ons.gov.uk/ons/rel/ghs/general-lifestyle-survey/2010/index.html [Accessed 8 January 2013].
- Office of National Statistics (2012a). *Statistical bulletin: Deaths registered in England and Wales in 2011, by cause*. [online] Available at: www.ons.gov.uk/ons/rel/vsob1/mortality-statistics--deaths-registered-in-england-and-wales--series-dr-/2011/stb-deaths-registered-in-england-and-wales-in-2011-by-cause.html#tab-Key-findings [Accessed 8 January 2013].
- Office of National Statistics (2012b). *Internet access quarterly update, Q3 2012*. [online] Available at: www.ons.gov.uk/ons/dcp171778_286665.pdf [Accessed 8 January 2013].
- The Residents and Relatives Association (2010). *Together but alone: isolated older people in care*. London: Voluntary Action Islington.
- Tijhuis MAR et al (1999). Changes in and factors related to loneliness in older men. *The Zutphen Elderly Study*, *Age and Ageing* 25 (5).
- UKHCA (2012). *Care is not a commodity*. Sutton: UKHCA.
-

Victor, C (2003). Loneliness, social isolation and living alone in later life. London: Economic and Social Research Council.

Victor, C et al (2005). The prevalence of, and risk factors for loneliness in later life: a survey of older people in Great Britain. *Ageing and Society* 25 (3).

Victor, C (2011). Loneliness in old age: the UK perspective in *Safeguarding the Convoy – A Call to Action*, Campaign to End Loneliness. Abindon: Age UK.

Weiss, S (1973). *Loneliness: the experience of emotional and social isolation*. Cambridge, Massachusetts: The MIT Press.

Welsh Assembly Government (2003). *The Strategy for Older People in Wales*. Cardiff: Welsh Government.

Welsh Assembly Government (2011a). *National dementia vision for Wales*. Cardiff: Welsh Government.

Welsh Assembly Government (2011b). *Sustainable Social Services for Wales: A framework for action*. Cardiff: Welsh Government.

Welsh Government (2012a). *Together for health – delivering end of life care. A delivery plan up to 2016 for NHS Wales*. Cardiff: Welsh Government.

Welsh Government (2012b). *General medical services contract – Quality and Outcomes Framework Statistics 2011–12*. Cardiff: Welsh Government.

Welsh Government (2012c). Press release [online] Available at: <http://wales.gov.uk/newsroom/healthandsocialcare/2012/120522dementia/?lang=en> [Accessed 7 January 2013].

Wilson, RS et al (2007). Loneliness and risk of Alzheimer's disease. *Archives of General Psychiatry* 64 (2).

WRVS (2011). *Voices on wellbeing: A report of research with older people*. Cardiff: WRVS.

WRVS (2012a). *Falls: measuring the impact on older people*. Cardiff: WRVS.

WRVS (2012b). *Loneliness amongst older people and the impact of family connections*. Cardiff: WRVS.

YouGov Survey Information:

Total sample size was 2287 adults. Fieldwork was undertaken between 14 and 16 January 2013. The survey was carried out online. The figures have been weighted and are representative of all UK adults (aged 18+).

Appendix 1: Summary of statistics

The statistics used throughout this report are presented below. The bold statistics indicate the latest figures for 2013.

Prevalence

800,000 people in the UK have dementia (Alzheimer's Society, 2012a).

665,065 of people in England have dementia, 44,598 in Wales and 18,862 in Northern Ireland (Alzheimer's Society, 2013a).

By 2021 there will be over 1 million people living with dementia in the UK (Alzheimer's Society, 2012a).

Quality of life for people with dementia

61% of people said that they were living well with dementia (Dementia 2013).

39% of respondents said that they were not living well with dementia (Dementia 2013).

54% of people surveyed think that the quality of life for people with dementia is very bad (YouGov poll).

Last year, in Dementia 2012, 44% of people with dementia said that they were always able to make choices about their day-to-day life. 14% of people with dementia said that they were not able to make choices about their day-to-day life and 2% said they did not know (Alzheimer's Society, 2012a).

In Dementia 2013, 65% of people with dementia said that they were able to make choices about their day-to-day life. 28% of people with dementia said that they were not able to make choices about their day-to-day life and 7% said they did not know (Dementia 2013).

In Dementia 2012, 17% of people with dementia said that they did not feel anxious or depressed. 9% of people said they always felt anxious or depressed, and 68% sometimes felt anxious or depressed (Alzheimer's Society, 2012a).

In Dementia 2013, 27% of people with dementia said that they never felt anxious or depressed. 63% of people with dementia said they feel anxious or depressed. 10% said they didn't know (Dementia 2013).

Dementia and loneliness

It is estimated that about 10% of the general population aged over 65 in the UK is lonely all or most of the time (Victor, 2011).

50% of people with dementia said they are lonely (38%) or don't know if they are lonely (12%) (Dementia 2013).

29% of people didn't think there were any barriers to having a conversation with people with dementia (YouGov poll).

28% of people identified time as a barrier to having a conversation with people with dementia (YouGov poll).

25% of people identified uncertainty about how the person would react as a barrier to having a conversation with people with dementia (YouGov poll).

21% identified concern over having a conversation with a person with dementia because they would get confused and not follow the conversation (YouGov poll).

Living alone with dementia

In 2010, 49% those aged over 75 in the UK lived alone (Office for National Statistics, 2010).

52% of the public who live alone stated that they felt lonely in the last month (YouGov poll).

62% of people with dementia living alone said that they feel lonely (Dementia 2013).

38% of all people with dementia said that they felt lonely (Dementia 2013).

Only 23% of people think that it is possible for people with dementia to live alone (YouGov poll).

50% of people with dementia living alone stated that they have stopped doing things that they used to do because they do not want to be a burden (Dementia 2013).

Social networks

75% of people with dementia said that they had enough people to count on for support (Dementia 2013).

15% of people with dementia said that they did not have enough people to count on for support. 10% said they did not know (Dementia 2013).

16% of people would not feel comfortable having a conversation with a person with dementia (YouGov poll).

19% of people do not know if they would feel comfortable talking to somebody with dementia (YouGov poll).

19% of people with dementia said that they spoke to their neighbours less than once a month (Dementia 2013).

39% of people with dementia said that they spoke with their neighbours every day (Dementia 2013).

In Dementia 2012, 28% of people with dementia said that they had lost some of their friends following their diagnosis. 12% of people with dementia said that they had lost some or all of their friends following their diagnosis. 4% of people with dementia had not told their friends of their diagnosis (Alzheimer's Society, 2012a).

In Dementia 2013, 33% of people with dementia said that they had lost friends after a diagnosis of dementia. 50% of people with dementia had not lost friends following their diagnosis. 5% of people with dementia had not told their friends of their diagnosis (Dementia 2013).

Social contact and dementia

12% of older people say that they feel trapped in their own home (Age UK, 2013).

9% of older people say they feel cut off from society (Age UK, 2013).

6% of older people leave their house once a week or less (Age UK, 2013).

63% of people with dementia said that they spoke to family or friends face-to-face every day. 24% of people with dementia said they spoke to family or friends face-to-face once a week. 13% of people with dementia said they spoke to family or friends face-to-face once a fortnight (Dementia 2013).

25% of people with dementia said that they spoke to friends or family on the telephone every day. 38% of people with dementia said they spoke to friends or family on the telephone once a week. 33% of people with dementia said that they spoke to friends or family on the telephone less than once a month. 12% of people with dementia did not know how often they spoke to friends and family on the telephone (Dementia 2013).

Electronic contact

87% of people with dementia did not use electronic communication or social networks to connect with people. 12% of people with dementia said that they did use electronic communication or social networks to connect with people. 6% of people with dementia said that they did not know if they used electronic communication or social networks to connect with people (Dementia 2013).

30% of adults aged 75 years and over had ever used the internet (Office of National Statistics 2012b).

3.24 million people over the age of 75 years had never used the internet (Office of National Statistics 2012b).

Diagnosis

Only 46% of people with dementia in the UK have a diagnosis. This comprises 44% in England, 39% in Wales and 63% in Northern Ireland (Alzheimer's Society, 2013a).

Dementia is the fifth leading cause of death in men and second in women in England and Wales (Office of National Statistics, 2012a).

In 2011, 37,000 death certificates listed dementia as a cause (Office of National Statistics, 2012a).

Up to one in three people have dementia when they die (Brayne et al, 2006).

Approximately 160,000 people every year die with dementia (Alzheimer's Society, 2012b).

Community-based care

Two-thirds of people with dementia live in the community (Alzheimer's Society, 2007).

Of those living in the community, one-third live alone in their own homes (Mirando-Costillo, 2010).

48% of people think that the access to services for people with dementia is very bad (13%) or fairly bad (36%) (YouGov Poll).

Care homes

One-third of people with dementia live in a care home (Alzheimer's Society, 2007).

80% or more of care home residents in the UK have dementia or significant memory problems (Alzheimer's Society, 2013b).

70% of the UK public would feel scared about moving into a care home following the several high profile scandals concerning undignified treatment in care homes (Alzheimer's Society, 2013b).

68% of the public thought that the quality of care in care homes was good (Alzheimer's Society, 2013b).

74% of carers would recommend the care home the person with dementia was in (Alzheimer's Society, 2013b).

41% of carers thought that the quality of life of the person with dementia living in the care home was good (Alzheimer's Society, 2013b).

Hospital care

Up to a quarter of hospital beds are occupied by people with dementia at any one time (Alzheimer's Society, 2009).

13% of the public think that the quality of care provided for people with dementia is very bad (YouGov poll).

36% of the public think that the quality of care provided for people with dementia is fairly bad (YouGov poll).

In 2012 the number of inappropriate prescriptions of antipsychotic medication to people with dementia had been reduced by 52% between 2008 and 2011 (NHS Information Centre, 2012).

Lack of support for people with dementia

60% of people do not think the government has responded well to the challenge of dementia (YouGov poll).

57% of the public thought a lack of formal or informal support from others to carry out the activity they want to was a barrier to people with dementia participating more fully in their community (YouGov poll).

24% of people with dementia said they have stopped doing things because of a lack of support from services (Dementia 2013).

36% of people with dementia who live alone have also said they have stopped doing things because of a lack of support from services (Dementia 2013).

71% of people living alone reported in the survey that they have had to stop doing some things due to a lack of confidence (Dementia 2013).

88% of all people with dementia rely on family or friends for transport. Among people with dementia living alone this is 92% (Dementia 2013).

Dementia-friendly and dementia-supportive communities

76% of people think it is important that everybody should be able to get out of their homes and feel comfortable in their local area (YouGov poll).

12% of people think that the inclusion of people with dementia in their communities is very bad (YouGov poll).

47% of people think that the inclusion of people with dementia in their communities is fairly bad (YouGov poll).

53% of people thought that a lack of appropriate activities for people with dementia is a barrier to them participating more fully in their community (YouGov poll).

68% of people with dementia have stopped doing things they used to because they worry about becoming confused (Dementia 2013).

60% people with dementia have stopped doing things that they used to because they worry about getting lost (Dementia 2013).

Nearly 50% of people with dementia only go out to do things in their local area once a week or less (Dementia 2013).

70% of people with dementia have stopped doing things they used to, due to a lack of confidence (Dementia 2013).

Almost 60% of all people living with dementia have stopped doing things that they used to because of mobility difficulties (Dementia 2013).

51% of people think that the symptoms of dementia restrict a person to their own homes, and form a barrier to people with dementia participating more fully in their community (YouGov poll).

40% of people think it is true that all people with dementia can take part in all activities they want to or enjoy (YouGov poll).

Costs

Dementia 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).

670,000 people in the UK act as primary carers for people with dementia, which saves the state £8 billion per year (Alzheimer's Society 2012a).



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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