

Dementia 2015: Aiming higher to transform lives



Document purpose

Dementia 2015: Aiming higher to transform lives is Alzheimer's Society's fourth annual report looking at quality of life for people with dementia in England. It contains the results of our annual survey of people with dementia and their carers, and an assessment of what is currently in place and needs to be done to improve dementia care and support in England over the next five years.

It looks at some key resources: our general election manifesto – The dementia promise, the content and ambitions of the Prime Minister's challenge on dementia 2020 and other recently published data and evidence. Following the calls to action in these publications, **Dementia 2015: Aiming higher to transform lives** sets out key areas of recommendation, with specific calls for a national action plan across government, health and social care.

Title

Dementia 2015: Aiming higher to transform lives

Publication date

July 2015

Target audiences

Dementia 2015: Aiming higher to transform lives is intended for a wide range of organisations and people who can improve quality of life for people with dementia. This includes central and local government, partners from the public sector, commissioners of healthcare, civic organisation, and researchers.

Acknowledgements

Alzheimer's Society would like to thank the people with dementia and carers who took part in our survey and shared their personal stories. The information provided by you made this report possible. Thanks also go to Alzheimer's Society staff and others, who supported people to complete the survey and contributed to the report's content.

Authors

Martina Kane, Senior Policy Officer
Gavin Terry, Policy Manager

Contact

Alzheimer's Society Public Policy team can be contacted on 020 7423 3500 or at ppa@alzheimers.org.uk

Web

alzheimers.org.uk/dementia2015

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Foreword



A handwritten signature in black ink that reads "Jeremy Hughes".

Jeremy Hughes
Chief Executive,
Alzheimer's Society

Alzheimer's Society is committed to charting the quality of life of people with dementia and assessing the quality of dementia care and support in England.

Our survey has run annually since 2012 to find out how well people are living with dementia. Dementia 2015 continues this commitment, highlighting progress in the last year and illustrating where improvements have yet to be made.

This report is published at a pivotal moment for dementia. Dementia is the subject of unprecedented focus. There is increased momentum to tackle the challenge presented by the condition, but this has not yet resulted in vital transformational change to embed sustainable change and improvements for people with dementia.

Dementia still remains a national challenge. While celebrating that we are all living longer, an ageing population brings with it unprecedented pressures on our health and social care systems and on already immensely squeezed budgets. Dementia is also more feared by those in the over 50s age group than any other health condition, including cancer. Bold reform, as well as being realistic about the need for adequate funding, is absolutely necessary. With an estimated 1 million people living with dementia in the UK by the end of the parliament, meeting the needs of people with dementia is essential.

Put simply, if our health and social care system fails to adequately meet the needs of people with dementia, then it is letting down a significant proportion of the ageing population, and importantly those who greatly rely on these vital services to maintain a good quality of life. This is reflected in the findings of our GP poll, the results of which are also included in this report.

Also reliant on the health and social care system are carers and younger people with dementia of working age, of whom there are more than ever before, and wider society. In light of this, and the findings contained within this report, it is clear that getting care and support right for people with dementia means getting it right for the frail elderly. In doing so, it is right to focus on dementia as the test to determine the success of initiatives to meet the need of an ageing population, in health, social care and beyond.

This report follows the same structure as the recent Prime Minister's challenge on dementia 2020 (Department of Health, 2015) and makes recommendations that highlight where real action is needed and how the agenda can press forward to make change a reality.

Executive summary

Dementia has never had such a high profile, or been prioritised in the way that we've seen during the last six years. Much has been done and much has been achieved, from the implementation of the National Dementia Strategy for England, the Prime Minister's challenge on dementia 2012, and global recognition of dementia and the development of research through the G8/G7 activity, to increased national awareness-raising through initiatives such as Dementia Friends and the real advancement of dementia-friendly communities.

We cannot let this falter. What has been achieved needs to be maintained, and what still remains to be done needs to be prioritised. Dementia needs to be seen as a national priority in its own right, in order to ensure that ambitions are transformed into action. Even with the changes in recent years, research investment and funding for care and support remains far behind other conditions such as cancer and heart disease.

At what continues to be a critical time in dementia policy, the disease still has a high profile, with a new government committed to improvements for people with dementia, and a Prime Minister who continues to see dementia as a personal priority. This is the crucial turning point for dementia, and the government's commitment to dementia needs to be met by a fully-fledged national action plan for the 2020 challenge.

Our report provides a snapshot of how well people are living with dementia, what support they are receiving and what barriers they face to living well. It makes practical recommendations to the new government on the steps that need to be taken to make quality of life better for people with dementia.

32% of people who responded to our survey said that they felt they were not living well with dementia or did not know.

53% of people responding to our survey said they had felt anxious or depressed recently. 36% said they had not and 11% said they didn't know.

Half (49%) of people with dementia said they were not getting enough support from government.

75% of people who responded to the survey said that they had another health condition in addition to their dementia.

Despite the achievements, many people with dementia are still not living well with the condition and tell us they are anxious or depressed. Three-quarters live with another condition alongside their dementia, yet have to try to navigate a fragmented health and social care system that does not meet their needs.

Good health and social care for people with dementia – from before diagnosis until end-of-life – remain an essential aspect of good quality of life. This report highlights the extent to which health and care for people with dementia needs improving.

We have assessed what is currently in place, and what needs to be done to improve dementia care and support in England over the next five years. We have done this by looking at the calls for improved care within our general election manifesto, The dementia promise (Alzheimer's Society, 2015a), the content and ambitions of the Prime Minister's challenge on dementia 2020 (Department of Health, 2015) and by drawing on evidence from other published data and information. We now set eight key areas of recommendation with specific calls for action. These calls not only detail what needs to be done, but more importantly by which organisations and agencies.

Over a quarter (26%) of people with dementia responding to our survey said they were not involved in decisions about their care and support. 61% said they were and 13% said they did not know.

A stronger research agenda could lead not only to a cure for dementia in the future, but better care for people with dementia now. Pledges for increased funding are welcome, however there is still a long way to go before the funding for dementia research matches the burden that the condition places on society. While the importance of research for a cure can't be understated, this report also calls for greater movement in areas that will make research relevant to the lives of people living with dementia, including more research into care, a regulatory system which will enable potentially repurposed drugs to get to people with dementia, and the involvement of people with dementia in setting priorities and in research itself.

More than half (51%) of people who responded to our survey, and who are therefore in contact with Alzheimer's Society, said they feel part of their community. Even among these people, nearly one-third (29%) said they did not feel part of the community. It is also notable that the longer people have been experiencing symptoms, the less they report feeling part of their community.

It's essential that the pioneering Dementia Friendly Communities programme is supported into the future, to continue to transform the lives of people with dementia. Much has been achieved with local areas, businesses, and community groups. We reached a landmark in 2015 by reaching 1 million Dementia Friends, however this is only approximately 1.6% of the population. It is essential to have more Dementia Friends so that all people with dementia can feel part of their community, and more people become dementia aware.

2015 has given us other new opportunities within the health agenda, with dementia specifically mentioned in NHS England's Five year forward view and Annual business plan, and the potential for the NHS New Models of Care Programme to deliver widely improved and tailored local services that meet the needs of people with dementia. Other new opportunities have also been made available within social care through the implementation of the Care Act and the Better Care Fund.

We must all work together to improve quality of life. Dementia 2015: Aiming higher to transform lives highlights the potential all of us have and the role we can play to deliver the change people with dementia expect and deserve.

Together we must:

- 1 Produce a national, funded action plan to deliver the Prime Minister's challenge on dementia 2020.**

- 2 Take action on risk management.**

- 3 Improve diagnosis and transform support after diagnosis.**

- 4 Support carers.**

- 5 Deliver dementia-friendly health and care settings.**

- 6 Tackle issues in dementia education, training and workforce.**

- 7 Drive forward dementia-friendly communities.**

- 8 Make the UK a leader in transformational dementia research.**

Introduction

The context of dementia

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, such as Alzheimer's disease or a series of small strokes (causing vascular dementia). Rarer causes of dementia include dementia with Lewy bodies and frontotemporal dementia.

Dementia is a progressive condition, meaning that people with dementia and their family and carers have to cope with changing abilities over time. These changes include an increasing and fluctuating impairment in the person's capacity to make decisions about major life events and circumstances as well as day-to-day situations.

Figure 1 Projected prevalence of dementia in the UK to 2051



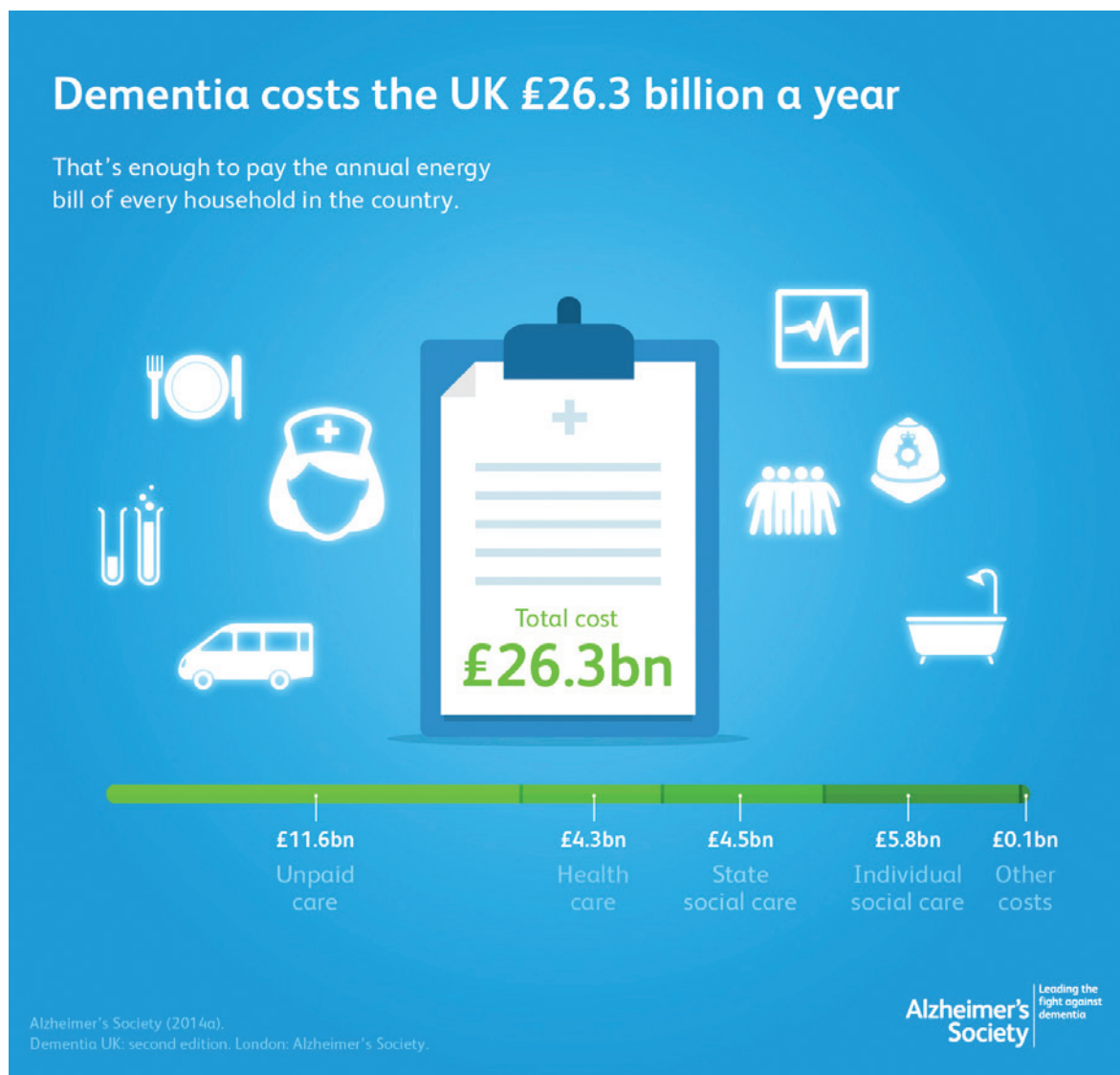
Prevalence

Using the internationally recognised Delphi consensus methodology, research shows that in 2015 there are 850,000 people with dementia in the UK, based on the current prevalence rate (Prince et al, 2014). This includes over 700,000 people in England. Over 40,000 younger people in the UK (65 years of age or below) have dementia, and an estimated 25,000 people from black, Asian and minority ethnic groups have the condition. The overall number is set to rise to 1 million by 2021 and, as such, health and social care systems must be prepared for a considerable number of people with dementia, many of whom will also spend time in hospitals.

The impact of dementia

Dementia now costs the UK economy £26.3 billion a year, with this figure set to rise (Prince et al, 2014). To put that into context, it's enough to pay the energy bills for a year of every household in the UK.

Figure 2 Total estimated cost of dementia to the UK



As the symptoms of dementia progress, people need increasing support, particularly to help them to remain living in their own home or alternative residential setting. Once the symptoms of dementia become severe, living in a care home where dementia is understood and care is tailored to dementia-specific needs can be the best option. One-third of people with dementia live in care homes (Prince et al, 2014), and around 70% of care home residents in the UK have dementia or significant memory problems (Prince et al, 2014). Delivering person-centred care in residential settings and providing front line staff with the skills and confidence to deliver responsive dementia care must be a priority.

People with dementia are frequent users of NHS services. At any one time, up to a quarter of hospital beds are occupied by people with dementia (Alzheimer's Society, 2009) and they tend to have longer stays than patients without dementia. National guidelines exist which aim to support health and social care professionals in providing quality care to people with dementia, but these alone are insufficient (NICE, 2010, 2011, 2013a, 2013b). Quality of care is inconsistent, and there are particular issues in the care that people with dementia receive when moving between different settings, for instance from hospital back into the community (CQC, 2014). In a survey of people with dementia and their carers, 98% of respondents felt that staff having a poor understanding of dementia was a barrier to the provision of good quality care (Royal College of Nursing, 2011).

Two-thirds of people with dementia live in the community (Prince et al, 2014). Of these, one-third live alone in their own homes (Mirando-Costillo et al, 2010). The UK Homecare Association estimates that 60% of people receiving care at home have a form of dementia (UKHCA, 2013), and yet minimum standardised training and sufficient workforce development opportunities are not commonplace. Unpaid carers save the state £11 billion per year (Prince et al, 2014). While recognition of family carers has increased, in reality access to sufficient support and assessment of their own needs is still inadequate.

Dementia costs UK business an estimated £1.6 billion per year (Centre for Economics and Business Research, 2014) and 89% of employers believe that dementia will become a bigger issue for their organisation and their staff (Employers for Carers, 2014). There is no doubt that dementia still remains a national challenge that goes beyond health and social care.

International context

At a pre-election event in March 2015, the Prime Minister stated that he wants to make Britain 'the most dementia-friendly country in the world'.

Up until now, the UK, and England in particular, have been seen as world leaders in dementia policy. Models of care which have long been standard in the UK are recognised in the Organisation for Economic Co-operation and Development's (OECD's) report *Addressing dementia: The OECD response* (2015). This report references the previous national strategy, and the fact that other countries' national action plans have looked to England as a template for what can be achieved. This, however, should not be mistaken for dementia care models that sufficiently meet the needs of people with dementia. There is still much more to do.

Following devolution in the UK, there is national variation – Scotland is on its second strategy, Northern Ireland has an open-ended strategy, Wales does not have a strategy, and England is taking forward the Prime Minister's challenge on dementia 2020.

Other countries have followed England's example and committed or re-committed to national strategies. For example, the USA has a national strategy until 2025 and France has commenced its fourth national plan.

The momentum generated by the G8 Summit in 2013, and its specific focus on advancing research, was maintained through a series of G7 legacy events that ran up until February 2015. France and Canada co-hosted a meeting that focused on closer links between academia and industry and the engagement of biotechnology and IT industries. Tokyo's event demonstrated Japan's patient-care initiatives and unique, community-based education. At the final event in Washington, discussion was on new strategies to prevent disease, new ways to assess and monitor dementia, and how to translate targets from basic science to clinical trials.

Global activity and focus has been boosted by the formation of the World Dementia Council and appointment of a World Dementia Envoy. The WHO and OECD are now devoting more resources to dementia in order to sustain the commitments made at the G8 and G7 events, adding to the existing work of organisations such as Alzheimer's Disease International, Alzheimer's Society and other members of Alzheimer Europe.

The first WHO ministerial conference on global action against dementia was held in Geneva in March 2015. The aim of the conference was to raise awareness of the socio-economic burden of dementia, and how commitment to placing dementia on the global public health agenda can help to tackle and reduce this burden. The conference specifically covered issues around research, drug regulation, care and human rights, before ministers had the opportunity to discuss dementia's global status. With over 80 government delegations, this conference highlighted the global spread of concern and commitment to action on dementia

Following this, Addressing dementia: The OECD response called for better policies to improve the lives of people living with dementia now, for communities to adjust to become more dementia friendly, and for better support for families who provide informal care (OECD, 2015).

Global action and co-operation must continue and build on the foundations of the last two years. From the perspective of the UK, these include:

1 Dementia Friends and dementia-friendly communities

There have been a significant number of expressions of interest from countries interested in replicating the Dementia Friends and dementia-friendly communities model, including the USA, Canada, and Denmark.

2 Global Alzheimer's and Dementia Action Alliance (GADAA)

Alzheimer's Society is continuing to play a leadership role on GADAA, bringing together international NGOs beyond those primarily connected with dementia.

3 World Dementia Council

There is a clear ongoing value of the Council as a forum for effective global action. It both leads and holds to account the actions of others, including governments, the research community and the World Health Organization. There is huge potential that, by working together across national boundaries, we can significantly advance progress to improve the lives of people with dementia.

In order to prioritise dementia for the 44 million people worldwide with the condition, the drive of the G8 and G7 activity must permeate through to other international bodies and countries, especially when considering the challenges of both ageing populations and the growing number of people with dementia in developing countries (World Health Organization, 2012).

Furthermore, as argued in this report, England can demonstrate its continued focus on dementia by publishing a national action plan setting out how the Prime Minister's challenge on dementia 2020 will be met. This will act as a clear message to other countries seeking to commit to act and support people with dementia in their countries, and we look forward to the need for resolution at the World Health Assembly 2016.

National context

Dementia has featured highly on the political agenda and received increased recognition as a national priority. The National Dementia Strategy for England (Department of Health, 2009) was given a significant boost in 2012 by the Prime Minister's challenge on dementia, which promised to 'push further and faster on major improvements in care and research by 2015' (Department of Health, 2012).

With the Prime Minister describing dementia as 'a national crisis' at its launch, the challenge had three main areas of focus: improvements to health and care, dementia-friendly communities and better research. At its conclusion in March 2015, significant progress had been made. The challenge had helped raise awareness of dementia by creating 1 million Dementia Friends and significantly increased the number of people with a dementia diagnosis, as well as making improvements to health and social care and highlighting the issue of research through the government's decision to host the G8 summit in 2013. This helped to increase momentum to tackle the challenge presented by dementia globally but still highlights the need to do more to reduce variation, increase consistency and quality in dementia care.

In March 2015, David Cameron launched the Prime Minister's challenge on dementia 2020 (Department of Health, 2015). This new five-year vision aims to make England the 'best country to live in for dementia care and support and the best place in the world to undertake research into dementia and other neurodegenerative diseases'. This signals the government's commitment to taking forward dementia care.

The Prime Minister's challenge on dementia 2020 rightly sets out an ambitious vision for dementia care in England. The Prime Minister's continued commitment, as well as that of the leaders of the other main political parties, provides a clear platform to deliver the challenge. However, to do so will require not only the highest level of political leadership, but also a clear commitment from the key levers for delivery, namely the health arm's length bodies (such as NHSE, Care Quality Commission, Health Education England and Public Health England), local government and social care leaders, as well as wider society. Without this it will be difficult for health and social care providers and others to accomplish the goals laid out in the Prime Minister's challenge on dementia 2020 and in turn affect the lives of people with dementia to the extent that is needed. Immediate action on this is necessary to ensure that the funding requirements of the Prime Minister's challenge on dementia 2020 can be part of the forthcoming spending review.

Key health arm's length bodies have prioritised dementia in their work and business plans. For example, dementia has been:

- the subject of a thematic review by the Care Quality Commission, followed by their report, Cracks in the pathway
- identified as a priority within NHS England's Five year forward view and their subsequent business plan for 2015 to 2016
- been prioritised within Public Health England's planning.

While this is encouraging, it does not automatically mean that dementia has become a priority at the front line. For example, despite the priority focus of dementia at a national level by Public Health England, this has not sufficiently transferred for dementia to be a main priority set by directors of public health or within local health and wellbeing board strategies. There are also significant challenges in social care to improve the experiences of people with dementia. Moving forward, connecting the national with the local, in a way that increases shared learning and best practice, will potentially drive up standards and outcomes.

Quality of life outcomes that are important to people with dementia

In recent years, there has been an increasing focus on identifying the issues that matter to people with dementia in how they live their lives. It is important to acknowledge that each individual will have personal aspirations, and there are 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 (DAA, 2010). This was developed by the Dementia Action Alliance (DAA), which brings together different organisations in England committed to delivering change. In the Declaration, 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 seven outcomes cover the key aspects that are important for quality of life for people with dementia and form the seven 'I' statements:

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

It is clear from this year's survey results that progress in public policy has not filtered down to grass-roots level enough to enable people with dementia to say these statements are now true.

Today, the challenge is to make sure that national commitments on dementia in England, including the Prime Minister's challenge on dementia 2020, make these outcomes a reality for people with dementia and their carers. Efforts are being made to develop effective outcomes in the Adult Social Care Outcomes Framework (ASCOF) and the NHS Outcomes Framework. There is a dementia-specific placeholder in both – but there is currently not one clear method of assessing the quality of life of people with dementia. Given the nature of the condition, it is understandably difficult to determine quality of life, particularly in the later stages of dementia. Using Patient Reported Outcome Measures (PROMs), health-related quality of life of people with mild to moderate dementia can be assessed using the DEMQOL method. Research is ongoing at the London School of Hygiene and Tropical Medicine to develop the DEMQOL method for assessing quality of life for people with dementia living in care homes, who are often in the later stages of the condition.

1 Producing a national action plan for dementia and securing funding

Key actions

- Capitalise on the improvements which have been made and move from improved diagnosis rates to better care.
- Produce a national plan to deliver the Prime Minister's challenge on dementia 2020.
- Map out how the plan will be funded and secure funding from the Spending Review.
- Decide who will be responsible for the delivery of key aspects of the action plan.

The Prime Minister's challenge on dementia (Department of Health, 2012) focused attention on specific areas, particularly health and care, dementia-friendly communities and better research, all of which have seen improvements since 2012. It is now time to capitalise on the improvements which have been made and move from improved diagnosis rates to better care throughout the course of the disease, from the establishment of dementia-friendly communities in some areas to a truly dementia-friendly society in all parts of England, and from increased investment in research to real breakthroughs that can provide improvements in prognosis and care

The current Prime Minister's challenge on dementia 2020 (Department of Health, 2015) sets out a number of commitments, but it is now important to move from commitment to transformation and planned action. Other recent government strategies provide a template for this, such as the mental health strategy, which had an initial overarching vision from Closing the gap (Department of Health, 2014a) and then a more detailed, funded three-stage implementation plan in Achieving better access to mental health services by 2020 (Department of Health, 2014b), which has been committed to by the new government.

Other long-term health conditions have been given a specific national focus for delivery. For example, NHS England's business plan for 2015 to 2016 and their document Five year forward view: Time to deliver also outline plans for publishing a new cancer strategy, and launching a nationwide diabetes prevention programme.

The government's reaffirmed commitment to dementia will only suffice if it is turned into meaningful action, funding and agreed specific outcomes in meeting objectives to improve dementia care and support in England that are on a par with, and receive the same level of attention as, other conditions such as cancer and diabetes. A national action plan is now needed to deliver real improvements for people affected by dementia. This national action plan should include:

- a new governance structure
 - information on how the vision set out in the Prime Minister's challenge on dementia 2020 will be delivered and funded
 - details on who will be responsible for key aspects of delivery, eg arm's length bodies, local government, providers, civil society.
-

2 Taking action on risk management

Key actions

- Challenge the current low levels of awareness of dementia and reduce stigma with an annual national awareness campaign as a priority for Public Health England.
- Include dementia in the NHS mid-life Health Check by 2016 as part of the programme to encourage adults to tackle modifying risk factors in mid-life such as smoking, drinking and exercise.
- Establish a public health observatory to routinely monitor dementia incidence and the effects of lifestyle trends.
- Prioritise dementia locally. This should be actioned by all health and wellbeing boards and directors of public health.
- Integrate dementia public health messages with existing healthy and risk reduction lifestyle messages.

There has been a recognisable shift in the perception of dementia in recent years from a condition which is inevitable for some, to one where there are modifiable risk factors. Increasing amounts of research show the risks of poor diet, lack of exercise, smoking and excessive drinking. The Blackfriars Consensus in 2014 stated that dementia shared common components with other non-communicable diseases and should be included in current risk reduction strategies. The World Alzheimer Report, published in September 2014 also focused on dementia and risk reduction. In January 2015, the World Dementia Council issued a statement calling on governments around the world to focus on dementia risk reduction.

There should also be recognition of the influence that lifestyle factors can have on the reduction of risk and slowing the progress of existing dementia. These include factors that are in common with other conditions and diseases, such as diet, exercise, smoking and alcohol consumption. However, for dementia there is a growing consideration of the promotion of an active lifestyle combining social, mental and physical activity, with research suggesting that people who are more socially active have a slightly reduced risk of developing dementia, and that people who take part in mental activities (such as reading and learning) are less likely to develop dementia compared with those who do not engage in these activities. These aspects of 'what's good for your head, is good for your heart' are mentioned in the Blackfriars Consensus and the World Alzheimer Report 2014, Dementia and risk reduction: An analysis of protective and modifiable factors.

Public Health England is currently consulting on reforming the Health Check to help people in mid-life understand their risk of dementia and make lifestyle changes accordingly. It is essential that Public Health England and NHS England deliver on the vision of the Blackfriars Consensus and include dementia in the information given to people in mid-life on modifying risk factors through the Health Check. While there has been development in this area, it has still not filtered through to the front line, so is not yet benefiting people who are at risk of developing dementia.

We were encouraged to see that the Prime Minister's challenge on dementia 2020 (Department of Health, 2015) wanted to see improved public awareness of the disease and a desire for a global consensus that risk reduction can reduce the global burden of dementia. To achieve this, the government must commit to Public Health England delivering an annual national campaign designed to improve awareness of dementia. This should have substantial ring-fenced funding and be committed to reaching out to different groups, including those hard to reach, with targeted messages to help raise awareness.

It is also clear that more longitudinal research is needed to establish the effects of these interventions on the incidence of dementia. Alzheimer's Society would like to see a public health observatory that routinely monitors dementia incidence and the effects of lifestyle trends. It is also essential that Public Health England, NICE and public health directors in local authorities not only recognise risk reduction, but prioritise the slowing of cognitive decline once someone has been diagnosed, and that this is reflected as a local priority.

Case study

Swimming with dementia

Physical activity, such as swimming, can improve quality of life and delay further cognitive decline in people with dementia. However, people with dementia can find attending swimming pools daunting. Alzheimer's Society is a partner for the Dementia Friendly Swimming project. This aims to enhance the provision and experience of swimming for people living with dementia and their carers. Local authorities, public health professionals, carers and community groups have worked together to create a network of dementia-friendly swimming pools across England.

The Dementia Friendly Swimming project, led by the Amateur Swimming Association (ASA), has begun in Durham and Manchester. In its second year, the project will expand to a further four cities, aiming to work with over 100 swimming pools by the end of the third year. It will have 300 trained key swimming staff. There have already been 18 inquiries from local authorities expressing interest for the third year.

By its end, the project will have improved the swimming experience of more than 3,000 people living with dementia and 1,500 carers.

3 Improving diagnosis and transforming support after diagnosis

Key actions

- A new national ambition for a 75% diagnosis rate for dementia by 2017 across every area of England.
- Offer a tailored, nationally assured package of post-diagnosis support, including a Dementia Adviser, to everyone diagnosed with dementia.
- Identify the data that is required by commissioners and clinicians, and learn from the data collected in other disease areas (such as cancer), to better enable planning and delivery of services for people living with dementia.
- Ensure that by 2020 no one has to wait for more than two weeks from referral to first appointment at a memory clinic, through annual improvements which tackle delay from first referral to diagnosis.
- The Health and Social Care Information Centre should assess current memory service capacity, identify a baseline of current waiting times and report on these to measure improvement and gather similar data on the provision of post-diagnosis support.

Improving diagnosis

NHS England has committed to extending the existing two-thirds target on the proportion of people with dementia who are diagnosed in England to 2016, in order to further achieve and maintain this target. Department of Health and NHS England initiatives since 2012 have encouraged agencies across the system to:

- identify if people in at risk groups are experiencing symptoms of dementia
- refer people experiencing symptoms for assessment
- record a diagnosis on the GP register when it is achieved.

There has also been action to raise awareness of dementia, such as the Alzheimer's Society's Worried About Your Memory campaign and the Dementia Roadshow, along with concerted campaigning through our Right to Know campaign.

One of the key successes of the focus on dementia diagnosis has been the way in which the majority of GPs led the drive to increase diagnosis from a shockingly low 42% in 2012 to over 61.6% by the end of Prime Minister's challenge on dementia in 2015. There is now real potential to continue to increase diagnosis rates and the benefits a timely diagnosis provides.

Dementia diagnosis rates in England

The increase of the average diagnosis rate to 61.6% is an achievement, however the figures behind it remain variable, where the best-performing areas regularly achieve a 75% or better diagnosis rate, and the worst have improved from around 40% to just over 50% (HSCIC, 2015).

Of the 90 clinical commissioning groups (CCGs) with the fastest rate of increase between 2012 and 2015, 66% were above the national diagnosis rate in both 2012 and 2015. This suggests that the fastest improving CCGs are predominately those that were already performing well. To correct this, we need a renewed focus on those CCGs not currently delivering the national ambition to ensure that more under-performing CCGs improve as rapidly as the best performing.

Figure 3 CCGs with above average diagnosis rate 2012 and 2015

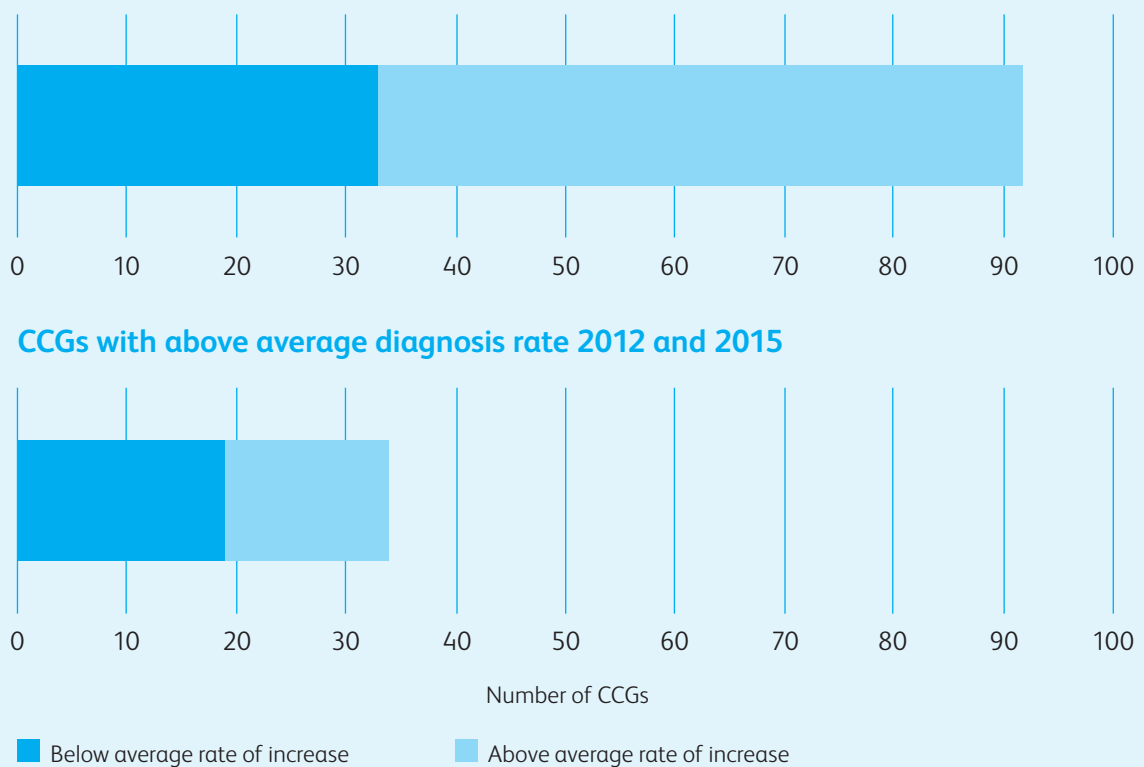
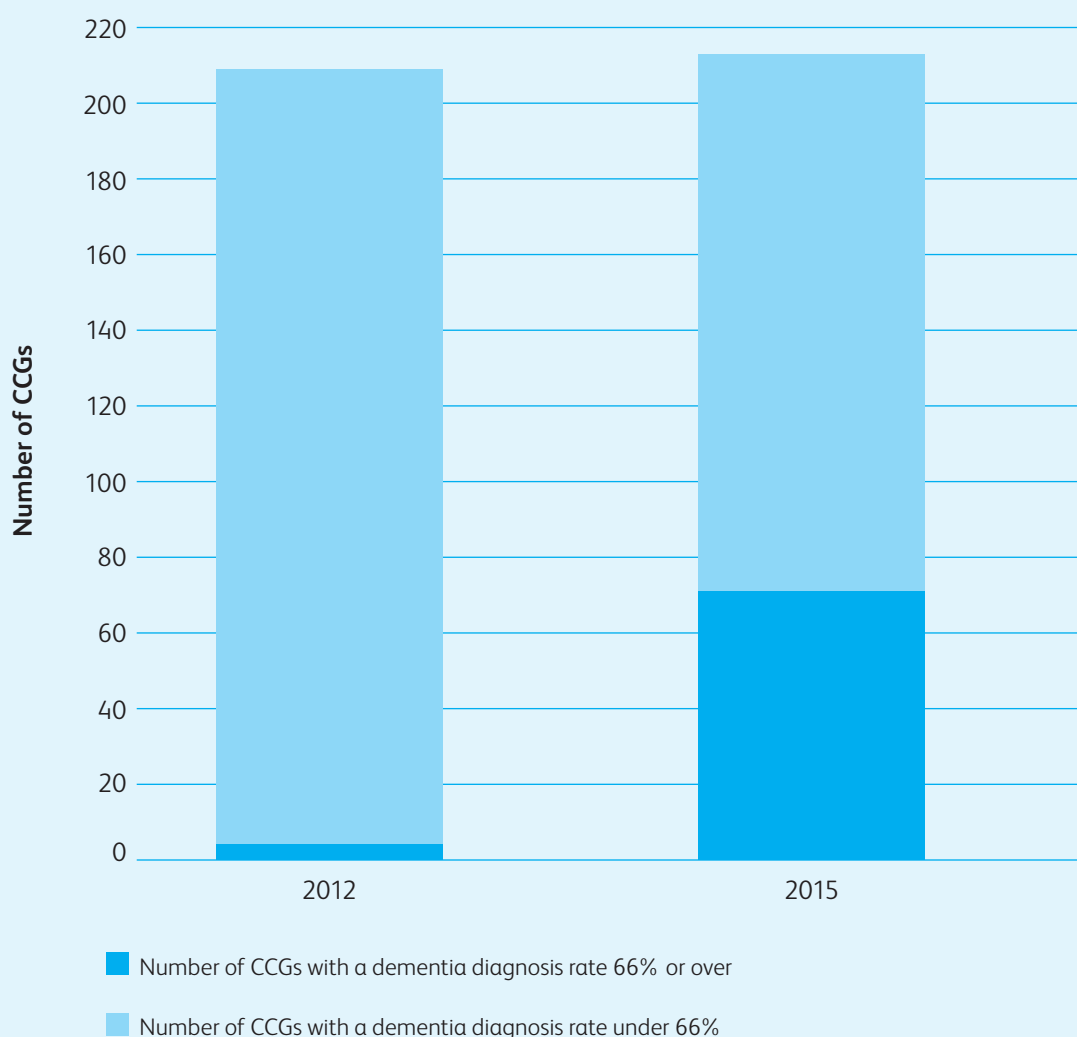


Figure 4 Number of CCGs with a dementia diagnosis rate of 66% or over in 2012 and 2015



Source: HSCIC 2015

The decision by NHS England to change the baseline data used to calculate dementia diagnosis rates needs to be communicated clearly, to ensure there is no reduced emphasis on the importance of diagnosis. Any changes which are charted over this period should be treated with caution and should take into account the change in data source when comparing year-on-year trends.

The last year has not been without its controversies in dementia diagnosis, in particular, the element of the Directed Enhanced Service for GPs on dementia that provided a £55 incentive for each addition to the Quality and Outcomes Framework (QOF) register. The financial incentive aspect of the programme was criticised in the media, although it was widely taken up by GPs and resulted in a 25% increase in the number of people on the QOF register during the months that it was in operation (HSCIC, 2015).

There has also been concern at the increased numbers of people being referred to memory clinics, and the impact this has on waiting times. The English National Memory Clinics Audit Report (Royal College of Psychiatrists, November 2013) showed that most clinics were meeting the standard set by the Memory Services National Accreditation Programme (that people should wait no more than 4–6 weeks between the receipt of referral and their first appointment). The average waiting time was 5.2 weeks. Nearly a quarter (24.3%) of clinics, however, had waiting times of over 6 weeks, and the maximum waiting time was 25 weeks. Audit data for 2014 is yet to be published.

Case study

Supporting diagnosis

In East Riding, Alzheimer's Society, in partnership with NHS England, funded one new Dementia Adviser through the Supporting Diagnosis project. As well as increasing the reach of post-diagnosis support provided in the area, the project has led to the Dementia Adviser becoming more integrated with GP practices, hospitals and memory clinics. The CCG has worked with the Dementia Adviser service to obtain use of a room in four GP practices for one day a week. The Dementia Adviser is also now working one day a week at the Hull Royal Infirmary to support discharge of patients with dementia, and also has a presence in the memory clinic and is part of the formal memory assessment process, providing a more seamless link to support after diagnosis.

This work has been supported by awareness-raising in the community, with the Roadshow bus visiting East Riding for four days. Alzheimer's Society has seen wider impact too, in that the local Dementia Action Alliance is attracting greater interest. The success of this work has led to the CCG extending the funding for the Dementia Adviser, as well as providing funding to deliver training sessions to GPs and for a new co-produced leaflet for GPs on the importance of diagnosis and with details of local support services, which has been shared through the Yorkshire & Humber NHS Strategic Clinical Network as an example of good practice.

NHS England's New Models of Care programme, launched in January 2015, focuses on the acceleration of the design and implementation of new models of care in the NHS, with a particular emphasis on achieving integration through the development of comprehensive local services. The programme offers a real opportunity to highlight existing and new services, particularly those provided by the voluntary sector that help improve integration and offer genuine person-centred care for people with dementia at the time of, and after, diagnosis.

Over a quarter (26%) of people with dementia responding to our survey said they were not involved in decisions about their care and support, while 61% said they were and 13% said they did not know.

It is crucial that a diagnosis translates into choice over care and support. Our survey found that over a quarter of people were still not involved in decisions about their care, despite the legal obligations on care providers to involve them as set out in the Mental Capacity Act 2005. It is essential that people are not left abandoned after a diagnosis, but can use this knowledge to plan for their future, through a guaranteed offer of post-diagnosis support. It is important that the ambition in the Prime Minister's challenge on dementia 2020 for all CCGs and health and wellbeing boards to have access to improved data to inform the commissioning and provision of data is realised. This will require an in-depth exploration of the data that commissioners and clinicians need, learning from the examples of types of data currently collected and how this is used in other disease areas, such as cancer, stroke, cardiovascular disease and diabetes.

We are pleased to see priority placed in the Prime Minister's challenge on dementia 2020 on the process of diagnosis, including waiting times. To see this vision become a reality, there would need to be considered investment in each geographical area to ensure sufficient memory service capacity to meet the needs of the area. Peer-to-peer learning, where areas with longer waiting times can learn from areas with shorter waiting times, must also be encouraged. In order to increase the number of people from black, Asian and minority ethnic backgrounds, the recommendations of the All-Party Parliamentary Group on Dementia 2013 report should be enacted to ensure that people from diverse backgrounds have access to a diagnosis (APPG, 2013). Alongside appropriate diagnosis tools, this also includes awareness-raising campaigns run by Public Health England targeted at, and culturally sensitive to, specific minority groups.

In order to monitor this, the Health and Social Care Information Centre should gather sufficient data on memory service capacity and a baseline of current waiting times. There should be a commitment to reporting on these in order to monitor progress and measure improvement.

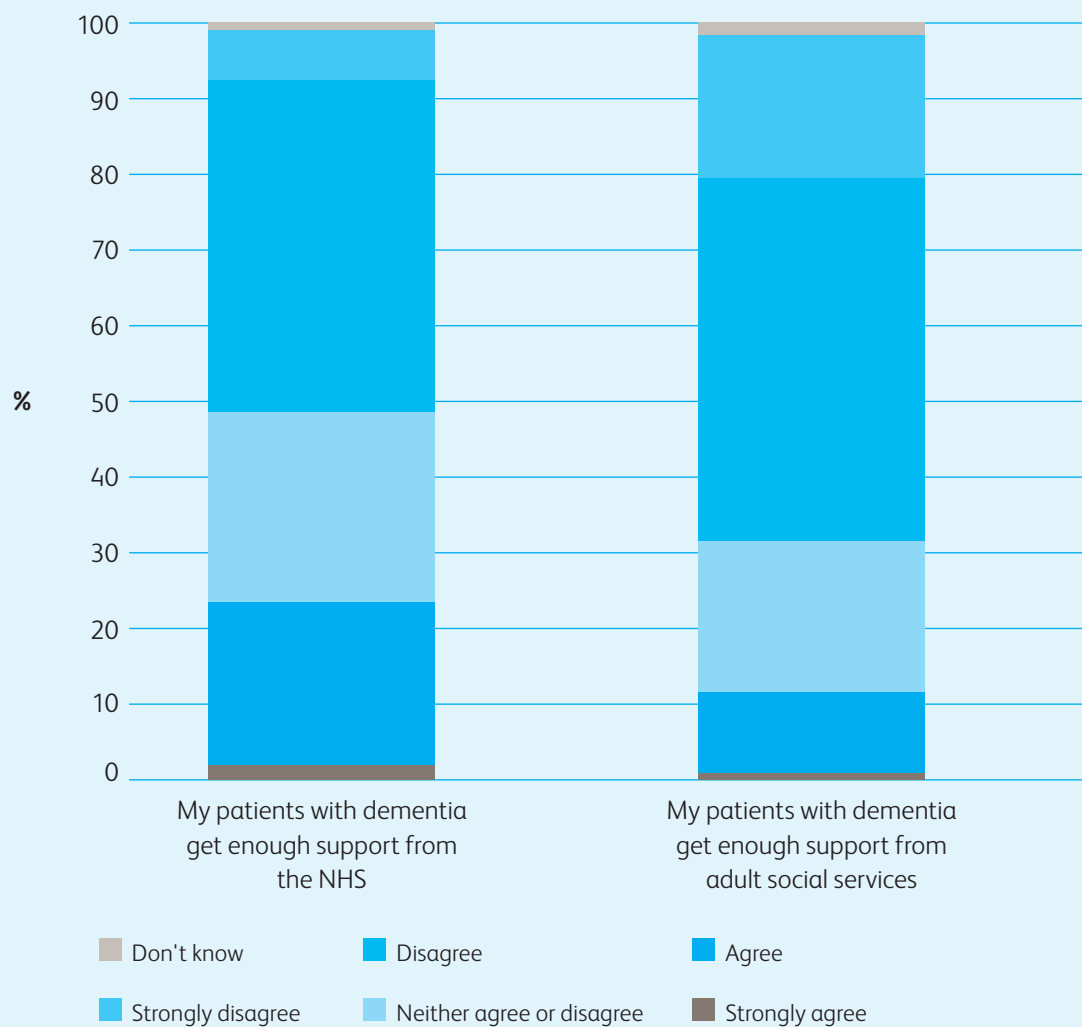
Accessing post-diagnosis support: Views of GPs

Alzheimer's Society commissioned a poll of 1,013 GPs through MedeConnect Healthcare Insight to seek their views on access to post-diagnosis support. It was clear from their responses that GPs believe that the level of support on offer from statutory services is not sufficient, with half or more saying that patients did not get enough support from the NHS or social services.

- **Half of GPs (50%) don't think their patients with dementia get enough support from the NHS.**
- **Over two-thirds (67%) of GPs don't think their patients with dementia get enough support from social services.**
- **More than three-quarters (77%) of GPs think their patients are having to rely on family members as they don't get enough support from health and adult social services. 73% said they have to rely on unpaid carers (eg friend, neighbours).**

- Less than 1 in 10 (9%) of GPs think their patients get enough support with isolation and loneliness from the NHS and social services.
- Less than 1 in 6 (16%) of GPs think their patients get enough day-to-day support to remain independent from the NHS and social services.

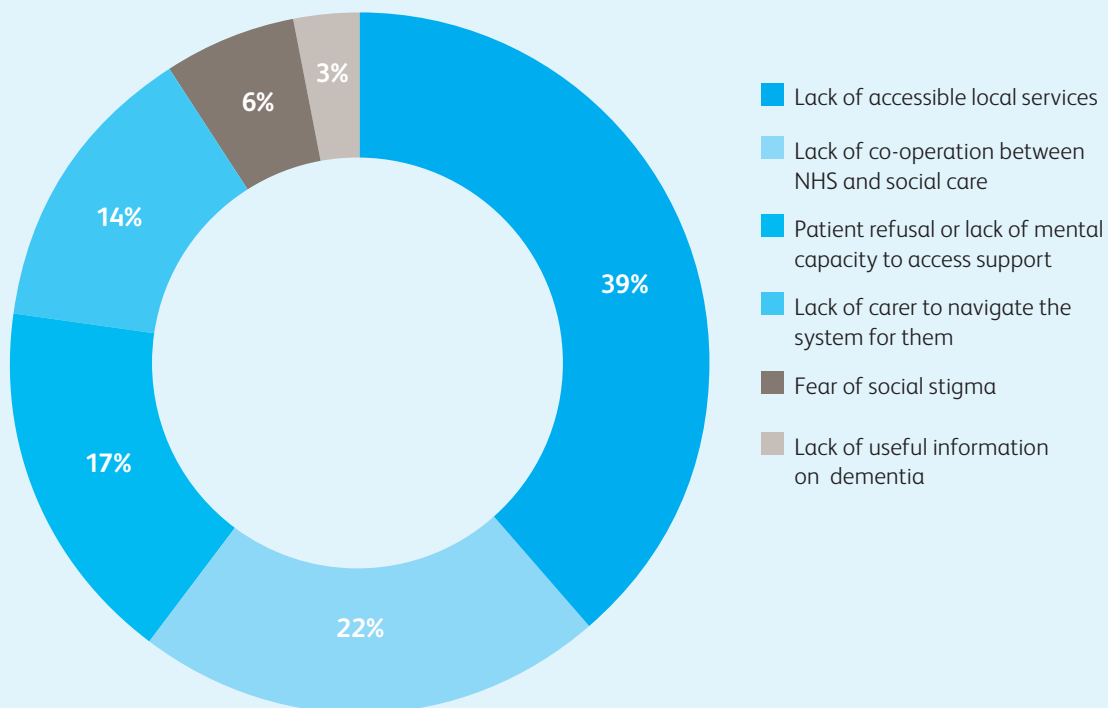
Figure 5 GP views on support from NHS and adult social care for people with dementia



GPs also report that the system is confusing for people with dementia and carers to navigate, and that a lack of accessible local services is a barrier to support. This reflects the impact of a lack of integration of services and of underfunding of community services for dementia, as discussed elsewhere in the report.

- 73% of GPs agree that it is confusing for people with dementia and carers to navigate the health and social care system.
- Only 1 in 5 (20%) said that there are integrated services for people with dementia in their area that deliver effective person-centred care. Nearly half (46 %) said that there were not.
- 70% of GPs cited lack of accessible local services as the main barrier to support.
- 64% of GPs also felt that lack of a carer to navigate the system for them was a barrier to someone with dementia getting the support that they need.

Figure 6 Main barriers for people with dementia getting the support they need following a diagnosis



It is clear that GPs also see a lack of support from services as a barrier to the person with dementia being able to access the support that GPs themselves could offer.

- **23% of GPs say they haven't had sufficient training in dementia to give them a good understanding of how to manage a person with the condition.**

- **Over a quarter of GPs (27 %) said they would be less likely to refer people with suspected dementia for a diagnosis if there isn't enough local support in place.**

- **23% of GPs would be less likely to diagnose/refer for a diagnosis where it is not clear what treatment or support they will get after the diagnosis.**

- **33% of GPs would be less likely to diagnose/refer for a diagnosis someone who lives in a care home.**

- **25% of GPs would be less likely to diagnose/refer for a diagnosis where the person's dementia is already very advanced.**

- **16% would be less likely to diagnose/refer for a diagnosis where the person has other complex health conditions.**

This evidence again demonstrates the importance of a joined-up approach for dementia, locally and nationally, designed to achieve change across the whole system. GPs do not work in isolation, and it is clear that the issues that they see in the rest of the system are having an impact on what should be a clear-cut decision to refer for diagnosis.

After a diagnosis of dementia, people may be anxious and unsure of where to go for information, support and guidance. Of those living with dementia who answered our survey, 53% said they had felt anxious or depressed recently, and this was highest among those who had started experiencing symptoms most recently (58% for those who had been experiencing symptoms for a year, and 56% for those who had been experiencing symptoms for 1–3 years). It is important that people are aware that it is possible to live well with dementia and are provided with information and advice on how best to do so early on in the course of the illness, while they have capacity and ability to plan and make decisions. Everyone should receive a copy of Alzheimer's Society post-diagnosis publication *The dementia guide*, and information on Alzheimer's Society's helpline or other community-based resources.

When asked whether they had felt anxious or depressed recently, 53% of people responding to our survey said yes, 36% said they had not and 11% said they didn't know.

More of the people who had been experiencing symptoms for a shorter period of time reported being anxious or depressed, with 58% of people who had been experiencing symptoms for 1 year saying they had been anxious or depressed and 56% who had been experiencing symptoms for 1–3 years saying the same. By contrast, only 50% of those who had symptoms for 7–9 years reported feeling anxious or depressed.

While it is important to maintain the focus on diagnosis, it is equally vital to ensure that this knowledge gives people in this position the benefits of accessing the care and support they need in a timely manner.

Effective post-diagnosis support allows people with dementia to access appropriate information, make adaptations to the condition and plan for the future. While there is growing consensus on the importance of this, there has, as yet, been little action to incentivise proactive work in this area. Alzheimer's Society welcomes the element of the Prime Minister's challenge on dementia 2020 for everyone to have a named GP (Department of Health, 2015). This must lead to a more joined-up approach in care for people with dementia, and GPs must have support to deliver this, for example through access to Dementia Advisers.

With the Right to Know Campaign, we take this call further, ie to ensure everybody diagnosed with dementia is entitled to an extensive package of post-diagnosis support that includes access to a Dementia Adviser. This reflects the Secretary of State for Health's ambition that everyone diagnosed with dementia should be offered high-quality support, and the commitment within the Prime Minister's challenge on dementia 2020 stating that this should be in accordance with published NICE Quality Standards.

Dementia Advisers offer personalised support from the point of diagnosis and help people with dementia and their carers navigate the health and care system. Dementia Advisers also help to make use of community resources and pre-existing social networks. It is vital that Dementia Advisers have specialist knowledge of dementia and the services available as the nature of dementia presents specific challenges to navigating the system.

Case study

Integrated services in Tower Hamlets

Tower Hamlets commissions a range of services with a community pathway that is entirely integrated across health and social care. This includes a diagnostic memory clinic, a community dementia team and an extra care sheltered scheme for people with dementia. As part of the community awareness-raising activities, an Alzheimer's Society employee trained 120 local imams to understand dementia and its issues. This resulted in the imams delivering special sessions devoted to teaching the local community about dementia in their mosques.

People attending the memory clinic are offered post-diagnostic counselling and pastoral support by the Alzheimer's Society Dementia Adviser service. Any person with a diagnosis of dementia in the borough is now offered the telephone number of a health and social worker who works in the dementia pathway. This could be a Dementia Adviser, if the person has mild problems associated with their dementia, or a doctor or nurse from the community dementia team, if they have more complex problems. The community dementia team provide ongoing support for anyone with moderate to severe needs and also provides outreach into care homes and into primary care. The team also provides various therapeutic groups.

Tower Hamlets has shown that integrated services can deliver improved diagnosis rates and financial savings. Within a year, referrals to the memory service doubled, with a proportionate increase in the black, Asian and minority ethnic community, and in 2012 the diagnosis rate increased by 9.6% to 50%, making Tower Hamlets the most improved organisation in England over this period.

We now need a national consensus on what would be a minimum level of post-diagnosis support. Adequate resource should be prioritised and available to fund this in every geographical area. Within this framework, support can remain flexible and adapted to the individual and their family. Health and social care professionals must ensure that any interactions with, and care provided for, a person with dementia is personalised to ensure the care meets the individual's needs. Inclusion of the needs of the carer is also essential, as part of this support.

Alzheimer's Society is encouraged by the government's introduction of progress tracking of post-diagnosis support. At present, there is no nationally held data on what support is commissioned for people with dementia and this must change.

Clinical commissioning groups and local authorities should be required to provide annual reports to the Health and Social Care Information Centre (HSCIC) detailing what has been commissioned. When measuring the success of post-diagnosis support, it is important to measure it against the aspirations and expectations of the person with dementia and their families, benchmarking it against a standardised national package of post-diagnosis support. It is therefore clear that information should not only be collected on what is being provided, but also on the outcomes of these services for the people they are working with.

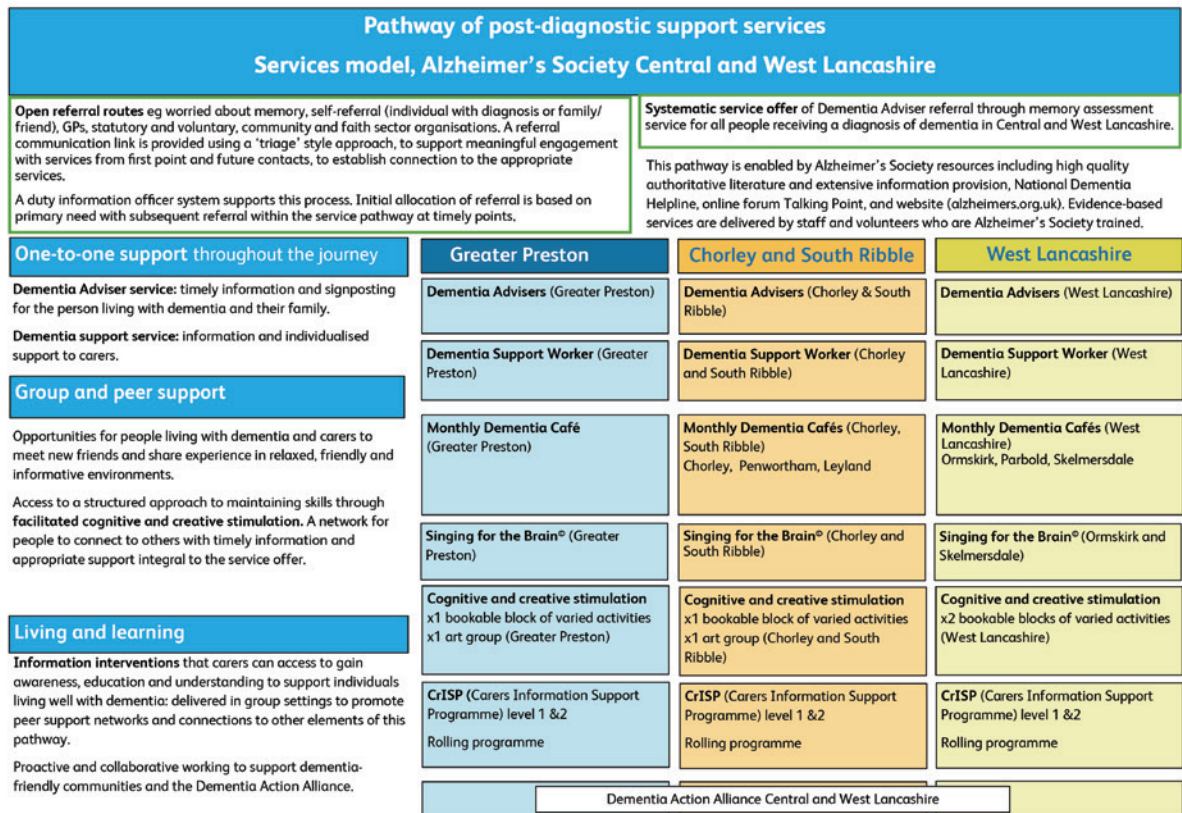
New models of dementia care

Alzheimer's Society's Supporting Diagnosis project, in partnership with NHS England and working with 28 CCGs, has demonstrated what an organised, tailored approach can achieve. This includes increased dementia awareness and post-diagnosis support, access to information for people who may be worried about their memory, and improved relationships between key stakeholders that lead to improved diagnosis rates, referral and uptake of support after diagnosis. This provides a model of dementia care that can be developed further to incorporate and join up hospital and residential care, in addition to care and support in the community and primary care.

Central Lancashire's pathway of post-diagnosis support services is one such example of genuinely person-centred care, available as an integral part of local care for people with dementia. It provides an offer of Dementia Adviser referral through the Memory Assessment Service for all people receiving a diagnosis in Central Lancashire. The service has introduced a one-stop visit for assessment and diagnosis for selected patients.

On receipt of the referral, service users are contacted by telephone within 24 hours to start the assessment process. Where appropriate, scan requests and other tests are arranged and information is sent to the patient in advance of their appointment. Suitable patients receive a one-stop single assessment with a nurse, including diagnosis and treatment, enabling 40% of users to leave clinic with a diagnosis. This in turn has improved clinic capacity, which has helped improve waiting times for assessment.

Figure 7 Central Lancashire’s pathway of post-diagnostic support services



Source: Alzheimer’s Society

4 Supporting carers

Key actions

- Local authorities should ensure that their assessments of carers under the Care Act are sensitive to the needs of dementia carers.
- Carers should have a right to access short breaks and respite, as well as support services such as befriending.
- Carers should be seen as partners in care and have a single point of access to help navigate and engage with care and support services.
- Local authorities and GPs should be trained to identify carers and the GMC should ensure that an indicator on the identification of carers is included in the QOF register from 2016/17.
- The government should create a legislative framework that requires employers to provide support to carers in order to reduce the 21% of carers of people with dementia who give up work or reduce their hours as a result of their caring responsibilities.
- Carers should have access to help and support through a single point of contact.

There are currently around 670,000 carers of people with dementia in the UK, who between them save the UK economy £11.6 billion a year through the care they provide (Prince et al, 2014). Their contribution, without which the health and care system could not function, can often come at a personal cost to the individual caring for the person with dementia. Caring for a person with dementia is unlike caring for a person with any other condition and many will experience high levels of stress and even depression (Carers Trust, 2013). Many report not being provided with information and advice on basic practical issues (Carers Trust, 2013).

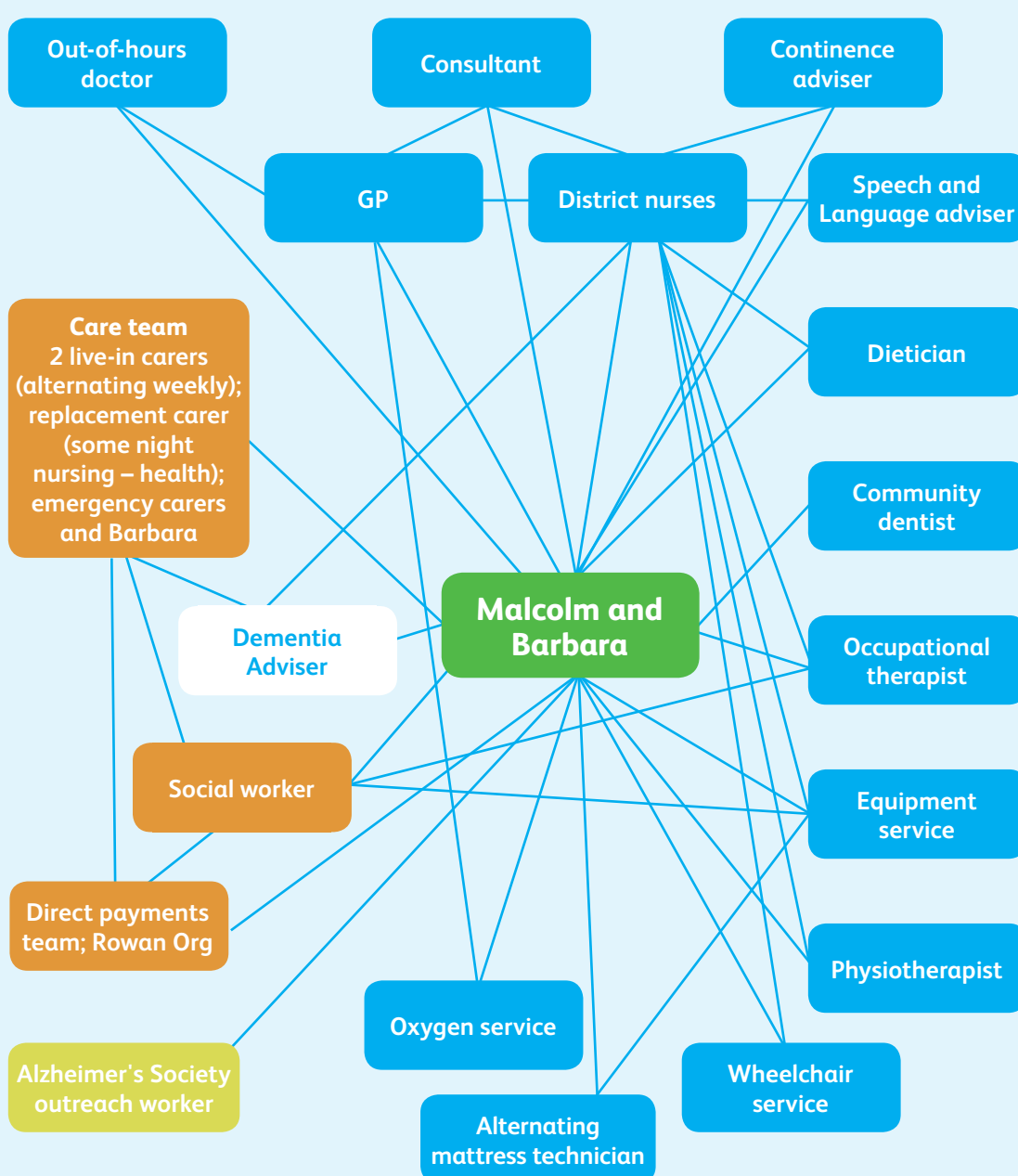
Nearly half of respondents to our survey (49%) said that their carer did not receive help, while 39% said their carer did receive help and 12% said they did not know.

The experiences of people with dementia and their carers depict a complex web of health and care services and staff with whom they have to interact and navigate in order to get the care and support they need. Much of this complexity stems from the differences between the types of care and the range of services they need, from day-to-day care, to managing personal budgets or direct payments, accessing out-of-hours doctors, and other things like equipment

services. And these are just the things that are related to their dementia. This complexity in navigating services is compounded by the fact that many people with dementia may have up to six other health conditions. The diagram below reflects this 'web of care'.

It highlights the complexity and difficulties that people with dementia and their carers face trying to navigate access to vital services and support. In contrast to this, having one named person as a point of contact for the person with dementia and carer holds the potential to transform this experience for the better and significantly improve access to care and support. A Dementia Adviser could play this important role.

Figure 8 Barbara Pointon's 'Web of Care' (last 7 years)



The Care Act 2014, which came into force in April 2015, provides a turning point in terms of recognition of the needs of carers in England. For the first time, local authorities must offer carers an assessment regardless of the needs of the person they care for. The assessment must consider how services would support the carer to achieve their own personal outcomes and whether the carer is willing and able to continue to care. It is currently still too early to tell how this is going to work in practice, but without any additional funding for social care, local authorities may face challenges to meet all the needs of carers of people with dementia.

Carers' feelings of being unsupported are recognised in the Prime Minister's challenge on dementia 2020 (Department of Health, 2015). However, transforming ambition into reality requires local authorities to ensure firstly, that their carers' assessments are sensitive to the needs of dementia carers, as well as being able to offer breaks and befriending where appropriate. It is also key that the importance of social action and befriending are recognised.

Case study

The Carer Information and Support Programme

Alzheimer's Society's Carer Information and Support Programme (CrISP) provides training to carers, enabling them to cope with the emotional and psychological pressures of caring for a person with dementia by giving them an insight into the condition (Barnes et al, 2013). The Programme also includes a session on legal and money matters, which includes how to arrange Lasting Power of Attorney.

Following its national roll-out, over 200 CrISP services started in 2014/15, reaching over 1,000 carers, building knowledge, sharing experiences and identifying local support.

Local authorities and GPs must also be skilled in identifying carers of people with dementia. It will require them to ask the right questions to ascertain the information and direct them to the right support. In 2013, NICE recommended that the Quality and Outcomes Framework (QOF) offered incentives to GPs to identify and record carers of people with dementia (NICE 2013); however, to date this has not yet appeared in the QOF. Doing so would be a positive step in identifying carers of people with dementia and ensuring they access the right services and support. The General Medical Council must take responsibility for ensuring that this indicator is adopted on to the QOF register from 2016/17.

The Prime Minister's challenge on dementia 2020 also includes an ambition to increase the numbers of employers who support carers to remain in work. In the survey for Employers for Carers, two-fifths (41%) of respondents stated that they would like more flexible working arrangements. In order for this vision to become a reality, the government must create a legislative framework to support employers to provide carer support schemes.

Often carers are balancing their own work and family life. In a survey for Employers for Carers in 2014 (Employers for Carers, 2014), just over half of respondents said that their work had been negatively affected by their caring responsibilities.

Developing and increasing further practical and emotional support for carers of people with dementia is vital. The cost of dementia to businesses in England research (CEBR, 2014) also found that around 12% of carers have to adjust their working patterns through either having to reduce their employment hours, take on less responsibilities at work or doing some form of flexible working. A total of 9% have to leave their job altogether.

Alzheimer's Society, in partnership with a number of external organisations, have produced *Creating a dementia-friendly workplace: A practical guide for employers*. This resource is designed to help employers – large, medium and small – to gain a better understanding of dementia and how it impacts on their workforce. It also provides practical advice for employers on how best to support people with dementia who are still in the employment. It outlines a variety of scenarios which can occur and provides a range of practical suggested responses.

Since the launch of the Guide in April 2015, over 2,000 copies have been sent to a range of organisations who we hope will implement the suggestions as part of their HR policies.

Case study

Alzheimer's Society National Dementia Helpline

Responding to over 36,000 calls and contacts a year, Alzheimer's Society's own National Dementia Helpline offers information, advice and emotional support to anyone affected by dementia in England, Northern Ireland and Wales.

The success of the helpline and its expansion into new and innovative ways of enabling people to access support and advice reflects not only the Society's commitment to helping people affected by dementia, but also the increased levels of demand from people who need that help, at a time of increased pressures and carers reaching crisis point.

Between April 2014 and March 2015, 62% of enquiries to the helpline were from carers, relatives or friends. 6% were from people concerned about their memory, 8% were from social/care workers and 2% of enquiries were from people who disclosed they had dementia.

- 26% of enquirers wanted information and advice on dementia
- 26% wanted information and advice on Alzheimer's Society and local services
- 18% asked for information and advice on care services
- 14% wanted information and advice about dementia treatments and care options
- 14% wanted information and advice on legal and financial matters relating to dementia

Case study

Alzheimer's Society National Dementia Helpline (continued)

In that same period, the National Dementia Helpline responded to:

- 36,328 enquiries, an increase of 38% compared to the previous year.
- 4,606 enquiries during the weekends, when other forms of support and advice are not as easily accessible. This was an increase of 46% compared to the previous year.

In addition, the helpline has developed several innovative ways of working to offer even more support and advice:

- Live Online Advice providing people with an alternative way to communicate with an adviser one-to-one in a confidential setting. Compared to its three month pilot in January 2014, where this service dealt with 57 enquiries, in the same period this year Live Online Advice dealt with 143 enquiries, an increase of 150%.
 - Opening hours on Mondays, Tuesdays and Wednesdays extended until 8pm, helping increase the number of people using the service, improve response rates to calls and emails, and enable the Live Online Advice service to be extended into the evenings.
 - Facebook advice sessions, where a Helpline adviser is available for an hour to answer questions on a specific topic. This, and further sessions have been well received, and these will also extend into the evenings and weekends.
 - Telephone helpdesk service to assist people registering with 'Join dementia research', a new national initiative that connects people with and without dementia to the latest research studies.
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5 Delivering dementia-friendly health and care settings

Key actions

- All health and social care settings to be dementia friendly by 2020.
- The government should support integration of health and social care by removing the barriers created by the different funding systems for the NHS and social care.
- Central government should regulate homecare providers to ensure visits are no less than 30 minutes.
- Local authorities should increase services that provide social interaction for people with dementia living at home to end the hidden and harmful epidemic of loneliness.
- Local NHS and councils must increase spending on community dementia services to reduce pressure on long-term care and acute services.
- The government should implement the recommendations of the Health Select Committee inquiry into end-of-life care and the recommendations of the choice review, including 100% coverage of electronic palliative care co-ordination systems by the end of 2018.
- The Health and Social Care Information Centre should repeat the audit of the use of antipsychotics so that progress towards the elimination of unacceptable use of antipsychotics can be monitored.

Care in hospitals

High quality, dementia-friendly care for people in hospitals exists in certain areas and should be acknowledged, however not all of these examples reach right across their organisations, and the level of awareness and dementia-friendliness may even vary in quality between wards or individual departments.

Hospitals are still frequently challenging and disorientating places for people with dementia, and more needs to be done to make them totally dementia-friendly environments.

Despite key national objectives and strategies to reduce variability and improve care, there is still unacceptable variation in the quality of care for people with dementia in hospital and at discharge. The Care Quality Commission's thematic review of dementia and their Cracks in the pathway report (Care Quality Commission, 2014), identified areas of good practice, but found that there are still many issues, with people with dementia being admitted to hospital when they do not need to be, and not being discharged quickly enough. The CQC concluded that the variation in experiences of people with dementia meant that they are 'likely to experience poor care at some point along their care pathway'.

The issues around hospital care for people with dementia have been the subject of numerous objectives and recommendations, including one of the objectives within the previous national strategy. One in four hospital beds are occupied by people with dementia. This amounted to a total of 3.2 million bed days in 2013/14 (Parliament.co.uk, 2014). Alzheimer's Society also commissioned independent research which showed that people with dementia stay in hospital longer than people who don't have dementia, and are more likely to suffer a fall in hospital. Where people with dementia have an increased length of stay, the effect on the symptoms of their dementia and their physical health means that discharge to a care home becomes more likely, as does the use of antipsychotic drugs (CHKS, 2015). Alzheimer's Society will publish further details of this research in Autumn 2015.

The Prime Minister's challenge on dementia 2020 (Department of Health, 2015) renews some of the key objectives on improving dementia care and support. In particular, it states that all hospitals and care homes should meet agreed criteria to becoming a dementia-friendly health and care setting. Significant progress has been made in this area through work such as Enhancing Healing Environments by the King's Fund, who have worked with more than 250 health and social care organisations including acute, mental health and community NHS trusts, care homes, and hospices.

Also stated in the Prime Minister's challenge on dementia 2020 is that there should be greater identification and referral of dementia in hospitals, and more targeted inspection of dementia care in hospitals, noting the CQC's commitment to appointing a new national specialist adviser for dementia care, and training of inspectors to understand what good dementia care looks like.

Similarly, there needs to be consistent understanding of what a 'dementia-friendly' hospital means, and using learning from established areas of good practice. This should be established by mid-2016.

Over 90% of hospitals signed up to the Dementia Action Alliance's Right care call to action launched in 2012, committing to becoming dementia friendly, but there is still a way to go to turn commitment into action. Since then, the DAA has developed the Right Care Hospital Charter (DAA, 2014). This provides a short, accessible and visible statement of the principles that contribute to a dementia-friendly hospital, and a set of expectations that people with dementia and carers can have when they access a dementia-friendly hospital.

2015 has seen the launch of John's Campaign. This calls for the rights of carers to be recognised for what they can do to aid people with dementia by staying with them in hospital. The focus is on enabling the person's needs to be met by making them comfortable and reassured and allowing clinical staff to focus on their clinical roles.

Co-morbidities and dementia

75% of people who responded to the survey said that they had another health condition in addition to their dementia.

The range of other conditions that people with dementia have is varied, but the most common ones are arthritis, hearing problems, heart disease or a physical disability (Prince et al, 2014).

Old age is already associated with high levels of co-morbidity, with the Newcastle 85+ cohort study finding that the median number of diseases is four for men and five for women (Collerton et al, 2009). There are particular issues around co-morbidity and dementia, and in particular how a person's dementia and the stage of dementia that they are at affect how they are able to manage other conditions. This creates more complex needs for people, who then have to interact with a range of health and social care services. It is essential that these people receive appropriate care and support for all their conditions, meaning that all of the health and social care professionals they come into contact with must have an adequate level of knowledge about dementia.

The findings of the study *Co-morbidity and dementia: Improving healthcare for people with dementia* (Bunn et al, 2015) suggested a lack of continuity of care for people with dementia and co-morbidities and poorer access to services with healthcare professionals often prioritising co-morbidity over dementia. As part of the challenge to coordinate care, the carer of the person with dementia can often end up playing a significant role in making the right links and transferring information across services.

Services need to be integrated to provide quality care to people with dementia who have multiple other conditions. It is difficult to meet their complex needs, and fragmented services result in a poorer experience of care.

Care in care homes

Care homes remain the largest institutional settings where people with dementia receive care, and the setting where the majority of people with dementia reach the end of their lives (Alzheimer's Society, 2012). A third of people with dementia live in care homes (Prince et al, 2014) and up to 70% of care home residents in the UK have dementia or significant memory problems (Alzheimer's Society, 2014a). 75% of the respondents to our survey had an additional health condition other than their dementia. It is likely that these conditions, as well as dementia alone, may require a hospital stay or someone to move into a care home.

It is essential that care home settings meet the needs of people with dementia. Research evidence shows that a care home's built environment has an impact on people with dementia's quality of life. Alzheimer's Society's 2015 election manifesto, *The dementia promise* called for the government to commit to all care home environments being dementia-friendly, and we are pleased to see this acknowledged in the Prime Minister's challenge on dementia 2020, however there needs to be cross-sector agreement on what this entails and action to make it a reality. To help lead the way, the Dementia Action Alliance is working with the architecture firm Pozzoni to share specialist knowledge and best practice to help improve the built environment of care homes for people with dementia.

2015 has also brought significant changes for the care home sector. On 1 April 2015, the Care Act, the biggest piece of legislation ever to affect adult social care in England, came into force. While measures relating to what people will need to pay for care fees, including the proposed cap on care costs, will not be implemented until 2016, there is concern among the sector about what the changes will mean for current business models. Local authorities' funding of care homes has not kept pace with inflation. In 2014–15, a survey of the country's care homes found that the cost of running a care home continued to rise at a rate that outstripped fees paid by local authorities. This amounts to a shortfall of £71 per week per person with dementia (LaingBuisson, 2015). This downward pressure on fees is set to continue. The annual Association of Directors of Adult Social Services budget survey has found that councils plan to save a further £32 million by freezing funding to care home fees in 2015/16 (ADASS, 2015).

This continued downward pressure on fees may have an adverse impact on the quality of care received by people with dementia. As ADASS have argued, the freeze on fees is already impacting on staff skills, staff training, staff remuneration and staff satisfaction. In addition, 56% of ADASS chief officer members agree that providers are facing financial difficulties. Alzheimer's Society strongly supports ADASS's call for adequate funding for care homes.

Care England have also reinforced the call for care workers to be paid the living wage, reflecting the complexity of the duties they carry out and the compassion they demonstrate in their roles. For more information on the residential care workforce, and dementia training, see Chapter 6.

Another significant event this year has been the impact of the Supreme Court ruling regarding Deprivation of Liberty Safeguards (DOLS). In hospitals and care homes, local authorities are responsible for authorising deprivation of liberty for care in a person's best interests. The Supreme Court ruling clarified many of the situations which would be considered to be a deprivation of liberty, and as a result more situations where a safeguard was required were brought to the attention of care homes. This has led to a dramatic increase in applications. The Law Commission is reviewing how deprivation of liberty should be authorised and supervised in hospitals and care homes. We want to see change in how this is approached, with much wider awareness and training to ensure that health and care staff know how to implement DOLS safely and appropriately.

Care at home

People with dementia benefit from being in familiar surroundings in which they are comfortable. Alzheimer's Society believes there needs to be a national focus on providing good quality care at home as, with the right support, it is possible for people with dementia to live independently in their own homes, sometimes until the end of their lives. It is encouraging that 82% of people responding to our survey said they had enough people to count on for support. However, 11% said they did not, and 7% said they did not know. We do not know if this constitutes a lack of support from family, communities or from formal care services.

While 82% of people responding to our survey said they had enough people to count on for support, 11% said they did not and 7% said they did not know.

Good quality care at home can reduce admissions to acute hospital care and early entry into care homes (Alzheimer's Society, 2011) providing savings for the health and social care economy. At present too many hospital beds are occupied by people with dementia who can't be discharged because there isn't adequate support in the community. People often have to move into care homes, when they could continue to live at home, because the support isn't in place. This needs to change.

Alzheimer's Society welcomes the ambition to increase numbers of people with dementia who will be able to live in their own homes, but believes many practical steps are required to improve homecare and to address the wider context of people with dementia who live at home. People with dementia should be provided with care that enables them to live fulfilled lives and remain independent for as long as possible. This is especially important when it's considered that two-thirds of people with dementia live in the community (Alzheimer's Society, 2007) and of those living in the community one-third live alone (Mirando-Costillo, 2010).

In providing appropriate care at home, it is vital that visits are no shorter than 30 minutes and the government should bring forward changes to regulations to ensure this. One survey (UKHCA, 2013) reported that 16% of visits lasted only 15 minutes, while the results of a request made under the Freedom of Information Act in February 2015 showed that from 2010/11 to 2012/13, eight councils provided more than 593,000 care visits to pensioners lasting just five minutes or less (the Telegraph, 2015). Any home visit must address the person's day-to-day needs, such as being washed and dressed, but there should also be regard to broader needs, for instance maintaining independence and recognition that people's dignity must be maintained. For example, it would be beneficial for homecare workers to be educated on assistive technologies, such as alarms, automatic lighting and telecare. Sharing this information with people with dementia and their loved ones could support them to remain in their own homes for longer.

It is important to recognise the importance of social interactions for people living with dementia. Care workers and Dementia Advisers should utilise existing social networks and local services so the person with dementia can remain socially active if they wish to. This could include engaging with befriending services or accessing local social networks such as walking groups or singing groups. Health and wellbeing boards should enable the commissioning of services such as these and ensure that there are sufficient numbers commissioned to match the needs of the population.

Case study

Reducing social isolation: Side by Side

Alzheimer's Society is trialling a new national service called Side by Side to help people with dementia keep doing the things they love with the support of a volunteer, or to try something new. It is being designed to help people with dementia to become an active part of their community again.

Volunteers support people to get out and about so they can do something they enjoy, whether it's to see a football match or for a chat over a cup of tea – it is entirely based on what the person with dementia wants.

Joan Evans manages the pilot project in Somerset, one of 17 areas where Side by Side is being trialled. People are referred to the service by health and social care professionals, or they can get in touch directly or through carers and friends.

She says: 'People with dementia can become very isolated and stop doing things because they lose confidence, but with a bit of support they can resume their hobbies and even try new things.'

Joan says that helping people to do simple things can make a big difference. 'Walking is popular, as is going to garden centres and cafés. Volunteers take people to Singing for the Brain sessions, and one younger person has said he would like to go to a music festival.'

'People aren't asking for the earth but if you don't go anywhere then getting out once a week can make all the difference.'

Joined-up services for people with dementia

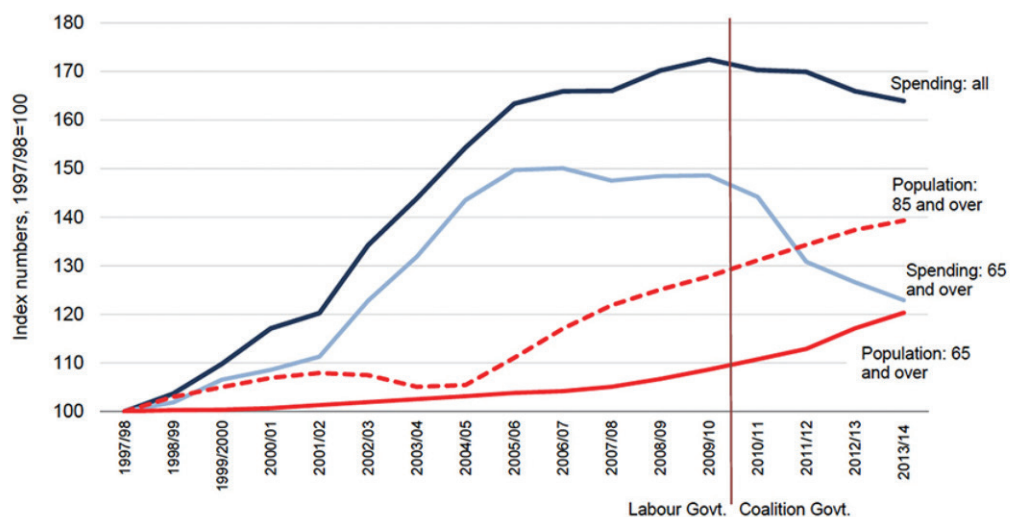
Person-centred care for people with dementia is key. If our current health and social care system is failing to meet the needs of people with dementia, then it is letting down a significant proportion of the ageing population and, importantly, those who require these vital services to maintain a good quality of life.

If services are to become truly integrated, focusing on the person's needs and those of their carer, and looking additionally at their needs beyond health and social care, then getting care and support right for people with dementia means getting it right for the frail elderly. We believe that there is a case for making dementia the test condition to determine the success of initiatives to meet the health, social care and other needs of an ageing population. In particular, within NHS England's New Models of Care programme, person-centred care for people with dementia is key to meeting the outcomes that this programme's Vanguard sites have been charged with achieving.

We want to see action from government drive forward the agenda on integration of health and social care. While there is pioneering work in a number of areas to achieve this, too many people with dementia fall between the two systems at the time when they most need care. By taking steps to remove the barriers to integration created by the charging system, the government would simultaneously make the system fairer for those facing the unfair charging associated with dementia care and help ensure better care.

Spending on adult social services in England has decreased by 12% since 2010 (ADASS, 2014). In such testing times, Alzheimer's Society believes that commissioners must prioritise spending on community dementia services to reduce pressure on long-term care and acute services. This will benefit the health and social care economy as well as enabling people to remain in their own homes for longer. It is also essential that the government addresses the crisis in social care funding identified by ADASS, and explores options to create a fairer settlement across health and social care. They should ensure that people with dementia have their care protected and do not end up going into hospital simply due to lack of care available to them.

Growth in population and changes in spending on adult social care, 1997/98–2012/13



Sources: *Personal Social Services Expenditure and Unit Cost in England 2013-14*, ONS population estimates.

Source: King's Fund

Housing

Homes and housing must be adapted, designed and built to meet the needs of our ageing population. At present, the majority of older people and people with dementia own their own home. Many of these homes are unsuitable. Only around 5% of older people live in a home that is purpose-built for older people and the majority of these homes are in the social sector (NHF, 2011). There will be an estimated shortfall of 240,000 homes for older people in the UK by 2030 (Housing LIN, 2013).

The Dementia Action Alliance has found that there has been little progress against the 2009 National Dementia Strategy's objective to 'consider the potential for housing-related support, housing services and telecare to support people with dementia and their carers' (DAA, 2014). In order to ensure that more people with dementia can live well in their own homes, government schemes such as the Department of Health's 2013–15 Specialised Care and Support Housing Fund should be expanded. In addition, housing associations should continue to work towards a dementia-friendly housing workforce. A first step is to raise awareness of dementia amongst the workforce and management, and provide relevant training (Housing LIN, 2014).

End-of-life care

Statistics released at the end of 2014 showed that dementia is now the leading cause of death among women (ONS, 2014). Despite this, the Voices survey of bereaved relatives found that the relatives of people with dementia rated the care from hospital doctors and nurses, as well as care from GPs, as worse than the people whose relative did not have dementia (ONS, 2014a).

In December 2014, Marie Curie and Alzheimer's Society published a report examining the issues with people with dementia and end-of-life care. It found that there were still barriers in identification, access to palliative care and in the quality of care that was received (Marie Curie and Alzheimer's Society, 2014). The Health Select Committee inquiry into end-of-life care found that round-the-clock palliative care in the community was important, but was too often difficult to access, especially for people with dementia (House of Commons Health Committee, 2015). It recommended early planning among this group and that social care at the end-of-life should not be charged for.

Equally, the review of choice in end-of-life care found that while some people were offered choices in their end-of-life care, many, including many with dementia, are not (Choice in End-of-life Care Programme Board, 2015). They recommended a national choice offer where each person who may be in need of end-of-life care is offered choices in their care focused on what is important to them. This should be made as soon as is practicable, based on honest conversations with health and care staff, supporting the person to make informed choices and consistently reviewed through conversations with health and care staff. It recommends that electronic palliative care co-ordination systems (EPACCs) are rolled out to all areas. There is also an issue with access to hospice care – only 1% of people with dementia die in hospices (Alzheimer's Society, 2012). Hospices should know how to work with people with dementia, and people with dementia should have clear choices around their preferred place of death.

It is clear that the specific issues which face people with advanced dementia, or who have dementia and are reaching the end of their life, are too often neglected. Alzheimer's Society calls for a stronger focus on what people with dementia need in the later stages and at the end of their lives, as neither the Prime Minister's challenge on dementia 2020, nor his original challenge, go far enough in addressing this important issue. Whilst the vision of the opportunity to plan early and the receipt of co-ordinated, compassionate care is laudable, concerted action is needed to realise this for the 44,000 people with dementia who die in England every year (ONS, 2014).

Implementing the recommendations of the choice review (Choice in End-of-life Care Programme Board, 2015), including 100% coverage of EPACCs by the end of 2018, is essential. Without systems such as this, even if people with dementia take advantage of the opportunity to plan for their end-of-life, there will remain a geographic variation around whether they will receive their preferred care. This is because some areas do not have systems that are accessible to all agencies and can record care plans.

There must also be central government action to remove the barriers to co-ordinated care at end-of-life for people with dementia. The recommendations of the Health Select Committee in their inquiry into end-of-life care could go some way to making this a reality, particularly if access to palliative care in the community is made easier.

Reducing the inappropriate use of antipsychotic medication

There had previously been great success in reducing the inappropriate prescription of antipsychotic medication between 2008 and 2011. However it is now not clear whether this has continued since 2012, remained static or increased once again, as the audit of prescribing of antipsychotics has not been repeated. The continuation of the audit is necessary to gauge progress on the reduction in the use of antipsychotics.

While Alzheimer's Society welcomes the commitments in the Prime Minister's challenge on dementia 2020, it is essential that any commitment in this area must also commit to a repeated and regular audit so progress can be monitored.

In order to see effective reduction, there needs to be substantive education for health and care staff which focuses on person-centred care, and which involves supervision and monitoring, such as the Alzheimer's Society FITS programme. This should be woven into essential standards for care staff, discussed on page 40.

Case study

An alternative to the use of antipsychotic medication

Alzheimer's Society has developed Focused Intervention Training and Support (FITS), an evidence-based training programme designed for care home staff. It trains staff in delivering person-centred care to help safely manage behavioural symptoms as an alternative to using medication.

Many people with dementia develop behavioural and psychological symptoms including restlessness, irritability, anxiety and aggression, and this may lead to behaviour that can be challenging and disruptive.

In some cases, antipsychotic drugs can have a short-term beneficial effect in reducing the intensity of these symptoms. However, they can result in serious side effects including grogginess, reduced mobility, falls, worsening of dementia symptoms and increased risk of stroke and death. The government has made a commitment to substantially reduce the use of antipsychotic drugs among people with dementia in the UK.

A person-centred approach to care recognises that each person with dementia is unique and involves gaining a better understanding of individual residents, taking into consideration their personality, interests, skills and life history. The needs of each person should be central to all care planning so that they have a supportive social environment and are able to experience activities that are meaningful to them. With this approach, staff can support people with dementia and their families to identify likely 'triggers' of behavioural symptoms and therefore help to prevent them from occurring.

The programme has been shown to successfully reduce the use of antipsychotic drugs by almost 50% in comparison with usual care, without worsening behavioural symptoms. It is now being rolled out to care homes across the UK and will provide staff with an understanding of the person-centred care framework as well as the skills to train other care staff.

There is strong evidence that this non-drugs based intervention will reduce the inappropriate use of antipsychotic drugs and improve health outcomes, so helping to enable people to live well with dementia.

6 Tackling issues in dementia education, training and workforce

Key actions

- Skills for Care and Health Education England, working with the care sector, must develop a dementia training quality mark, that includes continuing professional development, to allow employers and those using direct payments to easily understand a person's level of training and ensure that people with dementia receive high quality, safe care.
- Health Education England to lead Skills for Health, Skills for Care and others to deliver on provision of dementia-specific training. This would be for senior management, people delivering care, people carrying out needs assessments and people acting in the role of advocates under the Care Act.
- Central government must provide adequate resources to local authorities to tackle the crisis in social care staffing levels, allow providers to protect dementia training time and provide a consistent, integrated people-centred service based on the needs of those with dementia.
- The Care Quality Commission should monitor the impact that training is having on quality of care.

There are many challenges in ensuring that the health and care workforces are skilled to support people with dementia and their carers. Inroads have already been made in the NHS through Health Education England's tier one training and there are plans to roll out tier two and tier three training (see page 40). These commitments, made by NHS England, require sustained momentum to ensure they continue.

Tier one – awareness-raising, in terms of knowledge, skills and attitudes for all those working in health and care.

Tier two – knowledge, skills and attitudes for roles that have regular contact with people living with dementia.

Tier three – enhancing the knowledge, skills and attitudes for key staff (experts) working with people living with dementia designed to support them to play leadership roles.

In 2014, the All-Party Parliamentary Group on Dementia (APPG) recommended a need for a culture shift to improve the status and morale of the workforce in social care to ensure it is an attractive career choice (APPG, 2014). Some progress is being made with the Care Certificate, which came into force in April 2015 and includes a substantial section on dementia (Skills for Care, 2014). However, responsibility for the Care Certificate rests with employers, as does the responsibility for assuring quality.

Alzheimer's Society is pleased that within the social care workforce, it is estimated that around 300,000 people have received dementia-awareness training through the common induction standard, which is monitored through CQC inspections. However, a recent UNISON poll of homecare staff found that although 69% worked with people with dementia, 27% had received no training on how to do this (UNISON, 2015).

The fragmented nature of the social care sector means that there is also no equivalent resourcing in social care to Health Education England, and the sector as a whole suffers from high turnover which hinders sustained and consistent development of the workforce. It should also be noted that, while it is key to increasing knowledge and understanding of dementia and can complement education and training, Dementia Friends is not an adequate resource for meeting the training needs of health and care professionals.

As the Prime Minister's challenge on dementia 2020 states (Department of Health 2015), all relevant health and social care staff must be able to deliver high-quality care and support. Training must also extend not only to those delivering care, but to those responsible for carrying out needs assessments, such as for social care support or NHS continuing healthcare. Anecdotally, Alzheimer's Society hears that people with dementia do not get the services they need as many assessors do not understand the impact of dementia on their needs. The CQC found that, mainly in hospitals, people's needs were not assessed, or the focus was predominantly on physical needs (CQC, 2014). This means that people do not receive the care and support they need and the opportunity for an assessor to refer a person for a diagnosis may also be missed.

Alzheimer's Society also believes that Care Act advocates will play a crucial role in ensuring people with dementia can access the high-quality services they need. However, advocating for people with dementia requires specialist skills. Under their duties in the Care Act, local authorities must ensure that there are an adequate number of advocates with the right skills to support people with dementia in their area. There is also a need for dementia training at a provider and senior management level which would initiate this culture shift. It is essential that the impact of this training is understood. The CQC should monitor the impact on quality of care.

The increased use of direct payments to commission services requires care workers trained to a minimum standard. However, minimum standards in training are not called for in the Prime Minister's challenge on dementia 2020. Alzheimer's Society calls for a quality mark for training providers which would encourage quality training and enable commissioners to identify the best training packages, as well as assuring people with dementia that their care providers are qualified to support them. Skills for Care and Health Education England must work together to develop a training quality mark that includes continuing professional development.

Again, the issue of funding cannot be ignored in relation to developing the workforce. As social care budgets are still not ring-fenced, there continues to be a concern that local authorities will commission for price rather than for the quality of services. Person-centred care from consistent care staff is most important for people with dementia, who can be left confused by constant changes in care work staff.

Furthermore, in care home settings, it is important that staffing levels are adequate to support people with dementia. As the CQC found in its thematic review (CQC, 2014), people with dementia are affected by staff shortages, for example it can lead to behaviour changes which then affect how they live and how their dementia is managed. Local authorities must always base their commissioning decisions on the outcomes of people with dementia and look to integrate with healthcare service providers to do so, and central government should provide sufficient funding for them to be able to deliver this.

7 Driving forward dementia-friendly communities

Key actions

- Government, businesses and communities to support the recruitment of Dementia Friends to reach 4 million by 2020.
- All local authorities to be working to become dementia friendly by 2016.
- Department of Business Innovation and Skills to establish a taskforce to ensure that businesses and services recognise dementia as a disability under the Equality Act (2010) to avoid discrimination and ensure people with dementia and their carers are not disadvantaged.
- The Central government should commit all departments to rolling out Dementia Friends, so that the needs of people with dementia feature in the development of new national policies and the review of existing policy and legislation.
- All public-facing public sector roles to be given Dementia Friends awareness sessions.

The dementia challenge to society cannot be underestimated. From a low starting point in 2012, one of the greatest success stories has been the mobilisation of communities to rise to the challenge and commit to becoming dementia friendly. Action is now starting to make tangible differences to the lives of people with dementia in their local communities, achieved through improving awareness and increasing understanding about dementia, and making services more accessible and inclusive. It is essential that this momentum is maintained and that social action to improve the lives of people with dementia is made a reality across England.

Of those people with dementia who responded to our survey, 65% said they were able to get out of the house every day, 18% get out once a week or more and 4% go out less frequently than this.

This is an increase since the last survey in 2013, when less than 50% of people said that they were able to get out of the house every day, 35% went out once a week or more, and over one in 10 (13%) went out less frequently than this.

Yet it is clear that social isolation remains an issue for people with dementia. People still lose friends when they develop dementia and can feel a burden (Alzheimer's Society, 2013). Studies have highlighted several personal characteristics that 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, reduced mobility and cognitive impairment (Victor C et al, 2005) all increase in line with an older person's chances of being lonely (Tijhuis MAR et al, 1999, Victor C et al, 2005). It is important that organisations, communities and individuals tackle this hidden challenge.

There are now more than:

- **105 communities working to become dementia friendly**

- **1.1 million Dementia Friends and 10,000 Dementia Friends Champions**

- **151 local Dementia Action Alliances**

Dementia-friendly communities

There are now over 105 communities working to become dementia friendly and several thousands of businesses and organisations, from local independent traders to national high street retailers all embracing the concept of becoming dementia friendly.

The National Dementia Declaration for England (DAA, 2010) identifies that people with dementia want to live in communities that give them choice and control over their lives and provide services and support designed around their needs. Importantly, they want to feel valued, understood and part of family, community and civic life.

Creating dementia-friendly communities must be part of a social movement to help people live well with dementia. Both sustained national leadership and grassroots action on dementia are required to create a dementia-friendly Britain. The Prime Minister's challenge on dementia (Department of Health, 2012) acknowledged that the dementia challenge would not be met by health and social care alone.

There is still untapped potential in the community to help people with dementia and their carers. Everyone, from governments and health boards to the local corner shop and hairdresser, share part of the responsibility for ensuring that people with dementia feel active, engaged and valued in their local area. Areas already taking action have recognised some of the many ways to bring people together and rally to the cause of becoming dementia friendly.

Central to success has been pulling together a network or action group of interested parties that are personally committed to making a difference for people affected by dementia. Collaboration with local partners is essential; this can include the health and care sector, voluntary organisations and local businesses, for example. Support from local political leaders has also proven valuable to many of the projects.

More than half of people (51%) said they feel part of their community. Less than one-third (29%) said they did not.

This is a small improvement on when the questions were first asked in 2013. Then, just less than half (47%) said that they felt part of their community and more than a third (35%) said they did not.

Recognition of dementia-friendly communities

Alzheimer's Society has set up a defined process for communities to gain recognition for their work in becoming dementia friendly. There is an entry level to this process called the foundation stage, which over 105 communities have achieved since the recognition process launched in September 2013. This exceeded the original ambition to reach up to 20 communities by March 2015. However, it is essential that communities continue to sign up to becoming dementia friendly so that people with dementia, no matter where they live, can expect to be supported by those around them.

Building on the success of the foundation-stage recognition process, Alzheimer's Society has worked with the British Standards Institute (BSI) and other key organisations to produce a code of practice, or Publicly Available Specification (PAS) for dementia-friendly communities, published this year. The PAS provides more detailed guidance to communities working to become dementia friendly and makes recommendations.

Dementia-friendly communities code of practice

This code of practice provides more detailed guidance to communities working to become dementia friendly. It provides recommendations on:

- **who needs to be involved in setting up a dementia-friendly community**
- **areas that should be central to all dementia-friendly communities**
- **areas to focus on and the processes needed for a dementia-friendly community to operate successfully**
- **the positive changes for people with dementia that would be expected from a dementia-friendly community.**

All communities that are signed up the recognition process should use the code of practice as a guide for developing and expanding their local programmes. It also designed to encourage and inspire others to start activity in their own communities.

During 2015 and 2016, Alzheimer's Society will build on the recognition process with stakeholders in the Dementia Friendly Communities programme to ensure that it meets the needs of those communities making great progress in responding to the needs of people with dementia.

Local authorities are now leaders, commissioners, planners, regulators and service providers. To this end, they have a key role to play in supporting and leading the development of sustainable, responsive and community-led approaches that enable people living with dementia to live well in their communities. Local authorities' public health responsibilities, and their key role within health and wellbeing boards, provide an even greater impetus for their lead members and officers to engage in the development of dementia-friendly communities in their areas.

Case study

Crawley Dementia Alliance

Grant funding from the Prime Minister's Dementia Challenge Fund is helping Crawley Dementia Alliance reach out to new networks and make Crawley a dementia-friendly community. Bringing together a range of players across government, health, business and community, the Alliance aims to make Crawley: 'A town where the people living with dementia and their families are able to live well and are supported across the town to get the help they need to ensure everyday life and pursuit of leisure and cultural activities are made easy.'

The Alliance has taken a 'just get on with it' attitude towards new projects and ideas for becoming dementia friendly. It has launched a range of training opportunities, events and neighbourhood programs and also started the 'Forward Thinking' group which brings together people with dementia to find out their experiences and aspirations for the community. There has been outstanding commitment from participating organisations, from fire services to local colleges.

One of the neighbourhood programmes is focusing on breaking down the stigma of dementia often faced in Asian communities. This neighbourhood in particular has the highest density black, Asian and minority ethnic population in the local area. The local GP surgery is leading the work and encouraging their partners and staff to be a part of the social movement to become dementia friendly. The programme aims to build awareness throughout local businesses around the neighbourhood centre.

This year, 44% of people with dementia said that their local area helped them live well with dementia. Less than a quarter said that it did not. This is broadly similar to findings in 2013.

Dementia Friendly Communities Champion Group

While the recognition process sets out local community engagement in dementia action, the Prime Minister's challenge on dementia in 2012 responded to the need for national action on dementia-friendly communities by setting up a Champion Group, whose membership includes major public, private and voluntary sector organisations. The Champion Group established sector groups to take individual action in their areas. Each group has produced an output, often in the form of a charter, to help guide other similar organisations on the steps to becoming dementia friendly. Alzheimer's Society is pleased to see that the groups will continue their essential work under the Prime Minister's challenge on dementia 2020, and consider how the needs of people with dementia should be met with regard to:

- Assistive technology
- Power of Attorney and data protection
- Dementia-friendly employers
- Dementia-friendly retail
- Rural communities
- Civil society and voluntary sector
- Sport and leisure
- Arts sector
- Transport sector
- Maintaining personal wellbeing
- Schools and young people.

Alzheimer's Society is pleased that the government is supporting the ambition for all businesses to become dementia friendly. To realise this ambition the government must ensure that dementia is seen as a disability under the Equality Act (2010) and make reasonable adjustments to ensure people with dementia and their carers are not disadvantaged. A taskforce should be established, within the Department of Business, Innovation and Skills, to ensure that this is taken forward.

In addition, employers in the public, private and voluntary sector must rise to tackle the challenges of dementia. It's estimated that dementia costs businesses £1.6 billion a year (CEBR, 2014) and that in 2014, 50,000 carers will have stopped working due to caring responsibilities, and a further 66,000 will have had to make adjustments to their jobs. More flexible working conditions, and better support for those living with the condition and their carers, could reduce this expense dramatically. A legislative framework to enable this would provide great benefit to carers and employers.

Case study

Creating a dementia-friendly workplace: A practical guide for employers

Creating a dementia-friendly workplace is a guide, published by Alzheimer's Society, which helps employers gain an understanding of dementia, how it impacts organisations, and the practical steps they can take to support employees, clients and customers. It's designed for managers as a tool to review existing approaches to supporting people living with dementia in the workplace. It also aims to help organisations think differently about how to support colleagues living with dementia and their carers in the future.

The guide outlines the various ways dementia can impact on organisations – from members of the workforce living with the condition, to those who have caring responsibilities, or customers or clients affected by the condition. It includes information about dementia, its symptoms and common issues faced by people with dementia, including:

- information about responsibilities in relation to the protection of people with dementia from discrimination
- ideas to help develop awareness of dementia in the workplace
- step-by-step tips to help support members of staff who are affected by dementia at different stages of their dementia journey, covering a number of common workplace scenarios
- information and guidance on making reasonable adjustments to ensure people with dementia are not disadvantaged in the workplace
- a list of organisations that can give further advice and support to managers and to employees who either have dementia or care for someone with the illness.

The guide was put together by a group of experts from Alzheimer's Society's Employers working group. The group is made up of people from a wide range of organisations in the employment field, including Inclusive Employers, Joseph Rowntree Foundation, Public Health England and UNISON, and is part of Alzheimer's Society's Dementia Friendly Communities programme.

Case study

Lloyds Banking Group

Lloyds Banking Group has taken a number of positive steps to becoming a dementia-friendly organisation. As well as supporting its employees and customers who are affected by the condition and partnering with Alzheimer's Society, Lloyds has adopted a number of policies that have raised awareness of dementia across the organisation. This has helped its employees to understand the role they can play to support people impacted by the condition.

Additionally, the Group has engaged with a number of key Alzheimer's Society projects. These include running Dementia Friends sessions with over 9,000 of its employees, who as a result will have a better understanding of dementia. This has been particularly important for those working in the branch network, as it will be these colleagues who will come into contact with people with dementia on a regular basis.

Lloyds also played a pivotal role in the development of the Financial Services Charter, the aims of which are to encourage banks and other financial services firms to adopt a supportive approach to enable people affected by dementia to continue with their banking endeavours. Enabling people with dementia to continue with their daily lives in their local area is a key aim of the Dementia Friendly Communities programme.

Lloyds will continue to work with Alzheimer's Society on projects. Most recently they are supporting ongoing work with banks to explore the specific challenges people with dementia face when banking, and providing positive solutions.

Dementia Friends

Dementia Friends is one of the biggest social action movements since those bringing people together in England during the Second World War. It aims to give people across England a greater understanding of dementia, and the small things that can be done to make a real difference to people living with the condition.

Polling among the general public and a target group for Alzheimer's Society done by Lotus Research found that, since 2013:

- **more survey respondents feel motivated to get involved with dementia (increased from 66% in 2013 to 70% in 2015)**
- **more survey respondents feel well-informed about dementia (increased from 55% in 2013 to 60% in 2015)**
- **significantly more survey respondents believe that society is getting more sympathetic to dementia (increased from 52% in 2013 to 65% in 2015).**

Research commissioned by Alzheimer's Society shows that there have been some significant changes in attitudes since 2013. Increases in people feeling well-informed about dementia and motivated to get involved with dementia are accompanied by a significant jump in the number of people who believe that society is getting more sympathetic to dementia. It is clear that Dementia Friends and other concerted work to raise awareness is filtering through to the general public and to specific groups affected by dementia.

In February 2015, it was announced that the target of 1 million Dementia Friends had been reached, an indicator of the programme's success so far. We now also have over 10,000 Dementia Friends Champions. The Dementia Friends programme was co-funded by the Cabinet Office and the Department of Health until the end of March 2015. In May 2014, Public Health England funded a national television advert with celebrity endorsement calling on people to become a Dementia Friend, with extensive media coverage to aid in the awareness-raising programme. To build on these successes, a new target of 4 million Friends by 2020 has been set by Alzheimer's Society to ensure that people with dementia are met with understanding wherever they go, and Dementia Friends now covers all of the UK.

Businesses have also provided strong support for Dementia Friends with major employers such as ASDA, Aviva, EasyJet, Home Retail Group (Argos and Homebase), Marks and Spencer and Lloyds Banking Group creating Dementia Friends among their staff. Local authorities have responded in an equally positive way, with the Local Government Association asking each local authority to create a Dementia Friends Champion from within their organisation.

At a national level, we would like to see all government departments committed to their staff becoming Dementia Friends. This would help ensure that the needs of people with dementia feature in the development of new national policies and the review of existing policy and legislation. We would also like to see the programme extended so that all public-facing public-sector staff, such as those who work at Job Centre Plus and in other similar areas, are encouraged to become Dementia Friends, and that the interactions of people with dementia with government employees are informed by knowledge and understanding. This would place Dementia Friends as a standard part of staff induction, led by the example of government departments.

Case study

St Gregory's High School – Warrington

St Gregory's High was announced as a dementia-friendly school as part of its work in the wider community.

The school was invited to the celebrations – also joined by Sally Lindsay – of the Forget Me Not Dementia Unit at Warrington Hospital last month to mark its first anniversary. Last year, as part of the school's Heroes of Diversity week, pupils were asked to nominate people and organisations they felt the school could help with. Year 10 pupil Georgia Hatton nominated the Forget Me Not unit as she believed this would be a way of showing patients that young people care.

St Gregory's is committed to raising awareness of the condition and 25 members of staff have already volunteered to be trained as Dementia Friends as part of the national campaign sponsored by Alzheimer's Society. Head teacher Paul Heitzman said, 'It is so important that our young people understand what dementia is and how it might affect family members so that they are able to offer support.'

8 Making the UK a leader in transformational research

Action points

- Commitment to sustained growth in funding across the spectrum and including research across biomedical and psychosocial research.
- Ensuring strategic investment in early-career researchers, clinicians and health professionals to attract and retain people into dementia research.
- Make it easier for people with dementia to take part in clinical research, and embed research into part of their standard offer of care.
- Development of mechanisms to ensure that the discoveries of research are translated into benefits for people more quickly, whether this is for drug treatments, diagnostics or new models of care.
- Establish public health surveillance that routinely monitors dementia incidence and the effects of lifestyle trends.

At the end of 2013, the G8 Dementia Summit set out a bold ambition to make significant progress towards finding a disease-modifying treatment for dementia by 2025. In order to get there it was recognised that we need to see significant increases in funding for dementia research, global collaboration and data sharing within dementia research fields and improved regulation for clinical research. In line with Alzheimer's Society's position, it was also recognised that we need to see significantly more research into dementia care in order to better support people living with the disease today.

UK government and charities have made significant commitments to increasing their spending on dementia research and this is already starting to be realised, with investment increasing by about £10 million a year since 2009 (Alzheimer's Society, 2014a). Working with several pharmaceutical companies, this year the UK government launched a global fund to support preclinical dementia drug development research worth up to \$100 million.

However, despite recent commitments, funding for dementia research is still dwarfed by funding for other conditions and does not reflect the personal, social and economic impact of dementia. Cancer research still receives seven times the funding that is spent on dementia (Prince et al, 2014). The UK needs a national and long-term plan for dementia research that is funded in proportion to its impact on society and with greater co-ordination between funders of dementia research.

Alzheimer's Society was pleased to see so much of the Prime Minister's challenge on Dementia 2020 dedicated to dementia research and the commitment to double dementia research spend by 2025. However, it is essential the funding translates into a tangible difference for people with dementia. It is essential that there is action in the following areas to make change a reality.

Strengthening the dementia research community

The number of people working in all areas of dementia research in the UK is small compared to research into other health conditions such as cancer and heart disease (Alzheimer's Research UK, 2012), which hampers the rate of progress that can be made towards better diagnosis, better treatments and improved dementia care. However, despite a relatively small workforce, the UK is a world leader in dementia research, second only to the US in the number of research publications it produces, according to research carried out by RAND Europe and commissioned by Alzheimer's Society – to be published in September 2015. The government has a clear opportunity to capitalise on this. The UK is uniquely placed to support high-impact, high-relevance dementia research through its close links between academic researchers, clinicians in the NHS and a strong programme of patient and public involvement spearheaded by the Alzheimer's Society's award-winning Research Network.

Increased and sustained investment in dementia research with a focus on supporting a multidisciplinary research career pipeline is essential to attracting the best and brightest to study the condition. New funding opportunities to support and retain early-career dementia researchers should be made available across the whole spectrum of relevant research backgrounds, with a special focus on clinical and allied health professions. For example, through its Dementia Research Leaders programme, Alzheimer's Society established eight doctoral training centres in 2014/15 to support over 50 new PhD students entering the field and funded 10 new research fellows to take forward a range of biomedical, clinical, care and social science projects.

Finding a disease-modifying treatment by 2025

Although we now have four drug treatments approved for use in people with Alzheimer's disease, in recent times developing new dementia drug treatments has not been successful. Between 2002 and 2012, 98.2% of all phase III clinical trials conducted were unsuccessful (Cummings et al, 2014). Current drugs can help people to manage some of the symptoms of Alzheimer's disease but they do not interfere with the underlying disease process and eventually stop working. There are currently no drugs designed to treat people with vascular dementia, frontotemporal dementia or dementia with Lewy bodies.

Due to the challenges of developing drugs for neurodegenerative disorders, the ambition to identify a disease-modifying treatment for dementia by 2025 (as proposed in the Prime Minister's challenge on dementia 2020) is a bold one; it takes an average of 15 years to take a new drug compound from conception to market. Drug repurposing and repositioning is a promising avenue for the development of dementia drugs (Corbett et al, 2012), and is a key area of investment for Alzheimer's Society. Many existing drug types are currently under investigation for use in dementia, including drugs currently used for type 2 diabetes, high blood pressure, erectile dysfunction and rheumatoid arthritis. Currently almost 20% of all therapeutics being tested for dementia in clinical trials focus on drug repurposing (www.alzforum.org/therapeutics).

It is essential that there is a mechanism for making these treatments widely available to patients if they are found to be successful for the treatment of dementia. The MHRA and NICE need to work together to remove regulatory barriers around licencing of new medications, for instance considering dementia medications under the Early Access to Medicines Scheme, so that patients may receive access to new therapies on a conditional licence. They also need to develop a licencing framework and recommendation process for repurposed drug treatments.

Successful treatment of the diseases that cause dementia is unlikely to rely just on the use of drugs. To date, some of the most effective ways to slow cognitive decline have involved a combination of non-pharmacological interventions such as physical exercise, cardiovascular disease management, nutrition and cognitive stimulation (Ailev et al, 2013; Ngandu et al, 2015). We are pleased to see an emphasis in the Prime Minister's challenge on dementia 2020 on risk reduction, but it is clear that more longitudinal research is needed to establish the effects of these interventions on the incidence of dementia. Alzheimer's Society would like to see a public health observatory that routinely monitors dementia incidence and the effects of lifestyle trends. It is also essential that Public Health England, NICE and public health directors in local authorities recognise not only risk reduction, but prioritise the slowing of cognitive decline once someone has been diagnosed.

More research to help people live well with dementia

While searching for a disease-modifying treatment by 2025 is welcomed by Alzheimer's Society, it is unlikely to benefit the 850,000 people living with dementia in the UK today or the 670,000 family carers that support them. Current research efforts must adequately address the practical issues these groups face, and research findings must inform the development of new care pathways and support services. To achieve this, we would support more investment made available for research into care and services by government and other funders. This has the potential to alleviate the burden on the NHS and on social care services. As the leading funder of dementia care research in the UK, Alzheimer's Society invested £3.7 million into care and services research in 2014/15. Comparing this to the tens of millions invested in biomedical research shows that much more can and should be done in this area. There also needs to be greater investment in health economics research, in order to demonstrate the impact of services and support for people with dementia and their carers.

The Prime Minister's challenge on dementia 2020 rightly recognises the need to support the involvement of more people with dementia in research. People affected by dementia must be consulted on their priorities and involved in all stages of the research process to ensure current investment in care research is best targeted to meet their needs. Alzheimer's Society embeds patient and public involvement throughout our research programme (Alzheimer's Society, 2014b) and leads the way in supporting other researchers and research funders to involve people affected by dementia wherever possible (National Institute for Health Research, 2015). Assistive technologies show promise in supporting people with dementia to remain independent and in their own homes for longer. Further research into this area, as the Prime Minister's challenge on dementia 2020 promises, should involve people with dementia and their carers so that companies can be sure they are developing useful and appropriate products and technologies.

Case study

Patient Reported Outcome Measures in dementia

Led by the London School of Hygiene & Tropical Medicine, and with Alzheimer's Society as a key partner, the Patient Reported Outcome Measures (PROMs) in dementia study aims to use PROMs in two care settings: memory assessment services and residential care. The project will assess the impact of memory assessment services on quality of life and determine whether similar quality of life measurements can be obtained from people with dementia in residential care. Funded by the Department of Health, the £1 million study is refining the existing standardised quality of life assessment methods and will use these to look at the costs and benefits of different types of memory services. If successful in the residential care setting, this project will provide an innovative way of obtaining quality of life information from residents with dementia which in the future could be used to evaluate care.

Alzheimer's Society's dementia support staff are playing a key role in delivering the research. They have been trained in research methods, mental capacity assessment and administration of standardised questionnaires and are visiting people with dementia living in local residential homes to find out about their quality of life. The Society's Research Network of volunteers affected by dementia have also played an active role by advising the researchers on key issues, including giving feedback on wording of questionnaire items, providing expert opinion to aid conceptual understanding of the quality of life scores and practical advice based on their experience at memory assessments services.

It is also important that people with dementia are not only involved in setting priorities, but also are able to participate in research. The government's ambition to sign up 25% of people with a diagnosis to the Join Dementia Research service is bold and will only be achieved by embedding Join Dementia Research within the NHS clinical research infrastructure and by encouraging industry studies to use it. These steps are necessary in order to reach a target of 10% of people with a diagnosis of dementia involved in research.

Sharing research findings and putting them into practice

It is essential that everyone involved in dementia care, including the person themselves, has access to publicly available existing knowledge about what works for people with dementia. The Prime Minister's challenge on dementia 2020 has pledged to make research findings widely available through open access publications for all publicly-funded dementia research, which would be the first vital step to facilitating research translation. Alzheimer's Society has an open access publishing policy and is a member of Europe PMC. All other funders of dementia research should take similar steps to make the results of their research investment available.

In the UK, research and service delivery largely exist in two separate worlds, but for research to have the maximum possible impact these worlds need to harmonise. This need is urgent because delays in translating knowledge into practice results in wasted costs and in dementia-related death and morbidity that could have been prevented.

Effective partnership working is a second vital component of research translation. Significant investment is required from research and service funders to build relations between those affected by dementia, practitioners, researchers, and policy makers in order to clear the path for new knowledge to be taken up and put to best use. Investment is also required to generate new knowledge in implementation science, developing an understanding of what it takes to translate research into better outcomes for people with dementia in a range of settings.

As a research funder and a service-delivery organisation, Alzheimer's Society is well placed to enable the translation of dementia research into practice, but we cannot do this alone. The Society has established a research development function to identify the key partners and processes required for research mobilisation and has launched a new research implementation grant scheme. However, to achieve the large-scale change required, academic and clinical research institutions, other funders, the NHS and service-delivery organisations all need to join forces to drive forward this vital area of research development.

Conclusion

There has been good progress in the last six years, however there is still much to be done to improve the way that dementia services across the health and care landscape are funded, commissioned, provided and accessed.

Great strides have been made in improving diagnosis, raising awareness and in developing dementia-friendly communities. These successes need to be maintained and must continue to be taken forward, in order to keep the profile of dementia high, and to realise the vision of England and the UK as a world-leading country for dementia care, support and research.

The report highlights these successes but, more importantly, it emphasises what needs to be achieved in the areas of service development, funding and organisation, where there are long-standing objectives that have not been met. These issues must be dealt with so that we can move closer towards a genuine commitment to integrating health and social care, adequate funding for dementia care and realised actions that respond to the Prime Minister's challenge on dementia 2020.

Alzheimer's Society believes that, with joint action across central and local government, and health and social care, people with dementia and their carers should be able to live better.

We believe that if ambition turns into action, they will.

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Appendix 1: Summary of recommendations

Recommendation 1: Producing a national action plan for dementia and securing funding

- Capitalise on the improvements which have been made and move from improved diagnosis rates to better care.
- Produce a national plan to deliver the Prime Minister's challenge on dementia 2020.
- Map out how the plan will be funded and secure funding from the Spending Review.
- Decide who will be responsible for the delivery of key aspects of the action plan.

Recommendation 2: Taking action on risk management

- Challenge the current low levels of awareness of dementia and reduce stigma with an annual national awareness campaign as a priority for Public Health England.
 - Include dementia in the NHS mid-life Health Check by 2016 as part of the programme to encourage adults to tackle modifying risk factors in mid-life such as smoking, drinking and exercise.
 - Establish a public health observatory to routinely monitor dementia incidence and the effects of lifestyle trends.
 - Prioritise dementia locally. This should be actioned by all health and wellbeing boards and directors of public health.
 - Integrate dementia public health messages with existing healthy and risk reduction lifestyle messages.
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Recommendation 3: Improving diagnosis and transforming support after diagnosis

- A new national ambition for a 75% diagnosis rate for dementia by 2017 across every area of England.
- Offer a tailored, nationally assured package of post-diagnosis support, including a Dementia Adviser, to everyone diagnosed with dementia.
- Identify the data that is required by commissioners and clinicians, and learn from the data collected in other disease areas (such as cancer), to better enable planning and delivery of services for people living with dementia.
- Ensure that by 2020 no one has to wait for more than two weeks from referral to first appointment at a memory clinic, through annual improvements that tackle delay from first referral to diagnosis.
- The Health and Social Care Information Centre should assess current memory service capacity, identify a baseline of current waiting times and report on these to measure improvement and gather similar data on the provision of post-diagnosis support.

Recommendation 4: Supporting carers

- Local authorities should ensure that their assessments of carers under the Care Act are sensitive to the needs of dementia carers.
 - Carers should have a right to access short breaks and respite, as well as support services such as befriending.
 - Carers should be seen as partners in care and have a single point of access to help navigate and engage with care and support services.
 - Local authorities and GPs should be trained to identify carers and the GMC should ensure that an indicator on the identification of carers is included in the QOF register from 2016/17.
 - The government should create a legislative framework that requires employers to provide support to carers in order to reduce the 21% of carers of people with dementia who give up work or reduce their hours as a result of their caring responsibilities.
 - Carers should have access to help and support through a single point of contact.
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Recommendation 5: Delivering dementia-friendly health and care settings

- All health and social care settings to be dementia friendly by 2020.
- The government should support integration of health and social care by removing the barriers created by the different funding systems for the NHS and social care.
- Central government should regulate homecare providers to ensure visits are no less than 30 minutes.
- Local authorities should increase services that provide social interaction for people with dementia living at home to end the hidden and harmful epidemic of loneliness.
- Local NHS and councils must increase spending on community dementia services to reduce pressure on long-term care and acute services.
- The government should implement the recommendations of the Health Select Committee inquiry into end-of-life care and the recommendations of the choice review, including 100% coverage of electronic palliative care co-ordination systems by the end of 2018.
- The Health and Social Care Information Centre should repeat the audit of the use of antipsychotics so that progress towards the elimination of unacceptable use of antipsychotics can be monitored.

Recommendation 6: Tackling issues in dementia education, training and workforce

- Skills for Care and Health Education England, working with the care sector, must develop a dementia training quality mark, that includes continuing professional development, to allow employers and those using direct payments to easily understand a person's level of training and ensure that people with dementia receive high quality, safe care.
 - Health Education England to lead Skills for Health, Skills for Care and others to deliver on provision of dementia-specific training. This would be for senior management, people delivering care, people carrying out needs assessments and people acting in the role of advocates under the Care Act.
 - Central government must provide adequate resources to local authorities to tackle the crisis in social care staffing levels, allow providers to protect dementia training time and provide a consistent, integrated people-centred service based on the needs of those with dementia.
 - The Care Quality Commission should monitor the impact that training is having on quality of care.
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Recommendation 7: Driving forward dementia-friendly communities

- Government, businesses and communities to support the recruitment of Dementia Friends to reach 4 million by 2020.
- All local authorities to be working to become dementia friendly by 2016.
- Department of Business Innovation and Skills to establish a taskforce to ensure that businesses and services recognise dementia as a disability under the Equality Act (2010) to avoid discrimination and ensure people with dementia and their carers are not disadvantaged.
- Central government should commit all departments to rolling out Dementia Friends, so that the needs of people with dementia feature in the development of new national policies and the review of existing policy and legislation.
- All public-facing public sector roles to be given Dementia Friends awareness sessions.

Recommendation 8: Making the UK a leader in transformational research

- Commitment to sustained growth in funding across the spectrum and including research across biomedical and psychosocial research.
 - Ensuring strategic investment in early-career researchers, clinicians and health professionals to attract and retain people into dementia research.
 - Make it easier for people with dementia to take part in clinical research, and embed research into part of their standard offer of care.
 - Development of mechanisms to ensure that the discoveries of research are translated into benefits for people more quickly, whether this is for drug treatments, diagnostics or new models of care.
 - Establish public health surveillance that routinely monitors dementia incidence and the effects of lifestyle trends.
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Appendix 2: Report methodology

This report draws on existing research and current work in dementia. This includes a range of public policy documents, research literature, learning from good practice, research Alzheimer's Society has commissioned previously and existing indicators. This learning is informed by people affected by dementia.

Alzheimer's Society surveyed people with dementia in England to find out how well they were living. Separate reports looking at the experiences of people with dementia in Wales and Northern Ireland are due later in the year. The survey was distributed through Alzheimer's Society services, Alzheimer's Society and Dementia Friends social media, and promoted by partner organisations. People were invited to complete the survey between January and March 2015.

There were over 500 respondents to the survey in England.

Who filled in the survey?

- The majority (55%) completed the survey with their carer, or with a support worker or volunteer (8%).
- Some (16%) filled it out on their own.
- The remainder had the form filled out on their behalf (19%).

How old were the respondents?

- 7% of respondents were under 65.
 - A quarter (25%) were between 65 and 74.
 - 44% were between 75 and 84.
 - A fifth (19%) were over 84.
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How long had they been living with dementia?

- A small number (6%) had been living with the condition for less than a year.
- More than one-third (39%) had been living with the condition for 1–3 years.
- Just less than a third (30%) had been living with the condition for 4–6 years.
- 13% had lived with the condition for 7–10 years.
- The remaining participants had been living with the condition for longer than 10 years (6%) or did not answer (6%).

There are limitations to the sampling on which this survey was based. This is a self-selecting survey and the sample generally comprises of people in contact with Alzheimer's Society and therefore accessing some level of support. For this reason, it may not be as representative of people with dementia that are not in receipt of care. The questionnaire format also means that it is likely that evidence is collected from people who are predominately less affected by symptoms, as they need to be able to understand and respond to the questions, although the use of carers as proxy does mitigate this in some cases. The evidence provides a snapshot of how well people are living rather than a definitive evaluation covering all stages of living with dementia.

Appendix 3:

Summary of statistics

The statistics used throughout this report are presented below. The bold statistics indicate the figures produced by new research for this report.

Prevalence

In 2015, there will be 850,000 people with dementia in the UK based on the current prevalence rate (Prince et al, 2014).

This includes over 700,000 people in England. Over 40,000 younger people in the UK (65 years of age or below) have dementia, and an estimated 25,000 people from black, Asian and minority ethnic groups have the condition (Prince et al, 2014).

The overall number is set to rise to 1 million by 2021 (Alzheimer's Society, 2012).

Quality of life for people with dementia

68% of people felt they were living well with dementia. 15% said they were not and 17% said they did not know (Dementia 2015).

53% of people had felt anxious or depressed recently. 36% said they had not and 11% said they didn't know (Dementia 2015).

The feeling of anxiety or depression was highest among those who had started experiencing symptoms most recently (58% for those who had been experiencing symptoms for a year, and 56% for those who had been experiencing symptoms for 1–3 years) (Dementia 2015).

58% of people who had been experiencing symptoms for 1 year said they had been anxious or depressed and 56% who had been experiencing symptoms for 1–3 years (Dementia 2015).

50% of those who had symptoms for 7–9 years reported feeling anxious or depressed (Dementia 2015).

Over a quarter (26%) of people said they were not involved in decisions about their care and support. 61% said they were and 13% said they did not know (Dementia 2015).

Half of people (49%) said they were not getting enough support from the government (Dementia 2015).

44% of people said that their local area helped them lived well with dementia. Less than a quarter said that it did not (Dementia 2015).

Social networks

More than half of people (51%) said they feel part of their community. Less than one-third (29%) said they did not (Dementia 2015).

82% of people said they had enough people to count on for support. 11% said they did not, and 7% said they did not know (Dementia 2015).

Diagnosis

61.6% of people with dementia had a diagnosis at the end of the first Prime Minister's challenge period (HSCIC 2015) compared to only 42% of people with dementia in England in 2012 (APPG, 2012).

There remains variation in the figures behind the 61.6% diagnosis rate, as the best performing areas regularly achieve a 75% or better diagnosis rate and the worst have improved from around 40% to just over 50% (HSCIC 2015).

Over 1 in 3 people with dementia still do not have a diagnosis (HSCIC 2015).

Hospital care

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

People with dementia tend to have longer stays in hospital than patients without dementia (Alzheimer's Society, 2009).

People with dementia in the community

Two-thirds of people with dementia live in the community (Prince et al, 2014). Of these, one-third live alone in their own homes (Mirando-Costillo et al, 2010).

65% of people said they were able to get out of the house every day. 18% got out once a week or more. Only 4% went out less frequently than this (Dementia 2015).

Only around 5% of older people live in a home that is purpose-built for older people and the majority of these homes are in the social sector (NHF, 2011).

There will be an estimated shortfall of 240,000 homes for older people in the UK by 2030 (Housing LIN, 2013).

Workforce

69% of homecare staff worked with people with dementia but 27% had received no training on how to do this (Unison, 2015).

98% of people with dementia and their carers felt that staff having a poor understanding of dementia was a barrier to the provision of good quality care (Royal College of Nursing, 2011).

Care at home

The UK Homecare Association estimates that 60% of people receiving care at home have a form of dementia (UKHCA, 2013).

73% of local authority-funded homecare visits in England lasted just 30 minutes (UKHCA 2013).

16% of homecare visits lasted only 15 minutes (UKHCA 2013).

Care homes

One-third of people with dementia live in care homes (Prince et al, 2014).

Around 70% of care home residents in the UK have dementia or significant memory problems (Prince et al, 2014).

Care homes and hospitals remain the largest settings where people with dementia receive care, and are the settings where the majority of people with dementia reach the end of their lives (Alzheimer's Society, 2012).

Hospital care

A quarter of hospital beds are occupied by people with dementia (Alzheimer's Society, 2009).

Lack of support for people with dementia

Half of people (49%) with dementia said they were not getting enough support from the government. (Dementia 2015).

Carers

There are currently around 670,000 carers of people with dementia in the UK (Prince et al, 2014).

Unpaid carers save the state £11 billion per year (Prince et al, 2014).

Just over half of carers said that their work had been negatively affected by their caring responsibilities (Employers for Carers, 2014).

Two-fifths (41%) of carers stated that they would like more flexible working arrangements (Employers for Carers, 2014).

49% of respondents said their carer did not receive help. 39% said they did and 12% said they didn't know. (Dementia 2015).

50,000 carers in 2014 will have stopped working due to caring responsibilities, and a further 66,000 will have to make adjustments to their job (Centre for Economics and Business Research, 2014).

Costs

Dementia now costs the UK economy £26 billion a year (Prince et al, 2014).

Dementia costs UK business £1.6 billion per year (Centre for Economics and Business Research, 2014).

89% of employers believe that dementia will become a bigger issue for their organisation and their staff (Employers for Carers, 2014).

Spending on adult social services in England has decreased by 12% since 2010 (ADASS, 2014).

End-of-life

Statistics released at the end of 2014 showed that dementia is now the leading cause of death among women (ONS, 2014).

Only 1% of people with dementia die in hospices (Alzheimer's Society, 2012).

44,000 people with dementia die in England every year (ONS, 2014).

Co-morbidity

75% of people with dementia said that they had another health condition in addition to their dementia (Dementia 2015).

Research

Through the Dementia Research Leaders programme, Alzheimer's Society established eight doctoral training centres in 2014/15 to support over 50 new PhD students entering the field and funded 10 new research fellows to take forward a range of biomedical, clinical, care and social science projects (Dementia 2015).

98.2% of all phase III clinical trials conducted between 2002 and 2012 were unsuccessful (Cummings et al, 2014).

Currently almost 20% of all therapeutics being tested for dementia in clinical trials focus on drug repurposing (see www.alzforum.org/therapeutics).

Alzheimer's Society's portfolio of research is the largest it has ever been, worth a total of £12.9 million (Alzheimer's Society, 2015b).

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.

Alzheimer's Society

Devon House
58 St Katharine's Way
London E1W 1LB

T **020 7423 3500**
F **020 7423 3501**
E **info@alzheimers.org.uk**
W **alzheimers.org.uk**