

Dementia 2014: Opportunity for change



Document purpose **Dementia 2014: Opportunity for change** provides a comprehensive summary of some key areas affecting people with dementia over the last year in England, Wales and Northern Ireland. It considers the significant political and public attention on dementia in this period and what impact this is having for people living with the condition. It gives an update of aspects of dementia research including trials, cause, prevention, care and treatment. It explores how well people are living in their communities and details the changes that need to be made to improve their quality of life.

Title **Dementia 2014: Opportunity for change**

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Target audiences **Dementia 2014: Opportunity for change** is intended for a wide range of organisations and people who can improve quality of life for people with dementia. This includes partners from the public sector, local authorities, commissioners of healthcare, civic organisations, government and researchers.

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Authors Anna Dowrick, Senior Policy Officer and Alice Southern, Policy Officer

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

Web alzheimers.org.uk/dementia2014

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Contents

Foreword	v
Executive summary	vii
Context	vii
Dementia diagnosis	vii
A health and social care system fit for purpose	viii
Variable quality of care	viii
Progress towards building dementia-friendly communities	viii
Research that improves lives	ix
Actions to lead improvements	ix
Action 1: All statutory health and/or social care bodies in England, Wales and Northern Ireland to set targets for stepped yearly improvement in diagnosis rates up to 75% by 2017	ix
Action 2: Twelve weeks from referral to diagnosis	x
Action 3: Establish a minimum standard of integrated post-diagnosis support for people with dementia and carers	x
Action 4: Governments to build on progress and commit to appropriately resourced national strategies in England, Wales and Northern Ireland	x
Action 5: An open debate with citizens on the funding of quality health and social care that meets the needs of people affected by dementia	xi
Action 6: A fully integrated health and social care system that puts the needs of people first	xi
Action 7: People with dementia and their carers must be involved in the commissioning, design and development of services	xi
Action 8: High-quality mandatory training for all staff providing formal care to people with dementia	xii
Action 9: All communities to become more dementia friendly	xii
Action 10: Everyone should have improved awareness of dementia	xii
Action 11: All businesses and organisations to take steps towards becoming dementia friendly	xii
Action 12: Dementia research should receive a level of investment that matches the economic and human cost of the condition	xiii
Action 13: All people with dementia and carers should have access to the best evidence-based care and research	xiii
Action 14: People affected by dementia and their carers should be given greater opportunity to participate in dementia research	xiii

Introduction	1
Purpose	1
The context of dementia	1
Quality of life outcomes that are important to people living with dementia	3
Methodology	4
People affected by dementia	4
Public poll	4
1 Improving dementia diagnosis	5
Introduction	6
Importance of diagnosis	6
Actions for improving diagnosis	8
Action 1: All statutory health and/or social care bodies in England, Wales and Northern Ireland to set targets for stepped yearly improvement in diagnosis rates up to 75% by 2017	8
Barriers to diagnosis	9
Action 2: Twelve weeks from referral to diagnosis	10
Action 3: Establish a minimum standard of integrated post-diagnosis support for people with dementia and carers	13
Minimum standard of post-diagnosis support	13
Supporting carers	14
Commissioning support services	15
2 A health and social care system that works better for people affected by dementia	17
Introduction	18
Changes to health and social care systems	18
Actions for improving health and social care systems	20
Action 4: Governments to build on progress and commit to appropriately resourced national strategies in England, Wales and Northern Ireland	20
England	20
Wales	21
Northern Ireland	21
Action 5: An open debate with citizens on the funding of quality health and social care that meets the needs of people affected by dementia	22
Health and social care reforms	22
Action 6: A fully integrated health and social care system that puts the needs of people first	24
People with dementia with other conditions	25
Younger people with dementia	26
People with dementia from black, Asian and minority ethnic communities	26

3 Quality support in every care setting	28
Introduction	28
Measuring quality of care	29
Actions for improving quality of care	29
Action 7: People with dementia and their carers must be involved in the commissioning, design and development of services	32
Involvement in service planning	32
Personalisation	34
Action 8: High-quality mandatory training for all staff providing formal care to people with dementia	35
The Mental Capacity Act	36
4 Dementia-friendly communities	38
Introduction	38
Progress on building dementia-friendly communities	39
How well are people living with dementia today?	40
Actions for encouraging dementia-friendly communities	41
Action 9: All communities to become more dementia friendly	41
Action 10: Everyone should have improved awareness of dementia	43
Action 11: All businesses and organisations to take steps towards becoming dementia friendly	44
5 Research	45
Introduction	45
International action on research	46
Progress on research	46
Understanding causes	46
New treatments and clinical trials	47
Prevention strategies	48
Improving diagnosis and care	48
Actions to advance dementia research	49
Action 12: Dementia research should receive a level of investment that matches the economic and human cost of the condition	50
Action 13: All people with dementia and carers should have access to the best evidence-based care and research	50
Action 14: People affected by dementia and their carers should be given greater opportunity to participate in dementia research	52
Involvement in clinical trials	52
Involvement in the design and process of research	52
Conclusion	54
References	58
Appendix 1: UK spend on dementia research	64
Appendix 2: Summary of statistics	66

Foreword



Dementia is under the international spotlight. G7 governments have committed to finding a cure by 2025, and UK government and charities have pledged to more than double their investment in dementia research over the next 10 years.

The search for a cure is a welcome ambition, given the scale of the challenge of dementia. There are 835,000 people living with dementia in the UK in 2014, and by 2015 that figure will be 850,000. It is the most feared health condition for people over the age of 55, but touches people of all ages. Over 21 million people know close friends or family affected by the condition. Dementia costs the UK economy over £26 billion per year – higher than cancer, heart disease or stroke.

Despite the attention dementia is receiving at home and abroad, people with dementia continue to tell us that they aren't living as well as they could be.

These are just a selection of many examples of how we are still failing to support some of the most vulnerable people in our society:

- Limited local support and advice leaves too many people struggling to make sense of their diagnosis.
 - Homecare workers' visits are limited to 15 minutes, which sees individuals having to choose between assistance with getting dressed, making lunch or having a shower when they need all three.
 - People with dementia stay five days longer in hospital than those without dementia. On discharge they are more likely to have to go into residential care than back to their own family home.
 - People with dementia are still spending their life savings simply to try and meet the essential care needs that arise from their medical condition, such as help with washing or dressing.
 - Too many people are lonely and don't feel a part of their community. Almost 10% of people with dementia leave the house once a month or less.
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I welcome the focus that political leaders are giving to dementia, and to the drive among professionals in health, social care, housing and the community to make real change. However, progress has been slow. We are yet to see the vital transformational change we desperately need. This will only be achieved by a sustained approach and widespread action through a national response.

We all need to become dementia friendly, being aware of how the condition affects people but also taking steps to support those around us in our communities living with dementia. Some great work has begun through our Dementia Friendly Communities programme. Hundreds of thousands of people are becoming Dementia Friends. Change is on the horizon, as we see businesses, individuals and local organisations assessing the way they work and whether they provide what people with dementia need.

The fight against dementia has not been won. A lot of progress has been made and momentum is building, but we must sustain it to realise the vision for the UK to be the leader in dementia care, support and research. We want to see a dementia-friendly UK and ultimately a world without dementia.

A handwritten signature in black ink, reading "Jeremy Hughes". The signature is written in a cursive style with a long horizontal line extending from the end of the name.

Jeremy Hughes
Chief Executive, Alzheimer's Society

Executive summary

Dementia 2014: Opportunity for change provides a comprehensive summary of the key areas affecting people with dementia over the last year in England, Wales and Northern Ireland. It considers the significant political and public attention that dementia has received in this period and what impact this is having for people living with the condition. Building on the success of the G7 summit on dementia, it gives an update on aspects of dementia research including trials, cause, prevention, care and treatment. It explores how well people are living in their communities and details the changes that need to be made to improve their quality of life.

The report draws together evidence from our annual survey, which involved more than 1,000 people with dementia and their carers, alongside new analysis from Alzheimer's Society, King's College London and the London School of Economics.

Context

Dementia remains a national challenge in terms of its scale and impact. Research shows that in 2014 there are 835,000 people in the UK who have dementia (Alzheimer's Society, 2014a). This includes over 700,000 people in England, over 45,000 in Wales and nearly 20,000 in Northern Ireland. Over 40,000 younger people (65 years of age or below) live with the condition.

With an ageing population the numbers of people with dementia in the UK are increasing and so are the costs. Dementia now costs the UK economy £26 billion a year, with this set to rise (Alzheimer's Society, 2014a). An estimated 670,000 people in the UK act as primary carers for people with dementia, saving the state £11 billion per year (Alzheimer's Society, 2014a).

Two-thirds of people with dementia live in the community (Alzheimer's Society, 2007). Of these, one-third live alone in their own homes (Mirando-Costillo et al, 2010). One-third of people with dementia live in care homes (Alzheimer's Society, 2007), and up to 70% of care home residents in the UK have dementia or significant memory problems (Alzheimer's Society, 2014a).

Dementia diagnosis

The increase in diagnosis rates in England, Wales and Northern Ireland is welcome, but too many people are still living without a formal diagnosis. Variation in diagnosis rates within and between nations remains extreme, ranging from little more than a third in some areas to over 75% in others. Similarly, waiting times for specialist assessment vary depending on where you live.

Support following a diagnosis is not available to everyone, as there is no mandatory minimum provision of support. It is also unclear whether the responsibility for providing services should sit with the NHS or social care, or both. This means that too often access to a diagnosis and appropriate post-diagnosis support depends on where people live and the care and support options available in that area.

A health and social care system fit for purpose

People with dementia are frequent users of health and social care services. A quarter of hospital beds (Alzheimer's Society, 2009) and up to 70% of places in care homes are occupied by people with dementia (Alzheimer's Society, 2014a), and over 60% of people receiving homecare services have dementia (UKHCA, 2013). Unprecedented cuts to the care system and unco-ordinated reforms are leaving many people without access to the vital support they need to live well. Demand for services is increasing, as spend on social care in parts of the UK decreases (ADASS, 2014).

People with dementia and family carers can live well if they have access to good quality, integrated care that is affordable, and if they live in a housing environment that meets their needs. The rising cost of dementia to society can be attributed to the failure of our current health and social care services to appropriately deliver these requirements. Our survey found that fewer than one in five people thought they received enough support from the government. The gap is being filled by unpaid carers who are keeping the system afloat (Alzheimer's Society, 2014a).

Variable quality of care

Quality of care for people with dementia should be consistent across all health and social care settings. Our survey found that 72% of respondents were living with another medical condition or disability as well as dementia, which increases the complexity of their care needs. People with dementia in hospitals stay on average five days longer than people without dementia in a comparable situation (Alzheimer's Society, 2009). The UK Homecare Association estimates that 60% of people receiving care at home have a form of dementia (UKHCA, 2013) and 15-minute visits are still common (UKHCA, 2012).

National guidelines exist that aim to support health and social care professionals to provide quality care to people with dementia (NICE, 2010, 2011, 2013a, 2013b) and workforce development is increasingly prioritised. Despite this, care quality is highly variable, 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. Our survey found that 27% of people affected by dementia are not involved in decisions about their care and support. Inappropriate use of the Mental Capacity Act (2005) means that too often people with dementia may be being unlawfully deprived of their liberty (House of Lords, 2014).

Progress towards building dementia-friendly communities

Projects are now underway across the UK with the ambition of making our communities easier places for people affected by dementia to access services, socialise and live well. Furthermore, governments are recognising the importance of wellbeing by introducing legal reforms to care across England, Wales and Northern Ireland. However, the Dementia 2014 survey results indicate that still not enough has changed. Only 58% of people with dementia say they are living well, and less than half of people feel a part of their community. Approximately 40% of people felt lonely recently, and almost 10% only leave the house once a month.

It will take long-term sustained commitment to see the activity underway on building dementia-friendly communities translate into improved quality of life for people with dementia. Current projects may well be having a positive impact on the lives of people with dementia locally, but nationally most people with dementia are yet to feel the benefit of communities that fully recognise, understand and meet their needs.

Research that improves lives

The international research community is gearing up to make dementia a global priority. Over the next 10 years investment in dementia research is set to more than double in the UK alone. It is only through research that the causes of dementia can be fully understood, allowing the development of new treatments and potential cures; and helping us to understand the course of the condition, find out how to prevent dementia, and develop innovative ways to care for and support people affected by the condition.

As well as generating new knowledge, we must prioritise translation of research into practice. This requires active involvement of people with dementia in all stages of the research process. World-class dementia research can only bring about change if it is informed by people affected by the condition, and if this valuable learning is quickly adopted in practice.

Actions to lead improvements

As we approach 2015, Alzheimer's Society wants to see real commitments to action plans on dementia. The National Dementia Strategy for England (NDSE) finished in April 2014 and the Prime Minister's challenge on dementia ends in March 2015. In Wales there has been insufficient monitoring of the funding allocated from the National Dementia Vision and there is an urgent need for a specific dementia strategy with clear lines of accountability. Northern Ireland has seen implementation of its dementia strategy hampered by lack of government investment. There is a clear need for robust evaluation and national prioritisation of dementia. Without a national focus, the lives of individuals affected by the condition cannot improve.

Dementia 2014 provides us with an opportunity to reflect on where we are heading and what more needs to be done. As we move into new systems of social care in England, Wales and Northern Ireland, and with pressure on health and care set to increase, Dementia 2014 offers recommendations on what should be prioritised now to make a genuine impact on people's lives.

Alzheimer's Society recommends 14 actions that will ensure people affected by dementia can live well with the condition.

Action 1: All statutory health and/or social care bodies in England, Wales and Northern Ireland to set targets for stepped yearly improvement in diagnosis rates up to 75% by 2017

- It is unacceptable that diagnosis rates are variable across the UK. In some areas people have as little as a one-in-three chance of getting a diagnosis.
 - Diagnosis should be prioritised, with all areas in England, Wales and Northern Ireland aspiring to a 75% diagnosis rate.
-

Action 2: Twelve weeks from referral to diagnosis

- Waiting times for a diagnosis vary considerably depending on where you live. Unnecessarily long waiting times can cause undue stress to people already experiencing difficulties.
- Everyone affected by dementia should receive an equal service and wait no longer than 12 weeks from initial GP referral to receiving their diagnosis.
- It is not enough to focus on reducing the wait for an initial appointment, as more people wait longer between their initial appointment and diagnosis. The time that the whole diagnostic process takes must be standardised.

Action 3: Establish a minimum standard of integrated post-diagnosis support for people with dementia and carers

- Many people are left without support following a diagnosis. Only with support and advice can people live well and make important decisions about their future care.
- A guaranteed minimum standard of post-diagnosis support, which includes information, advice and support, should be made available to everyone affected by dementia.
- Everybody diagnosed with dementia should be guaranteed a dementia adviser, or equivalent.

Action 4: Governments to build on progress and commit to appropriately resourced national strategies in England, Wales and Northern Ireland

- Governments in England, Wales and Northern Ireland have made significant progress in improving the care of people with dementia, but more can be done to meet this challenge.
 - The National Dementia Strategy for England (NDSE) on dementia has ended, though there are government commitments that last until March 2015.
 - In Wales and Northern Ireland, national strategies have been difficult to implement due to a lack of monitoring and investment.
 - Change cannot happen without national leadership. Each nation should ensure that they have in place an ambitious national strategy that is underpinned by appropriate resources.
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Action 5: An open debate with citizens on the funding of quality health and social care that meets the needs of people affected by dementia

- People with dementia are unfairly disadvantaged by our health and social care system, having to pay for essential care needs that result from their medical condition, such as help with washing or dressing.
- An individual's life savings can be spent on meeting their basic needs, which cannot be effectively met through the current system of the still common 15-minute visit (UKHCA, 2012).
- We urgently need an appropriately funded, person-centred system in which people with dementia have equal access to quality care as people with any other medical condition.
- A national debate with citizens on the future of health and social care funding is essential and must be prioritised.

Action 6: A fully integrated health and social care system that puts the needs of people first

- Dementia is a complex condition and those affected come into contact with a wide range of health and social care professionals within a system that is often difficult to navigate.
- In England and Wales people with dementia receive fragmented care because health and social care services are not formally linked.
- Integration of services is essential in order to provide seamless care to people with dementia regardless of the setting. This is particularly important for people with co-morbidities, younger people with dementia and people from black, Asian and minority ethnic communities.

Action 7: People with dementia and their carers must be involved in the commissioning, design and development of services

- People with dementia and their carers should be able to inform decisions made about the services available to them. They are experts by experience, and know what support is needed to help them live well.
 - People with dementia with eligible needs should have access to personal budgets so they can make choices about what care they receive.
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Action 8: High-quality mandatory training for all staff providing formal care to people with dementia

- People with dementia interact with a wide range of health and social care professionals. It is vital that these professionals understand the complexity of the condition and are able to provide high-quality care.
- Compulsory, quality-assured training for all front-line health and care staff will raise the bar for dementia care.

Action 9: All communities to become more dementia friendly

- Every person with dementia has the right to live well in their community, but few communities exist where people are supported to do this.
- More communities in England, Wales and Northern Ireland should sign up for the recognition process for becoming dementia friendly and establish local Dementia Action Alliances.

Action 10: Everyone should have improved awareness of dementia

- Negative attitudes towards dementia remain a significant barrier to people with dementia living well with the condition.
- Everyone should take part in the Dementia Friends awareness-raising campaign so they can play their part in enabling people with dementia to live the lives they want to.
- There should be increased social action in the community to support people with dementia to live well.

Action 11: All businesses and organisations to take steps towards becoming dementia friendly

- Dementia is a growing problem and, as the working age rises, it will become more common among those in employment.
 - Businesses and organisations should establish strategies to support employees with dementia, or employees who are caring for someone with dementia.
-

Action 12: Dementia research should receive a level of investment that matches the economic and human cost of the condition

- Dementia costs the UK more than cancer, heart disease or diabetes. Despite this, research funding for dementia is currently only £74 million a year, in comparison with the £503 million a year spent on cancer.
- Over the next 10 years investment in dementia research is set to more than double in the UK alone. This amount still lags far behind what is needed to achieve parity with other diseases.
- 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.

Action 13: All people with dementia and carers should have access to the best evidence-based care and research

- Research is driving forward advances in understanding the causes of dementia, new treatments and prevention strategies, as well as improved ways to care.
- Academics and commissioners of services should work together to speed up the identification of emerging research findings around care and support that have been shown to be effective, and strengthen links between academia and those in service delivery.
- New research findings should be made available quickly to people with dementia to help them have the highest quality of life possible.

Action 14: People affected by dementia and their carers should be given greater opportunity to participate in dementia research

- Currently less than 4% of people with a diagnosis of dementia are involved in a clinical research study. People affected by dementia must be given greater opportunity to participate in clinical research.
 - People with dementia should have increased opportunities to influence research that is carried out and to participate in research studies.
-

Introduction

Purpose

Now is a crucial time for action on dementia. Dementia is receiving unprecedented global attention, with bold commitments to increase research funding over the next 10 years. In the UK, governments have spoken out on the issue of dementia and highlighted its importance, and professional leaders across health, social care and housing have identified dementia as a priority.

There has been a significant change in attitudes and behaviours towards dementia, but we have not yet seen the transformational change required in health and social care to deliver the improvements that people with dementia and their carers want and need. While it is important to look to the future and search for a cure, we must also look at the state of dementia care and support today and how we can make real changes now that will improve quality of life.

This report is informed and shaped by the perspectives of people with dementia, and reviews progress made in the areas of diagnosis, health and social care reform, quality of care and community life. It describes the state of dementia in the UK and sets out the actions that need to be taken by governments and providers of care in England, Wales and Northern Ireland¹ to ensure that people with dementia and their carers can live well.

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. Rarer causes of dementia include dementia with Lewy bodies and frontotemporal dementia.

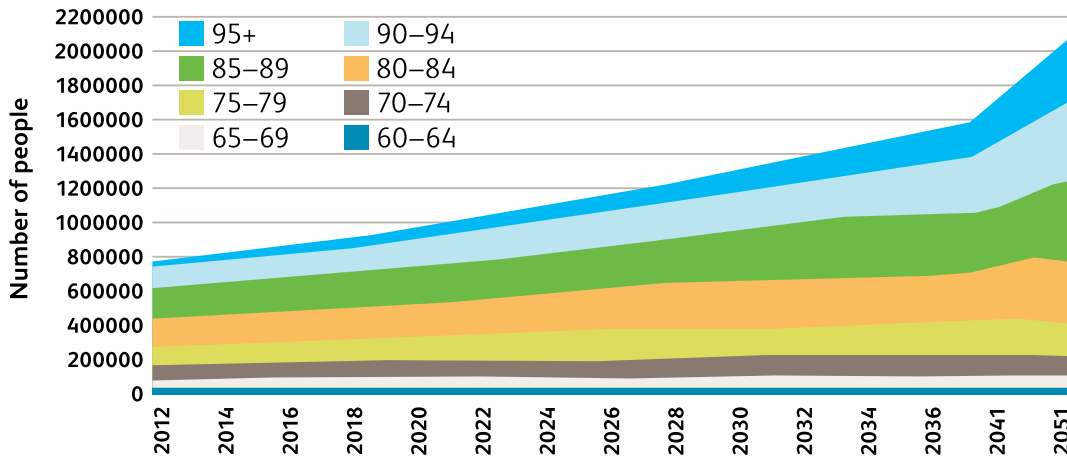
Dementia is a progressive condition, meaning that people with dementia and their family carers have to cope with changing abilities over time. These changes include an increasing and fluctuating impairment in the person's capacity to make decisions, about major life events and circumstances as well as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

Research shows that in 2014 there are 835,000 people in the UK who have dementia (Alzheimer's Society, 2014a). This includes over 700,000 people in England, over 45,000 in Wales and nearly 20,000 in Northern Ireland. Over 40,000 younger people (65 years of age or below) have dementia, and an estimated 25,000 people from black, Asian and minority ethnic groups have the condition. Dementia costs UK business £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).

With an ageing population the numbers of people with dementia in the UK are increasing and so are the costs. Dementia now costs the UK economy £26 billion a year, with this price tag set to rise.

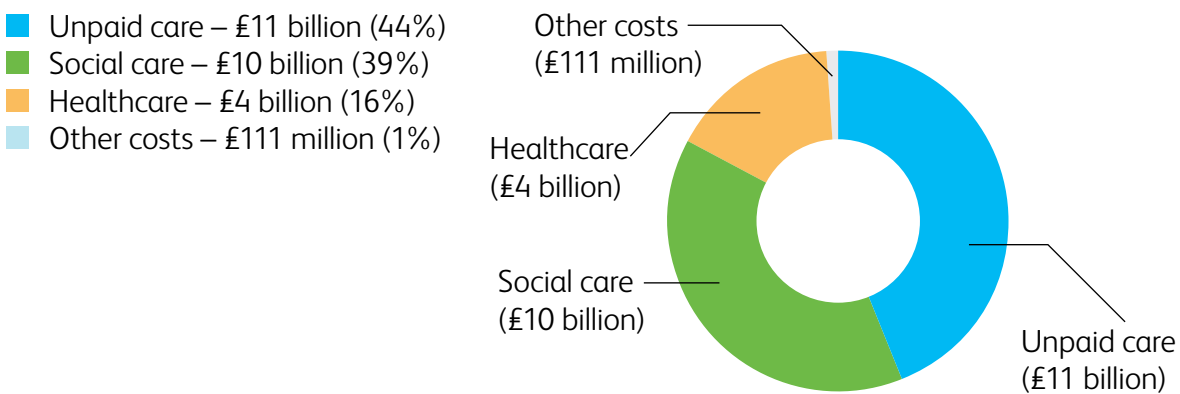
¹ These are the three countries in which Alzheimer's Society operates.

Projected increases in the number of people with dementia



According to these projections, there will be over 850,000 people with dementia in the UK by 2015 (856,700) over 1 million by 2021 (1,007,485) and 2 million by 2051 (2,092,945).

Cost of dementia care by location and type



The total annual cost per person with dementia in different settings is estimated as follows:

People in the community with mild dementia	£25,723
People in the community with moderate dementia	£42,841
People in the community with severe dementia	£55,197
People in care homes with dementia	£36,738

Two-thirds of people with dementia live in the community (Alzheimer’s Society, 2007). Of these, one-third live alone in their own homes (Mirando-Costillo et al, 2010). The UK Homecare Association estimate that 60% of people receiving care at home have a form of dementia (UKHCA, 2013). Unpaid carers save the state £11 billion per year.

As the symptoms of dementia progress, people need increasing support. 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 (Alzheimer’s Society, 2007), and around 70% of care home residents in the UK have dementia or significant memory problems (Alzheimer’s Society, 2014a).

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). National guidelines exist which aim to support health and social care professionals in providing quality care to people with dementia (NICE, 2010, 2011, 2013a, 2013b). However, 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.

Dementia diagnosis rates are increasing, but variation within and between nations remains extreme. Support following a diagnosis is not available to everyone, as there is no mandatory minimum provision of support. It is also unclear whether the responsibility for providing services should sit with the NHS or social care, or both. This means that too often access to a diagnosis and appropriate post-diagnosis support is dependent on the services available in that area.

However, dementia is now a public and political priority in a way that it has never been before. Starting with England in 2009 and followed by Wales and Northern Ireland in 2011, national plans on dementia were launched in each country increasing the political attention across the nations. In England, the strategy on dementia was supported 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, 2012a). These policy commitments are delivering improvements, but have not yet achieved the transformational change to the system that is needed to generate a better quality of life for people with dementia.

That is why, as we approach 2015, Alzheimer's Society wants to see long-term national plans on dementia. The English strategy finished in April 2014; there is insufficient monitoring of the funding allocated for the National Dementia Vision in Wales and an urgent need for a specific dementia strategy with clear lines of accountability; and implementation of the strategy in Northern Ireland has been hampered by lack of government investment. Given these factors, there is a clear need for robust evaluation and national prioritisation of dementia. Without a national focus, the lives of individuals affected by the condition cannot improve.

Quality of life outcomes that are important to people living 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. While it is important to acknowledge that each individual will have personal aspirations, 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. This was developed by the Dementia Action Alliance (DAA), which brings together different organisations in England interested in 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:

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

The success of policy changes in dementia must be measured against these outcomes. Today the challenge is to make sure that national commitments on dementia in England, Wales and Northern Ireland will make these outcomes a reality for people with dementia and their carers. In areas of policy where this has not yet occurred, this report details actions that must be taken to achieve this.

Methodology

The report draws on existing research and current work in dementia. This includes a range of public policy documents, research literature, learning from good practice and existing indicators. This learning is informed by people affected by dementia.

People affected by dementia

Alzheimer's Society surveyed people with dementia in England, Wales and Northern Ireland to find out how well they were living. The survey was distributed via Alzheimer's Society services, made available online and promoted by partner organisations. People were invited to complete the survey between October and December 2013.

The total number of respondents to the survey was 1,327. The majority of respondents (66%) were people with dementia, either filling in the survey alone (18%) or with support (48%). The number of carer respondents who were completing the survey on behalf of someone with dementia was 32%. In addition:

- The majority of respondents were aged 65 and over: 9% were under 65 years; 67% were 65–85 years and 23% were over 85.
- Many people had been living with dementia for several years: 5% had been living with the condition for under a year; 42% for 1–3 years; 34% for 4–6 years; 13% for 7–9 years; and 6% for over 10 years.
- When asked where they live, 18% of respondents said on their own; 62% said with a carer; 5% said with someone who is not a carer; 10% said in a care home; and 9% said other.

This is a significant number of people with dementia and the survey provides an important evidence base from which to establish how well people are living with the condition. However, there are limitations to the sampling on which it is based. This is a self-selecting survey and the sample comprises people in touch 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 evidence provides a robust snapshot of how well people are living, rather than a definitive evaluation covering all stages of living with dementia.

Public poll

Alzheimer's Society commissioned a YouGov poll of UK adults. In May 2014, 2,289 individuals were asked about both their own quality of life and their perceptions of how well people are able to live with dementia. The findings are discussed throughout the report.

1 Improving dementia diagnosis

Key points

‘I have support that helps me live my life.’

‘I have the knowledge and know-how to get what I need.’

- There is an urgent need to improve access to quality dementia diagnosis and post-diagnosis support:
 - Diagnosis rates are variable across the UK. In some areas people have as little as a one-in-three chance of getting a diagnosis.
 - Waiting times for a diagnosis vary considerably depending on where you live. Unnecessarily long waiting times can cause undue stress to people already experiencing difficulties.
 - Many people are left without support following a diagnosis. Only with support and advice can people live well and make important decisions about their future care.
 - Diagnosis should be prioritised, with all areas in England, Wales and Northern Ireland aspiring to a 75% diagnosis rate.
 - Everyone affected by dementia should receive an equal service and wait no longer than 12 weeks from initial GP referral to receiving their diagnosis.
 - A guaranteed minimum standard of post-diagnosis support, which includes information, advice and support, should be made available to everyone affected by dementia.
 - Everybody diagnosed with dementia should be guaranteed a dementia adviser, or equivalent.
-

Introduction

Ensuring a timely, quality diagnosis of dementia must remain a priority in the UK. Many people are getting the diagnosis they need too late or not at all. In the UK, diagnosis rates range from less than 40% to over 75%. Assessment and diagnosis of dementia soon after someone has experienced symptoms is essential. It means they, and their carers, can access the care and support they need.

Once a diagnosis is received, people need access to information, support and care to help them live well now and plan for the future. Every day people with a diagnosis tell us of the benefits it has brought to their lives.

In both care homes and hospitals, health and care professionals need to recognise the importance of diagnosing and supporting people with dementia from early on in the condition through to the advanced stages. Unfortunately, this is still not universally accepted.

A combination of better awareness and understanding of dementia, prioritisation of the condition by decision-makers and improved data mean that diagnosis rates are increasing. We need to go further, and get a strong and sustained commitment for transformational change within our health and social care system so more people with dementia are identified and supported. This requires a workforce that is well trained and supported. As well as a focus on continuous stepped improvement in diagnosis rates, appropriate post-diagnosis support must be prioritised.

Importance of diagnosis

Quality of life for a person with dementia depends on receiving a timely diagnosis. A diagnosis allows someone with dementia to access services and, in some cases, medication that can slow the progress of their condition. It may also allow them time to make critical decisions about their health and welfare both now and in the future while they have the capacity to discuss their wishes and to make their views known (APPG, 2012). The first step towards achieving the outcomes defined as important in the Dementia Declaration is diagnosis (DAA, 2010).

Alzheimer's Society believes everyone with dementia should be able to access a timely diagnosis. This can be understood as a diagnosis at a point where the symptoms of dementia are starting to have an impact on daily life (Brooker et al, 2013).

For a person with dementia, a timely diagnosis means:

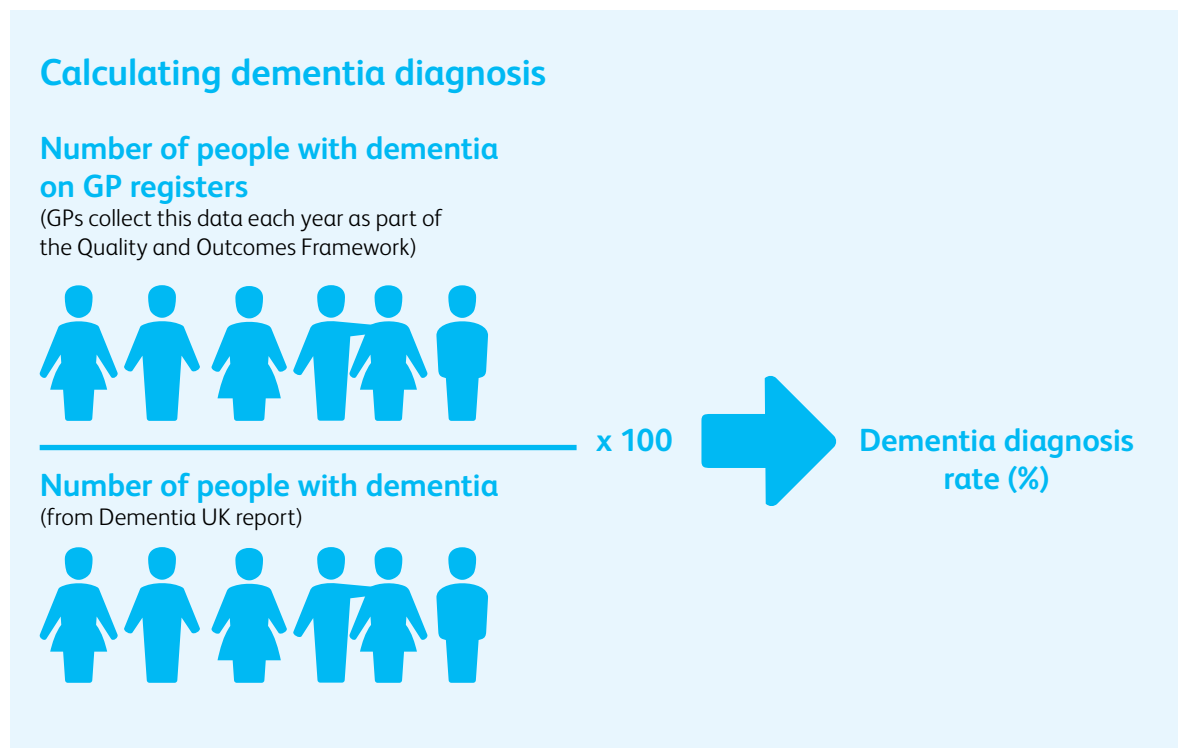
- access to information and advice that can help them cope with their condition and live better now
 - access to potential treatments and support services
 - better management of other health conditions where dementia may affect how they cope with that condition
 - time to plan ahead and make informed decisions about future health and social care needs, as well as personal finances.
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For the health and social care system, a timely diagnosis means:

- appropriate use of local resources
- opportunity to plan for future care needs at a population level
- avoidance of crisis and emergency admissions
- improved clinical management of multiple, complex conditions.

In the future, earlier diagnosis before the onset of symptoms could be advisable if new treatments are available or there is more certainty about those at risk of developing symptoms. At present there is not enough evidence of the benefits of this approach to make it national policy.

Dementia diagnosis rates



Understanding how many people there are living with dementia is necessary to determine how many people have a diagnosis. The most recent figures available for the number of people with dementia on GPs' registers dates from 2013 when there were 816,000 people with dementia in the UK (Alzheimer's Society, 2014a).

Access to timely diagnosis of dementia remains variable depending on where you live. In some areas less than 40% of people with dementia have a diagnosis, while more than 75% are diagnosed in others. Provision of post-diagnosis support is patchy at best.

Actions for improving diagnosis

Alzheimer's Society recommends three actions to ensure that people with dementia receive a quality, timely diagnosis:

- All statutory health and/or social care bodies in England, Wales and Northern Ireland to set targets for stepped yearly improvement in diagnosis rates up to 75% by 2017 (Action 1).
- Twelve weeks waiting time from referral to diagnosis (Action 2).
- Governments to establish a minimum standard of integrated post-diagnosis support for people with dementia and carers, including a dementia adviser or equivalent (Action 3).

Action 1: All statutory health and/or social care bodies in England, Wales and Northern Ireland to set targets for stepped yearly improvement in diagnosis rates up to 75% by 2017

Improving dementia diagnosis rates has been acknowledged as an important issue in England (Department of Health, 2009), Wales (Welsh Assembly Government, 2011) and Northern Ireland (DHSSPS, 2011) and commitments have been incorporated into government national strategies. However, much more work still needs to be done to reduce the numbers of people with dementia who are undiagnosed and unsupported.

In England the Prime Minister's challenge on dementia has prioritised getting more people with dementia a formal diagnosis (Department of Health, 2012a) and the ambition is to achieve a national diagnosis rate of 66% by March 2015. Following from these national commitments on diagnosis, there are policy tools that help deliver results. These include written guidance, data resources such as the Dementia Prevalence Calculator, indicators on dementia in health and social care policy frameworks and financial incentives for hospitals and GP practices to improve identification of people with dementia. There has also been a grass-roots approach to improving local diagnosis rates such as Alzheimer's Society's Worried about your memory? campaign. Dementia diagnosis has also been identified as an important area on which to focus efforts in linking health and social care services.

In Northern Ireland average diagnosis rates are relatively high in comparison with parts of England and Wales, but significant disparities still exist between the five health and social care trusts. The Strategy Implementation Group has set up a regional memory services work plan, to standardise diagnostic services based on the principles of the Royal College of Psychiatrists' accreditation programme. This includes provision of post-diagnosis advice and information services and protocols for referral by GPs to memory services. However, progress to date has been hampered by insufficient resources.

Diagnosis rates in Wales are among the worst in the UK, with little improvement in recent years. Although the issue has been acknowledged by politicians, clinicians and commissioners, no firm policy levers have been put in place to drive change. Improving diagnosis rates will require proactive leadership from a range of organisations, including Welsh government.

Barriers to diagnosis

There are many barriers to diagnosing dementia: lack of strategic approach to dementia at local level; low public awareness of dementia; poor understanding of dementia by health and social care professionals; disinclination to diagnose in areas where support services are not available; and limited partnership between health and social care providers (APPG, 2012).

Dementia among black, Asian and minority ethnic communities is particularly undiagnosed. Research published by the Social Care Institute for Excellence (SCIE) has found that people from these groups are less likely to use dementia services. They are also less likely to receive a diagnosis or are diagnosed at a more advanced stage of illness than white British people (Moriarty et al, 2011).

The 2013 All-Party Parliamentary Group (APPG) inquiry on dementia in black, Asian and minority ethnic communities found low levels of awareness of dementia, late diagnosis and lack of provision of culturally sensitive services. All of this makes it more difficult for people with dementia from these communities to get the support they need. The proportion of the black, Asian and minority ethnic population over 65 years old is rapidly increasing, making the need for culturally appropriate services a priority. Black, Asian and minority ethnic organisations are also strengthening their focus on what they can do to increase awareness of dementia.

Efforts have been made in England, Wales and Northern Ireland to raise the profile of dementia among health and social care professionals. However, this has not yet led to success in engaging the professional workforce in the design of a sustainable pathway for dementia diagnosis. In Wales, particular investment has been made in professional development through the Wales Mental Health in Primary Care Network, though this hasn't yet translated into increased diagnosis rates.

In order to achieve system-wide improvement there is a need to change the way health and social care professionals think about caring for people with dementia. Existing commissioning guidance needs to be applied to redesigning systems and workforce development, and will require appropriate investment if we want to see transformational change.

Improving diagnosis rates involves more than just improving numbers – it involves designing a diagnostic pathway that takes people from their first appointment with their GP through to the support they receive in the years following a diagnosis. This requires investment, joint working across health and social care, and leadership. Political commitments and top-down policy directives are starting to yield improvements, but must also be met with local services designed around the needs and voices of people with dementia.

Action 2: Twelve weeks from referral to diagnosis

Currently, where dementia is suspected, GPs carry out initial reviews of cognitive and physical health and refer people to a specialist secondary service (a memory clinic/service) for full diagnostic assessments. Increased emphasis on diagnosing dementia is going to place additional pressures on memory clinics. Appropriate investment must be made at the outset by commissioners to ensure resulting improvements in access to diagnosis services are sustainable.

Case study

Wokingham Memory Clinic

Wokingham Memory Clinic is based in Wokingham Hospital, Berkshire. The Memory Clinic is able to provide early diagnosis, treatment, education and support for both patients and carers in the community, enabling people to remain in their own homes for as long as possible.

The Memory Clinic is staffed by a multi-professional team of doctors, dedicated memory clinic nurses, an occupational therapist, a memory clinic assistant, psychologists and a speech and language therapist.

On receipt of a referral, usually from the GP, an appointment at a mutually agreed time and place (home visits are available) is arranged by telephone with the person referred, or their carer if more appropriate. This is followed up by an appointment letter and a leaflet giving details of what is likely to happen at a first memory clinic appointment. All appropriate referrals are usually seen within four weeks. On the appointment day, 62% of people seen are given a diagnosis of dementia or mild cognitive disorder.

The first appointment lasts for up to 90 minutes and the patient and carer are interviewed separately. A few weeks later there would usually be a 45-minute feedback appointment with the doctor to discuss the results of any tests and provide post-diagnostic support. Each person is offered either a personalised letter or a copy of the letter to the GP, which will remind them about what has been discussed and will contain a copy of their care plan.

A variety of support is provided upon diagnosis:

- People diagnosed with dementia and carers are given a copy of Alzheimer's Society's The dementia guide and tailored information from the local information pack.

Wokingham Memory Clinic (continued)

- The person with dementia is invited to the 14-session cognitive stimulation therapy programme, which includes a weekly session offering post diagnostic education and support, if they fulfil the referral criteria.
- The family carer is invited to the six-session Understanding dementia course.
- Younger people with dementia and their carers are offered more tailored versions of these courses.
- People with a diagnosis of dementia are signposted to the local dementia care advisers and younger people are directed to an Admiral Nurse (a mental health nurse specialising in dementia) who can assist with further appropriate support and engagement in the community.

Feedback is regularly collected from patients and carers on how to improve the service. Last year there were four 'Big Conversations' for both patients and carers, each with up to 16 people attending. Services are adapted as a result of patient and carer feedback, for example, improving the environment and providing more information prior to the first appointment.

Wokingham Memory Clinic has taken part in the Memory Services National Accreditation Programme (MSNAP). This has improved team cohesion and morale and helped the team in reviewing all of the Memory Clinic processes, documentation, environment and the level and type of service provided. It has raised the profile of Wokingham Memory Clinic in the local Academic Health Science Network.

In April 2014 the clinic was accredited as excellent for the provision of, assessment and diagnosis of dementia and accredited as excellent for the provision of psychosocial interventions for dementia.

Memory clinics are found across the UK, however there is particular commitment to increasing provision in England. In 2009, £60 million was attached to the delivery of the National Dementia Strategy for England, one of the aims of which was to create more memory clinics (Department of Health, 2009). This was reinforced by the introduction of the Prime Minister's challenge on dementia in 2012, which recommended widespread provision and accreditation of memory clinics (Department of Health, 2012a).

The Audit of Memory Clinics in England (Royal College of Psychiatrists, 2013a) found huge variation in waiting times from GP referral to initial appointment at the memory service clinic, and between initial appointment and diagnosis. The range of time between referral and initial appointment is 1–25 weeks, and between initial appointment and diagnosis is 1–21 weeks.

In Wales, a similar audit has been run by Public Health Wales. The results were published in August 2014 and show that there is considerable variation across Wales. On average, people in Wales wait 5.2 weeks from the point of referral to receiving their memory assessment,

and an additional 9.6 weeks from the point of having the assessment to receiving the diagnosis. Nearly one third of clinics in Wales are currently failing to meet the standard set by the Memory Services National Accreditation Programme that states that people should wait no more than 4–6 weeks between the receipt of referral and their first appointment. The report also concluded that very few clinics in Wales have sufficient capacity to cope with the numbers of new patients who would need assessment if diagnosis rates were to improve (Public Health Wales, 2014).

In Northern Ireland, a dementia strategy commitment to review effectiveness of memory services, by the Regulation and Quality Improvement Authority (RQIA), has not yet commenced – its target date is December 2014.

People with dementia should not wait for longer than necessary for appointments and diagnosis. This causes undue, avoidable stress. A prompt, efficient diagnostic process of no longer than 12 weeks should be available to all. Further time may be needed to determine sub-type in particularly complex cases, but an initial diagnosis should nonetheless be given within 12 weeks. Long waits can be a result of inadequate resourcing and pathway design rather than a lengthy clinical process. Memory clinics have been subject to public scrutiny with regard to waiting times. The Secretary of State for Health in England made a public commitment in 2014 that waiting times for initial appointments should be no longer than six weeks. However, this commitment does not extend to putting a cap on the overall period of diagnosis. Focus on reducing the wait for an initial appointment is not enough, as more people wait longer between initial appointment and diagnosis (Royal College of Psychiatrists, 2014). The time that the whole diagnostic process takes must be standardised.

There is no fixed template for a memory service. They are commissioned according to local need and to complement existing structures and services. However, variability in form should not lead to variability in function, as is currently the case. Furthermore, there is no nationally held database of memory clinics and this limits how well their progress can be monitored.

The Memory Services National Accreditation Programme (MSNAP) was established in 2009. It is a quality improvement programme which reviews memory clinics against a set of evidence-based standards, and supports clinics to achieve accreditation. The scheme is voluntary and has an attached fee. To date there are 56 accredited memory services and 93 members in England and Wales. A service improvement programme modelled on the MSNAP standards is being introduced in Northern Ireland.

MSNAP allows independent quality assurance of the diagnostic process. However, the costs and time involved discourage some memory clinics from joining. Also, some smaller services struggle to meet all of the standards required for accreditation. MSNAP, though developed using national guidance, would benefit from an independent evaluation to provide evidence of the success of the programme. This could also explore other quality assurance measures for memory services, particularly those with fewer staff.

People with dementia should not be subject to the variation across different local areas for appointments at memory clinics. Long waiting times can and must be resolved by a patient-centred approach to service design using existing guidance. Health service commissioners should prioritise investment in memory services when designing dementia pathways. They should also ensure that memory services are resourced appropriately to achieve the minimum diagnosis rate of two-thirds of their population with dementia, with a commitment to reaching a 75% diagnosis rate by 2017.

Action 3: Establish a minimum standard of integrated post-diagnosis support for people with dementia and carers

Post-diagnosis support consists of information, advice and support for people with dementia and carers. Support following a diagnosis is critical in helping people with dementia to live well and has been identified as important by governments in England (Department of Health, 2009), Wales (Welsh Assembly Government, 2011) and Northern Ireland (DHSSPS, 2011). However, at present there is no guidance on a minimum provision of support and it is unclear in England and Wales whether the responsibility for commissioning services lies with health or social care. As a result access to support after a diagnosis is inconsistent.

There is no nationally held data on what support is currently commissioned for people with dementia. Where support does exist there are no quality standards, and health and social care professionals are often unsure of how to make referrals into services. This is unacceptable. Everyone affected by dementia should be guaranteed support to live well following a diagnosis. This should be the focus of public policy on diagnosis over the next five years.

Minimum standard of post-diagnosis support

Each individual will have different support needs, which change over time, and not all diagnoses will be given early during the course of the disease.

Alzheimer's Society believes that key support services should be available to each person diagnosed with dementia as well as carers – these are listed below. These should be appropriate for the individual, tailored to their specific needs and written into a formal care plan. This plan should be reviewed at least annually, reflecting the changing needs of people with dementia and carers as the condition progresses.

Post-diagnostic support services for people with dementia:

- 1** Comprehensive information on all aspects of the condition and access to universal support services, such as a helpline.
 - 2** Expert practical guidance on how to navigate services, support and decisions given by a dementia adviser or equivalent.
 - 3** Support to manage and live well with the condition. This can be delivered individually and/or in a group.
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Case study

Dementia Adviser service

A diagnosis of dementia means a gradual process of adjustment, during which access to information and support will be important for many. Having the opportunity and being given the time to think and talk things through with a trusted, skilled and knowledgeable adviser, to better understand dementia and to find out about the support and services available to you, is essential if people are to live well.

Alzheimer's Society Dementia Advisers provide people with information about dementia and signpost to other support and services. They remain a point of contact for information as a person's condition progresses. The minimum contact people have with their Adviser is twice a year – to check how things are going, identify if there are any concerns or changes and determine areas where support can be offered.

Dementia Advisers take a person-centred approach to information provision, taking into account a person's understanding of their dementia and their coping strategies and adjustment following diagnosis. Time spent with a Dementia Adviser enables people to identify and prioritise their own information needs. Dementia Advisers working for the service spend a lot of time getting to know the local area and familiarising themselves with the support and services available. Where there is limited availability of the support that people with dementia and their families want, Dementia Advisers are well-placed to identify gaps in provision and ensure instances of unmet need are communicated to local commissioners and service providers.

Supporting carers

This minimum provision of support should be available to carers as well as people with dementia.

There are 670,000 carers of people with dementia living in the UK today, saving the UK economy £11 billion every year. Without the right support, carers are unable to care for the person with dementia. If carers are identified and supported, the potential savings to health and social care could be significant.

The Care Act (2014) puts new requirements on local authorities in England to assess carers' needs for support. The Act will introduce a new legal right for carers to access support services, in accordance with national eligibility criteria. This package should include a support plan and access to a personal budget. This must be tailored to address the specific needs of carers for people with dementia. Similar provisions have been introduced in Wales as part of the Social Services and Well-being Act.

In Northern Ireland the offer of a carer's assessment has been a statutory duty since 2002. The Northern Ireland Single Assessment Tool (NISAT), which was developed to address the fragmented nature of assessment processes applied to older people, led to the development of the Carer's Support and Needs Assessment. This covers the impact on the carer, social security benefits and use of direct payments as a means of providing personalised services. A Vision of Community Care called for the full implementation of NISAT across Northern Ireland to support a holistic person-centred assessment of the often complex health and social care needs of the older person.

Commissioning support services

A range of guidance has been produced to assist in the planning and development of dementia support pathways, which put the needs of patients at the heart of a network of care:

- NICE dementia quality standard (NICE, 2010)
- Commissioning framework for dementia (Department of Health, 2011)
- NICE clinical guideline on dementia (NICE, 2011)
- South West commissioning guidance (NHS England Strategic Clinical Networks, 2013)
- NICE commissioning guide on support for commissioning of dementia care (NICE, 2013a)
- NICE quality standard on support for people with dementia (NICE, 2013b)

Each has a clear emphasis on provision of support for the person with dementia and their carer following diagnosis as a core part of a cohesive, strategic pathway.

There is also increasing evidence that supporting people with dementia allows a better quality of life, and means people can achieve the outcomes outlined in the Dementia Declaration. The 2013 evaluation of peer support networks and dementia advisers (Department of Health, 2013a) found that these services helped people affected by dementia to live better and feel more in control of their lives. Similarly, an independent evaluation of the Alzheimer's Society Carer Information and Support Programme (Barnes et al, 2013) found that support and access to information for carers improved care for themselves and for the person with dementia.

The evidence on improvements in quality of life through investment in support services is strong. More evidence is needed to demonstrate the cost-efficiency of investment in dementia services at a societal level, though a recent study by the PSSRU (Knapp et al, 2014) has shown that care and support interventions could be cost-effective on a larger scale.

Despite quality guidance on how to commission services for people with dementia, many of those affected by the condition continue to be left without support. Where there is an absence of local leadership on dementia and clear local strategies, it is difficult to provide quality dementia services and communicate their benefits effectively (NHS England, 2014). There is a placeholder in the NHS Mandate on measuring outcomes for post-diagnosis support, but little action has been taken on fulfilling this vital point of data collection. We would like to see progress on this important commitment without delay.

Where services are being commissioned by local authorities, increasing financial pressures on local government often mean that services are commissioned based on cost rather than quality. Almost three-quarters (74%) of providers say that the councils they have contracts with have become more interested in securing a low price than they are in the quality of service delivered (UKHCA, 2012). The importance of quality has been attested through independent evaluation (Department of Health, 2013a), yet dwindling public funds make prioritising quality difficult.

Excellent services for people affected by dementia exist across England, Wales and Northern Ireland. It would be inappropriate to stifle innovation through a prescriptive framework of support. However, a guaranteed minimum provision of support for both people with dementia and carers is vital to ensure continued quality of life and avoid crisis in the later stages of the condition.

Giving information, advice and support to both people with dementia and carers can be locally determined with shared national outcomes.

In England, the Secretary of State for Health has committed to improving provision of support for people with dementia by March 2015, though details of what this looks like remain to be seen. No commitments to post-diagnosis support have been made in Wales or Northern Ireland. National governments must guarantee and appropriately resource a minimum provision of information, advice and support to people with dementia and carers following a diagnosis.

We are committed to supporting more people with dementia to access a diagnosis and appropriate post-diagnosis support. We provide over 2,000 local services in England, Wales and Northern Ireland, and support people via universal services such as our information resources, helpline, website and online forum. We have launched a new campaign on diagnosis, Right to Know, and we are targeting national and local decision-makers to ensure dementia diagnosis is a priority. Our public-awareness campaign, Worried about your memory?, is ongoing and aims to improve professional and public understanding of dementia. We are also working to improve community understanding of dementia through our Dementia Friendly Communities and Dementia Friends programmes.

2 A health and social care system that works better for people affected by dementia

Key points

‘I know that services are designed around me and my needs.’

- Governments in England, Wales and Northern Ireland have made significant progress in improving the care of people with dementia, but more needs to be done to meet this challenge.
 - Dementia is a complex condition and those affected come into contact with a wide range of health and social care professionals within a system that is often difficult to navigate.
 - People with dementia are unfairly disadvantaged by our health and social care system, having to pay for essential care needs that result from their medical condition, such as help washing or dressing.
 - Integration of services is essential in order to provide seamless care to people with dementia regardless of the setting. This is particularly important for people with co-morbidities, younger people with dementia and people from black, Asian and minority ethnic communities.
 - A national debate with citizens on the future of health and social care funding is essential and must be prioritised.
 - Change cannot happen without national leadership. Each nation should ensure that they have in place an ambitious national strategy prioritising person-centred, integrated care that is underpinned by appropriate resources.
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Introduction

People with dementia are frequent users of health and social care services. A quarter of hospital beds and up to 70% of places in care homes are occupied by people with dementia, and over 60% of people receiving homecare services have some form of dementia (UKHCA, 2013). Despite this, unprecedented cuts to the care system and unco-ordinated reform are leaving many people isolated, without access to the vital support they need to live well.

New research shows that the cost of dementia has risen to £26 billion per year (Alzheimer's Society 2014a). This increase in cost can be attributed to the failure of our current health and social care services to care for people with dementia appropriately, with the costs of unpaid care soaring.

It is essential that health and social care services are designed around the needs of people with dementia. People with dementia and family carers can live well if they have access to good quality, integrated care that is affordable. They should also be able to die with dignity with appropriate end-of-life services in place. This requires transformational change at a systemic level.

In England the NHS faces a funding gap of up to £54 billion by 2021 (Nuffield Trust, 2012) and cuts to social care have left thousands of people without the crucial support they need. These funding issues have been compounded in parts of the UK by difficulties in ensuring health and social care work together to deliver truly person-centred care.

We have created a system that is set up to reward crisis admissions rather than delivering on the outcomes that matter most to people, such as those identified in the Dementia Declaration. In places where health and social care are not linked, the problems caused by poorly integrated care are well-known. There can be gaps in support and information, and families and individuals may not know who to ask for help. People receive duplicate assessments and have to retell their story repeatedly.

A preventative approach should be adopted in health and social care. Rather than waiting until the point of crisis, healthcare services should be central in promoting prevention, and commissioning must be about quality and outcomes.

Changes to health and social care systems

The Care Act in England, the Social Services and Well-being Act in Wales and Transforming Your Care in Northern Ireland have caused substantial debate about structural and legal issues relating to our health and social care system. Each proposes substantial reform that will impact on how care is provided in their jurisdictions.

The changes that will be implemented when they come into force represent a step in the right direction towards improving care and support. However, they are still substantially removed from the significant changes that are necessary to redesign the health and social care system so that it meets the needs of people with dementia.

Legal changes to care: the Care Act, the Social Services and Well-being Act and Transforming Your Care

Across England, Wales and Northern Ireland, governments have been introducing structural reforms on how care and support is organised and delivered in communities. Each government has recognised the necessity to maximise independence through the provision of preventative services.

The Care Act 2014 in England and the Social Services and Well-being Act in Wales significantly overhaul and modernise the social care system in each country. Both the Acts seek to set out clearly what kind of care people should expect and what they will receive, centred on the principle of wellbeing.

Under the Care Act 2014, people with dementia and their carers will have significant new rights, such as the right to independent advocacy and an assessment of carer needs and provision of support. Amongst the new measures, local authorities must adhere to a national minimum eligibility threshold for determining when they have to provide social care to people. From April 2016, a 'cap' on the amount anyone will have to pay towards the costs of their care will operate with the intention of providing certainty and safety from the most extreme of care costs.

The provisions of the Social Services and Well-being Act in Wales are similar to those of the Care Act. Each local authority – with the assistance of their local health board (LHB) partners – must provide people with information and advice relating to care and support in their area, assess people's support needs and prepare a care plan if they are eligible.

In Northern Ireland, Transforming Your Care signals a shift away from over-reliance on acute care and towards providing integrated care through integrated Care Partnerships, at or close to home. The emphasis on prevention and maintenance of wellbeing and independence are cause for optimism but implementing significant structural and cultural changes of this nature will require political commitment if they are to be achieved. Recent and very public retreat on the issue of statutory care home closures calls that resolve into question.

In each country, these reforms will see significant changes to what statutory agencies are expected to provide and the manner in which they provide services.

These reforms do little to fix the serious funding gaps within the social care system. Statutory agency budgets have consistently decreased while demand for care is increasing. The social care workforce has faced major challenges around the commissioning of services, insufficient funding, and workforce development and staffing issues such as low pay, conditions and training. While all of the reforms attempt to address these longstanding issues, the absence of a serious funding commitment will prevent real change.

The costs of dementia to society and to individuals are rising, with the total cost to the UK now more than £26 billion. These spiralling costs cannot continue unchecked. System reform is essential to make sure people with dementia and carers have access to support.

Actions for improving health and social care systems

Alzheimer's Society recommends three actions for creating a health and social care system that works for people affected by dementia:

- Governments to build on progress and commit to appropriately resourced national strategies in England, Wales and Northern Ireland (Action 4).
- Governments to hold an open debate with citizens on how to fund quality health and social care that meets the needs of people affected by dementia (Action 5).
- Governments to develop a fully integrated health and social care system that puts the needs of people first (Action 6).

Action 4: Governments to build on progress and commit to appropriately resourced national strategies in England, Wales and Northern Ireland

England (Department of Health, 2009), Wales (Welsh Assembly Government, 2011) and Northern Ireland (DHSSPS, 2011) have all developed national strategies to support people living with dementia. This level of government commitment was unprecedented, and demonstrated to people living with the condition that their needs were a priority. The strategy in England ended in 2014, though the Prime Minister's challenge on dementia carries forward some of the commitments from the National Dementia Strategy for England (NDSE) through till March 2015. Governments in all nations must ensure that ambitious national strategies are in place that have adequate funding to carry through their commitments.

Dementia has received attention at a global level, with a recent G7 summit putting an international spotlight on the issue. Governments across the globe, in particular in the USA and France, are making serious strategic commitments to tackle the issues presented by dementia. The UK cannot be seen to be lagging behind.

England

Launched in February 2009, *Living well with dementia: A national dementia strategy for England (NDSE)* set out the government's intentions to improve care and support for people with dementia living in England. The All-Party Parliamentary Group (APPG) on dementia reviewed progress made in England towards achieving the objectives of the NDSE (APPG, 2014). Their overarching recommendation was the development of a new, long-term dementia strategy, and they identified post-diagnosis support, integrated commissioning, local leadership, quality-of-life measures and workforce development as key areas of focus for the next strategy.

With the end of the Prime Minister's challenge on dementia in sight and no firm commitment to a refreshed strategy in England, there is a real possibility that the progress that has been made so far will stall.

Wales

The National Dementia Vision for Wales (NDVW) was launched in 2011 and aimed to support the creation of dementia-supportive communities across the country.

The Vision identified six strategic priorities:

- 1 Improving joint working between health and social care
- 2 Improving information provision
- 3 Improving awareness
- 4 Improving training
- 5 Supporting research
- 6 Developing a long-term vision.

Within these broad targets were commitments to reducing times on diagnosis, improving care on general hospital wards, and ensuring appropriate use of antipsychotic drugs.

Progress on achieving the ambitious aims of the vision have been hampered by a lack of resourcing, monitoring and ownership of the action plans. The Older People's Commissioner will publish a review of the Wales dementia vision in spring 2015. Learning from this will inform the development of a new strategy. This should prioritise improving diagnosis rates in Wales, which lag behind the rest of the UK.

Northern Ireland

Improving Dementia Services in Northern Ireland is a four-year regional strategy launched in November 2011 by Edwin Poots, Minister for Health, Social Services and Public Safety. The Minister stated his confidence that funds already dedicated to dementia could be made to cover the strategy's implementation. His optimism, some three years down the line, appears to have been somewhat misplaced. A significant number of the key actions have had target dates quietly pushed back and capacity to implement within existing funds is evidently not a realistic prospect.

Improving Dementia Services in Northern Ireland proposed a holistic model of care, incorporating awareness, risk reduction and early intervention that supports people with dementia and their family carers to be involved in decision making with advocacy provided for those who need it. It called for a regional approach to development of service specifications and promotion of person-centred care that helps maintain independence, wellbeing and social inclusion.

These ambitious aims cannot be met without appropriate investment and resourcing to deliver the strategy.

Action 5: An open debate with citizens on the funding of quality health and social care that meets the needs of people affected by dementia

The current system unfairly disadvantages people affected by dementia. Despite dementia being a physical disease of the brain, most of the essential care required as a result of the disease is to support daily activities such as washing and dressing. This means that over recent years too many families have been left to pay all their care costs whilst the care needs arising from other diseases are paid for by the NHS. In addition, people with dementia and carers are paying for services that have not been designed with their condition in mind, meaning they do not always meet their needs.

Reductions in service provision have had a particular impact on those who require help to live independently in their own homes. 60% of local authorities now commission 15-minute visits, despite overwhelming agreement from service users that a 15-minute visit is not long enough to support a disabled or older person to do everyday things like wash, dress and get out of bed in the morning (Leonard Cheshire Disability, 2013). UNISON found that 79% of homecare workers reported that their work schedule results in them being rushed or leaving clients early to get to their next visit on time (UNISON, 2012).

The UK Homecare Association found that across the UK, Northern Ireland has the highest proportion (28%) of homecare visits of less than 15 minutes and the lowest proportion (13%) of visits over 45 minutes in duration. When providers were asked to describe the care they were required to give in the shortest visits, concerns were expressed by 87% of respondents in Northern Ireland, that care could be undignified (UKHCA, 2012).

However, domiciliary care (personal care services provided in a person's own home) are free of charge in Northern Ireland, as is day care provided away from a person's own home. Costs in Wales are capped. In England most people with dementia have to pay out of their own pocket for this essential support.

Findings from the Personal Social Services Research Unit (Fernandez et al, 2013) confirm that over the last five years both the level of provision of social care has reduced and funding has fallen. This means that 453,000 (36%) older and disabled people who would have received social care five years ago, now receive no support. Funding of social care has dropped by £210 million. Just to keep pace with demographic changes, spending on social care on older people would have needed to rise by £1.6 billion over the last five years.

A budgetary review by the Association of Directors of Adult Social Services (ADASS) in England recently concluded that adult social care services in England will become unsustainable if current budgetary pressures continue. As demand for services increases, spending has decreased by 12% since 2010 (ADASS, 2014).

Health and social care reforms

Proposed reforms to care costs and eligibility criteria in England and Wales are welcome as important steps in the right direction. However, the changes are a long way from being sufficient to solve the crisis in social care funding. The cap on care in England is much higher than the £35,000 proposed in the Dilnot Commission's report into the funding for care and support (Dilnot Commission, 2011).

The cap implemented in the Care Act will only assist those in most extreme of cases, with only 8% of men and 15% of women entering care aged 85 today likely to reach the new social care cap (Products Research Group of the Pensions and Long Term Care Working Party, 2014). Furthermore, the weekly cap on non-residential care charges has been raised in Wales, from £50 per week in 2011 to £60 per week from April 2015.

In a YouGov poll commissioned by Alzheimer's Society, 37% of respondents didn't know that they would be likely to pay for their own social care costs. This demonstrates that a significant proportion of the public are not aware of the huge potential care costs they could expect in the future.

Alzheimer's Society believes that these reforms do not go far enough and that we urgently need a fair system that is appropriately funded to ensure people affected by dementia can access the care and support that they need. In our survey of people with dementia, only 18% of respondents said that they thought they received enough support from the government.

We also need to see eligibility for social care set at a 'moderate' level. Having eligibility for social care set at a threshold equivalent of 'substantial' means that people who cannot carry out basic personal care tasks or maintain important family relationships will remain ineligible for support from the state. The guiding principle of the reforms is promoting wellbeing and preventing escalating needs. Supporting those with moderate needs will achieve this.

The current system rewards crisis admissions to hospital rather than delivering the outcomes that matter most to people. Investments in preventative services, which meet the needs of people early on rather than waiting for crises, are more cost-effective. This has been difficult in practice due to financial constraints, meaning that there is a substantial amount of unmet need in the community.

A better funded health and social care system would place a higher priority on services to support carers of people with dementia. Carers of people with dementia save the UK £11 billion every year (Alzheimer's Society 2014a), but many carers are insufficiently supported in their role or face considerable financial hardship. Only 47% of people with dementia responding to our survey said that their carer received any help in caring for them. Carers should be guaranteed comprehensive support, including emotional support, assistance with day-to-day caring and access to respite and short breaks.

Alzheimer's Society believes that there should be an open, national debate with citizens about what level of health and social care funding is required to meet the needs of the UK population now and in the future. This should be followed by formal plans which detail the changes that need to be made and how they can be achieved.

We are committed to using our influence to shape a health and social care system that works for people with dementia. At a national and local level we are engaging in debates on planning of local services and social care reform. We act as the voice for people with dementia, and ensure that their views are heard by decision-makers.

These issues are too wide-reaching to be tackled by any one organisation. Alzheimer's Society works in coalition with a range of other organisations such as the Care and Support Alliance and the Ready for Ageing Alliance, to influence strategically these important areas of work.

Action 6: A fully integrated health and social care system that puts the needs of people first

Dementia is a complex condition combining features of chronic neurological disease, mental illness, physical frailty and communication problems. People with dementia often receive care from a range of health and social care professionals and regularly move between services. Effective integration, with a system of care centred around the individual, is essential to meet the complex needs of people with dementia. This should be underpinned by sustained investment to translate into improved quality of care.

An integrated care system is one that provides a seamless transition between care providers and is designed around a person's needs rather than organisational or service boundaries. The divide between health and social care in England and Wales is one that causes particular difficulties for people with dementia. Commissioning should be a joint and collaborative exercise between health and social care, informed by local needs and focused on quality.

The problems for people with dementia caused by poorly integrated care and support are widely recognised: duplicate assessments and requests for information; gaps in support; families and individuals not knowing who to contact with queries because of the range of professionals involved; lack of a lead professional with an understanding of the person's case; delays in provision because of disputes about responsibility of funding.

In Northern Ireland health and social care services are integrated. This may account in part for the fact that diagnosis rates are significantly higher than in either England or Wales. However, regional variation in access to diagnosis and support remains.

Better Care Fund

In June 2013, the government in England announced the creation of a 'Better Care Fund', with £3.8 billion to be spent on improving outcomes in adult social care.

This fund pools budgets from health and social care and requires local authorities and clinical commissioning groups to come together to agree on a five-year plan. Joint plans are approved by health and wellbeing boards.

The money will be routed through clinical commissioning groups, though drawn from both health and social care budgets, and will be available for the financial year 2015/16.

There have been significant concerns about the feasibility of the Better Care Fund in practice, given the existing financial pressures on the NHS and social care services.

In England, health spending is ring-fenced whereas social care is not. Tentative steps towards integrating services are being made through the Better Care Fund, which aims to pool resources from health and social care and use these for commissioning services that improve adult social care outcomes. This is a welcome initiative but is not ambitious enough. This valuable work must lead changes across the system towards more integrated, appropriately financed care.

In Wales, a framework for delivering integrated health and social care for older people with complex needs has just been announced. The Integrated Assessment Planning and Review Arrangements for Older People contains guiding statements that health and social care professionals should apply when assessing or reviewing needs and planning care. This framework sets out a programme of work for health boards and local authorities to deliver integrated services for older people with complex needs by December 2014, linking housing, social services and the NHS.

In England and Wales, sufficient funding and infrastructure must be put in place in order to allow committed professionals to make integration a reality. Learning from Northern Ireland and the 14 integration pioneers in England on how to tackle issues such as pooled funding and effective joint commissioning will be invaluable.

There are three key populations for whom services are currently underdeveloped and whose needs must be particularly considered in this new approach to integrated care delivery.

People with dementia with other conditions

Our survey found that 72% of respondents were living with another medical condition or disability as well as dementia. Most respondents were living with one or two conditions, but some were living with up to 12. The range of conditions varied considerably, but the most common ones were arthritis, hearing problems, heart disease or a physical disability.

Old age is already associated with high levels of co-morbidity. For example, the Newcastle 85+ cohort study has found the median number of diseases to be four for men and five for women (Collerton et al, 2009). However, there can be particular issues around co-morbidity and dementia. These results clearly indicate a population with complex needs who will come into contact with a range of health and social care services. It is essential that these people receive support that is appropriate to all their conditions. For this to happen, all of the health and social care professionals they come into contact with must have an adequate level of knowledge about dementia.

The study *Co-morbidity and dementia: Improving healthcare for people with dementia* (Bunn et al, in press) is one of the first studies looking at health service delivery for people with dementia and co-morbidities. Preliminary findings suggest a lack of continuity of care for people with dementia and co-morbidities and poorer access to services. Healthcare professionals frequently prioritise co-morbidity over dementia. The carer of the person with dementia can often end up playing a significant role in co-ordinating healthcare and transferring information across services.

Evidence increasingly shows that 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.

Younger people with dementia

The provision of appropriate care for younger people with dementia (under 65 years old) can pose particular challenges. This is partly because their numbers are small and dispersed geographically, but also because their life circumstances are likely to be different from those of older people.

Younger people with dementia will face different issues, especially if they are still working when they receive a diagnosis. They may face discrimination at work and have to give up work earlier than they would like. As the population ages and the retirement age increases, it is more likely that more people will be diagnosed with dementia while they are still in work.

Dementia care services are usually designed for older people. Some dementia services have a minimum age criterion of 65 and even if services accept younger users the type of care they provide may not be appropriate. This means that younger people with dementia may have to travel considerable distances to access appropriate services or they may be left without the support they need.

It is essential that younger people with dementia have access to a range of specialised services that address their particular needs and enable them to live well with dementia. This should include not only health and social care services, but also wider services that promote their wellbeing such as financial advice and support to remain in work should they choose to do so.

People with dementia from black, Asian and minority ethnic communities

It is only now that larger numbers of black, Asian and other minority ethnic people in the UK are reaching ages where dementia becomes common. Currently people from these communities are under-represented in services (Moriarty et al, 2011) and they are often diagnosed at a later stage of the illness or not at all. The increase in numbers of people with dementia from black, Asian and minority ethnic communities creates an urgent need to address the current situation of under-diagnosis and failure to provide appropriate services.

The 2013 APPG inquiry looked at services and support for people living with dementia in the UK from black, Asian and minority ethnic groups. It found that dementia in these groups often led to people forgetting English as a language and their recent history of living in the UK. Both these factors make social interaction increasingly difficult. The inquiry heard about many high-quality services that were tailored to support people with dementia from black, Asian and minority ethnic communities, but it also learnt that service provision for people with dementia from these communities is thinly spread (APPG, 2013).

Many families from black, Asian and minority ethnic communities feel that there is a lack of culturally sensitive dementia services and are reluctant to use services that do not meet their cultural or religious needs.

Statutory bodies should ensure that information on the numbers of people from black, Asian and minority ethnic communities, their age profile and the resulting estimates of people with dementia are included in any strategic planning. In England, Joint Strategic Needs Assessments should assess the adequacy of services available to support people with dementia from black, Asian and minority ethnic communities and address any gaps.

Substantial benefit could potentially be gained from closer liaison between ethnic minority groups and local specialist dementia services. Specialist dementia staff can offer training to community groups to enable them to offer high-quality support to people with dementia.

Case study

Connecting Communities

Connecting Communities is an Alzheimer's Society project based in London. It is estimated that there are 25,000 people with dementia from black, Asian and minority ethnic groups in the UK and this number is predicted to double by 2016 due to an ageing population. Our three-year project works with these communities in eight London boroughs to raise awareness of dementia.

We engage volunteers from black, Asian and minority ethnic communities to design and deliver awareness-raising activities appropriate for diverse communities. Our original targets included enabling 1,950 people from these communities to receive accessible information about dementia, about the benefits of getting a diagnosis and how to access local services. Within the first 16 months our four volunteering officers reached over 4,000 people.

We have worked with 150 organisations to help establish the Dementia Action Alliance in Enfield and set up an innovating Singing for the Brain group in Newham for South Asian older people affected by dementia.

Our project is also enabling black, Asian and minority ethnic communities to influence local commissioning and start to shape services for the future. We are working on a black, Asian and minority ethnic dementia forum in Croydon to bring together commissioners, service providers and service users to consider the future needs of older people with dementia from these groups.

3 Quality support in every care setting

Key points

'I have personal choice and control or influence over decisions about me.'

- People with dementia frequently use health and social care services, but the quality of care they receive is inconsistent, particularly as they move between care settings, for instance from hospital into a care home.
- Because people with dementia interact with a wide range of health and social care professionals, it is vital that these professionals understand the complexity of the condition and are able to provide high-quality care.
- Compulsory, quality-assured training for all front-line health and care staff will raise the bar for dementia care.
- People with dementia and their carers should be able to inform decisions made about the services available to them. They are experts by experience, and know what support is needed to help them live well.
- People with dementia with eligible needs should have access to personal budgets so they can make choices about what care they receive.

Introduction

Without the right training, it can be difficult for health and care professionals to understand how to interact with people with dementia. This means people with dementia are often unable to communicate their wishes, which can result in poorer quality of care.

People with dementia receive care in a variety of different settings as their condition progresses. These can include their local GP, homecare services, hospitals, care homes and hospices. The quality of care they receive should be consistent across all of these settings, but this is not always the case. People with dementia stay in hospital longer than patients in the same circumstances without dementia, and are more likely to be readmitted or die in hospital (CQC, 2013).

In our survey of people with dementia, only 58% said that they were living well with dementia. Quality of care can be closely linked with quality of life. While there are many examples of excellent care, too often we hear about formal care not being focused on meeting people's needs and aspirations, and failing to treat people with dignity and respect.

The success of a system of care and support is underpinned by those who deliver and those who receive care working together. A dedicated, trained workforce that is sufficiently rewarded and supported is vital to ensure seamless care. This reflects the high level of skill required to support people with dementia to maximise their quality of life. Equally, it is important to have engaged service users who are able to feed back meaningfully and shape the services they receive.

Everyone affected by dementia should have access to a range of high-quality services that address their individual needs. In having some choice over what support they get, people with dementia can set and achieve their own goals.

Measuring quality of care

The evidence consistently suggests that people with dementia experience poorer health and wellbeing outcomes than their counterparts without the condition. The Care Quality Commission's (CQC) 2013 Care update demonstrated that adult social care provision in England is struggling to care adequately for people with dementia and that in more than half of the areas investigated, people with dementia living in a care home were more likely to go into hospital with avoidable conditions (such as dehydration or pressure sores) than similar people without dementia.

Research from NAPP Pharmaceuticals also suggests that over 30% of people with dementia living in care homes may be suffering from unidentified and untreated pain (NAPP Pharmaceuticals, 2014).

In Wales, the recent Trusted to care report (Andrews and Butler, 2014) has been having significant repercussions for dementia care in hospitals, particularly around appropriate use of antipsychotic medication, hydration, continence and medicine management. The National Audit of Dementia: Report for Wales found that in hospitals across Wales important elements of mental health assessment are not routinely carried out and that only a third of hospitals include dementia awareness in their staff induction programmes (Royal College of Psychiatrists, 2013b).

Industry leaders and providers have demonstrated grassroots leadership in improving practice. For example, the Dementia Pledge was created in partnership between employers and Care England to develop principles that care providers could use to nurture their whole workforce, and Camden and Islington's Social Care Campaign recognises the relationship between receiving a quality service and the links to appropriate remuneration, training and commissioning practices.

Similarly, the Dementia Care and Support Compact, a Dementia Action Alliance initiative, aims to set a benchmark for high-quality, relationship-based care and support for people with dementia, inspiring and encouraging the sector to take responsibility for delivering this, building on existing good practice. The principles of the Care and Support Compact should be embedded within regulations, and could be used as part of care home registration with the regulatory bodies.

Actions for improving quality of care

Alzheimer's Society's vision is for people with dementia to be confident that they will be able to access a range of good-quality services that meet their specific needs and goals. We urgently need to see a system where all staff are empowered to deliver consistent good-quality care. The focus on dementia in recent years has meant that, for the most part, the necessary guidance about good dementia care is already available.

Alzheimer's Society recommends two actions for ensuring people with dementia receive the best possible quality of care:

- People with dementia and their carers must be involved in the commissioning, design and development of services (Action 7).
- High-quality mandatory training for all staff providing formal care to people with dementia (Action 8).

Case study

Quality of care across the course of dementia

Diane was diagnosed with dementia at the age of 57. Although she struggled for three years to get her diagnosis because of her young age, she was still able to receive her diagnosis while in the early stages. Diane was the first to notice symptoms when she started to struggle in her job as a teacher. She was forgetting things and finding it difficult to organise her classes. She was struggling with numbers and couldn't count coins when she went shopping.

The diagnosis was fairly quick, though she had to wait a couple of months to see the specialist at the memory service clinic. Diane was put on Aricept straight after her diagnosis and this made a huge positive difference to her quality of life. She said life didn't have to end after receiving a diagnosis; you just have to start making different choices.

Shortly after being diagnosed Diane and her husband Michael got in touch with their local Alzheimer's Society service. Michael was signposted by a dementia support worker to an eight-week carer's course where he met other carers in a similar situation to his own, and received a lot of useful support and advice. Diane attended a monthly peer support group organised by Alzheimer's Society with other people who have dementia. Both Diane and Michael found it really helpful to share experiences with people in the same position. They also got support from their Dementia Adviser with all their legal and financial questions, particularly when they were putting in place a lasting power of attorney.

Diane and Michael experienced contrasting responses from friends. Diane lost friends following her diagnosis, though some very good friends stayed in contact and were able to accept what had happened. Their neighbours were very supportive – Michael could go there anytime he needed a break. They were very good with Diane and treated her exactly the same as they did before her dementia diagnosis.

In their local newsagent's the manager was also excellent. Sometimes Diane would be confused about money and forget to pay for the paper when she went to the shop in the morning. Because the staff knew Diane, they arranged with Michael that they'd keep track of any money that was owed. This meant Diane could still go for her morning walk to the shops, which she really enjoyed.

Quality of care across the course of dementia (continued)

Michael cared for Diane at home with help for several years. Someone arrived at 8am to wash and dress Diane and then she either had another carer for the day while Michael went to work, or she went to a day centre. Social services organised this. Michael thought the homecare was good. He received financial help and paid about £100–150 per week of the balance.

While the homecare was good quality it was difficult to access. To begin with, Michael wasn't given any help or advice and there was little communication between departments he spoke to. The situation got so bad that his doctor wrote to social services to warn them that if they didn't provide support, they would have to deal with two admissions to hospital: both Michael and Diane.

Diane had to stay in her local hospital after a fall. Her experience was exemplary. Both Michael and she felt that the staff understood her condition and how best to communicate with her. The signage was focused on patients with dementia, using the right colours, symbols and pictures as well as wording and simple language.

It wasn't just the clinical staff who were helpful – it was everyone. The hospital ran in-house training courses on dementia for nurses as well as a course for all other front-line staff, including security guards and porters. This made what could have been a frightening experience much more positive. They were encouraged to give feedback on the care they received, and felt involved in the service.

As her condition progressed Michael felt less able to care for Diane. With the help of family he made the decision for Diane to move into a care home. The first home they looked round was terrible – staff morale was very low and the owner was disengaged. The staff there weren't used to having a moderate-to-advanced dementia patient so a friend recommended another home where the staff were dementia trained. This home was absolutely fantastic – it was like walking into a family. They knew exactly how to relate to Diane. Michael arranged for the room at the nursing home to be re-decorated, bought new bed linen, took in plants and photos and other items to decorate it. The home had outdoor space for residents to use, which was fantastic as having a garden was really important for Diane.

As her condition progressed, and after a few more trips to hospital due to pneumonia and dehydration, Michael was advised by the consultant that Diane was nearing the end of her life. Diane went back into the care home and Michael visited her almost every day. He would massage her hands, arms and face to relax her when she got agitated or confused.

From what Michael knew of Diane, he knew that her end-of-life wishes would involve dying with her family around her. He arranged for different family members to visit every day and was confident, although she could no longer communicate, that she felt loved when she passed away.

This is an example case study drawn from the stories of real people living with dementia.

Action 7: People with dementia and their carers must be involved in the commissioning, design and development of services

Involvement in service planning

People with dementia and their carers must be involved in commissioning and developing services. Their guidance and feedback will ensure that services support them in a way that is important to them. Opportunities for involving people affected by dementia are needed across all of the settings in which they receive care.

Public policy developments mean that patient and service user involvement at every stage of the commissioning process is already a priority for many commissioners in England. Understanding how people feel about their care is a priority in the Mandate to NHS England (Department of Health, 2012b). The Health and Social Care Act, which came into force in April 2013, sets out duties to commissioners with regard to public and patient participation in England. Commissioners should make arrangements for, and promote individual participation in, care and treatment through commissioning activity, and listen and act on patient and carer feedback at all stages of the commissioning cycle.

The NICE guide, Support for commissioning dementia care (NICE, 2013a), suggests models of collaboration and integrated ways of working. The guide recommends working with people with dementia and their carers, as well as across all health and social care services and voluntary organisations, in order to commission high-quality dementia services.

If a person with dementia has a carer it is essential that they are recognised as a full partner in their care and should similarly be involved in development of services. The 'triangle of care' model for involving carers of people with dementia highlights the importance of collaboration and partnership with carers (Carers Trust, 2013). The Dementia Action Alliance's Carers' Call to Action also champions the recognition of carers as recognised partners in care.

However, moving towards this model of co-production is a considerable shift for practitioners and users alike. Voluntary organisations have an in-depth knowledge of the outcomes that matter to the groups they serve and often have more experience of engaging with these groups. It is essential that health and care providers learn from the skills and expertise of voluntary organisations in this area.

At Alzheimer's Society people with dementia are at the heart of all of our work. Meaningfully involving people with dementia in our organisation allows us to:

- develop services that best meet the needs of people with dementia and their carers
 - monitor and maintain the quality of our services and highlight priorities for developing and improving our services
 - understand and address the barriers to people receiving the help they want and need
 - gather essential information and guidance to inform our fundraising and campaigning programmes
-

- educate, inspire and challenge public perceptions of dementia
- ensure that our research funding is prioritised towards areas where it is needed the most and that research outcomes are improved.

We call for the involvement of people with dementia to be embedded across public services, particularly health and social care, but also in the wider community.

Case study

Younger people with dementia in Gwent

In 2011 Alzheimer's Society set up a service user forum to identify the needs of young people living with dementia in Gwent. The forum provided an opportunity for participants to raise and discuss issues that they might not otherwise have the opportunity to talk about. Lack of age-appropriate services was the focus of the discussion. The group were asked: 'currently there is no service, but if there was, what it would look like?'

That activity resulted in the concept of 'everything under one roof' – day service, respite and longer-term care when required.

One service user said: 'I suppose that this is a paper exercise and we will not hear any more about it.' But that was not the case – the feedback from this discussion was shared with as many people as possible, including commissioners, and the lack of services was raised at every opportunity.

In 2012 another forum was held and key professionals were invited to attend part of the session so they were able to see and hear for themselves what the group needed and wanted. One of those professionals then had a chance meeting with a housing and support provider who had a building that they were not sure what to do with.

The individual raised the issue of a lack of accommodation for young people with dementia and since then, Alzheimer Society's vision of 'everything under one roof' looks like becoming a reality. And, even better, people with dementia have been and remain in consultation with the provider in designing this proposed centre of excellence.

The user, who had expected the idea to disappear, was invited to be part of the ongoing forum, and got the chance to see it become a reality. Co-producing care is the way forward and was the topic of a recent discussion at the Welsh Assembly, where the progress in Gwent was shared with Mark Drakeford, Minister for Health and Social Services and a packed house of professionals.

Personalisation

As well as involving people in how services operate, people with dementia should also be involved in decisions about the services they receive. Personalisation is a way of thinking and working that puts the service user at the centre of public services. It does this by taking a person-led approach, understanding the preferences and aspirations of the service user and enabling them to be in control of their own care and support. Taken to its logical end, in personalisation, service users become active participants in planning and purchasing services rather than passive recipients.

Personal budgets are available in England, Wales and Northern Ireland. Alzheimer's Society's report *Getting personal? Making personal budgets work for people with dementia* found overwhelmingly that people with dementia are not accessing personal budgets (Alzheimer's Society, 2011). More than three-quarters of people with dementia who receive social care support at home are not using direct payments or other personal budgets.

Around 300,000 people with dementia living in the community are currently in receipt of social care services for help with things such as eating meals, washing or going to the toilet. Yet less than 40% have been offered a direct payment or other personal budget and 15% of those offered them turned them down.

Case study

Direct payments and personalised care

Ann switched to direct payments when she realised that she needed a more consistent and reliable homecare service for her husband who has dementia.

'I had agency carers coming in and they sent different workers and visits were often late which meant my husband was waiting for an hour or even two hours to be washed and dressed. I never knew who was coming – it was a different person every week.'

It was at this point that Ann decided to take control and organise the support via a direct payment.

'I like the fact that with a direct payment I can keep hold of the purse strings. I can talk directly to the agency now and make changes to the days and times that support is provided to fit around our needs. It works so much better for us. You have the clout to change things when you have a direct payment.'

Personalisation is a central element of the government's agenda in England to transform the health and social care system and is increasingly being emphasised in Wales. Similarly the Northern Ireland dementia strategy envisages a holistic model for supporting people with dementia. Despite this policy and government attention on personalisation, little has changed in real terms.

Reasons for this include: a lack of dementia-specific information on personalisation, particularly among black, Asian and minority ethnic communities; processes that are overly complex and intimidating; eligibility criteria being set too high to achieve the best outcomes from a personal budget; an absence of skilled dementia support and brokerage services; and low expectations from many front-line staff. These factors seem to be preventing wider-scale take-up of personal budgets by older people with dementia.

We need to ensure people with dementia are able to be involved as much as possible in directing how their budget is used. People with dementia are often put on a managed budget with little or no discussion about how that money could be used differently for more personalised outcomes. There should also be more opportunity to pool personal budgets, so that individuals with similar needs and interests can commission services as a group.

Personalisation is at the heart of the Care Act in England and provides an opportunity to allow people to make meaningful choices about the care they receive. As of April 2015, local authorities will be required to conduct assessments of both people with dementia and their carers. Where needs are assessed as eligible, people will be entitled to access a personal budget. Alongside this should be advocacy services which support people with dementia to make informed choices about their care. These need to be available in both hospital and residential settings.

Action 8: High-quality mandatory training for all staff providing formal care to people with dementia

People with dementia come into contact with a wide range of health and social care professionals, and deserve a consistent level of care. The high level of skill required to support people with dementia to maximise their quality of life means that care must be provided by staff who have received relevant training in dementia care and who are sufficiently rewarded and supported in their work.

The 2014 APPG report on dementia, *Building on the National Dementia Strategy: change, progress and priorities*, identified that workforce development was an area of particular concern. Parliamentarians recommended a cultural shift in how care is perceived, as well as a government commission focusing on how to build up the dementia workforce.

The low wages and low status of the caring workforce also mean it can be difficult to recruit the best staff to deliver high-quality care. More than half of homecare workers (56%) receive between the national minimum wage (£6.08) an hour and £8 an hour (UNISON, 2012).

There is a clear and definite need to raise the bar in terms of the expectations of front-line health and social care staff. To do this there must be mandatory minimum standards of training and appropriate rewards. Alzheimer's Society believes that a quality mark for training providers is necessary to encourage quality and consistency in training standards and to enable commissioners to find the best training packages.

The exact content of training will need to be tailored to a person's role and responsibilities. In the housing sector, it has been identified that dementia training is required by all staff, but at a level appropriate to contact with people with dementia (Garwood, 2014). A similar need has yet to be publicly identified by the health and social care sectors, though Health Education England's commitment to ensure that all NHS staff in England have received tier-one dementia training by 2018 is a positive step. This needs to be extended beyond tier one to include all tier-two training.

The Mental Capacity Act

There is a particular need for front-line staff to receive further training in the principles of the Mental Capacity Act.

The Mental Capacity Act

In England and Wales, the rights of those who do not have capacity to make a particular decision themselves are governed by the Mental Capacity Act 2005 (MCA). The Act covers all decisions, from large-scale decisions relating to an individual's property, financial affairs, and health and social care to everyday decisions, such as personal care, what to wear and what to eat.

This year, three significant appeals have been upheld that have dramatically changed the law surrounding Deprivation of Liberty Safeguards (DoLS), a feature of the MCA. The Supreme Court clarified a deprivation of liberty as any deprivation where a person is placed under 'continuous supervision and control and are not able to leave'. These specific cases considered supported living arrangements, and the Supreme Court has now said that DoLS can be applied to people in supported living rather than just those in care homes and hospitals, as was the understanding previously.

A report this year from the House of Lords committee tasked with reviewing the legislation found that awareness of the Act was low and the principles were often not put into practice by health and social care staff (House of Lords, 2014). The two main recommendations were that DoLS needed to be seriously addressed, and that an independent body should be created to monitor and review the MCA – both of these were rejected by government. Instead, there are commitments to establishing a MCA working group and to raising awareness about the MCA and lasting powers of attorney. These may not bring about the improvements needed in application of this important piece of legislation.

The Mental Capacity Act (2005) does not extend to Northern Ireland but the draft Mental Capacity Bill has recently been the subject of public consultation and is expected to be made law within the current Assembly Term (2016). It will be a single bill that covers mental and physical health interventions as well as welfare and finance. It will replace the Mental Health (NI) Order 1986. The bill will establish a legal framework for decision making for those who lack capacity, including people with dementia. The existing legal gap presents difficulties when assessing capacity and leaves people with dementia in Northern Ireland vulnerable.

People with dementia may experience problems communicating and may struggle to express their preferences and needs. Failure to communicate effectively with the person with dementia can result in inappropriate decisions being made about their care and negative consequences for the person with dementia.

The symptoms of dementia impair a person's cognitive ability and this can affect a person with dementia's ability to make certain decisions, particularly as the condition progresses. However, the principles of the Mental Capacity Act are essential to making sure that people with dementia get the right support, which enables them to continue to have choice and control over many aspects of their day-to-day lives.

The findings from the Dementia 2014 survey suggest that too many people with dementia are not being supported to make decisions about their day-to-day lives. Only 62% of those surveyed said that they were able to make choices about how they spend their time. Similarly, when asked whether they were involved in decisions about their care and support, 27% said they were not. It is likely that this is a result of the continuing assumption, sustained by a general lack of awareness of dementia, that people with dementia do not have capacity to make decisions about their day-to-day lives.

The Mental Capacity Act has the potential to help transform the culture of rights and decision making for people who may lack capacity. However, Alzheimer's Society believes that further work is required to ensure that the public understands their rights under the Act and that professionals understand the requirements of the Act and the powers that it creates.

Improving understanding of the MCA will require a new concerted push involving widespread training for professionals using: real case examples; work by professional bodies to raise awareness of the implications of the Act for professional practice; and the government to play a leadership role. The House of Lords Committee report on the Mental Capacity Act (House of Lords, 2014) recommended that a single body be appointed to co-ordinate implementation and raise awareness of the Mental Capacity Act.

4 Dementia-friendly communities

Key points

‘I live in an enabling and supportive environment where I feel valued and understood.’

‘I have a sense of belonging and of being a valued part of family, community and civic life.’

- Every person with dementia has the right to live well in their community. Dementia is a growing problem and, as the working age rises, it will become more common among those in employment.
- Great progress has been made on developing dementia-friendly communities, but there are still too few communities where people are supported to live the lives they want to.
- Negative attitudes towards dementia remain a significant barrier to people with dementia living well with the condition.
- More communities in England, Wales and Northern Ireland should sign up for the recognition process for becoming dementia friendly and establish local Dementia Action Alliances.
- Increased social action in the community will support people with dementia to live well. Everyone should take part in the Dementia Friends awareness-raising campaign so they can play their part in enabling people with dementia to live better.
- Businesses and organisations should establish strategies to support employees with dementia, or employees who are caring for someone with dementia.

Introduction

Two-thirds of people with dementia live in their own homes in the community, with a third of these living on their own (Mirando-Costillo et al, 2010). For many, the idea of living well and having a good quality of life is still impossible. One significant part of the problem is that communities and society as a whole are not geared up to deal with dementia. There is a need to encourage all sectors of society, from individuals through to businesses, to make their communities more dementia-friendly.

In September 2013 Alzheimer's Society launched its report *Building dementia-friendly communities: a priority for everyone*. This report added to the growing evidence base about what being a dementia-friendly community means from the perspective of people affected by dementia. The report found high levels of social isolation among people with dementia. It explored the barriers that people face in their community, how they like to be engaged in their local area and the support they need to empower them to do so.

The report defined a dementia-friendly community as one in which people with dementia are empowered to have high aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them.

Many people with dementia feel that the support they need to participate in their community and to do the everyday things they want to do, for example shopping, socialising or using public transport, is not available. Many do not feel that they are a part of their local communities. The creation of dementia-friendly communities is an attempt to meet this need.

Progress on building dementia-friendly communities

It is now over two years since Alzheimer's Society launched its Dementia Friendly Communities programme, which has been supported in England by the Prime Minister's challenge on dementia. There are now a growing number of private, public and voluntary organisations involved in the work of the Dementia Friendly Communities Champion Group.

There are six task and finish groups aimed at significantly enhancing the work towards becoming dementia friendly in specific areas or sectors, including a retail task and finish group, a group looking at power of attorney and data protection and a group focused on rural communities.

Projects are now underway across the UK with the ambition of making our communities easier places for people affected by dementia to access services, socialise and live well. For example:

- Joseph Rowntree Foundation has been working for some time to ensure that the UK is a good place for people with dementia to live well. Its *Dementia Without Walls* programme has focused attention on challenging attitudes, understanding and behaviours, inspiring local communities to be more aware and understanding of dementia and supporting the collective engagement of people with dementia.
 - Innovations in Dementia have worked on several projects that aim to support people with dementia in playing an active role in their communities. As well as contributing to the *Dementia Without Walls* programme, Innovations in Dementia have also been involved in other projects such as finding out what makes a good community for people with dementia to live in (*Innovations in Dementia*, 2011), producing a dementia-friendly communities toolkit designed to support work at a local level (*Innovations in Dementia*, 2012), and developing circles of support for people with dementia.
 - The Housing Learning and Innovation Network regularly publishes information about the role housing design can play in working towards dementia-friendly communities and shares best practice case studies on dementia-friendly housing (*Housing LIN*, 2012).
-

The Dementia Action Alliance now has over 1,400 national members that seek to influence national policy and attitudes towards dementia. Alzheimer's Society has been leading the way in the creation of Local Dementia Action Alliances across England, who are initiating and taking action in their own communities to support people with dementia.

While a vast range of projects have been launched, there is also a growing recognition that no community can be branded as having become 'dementia friendly'. It is not an end goal, rather a process of continuous improvement.

Alzheimer's Society launched a recognition process for communities working towards becoming dementia friendly. Over 50 communities across England signed up to the national dementia-friendly communities recognition process within the first six months. This work is now being extended into a formal Code of Practice, in partnership with the British Standards Institution, to ensure that communities are stretching their reach.

In April 2013 Alzheimer's Society in Wales hosted an event in the National Assembly to launch the Society's role working with people with dementia and key partners to define and develop dementia-supportive communities. Since then a great deal of progress has been made and there are now 12 communities in Wales that are working towards becoming dementia friendly, following a variety of different schemes.

In Northern Ireland the Dementia Friendly Communities programme is progressing well with 16 communities or organisations now signed up to work to become dementia friendly. Most recently Coleraine in the north west launched as the first town in Northern Ireland that is working to become dementia friendly.

How well are people living with dementia today?

The Dementia 2014 survey indicates that still not enough has changed and that it will take long-term sustained commitment to see the fantastic activity underway translate into improved quality of life for people with dementia. Current projects may well be having a positive impact on the lives of people with dementia locally, but nationally most people with dementia are yet to feel the benefit of dementia-friendly communities.

Table 1: Quality of life: comparisons between 2013 and 2014

Quality-of-life measure	2014	2013
People who are living well with dementia	58%	61%
People who have felt lonely recently	40%	38%
People who have felt anxious or depressed recently	61%	63%
People who are able to make choices about how they spend their time	62%	65%
People whose local area helps them to live well with dementia	46%	42%
People who feel a part of their local community	44%	47%
People who speak to family or friends face-to-face every day	75%	63%
People who get out of the house every day	60%	47%
People who get out of the house less than once a month	6%	7%

The survey found that only small changes have been made in people's quality of life over the past year. People with dementia are getting out of their houses more frequently: 60% said that they left the house every day, in comparison to 47% in 2013; with very slightly fewer saying that they left the house once a month or less frequently, down to 6%.

Slightly more people are saying that their local area helps them to live well with dementia (46% in comparison to 42% in 2013), but slightly fewer are saying that they feel a part of their community (44% in comparison to 47% in 2013). Of those people with dementia who were surveyed, 40% said that they had felt lonely recently, a slight increase on 38% the previous year.

It is clear from these survey results that, despite all of the good work, there is still much more that needs to be done to make sure that people with dementia are able to live well in their communities. Part of the problem is that communities and society as a whole are not engaged in the issue of dementia. We need to encourage all sectors of society, individuals through to businesses, to make communities dementia friendly.

Actions for encouraging dementia-friendly communities

Alzheimer's Society recommends three actions to make dementia-friendly communities a reality:

- All communities to become more dementia friendly (Action 9).
- Everyone should have improved awareness of dementia (Action 10).
- All businesses and organisations to take steps towards becoming dementia friendly (Action 11).

Action 9: All communities to become more dementia friendly

Although good progress has been made, the majority of communities are not yet working towards becoming dementia friendly. Every person with dementia, regardless of where they live, has the right to live well in their community and everyone, from governments and communities to businesses and individuals, has a role to play in making this a reality. It is therefore Alzheimer's Society's ambition that all communities will one day commit to working towards becoming more dementia friendly.

Alzheimer's Society intends to continue the progress that has already been made. There is an ambition by March 2015 to reach 75 communities in England signed up to our recognition process and 15 communities signed up to the code of practice. Increasing participation in the programme in Wales and Northern Ireland will be prioritised.

An essential aspect of becoming more dementia friendly is engaging with a wide range of partner organisations as well as with people with dementia. In England, all communities wanting to become more dementia friendly should look to forming a local Dementia Action Alliance (DAA). Volunteers in Wales and Northern Ireland should look to make equivalent arrangements for engaging the community in becoming more dementia friendly.

Case study

Three dementia-friendly communities in action

Salford Institute for Dementia, Manchester

The Salford Institute for Dementia aims to improve the lives of people living with dementia through research across a wide range of areas, including technology, the performing arts and the built environment.

Engagement with people affected by dementia is a core feature of their work. Academic environments can feel intimidating so they aim to be an 'institute without walls', involving people with dementia and carers directly in defining priorities, designing projects and implementing strategies.

They are also working towards making the University of Salford more dementia friendly. This includes encouraging staff and students to become Dementia Friends and Dementia Friends Champions, and working with colleagues to ensure dementia is included in degree curricula where appropriate.

By including people with dementia in setting the priorities for our research, we can ensure it is relevant and has a genuine impact on people's lives.

Dixons Allerton Academy, Bradford

To gain an understanding of dementia, students from Dixons Allerton Academy visited Bradford Royal Infirmary to learn from experts and see how one of the wards has been transformed to assist patients with dementia. They also watched videos on dementia in preparation for working with residents at a local care home. During art workshops, the students made collages with residents, which were then professionally made into placemats. They are now also working with the South Asian community, and are looking to set up a 'memory mat' social enterprise.

The students have grown into a strong group committed to educating the whole school about dementia. They are making a short film about dementia aimed at young people, which will include interviews with some of the older people, nurses, care workers and support workers they have worked with, as well as animation clips.

They have developed a scheme of work on dementia that the whole school will undertake. This includes challenging school houses to run a pop-up memory cafe, inviting older people into the school and allowing more students to experience the special intergenerational relationship developed through helping others.

Dementia Support South Lincs

Dementia Support South Lincs work with around 200 families in south Lincolnshire, helping to improve the quality of life of people living with dementia and their carers, and reduce the sense of social isolation associated with the condition.

The services include one-to-one advice and information, emotional support from a memory healthcare worker and peer support at monthly meetings. There is also a very active group of younger people with dementia.

A recent success is Square Hole Club, a fortnightly day club for younger people with dementia or those in the early stages of the illness. It takes place at a local sports and social club. The name came from a member who was frustrated that day services were not geared up to younger people, saying, 'I feel like a square peg being forced into a round hole'. So Square Hole Club was born.

Another aspect of their work is campaigning to raise awareness of dementia in the wider community, holding regular meetings with MPs and councillors and actively engaging with GPs. By providing services alongside campaigning locally, they ensure that care for people with dementia is an integrated part of the community and reaches people beyond those who are provided direct services.

Action 10: Everyone should have improved awareness of dementia

Negative attitudes towards dementia, such as stigma or simply a lack of understanding, remain a significant barrier to improving quality of life for people with dementia.

Stigma and lack of understanding can result in people who are worried about their memory delaying visiting their doctor and potentially missing out on treatment and services that could improve their quality of life. It can also make it much harder for people with dementia to feel a part of their community.

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.

The Dementia Friends initiative is raising awareness of dementia, improving attitudes towards the condition and creating a more dementia-friendly society by encouraging 1 million people to become Dementia Friends. The programme is being delivered by Alzheimer's Society in partnership with Public Health England. So far there are over 300,000 Dementia Friends in England, with corporate commitments to reach a further 100,000. The programme is also being delivered in Wales and Northern Ireland, with 4,000 and 5,500 Friends respectively to date.

Ways of becoming a Dementia Friend include attending an information session (lasting between 45 minutes to one hour), learning a little bit more about what it is like to live with dementia and then turning that understanding into practical action that could help someone with dementia living in their community.

Through collaborative effort between the voluntary sector and the government, dementia awareness is slowly increasing. In January 2013, a YouGov survey revealed that only 48% of people think that they have a good understanding of dementia. This has risen to 58% in our most recent YouGov poll.

Alzheimer's Society believes that everyone should become a Dementia Friend, but that organisations providing services to the public or those funding or commissioning health and social care services should make participation in the campaign a priority.

Action 11: All businesses and organisations to take steps towards becoming dementia friendly

The creation of dementia-friendly communities is the responsibility of everyone. However, there is a particular need for businesses and organisations to establish strategies to support employees who have dementia or who are caring for someone with dementia, as well as strategies that support people with dementia to access and use services. Dementia costs UK business £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).

Several organisations, including Argos, Homebase, Lloyds Banking Group, Lloyds Pharmacy and Marks and Spencer, have all committed to recruiting Dementia Friends throughout their workforces. There has also been excellent commitment from the NHS and social care providers, as well as government departments. However, there is an urgent need to continue this work, and awareness of dementia should be promoted in all shops, businesses and services so that staff demonstrate understanding and know how to recognise symptoms.

Earlier this year Alzheimer's Society launched *How to help people with dementia: A guide for customer-facing staff* (Alzheimer's Society, 2014b). This resource is an introductory guide to dementia for anyone who works with the general public. It promotes awareness of dementia so that staff involved in customer services are able to help people with dementia continue to do the things that matter to them.

In October 2013, Alzheimer's Society launched the charter: *Dementia-friendly financial services* (Alzheimer's Society, 2013d). This guide for banks and insurers was developed by over 20 financial organisations and institutions. It was designed to help financial services organisations recognise, understand and respond to the needs of customers living with dementia and their carers and sets out ways in which financial services organisations can work to become more dementia friendly.

In summer 2014, Alzheimer's Society also launched a criteria for businesses and organisations for how they can work towards becoming dementia-friendly, with the ambition of 10 businesses or organisations signing up to this process by March 2015.

Alzheimer's Society will continue to work with industry leaders to develop similar resources for sectors and industries to become more dementia friendly.

5 Research

Key points

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

- Research is driving forward advances in understanding the causes of dementia, new treatment and prevention strategies, as well as improved ways to care.
- Significantly increased investment in research is needed to make lasting change. For too long funding for dementia research has been disproportionate to the economic and social impact of the disease.
- Academics and those that commission and deliver services should work together to speed up the identification of emerging research findings around care and support that have been shown to be effective.
- New research findings should be made available quickly to people with dementia to help them have the highest quality of life possible.
- Currently less than 4% of people with a diagnosis of dementia are involved in a clinical research study. People affected by dementia must be given greater opportunity to participate in clinical research.
- People with dementia should have increased opportunities to influence research that is carried out and to participate in research studies.

Introduction

It is only through research that the causes of dementia can be fully understood, allowing us to develop new treatments and potential cures. Research is necessary for finding out how to prevent dementia and develop innovative ways to care for and support people affected by the condition. Research can help us to understand the course of dementia so people with the condition, as well their carers, can know what to expect and make plans for their future.

Until recently, research into dementia has been largely neglected, with the amount spent on dementia research being dwarfed by what is spent on cancer and heart disease research. Steps are being made in the right direction though, with an increase in government funding for dementia research, and global political commitments to research. Despite these initial advances, it is vital that we increase and sustain funding to ensure that we find treatments that prevent, slow or halt the disease, whilst also improving care for people living with dementia today.

As well as securing investment in research, we must prioritise translation of research into practice and active involvement of people with dementia in all stages of the research process. World-class dementia research can only bring about change if it is informed by people affected by the condition, and its valuable learning quickly adopted in practice.

While the amount spent on research is increasing (see Table 3), it still lags far behind the £503 million spent on cancer by the 22 National Cancer Research Initiative (NCRI) partners in 2013. An often used comparison is the relative spend on cancer and dementia research. The last detailed comparison of spend in 2007/8 found that cancer research received 12 times more funding than dementia research. The increase in dementia research funding means that, proportionally, this gap has closed. However, in 2012/13 cancer research still received seven times that spent on dementia (see Appendix 1).

International action on research

The UK government used its presidency of the G7 nations to hold a summit on dementia in December 2013. Collectively, the G7 called upon all sectors of society to treat people affected by dementia with dignity and respect, tackle stigma, exclusion and fear and to enhance their contribution to dementia prevention, care and treatment where they can. The G7 also pledged to significantly increase the amount of funding for dementia research, with the ambition to identify a cure or a disease-modifying therapy for dementia by 2025.

A World Dementia Innovation Envoy was appointed to draw together international expertise on dementia. The purpose of the Envoy is to stimulate innovation and co-ordinate international efforts to attract new sources of finance, including exploring the possibility of developing a private and philanthropic fund to support global dementia innovation. Throughout 2014, a series of high-level international forums have been organised to address and advance these ambitions.

Progress on research

There is now more research being conducted into dementia than ever before and progress is being made across areas including understanding the causes of dementia, finding new treatments and prevention strategies, and improving care and diagnosis.

Understanding causes

Historically, much of the preclinical laboratory work has focused on understanding the role of two proteins – amyloid and tau – in the development of Alzheimer’s disease. The amyloid hypothesis has been researched extensively over the last two decades (Hardy, 2009). However, despite some understanding of the potential role of amyloid in preclinical models, trials of therapies targeted against amyloid have not to date proven effective in halting disease progression.

Research is opening up new avenues of investigation. There is now more recognition that inflammation has a role to play in the aetiology of the disease (Holmes, 2013), and that blood flow and its regulation may be important in the development of Alzheimer’s (Horsburgh et al, 2011). Progress in genetics has meant that upwards of 20 genes have been identified that affect a person’s risk of developing Alzheimer’s disease, and these are now the subject of intense scientific investigation. Clarifying the function of these genes may identify new pathways around the causation of disease (Karch et al, 2014).

With regards to other forms of dementia there remains a lack of understanding of the biological basis of vascular dementia, the second most common cause of dementia, and further research is needed to identify new targets for treatment (Akinyemi et al, 2013). Research into frontotemporal dementia has found several genes linked to the condition. Recent research has found overlap in genes that cause frontotemporal dementia and motor neurone disease, and understanding the mechanism of disease is an important area for research (Warren et al, 2013).

New treatments and clinical trials

There has not been a new treatment for Alzheimer's disease or any form of dementia in over a decade. Between 2002 and 2012, almost 250 different drug compounds were assessed in clinical trials and while some are still the subject of ongoing investigation, only one drug – memantine – has been shown to be successful and has been approved for use. Recently, it has been calculated that the failure rate for Alzheimer's drugs is as high as 99.6%, which is possibly the reason that some pharmaceutical companies have closed down their research programmes into Alzheimer's (Cummings et al, 2014).

There are a number of proposed reasons for the recent failure of clinical trials for Alzheimer's disease, and it is also likely that no single reason is at fault. Research indicates that the pathology of Alzheimer's disease starts many years before the onset of symptoms, and it is proposed that recent trials may have failed because the drugs were tested too late in the disease process. Other possible reasons include too much focus on the importance of amyloid in the development of Alzheimer's disease (two-thirds of all disease-modifying treatments trials between 2002 and 2012 focused on this target), as well as a lack of strong preclinical models that represent all elements of clinical late-onset Alzheimer's disease.

A further reason is the sheer paucity of clinical trials that have been and are being conducted into Alzheimer's disease and other dementias. Table 2 shows the number of clinical drug trial in various areas of health. This likely reflects the years of chronic underinvestment in dementia research and the identification of drug targets.

Table 2: Clinical trials on dementia and other illnesses

Subject of the trial	Total number of ongoing trials (phases 1–3)
Alzheimer's disease	99
Vascular dementia	16
Frontotemporal dementia	10
Cancer	5,755
Heart disease	454
Allergic rhinitis (hayfever)	16
Psoriasis	76

Note: Search conducted on clinicaltrials.gov on 8 July 2013. Search criteria – Interventional (drug) studies phase 1–3, with ongoing (not unknown) status.

However, there is hope for the future. The next generation of trials – testing drugs in earlier stages of Alzheimer’s disease or in the even earlier pre-symptomatic stages of the disease – is underway that may overcome some of the problems of drugs being given too late in the disease process. Some of these trials will finish in late 2016 (Mullard, 2012). There are also drugs with new mechanisms of action coming through, including compounds targeted at tau, but given the high failure rate and complex aetiology new targets and more compounds are needed (Cummings et al, 2014).

Prevention strategies

While the causes of dementia remain unclear, it is known that a good diet, regular physical exercise and avoiding smoking and excessive alcohol consumption can reduce the risk of developing dementia (Barnes and Yaffe, 2011; Mangialasche et al, 2012).

Interventions focusing on encouraging a healthier diet, regular exercise, reducing smoking and avoiding excessive alcohol consumption would therefore likely reduce future incidence of dementia. While a lifelong approach to good cardiovascular health is recommended for some conditions (for example high blood pressure, blood cholesterol or BMI), a healthy lifestyle from midlife onwards is likely to be particularly effective at combating dementia (Barnes and Yaffe, 2011).

In addition to these vascular approaches, psychosocial factors such as educational attainment, complex work, and mental and social stimulation throughout life also reduce the risk of developing dementia. They are thought to do so by building up a cognitive reserve (Stern, 2012; Meng and D’Arcy, 2012). Growing evidence also suggests that midlife depression is a probable risk factor for later dementia (Byers and Yaffe, 2012), and its treatment should be encouraged.

Emerging evidence suggests that the prevalence of dementia among certain age cohorts may have fallen over the last 20 years (Matthews, 2013; Alzheimer’s Society 2014a), due to efforts made to improve heart health and prevent stroke and heart attacks. However, because the greatest risk factor for dementia is age and people are on average living longer, the number of people living with dementia is still set to rise.

Furthermore, the majority of evidence addresses modifiable aspects of Alzheimer’s disease and vascular dementia. There is no evidence specifically for other dementia sub-types, such as dementia with Lewy bodies or frontotemporal dementia.

The potential to reduce risk of dementia is good news. It demonstrates the benefits of improved cardiovascular health across life, reduced incidence of smoking and improved access to education among the current population of over-65s (UK Health Forum, 2014). This builds the case for further research into prevention of dementia and risk reduction and for a proactive approach to public-health messaging on dementia.

Improving diagnosis and care

It is now understood that the changes in the brain associated with dementia probably start around midlife and several decades before the onset of symptoms. Research is progressing on identifying markers of the disease, including biomarkers that are measurable before the development of symptoms and may therefore be used in identifying people at much-increased risk of developing dementia in the future. This includes neuroimaging approaches, the careful analysis of blood and cerebral-spinal fluid for markers correlated with the disease, and sensitive neuropsychological tests.

Currently, there are no tests available with the accuracy needed to consider screening the population for dementia at large (Iliffe et al, 2009) The most immediate use of these tests may be to improve clinical trials, by identifying individuals in the early or preclinical stages of dementia who can then take part in the testing of therapeutic approaches. There is also little evidence to suggest that population screening would bring significant benefits to all people with dementia in the absence of disease-modifying treatments.

There is also considerable ongoing research into how care can be delivered and organised in a range of different settings, to improve quality of life for people with dementia. Seminal research from Tom Kitwood in the early 1990s firmly established the theory and principles of a person-centred approach to dementia care (Kitwood and Bredin, 1992), and there is now a considerable body of ongoing research that seeks to establish how to implement person-centred care in a wide variety of settings, throughout all health and social care. Research is also putting increasing emphasis on maintaining the independence of the person with dementia, so that they can live in their own home for as long as possible.

A range of non-pharmacological approaches have been investigated, with different outcomes measured – such as their effect on carer burden, maintaining quality of life and delay in institutionalisation (Olazarán et al, 2010). The strength of evidence for different interventions varies, and it is generally accepted that research needs more, extensive high-quality trials of psychosocial interventions.

Overall, there remain many questions across all areas of dementia research, and investment in all aspects is required. A recent priority-setting exercise led by the James Lind Alliance produced some consensus questions, jointly agreed by patients, the public and practitioners, which might support the prioritisation of research funding.

Actions to advance dementia research

The mission of Alzheimer's Society is to reduce the impact of dementia on lives today and create a world without dementia tomorrow. We are dedicated to defeating dementia through research, and we support a broad programme of research investigating cause, cure, care and prevention of all forms of dementia. We have committed to invest at least £100 million over the next decade.

Alzheimer's Society recommends three actions to drive world-class dementia research that changes lives:

- Dementia research should receive a level of investment that matches the economic and human cost of the condition (Action 12).
 - All people with dementia and carers should have access to the best evidence-based care and research (Action 13).
 - People affected by dementia and their carers should be given greater opportunity to participate in dementia research (Action 14).
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Action 12: Dementia research should receive a level of investment that matches the economic and human cost of the condition

The total cost of dementia to the UK is estimated at £26 billion a year (Alzheimer's Society 2014a), yet only a fraction of this amount is spent on research. 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.

Progress is being made in securing further investment in dementia research. Since 2009/10, government and charity spend on dementia research has increased from £43.6 million to almost £74 million in 2013.

Table 3: Estimated UK spend on dementia research 2009 – 2013 (in millions)

	2009/10	2010/11	2011/12	2012/13
Government	30.2	36.9	45.4	52.9
Charities	13.4	16.3	19.2	20.9
Total	43.6	53.2	64.6	73.8

Note: See Appendix 1 for how these figures were calculated.

Alzheimer's Society believes that the current funding for dementia research does not reflect the disease burden on society and that the government and others must invest more in dementia research. The UK needs a national and long-term plan for dementia research that it is funded in proportion to its impact on society and with greater co-ordination between funders of dementia research.

Action 13: All people with dementia and carers should have access to the best evidence-based care and research

Realising benefit from research does not stop at the publication of a journal article; evidence must translate into improved quality of life for people affected by dementia. People with dementia should be provided with evidence-based care and services that are known to be effective.

Given the high level of unmet need among people with dementia, and the few treatments available, there should be systems and incentives put in place to stimulate treatment development and ensure that if and when new treatments become available they are readily and rapidly accessible to people with dementia. This has been achieved before with HIV treatments, to the tremendous benefit of people living with the condition. It should also be a realistic goal for dementia treatments.

We must create an environment that enables swift implementation of research findings and overcomes the translation gap. Those who commission and provide services for people with dementia should use research evidence to inform their decisions about how to best support people affected by the condition.

This requires commitment from each individual clinical commissioning group and local statutory body on how they will support translation and implementation of evidence-based interventions, strengthening links between academia and those in service delivery. This also involves making research evidence readily accessible to those who purchase services, and to people with dementia, to empower them to demand better care.

Case study

Implementation of research into practice – a care home training programme to reduce use of harmful antipsychotics

Antipsychotic drugs are currently over-prescribed to people with dementia, particularly in care homes. They are known to be harmful, causing severe side effects and increasing the risk of mortality.

The FITS (Focused Intervention for Training of Staff) programme is based on a study that was funded by Alzheimer's Society. It is an extensive training programme for care home staff based on principles of person-centred care. The research trial showed that the programme, which comprises a 10-day training course followed by a nine-month supervision and monitoring process, reduced the use of harmful antipsychotic drugs in people with dementia by 40%.

The findings were published in the British Medical Journal (Fossey et al, 2006). The FITS programme was then made into a training manual. This has now been scaled up and completed by staff in 67 care homes across the UK, in what is one of the largest formal evaluations of a training programme ever conducted.

Over 100 care homes were recruited to take part in the programme – which equips staff to understand complex behaviours in people with dementia and to deliver person-centred care as an alternative to harmful antipsychotics. When medication was reviewed, residents were more alert, communicative and active, with improvements in mobility, eating, sleeping and in achieving personal goals.

Action 14: People affected by dementia and their carers should be given greater opportunity to participate in dementia research

Involvement in clinical trials

People with dementia must be given greater opportunity to participate in dementia research. This allows those individuals the opportunity to benefit from new treatments sooner, and paves the way for future breakthroughs in dementia treatments and care.

Currently less than 4% of people with a diagnosis of dementia are involved in a clinical research study. The Prime Minister's challenge on dementia (Department of Health, 2012a) called for 10% of people with dementia to take part in research. To help achieve this, the opportunity to participate in research will be one of the conditions for accreditation of memory services through the Memory Services National Accreditation Programme (MSNAP).

Both Alzheimer's Society and Alzheimer's Research UK (ARUK) are working with the National Institute for Health Research (NIHR) to launch a new service called Join Dementia Research. This will connect people with dementia, their family members and carers to research studies taking place in their local area. Join Dementia Research will make participation in dementia research simple. It involves an online service where people who are interested in taking part in a study can enter their details into a secure database, allowing researchers to find people in their area that are eligible for their research. Anyone can sign up to Join Dementia Research because in addition to people with dementia, research studies also need to recruit healthy participants as controls. Alzheimer's Society and ARUK will make this as accessible as possible to people with dementia by providing helpline support to those who don't have internet access.

Involvement in the design and process of research

User involvement in the design and delivery of services is increasingly recognised as essential (NICE, 2013a, 2013b). This is equally true of involvement in the design and delivery of research. People with dementia are in a unique position to advise on the research questions that matter to them, and inform how the process and outputs of research can benefit those affected by the condition.

Alzheimer's Society has supported public involvement in dementia research for over 15 years. We have shown that people with dementia and their carers can make a unique and valuable contribution to dementia research. Their knowledge and passion ensures our research funding is allocated to projects that address the real needs and concerns of people with dementia and their carers.

The Research Network is a team of over 250 carers, former carers and people with dementia. Research Network volunteers play an integral role in the delivery of research and demonstrate the roles that people with dementia can play in all stages of research. These include: setting research priorities; reviewing funding applications; monitoring and supporting the delivery of research; telling others about the results of research; and ensuring that outcomes are translated into tangible benefits for people affected by dementia.

Case study

The Research Network and best practice in public involvement

Alzheimer's Society's Research Network provided pivotal support to the National Institute of Health Research (NIHR)'s 'Dementia Themed Call' in 2011.

This included an innovative workshop that brought together the combined expertise of 30 researchers and 40 Research Network volunteers. The workshop matched the experiences of people affected by dementia with the topics of the researchers' projects that were in development. Speed networking and focused discussions provided immediate feedback and refinement of the applications, strengthening both the likelihood of receiving funding and the output of the research on people's lives.

Over 40 applications in total were supported by the Society, with £14 million of the total £22 million of research projects receiving input from the Research Network. The NIHR increased the amount of funding available to support this call, citing the strength of public and patient involvement as an important factor in the decision. The Research Network are now playing leading roles in delivering these projects, including running focus groups, interviewing people with dementia and advising on patient recruitment.

Conclusion

People with dementia can and should be able to live better. Despite good progress and strong support from politicians, clinicians and academics alike, there is still a great deal that can be done to provide people affected by the condition with a better life.

In this report Alzheimer's Society has explored dementia in England, Wales and Northern Ireland and identified areas where further work is needed. These are:

- diagnosis and provision of post-diagnosis support
- health and social care reform
- assuring quality care
- establishing dementia-friendly communities.

Alzheimer's Society recommends 14 actions that will ensure people affected by dementia can live well with the condition.

Action 1: All statutory health and/or social care bodies in England, Wales and Northern Ireland to set targets for stepped yearly improvement in diagnosis rates up to 75% by 2017

- It is unacceptable that diagnosis rates are variable across the UK. In some areas people have as little as a one-in-three chance of getting a diagnosis.
- Diagnosis should be prioritised, with all areas in England, Wales and Northern Ireland aspiring to a 75% diagnosis rate.

Action 2: Twelve weeks from referral to diagnosis

- Waiting times for a diagnosis vary considerably depending on where you live. Unnecessarily long waiting times can cause undue stress to people already experiencing difficulties.
 - Everyone affected by dementia should receive an equal service and wait no longer than 12 weeks from initial GP referral to receiving their diagnosis.
 - It is not enough to focus on reducing the wait for an initial appointment, as more people wait longer between their initial appointment and diagnosis. The time that the whole diagnostic process takes must be standardised.
-

Action 3: Establish a minimum standard of integrated post-diagnosis support for people with dementia and carers

- Many people are left without support following a diagnosis. Only with support and advice can people live well and make important decisions about their future care.
- A guaranteed minimum standard of post-diagnosis support, which includes information, advice and support, should be made available to everyone affected by dementia.
- Everybody diagnosed with dementia should be guaranteed a dementia adviser, or equivalent.

Action 4: Governments to build on progress and commit to appropriately resourced national strategies in England, Wales and Northern Ireland

- Governments in England, Wales and Northern Ireland have made significant progress in improving the care of people with dementia, but more can be done to meet this challenge.
- The National Dementia Strategy for England (NDSE) has ended, though there are government commitments that last until March 2015.
- In Wales and Northern Ireland, national strategies have been difficult to implement due to a lack of monitoring and investment.
- Change cannot happen without national leadership. Each nation should ensure that they have in place an ambitious national strategy that is underpinned by appropriate resources.

Action 5: An open debate with citizens on the funding of quality health and social care that meets the needs of people affected by dementia

- People with dementia are unfairly disadvantaged by our health and social care system, having to pay for essential care needs that result from their medical condition, such as help with washing or dressing.
 - An individual's life savings can be spent on meeting their basic needs, which cannot be effectively met through the current system of the still common 15-minute visit (UKHCA, 2012).
 - We urgently need an appropriately funded, person-centred system in which people with dementia have equal access to quality care as people with any other medical condition.
 - A national debate with citizens on the future of health and social care funding is essential and must be prioritised.
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Action 6: A fully integrated health and social care system that puts the needs of people first

- Dementia is a complex condition and those affected come into contact with a wide range of health and social care professionals within a system that is often difficult to navigate.
- In England and Wales people with dementia receive fragmented care because health and social care services are not formally linked.
- Integration of services is essential in order to provide seamless care to people with dementia regardless of the setting. This is particularly important for people with co-morbidities, younger people with dementia and people from black, Asian and minority ethnic communities.

Action 7: People with dementia and their carers must be involved in the commissioning, design and development of services

- People with dementia and their carers should be able to inform decisions made about the services available to them. They are experts by experience, and know what support is needed to help them live well.
- People with dementia with eligible needs should have access to personal budgets so they can make choices about what care they receive.

Action 8: High-quality mandatory training for all staff providing formal care to people with dementia

- People with dementia interact with a wide range of health and social care professionals. It is vital that these professionals understand the complexity of the condition and are able to provide high-quality care.
- Compulsory, quality-assured training for all front-line health and care staff will raise the bar for dementia care.

Action 9: All communities to become more dementia friendly

- Every person with dementia has the right to live well in their community, but few communities exist where people are supported to do this.
- More communities in England, Wales and Northern Ireland should sign up for the recognition process for becoming dementia friendly and establish local Dementia Action Alliances.

Action 10: Everyone should have improved awareness of dementia

- Negative attitudes towards dementia remain a significant barrier to people with dementia living well with the condition.
 - Everyone should take part in the Dementia Friends awareness-raising campaign so they can play their part in enabling people with dementia to live the lives they want to.
 - There should be increased social action in the community to support people with dementia to live well.
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Action 11: All businesses and organisations to take steps towards becoming dementia friendly

- Dementia is a growing problem and, as the working age rises, it will become more common among those in employment.
- Businesses and organisations should establish strategies to support employees with dementia, or employees who are caring for someone with dementia.

Action 12: Dementia research should receive a level of investment that matches the economic and human cost of the condition

- Dementia costs the UK economy more than cancer, heart disease or diabetes. Despite this, research funding for dementia is currently only £74 million a year, in comparison with the £503 million a year spent on cancer.
- Over the next 10 years investment in dementia research is set to more than double in the UK alone. This amount still lags far behind what is needed to achieve parity with other diseases.
- 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.

Action 13: All people with dementia and carers should have access to the best evidence-based care and research

- Research is driving forward advances in understanding the causes of dementia, new treatments and prevention strategies, as well as improved ways to care.
- Academics and commissioners of services should work together to speed up the identification of emerging research findings around care and support that have been shown to be effective and strengthen links between academia and those in service delivery.
- New research findings should be made available quickly to people with dementia to help them achieve the highest quality of life possible.

Action 14: People affected by dementia and their carers should be given greater opportunity to participate in dementia research

- Currently less than 4% of people with a diagnosis of dementia are involved in a clinical research study. People affected by dementia must be given greater opportunity to participate in clinical research.
 - People with dementia should have increased opportunities to influence research that is carried out and to participate in research studies.
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References

Akinyemi, RO et al (2013). Vascular risk factors and neurodegeneration in ageing related dementia: Alzheimer's disease and vascular dementia. *Current Alzheimer Research* 10 (6): 642-53.

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

All-Party Parliamentary Group on Dementia (2013). *Dementia does not discriminate*. London: Alzheimer's Society.

All-Party Parliamentary Group on Dementia (2014). *Building on the National Dementia Strategy: change, progress and priorities*. London: Alzheimer's Society.

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

Alzheimer's Society (2009). *Counting the cost: Caring for people with dementia on hospital wards*. London: Alzheimer's Society.

Alzheimer's Society (2011). *Getting personal? Making personal budgets work for people with dementia*. London: Alzheimer's Society.

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

Alzheimer's Society (2013a). *Dementia 2013: The hidden voice of loneliness*. London: Alzheimer's Society.

Alzheimer's Society (2013b). *Building dementia-friendly communities: A priority for everyone*. London: Alzheimer's Society.

Alzheimer's Society (2013c). *Dementia-friendly financial services: A charter for improving the customer experience of people living with dementia when dealing with financial service organisations*. London: Alzheimer's Society.

Alzheimer's Society (2014a). *Dementia UK: 2014 edition*. London: Alzheimer's Society.

Alzheimer's Society (2014b). *How to help people with dementia: A guide for customer-facing staff*. London: Alzheimer's Society.

Andrews, J and Butler, M (2014). *Trusted to care: An independent review of the Princess of Wales Hospital and Neath Port Talbot Hospital at Abertawe Bro Morgannwg University Health Board*. Bangor: Dementia Services Development Centre.

Association of Directors of Adult Social Care (2014). *ADASS Budget Survey Report 2014: Final*. [online] Available at: www.adass.org.uk/adass-budget-survey-2014/ [Accessed 1 July 2014].

- Barnes, DE and Yaffe, K (2011). The projected effect of risk factor reduction on Alzheimer's disease prevalence. *Lancet Neurology* 10 (9): 819-28.
- Barnes, M et al (2013). External evaluation of the Alzheimer's Society Carer Information and Support Programme (CrISP). Brighton: University of Brighton Press.
- Brooker, D et al (2013). Timely diagnosis of dementia: ALCOVE WP5 Task 1 and 2. Worcester: Association for Dementia Studies.
- Bunn et al (in press). Co-morbidity and dementia: Improving health care for people with dementia. University of Hertfordshire.
- Byers, AL and Yaffe, K (2011). Depression and risk of developing dementia. *National Review of Neurology* 7 (6): 323-31.
- Care Quality Commission (2013). Care update. Issue 2: March 2013. [online] Available at: http://www.cqc.org.uk/sites/default/files/documents/cqc_care_update_issue_2.pdf [Accessed 1 July 2014].
- Carers Trust (2013). Triangle of care – carers included: A guide to best practice for dementia care. London: Carers Trust.
- Centre for Economics and Business Research (2014). Cost of dementia to business. London: Centre for Economics and Business Research.
- Collerton, J et al (2009). Health and disease in 85 year olds: baseline findings from the Newcastle 85+ cohort study. *BMJ* 339: b4904. [online] Available at: <http://dx.doi.org/10.1136/bmj.b4904> [Accessed 1 July 2014].
- Cummings, JL et al (2014). Alzheimer's disease drug-development pipeline: few candidates, frequent failures. *Alzheimer's Research & Therapy* 6: 37.
- Dementia Action Alliance (2010). National dementia declaration. London: Dementia Action Alliance.
- Department of Health (2009). Living well with dementia: A national dementia strategy for England. London: Department of Health.
- Department of Health (2011). Dementia Commissioning Pack. London: Department of Health.
- Department of Health (2012a). Prime Minister's challenge on dementia: delivering major improvements in dementia care and research by 2015. London: Department of Health.
- Department of Health (2012b). The mandate: A mandate from the government to the NHS Commissioning Board: April 2013 to March 2015. London: Department of Health.
- Department of Health (2013a). Healthbridge: the national evaluation of peer support networks and dementia advisers in implementation of the National Dementia Strategy for England. London: Department of Health.
-

Department of Health (2013b). The mandate: A mandate from the government to NHS England: April 2014 to March 2015. [online] Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/256406/Mandate_14_15.pdf [Accessed 1 July 2014].

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

Dilnot Commission (2011). Fairer care funding: The report of the Commission on Funding of Care and Support. London: Commission on Funding of Care and Support.

Employers for Carers (2014). Supporting employees who are caring for someone with dementia. London: Carers UK.

Fernandez, JL et al (2013). Changes in the patterns of social care provision in England: 2005/6 to 2012/13. Personal Social Services Research Unit, London School of Economics and Political Science: London. [online] Available at: <http://www.pssru.ac.uk/archive/pdf/dp2867.pdf> [Accessed 1 July 2014].

Fossey, J et al (2006). Effect of enhanced psychosocial care on antipsychotic use in nursing home residents with severe dementia: cluster randomised trial. *British Medical Journal* 2006; 332:756.

Garwood, S (2014). Making a start: Dementia – skilling the general needs housing workforce. London: Housing and Dementia Working Group.

Hardy, J (2009). The amyloid hypothesis for Alzheimer's disease: a critical reappraisal. *Journal of Neurochemistry* 110 (4): 1129-34.

Holmes, C (2013). Review: a systemic inflammation and Alzheimer's disease. *Neuropathology and Applied Neurobiology* 39 (1): 51-68.

Horsburgh, K et al (2011). Axon-glial disruption: the link between vascular disease and Alzheimer's disease? *Biochemical Society Transactions* 39 (4): 881-5.

House of Lords: Select Committee on the Mental Capacity Act 2005 (2014). Mental Capacity Act (2005): post-legislative scrutiny. London: HMSO.

Housing Learning and Improvement Network (2012). Breaking new ground: the quest for dementia-friendly communities. [online] Available at: www.housinglin.org.uk/_library/Resources/Housing/Support_materials/Viewpoints/Viewpoint25_Dementia_Friendly_Communities.pdf [Accessed 1 July 2014].

Iliffe, S et al (2009). Primary care and dementia: 1. Diagnosis, screening and disclosure. *International Journal of Geriatric Psychiatry* 24 (9): 895-901.

Innovations in Dementia (2011). Dementia Capable Communities: the views of people with dementia and their supporters. Exeter: Innovations in Dementia. [online] Available at: www.innovationsindementia.org.uk/DementiaCapableCommunities_fullreportFeb2011.pdf [Accessed 1 July 2014]

- Innovations in Dementia, Hampshire County Council, Local Government Association (2012). Dementia-friendly Hampshire Toolkit. [online] Available at: <http://www3.hants.gov.uk/adult-services/adultservices-professionals/dementia/dementia-friendly-toolkit.htm> [Accessed 1 July 2014].
- Karch, CM et al (2014). Alzheimer's disease genetics: from the bench to the clinic. *Neuron* 83 (1): 11-26.
- Kitwood, T and Bredin, K (1992). Towards a theory of dementia care: personhood and wellbeing. *Ageing Society* 12: 269-87.
- Knapp, M et al (2014). Scenarios of dementia care: what are the impacts on cost and quality of life? [online] Available at: <http://www.pssru.ac.uk/archive/pdf/dp2878.pdf> [Accessed 1 July 2014].
- Leonard Cheshire Disability (2013). Ending 15-minute care. London: Leonard Cheshire Disability.
- Mangialasche, F et al (2012). Dementia prevention: current epidemiological evidence and future perspective. *Alzheimer's Research & Therapy* 4: 6.
- Matthews, FE (2013). A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing study I and II. *The Lancet* 382 (9902): 1405–12.
- Meng, X and D'Arcy, C (2012). Education and dementia in the context of the cognitive reserve hypothesis: A systematic review with meta-analysis and qualitative analyses. *PLoS ONE* 7 (6): e38268.
- Mirando-Costillo, C et al (2010). People with dementia living alone: what are their needs and what kind of support are they receiving? *International Psychogeriatrics* 22(4): 607–17.
- Moriarty, J, Sharif, N and Robinson, J (2011). Black and minority ethnic people with dementia and their access to support and services. Research Briefing 35. [online] available at: www.scie.org.uk/publications/briefings/files/briefing35.pdf [Accessed 1 July 2014].
- Mullard, A (2012). Sting of Alzheimer's failures offset by upcoming prevention trials. *Nature Reviews Drug Discovery* 11: 657–60.
- NAPP Pharmaceuticals (2014). See change: think pain. London: NAPP Pharmaceuticals Ltd. [online] Available at: <http://www.carechartsuk.co.uk/wp-content/uploads/2014/03/See-Change-Think-Pain-Napp-Report.pdf> [Accessed 1 July 2014].
- National Institute for Health and Clinical Excellence (2010). NICE quality standard 1: Dementia quality standard. London: National Institute for Health and Care Excellence.
- National Institute for Health and Clinical Excellence (2011). NICE clinical guideline 42: Dementia: supporting people with dementia and their carers in health and social care. London: National Institute for Health and Care Excellence.
-

National Institute for Health and Care Excellence (2013a). NICE commissioning guide 48: Support for commissioning of dementia care. London: National Institute for Health and Care Excellence.

National Institute for Health and Care Excellence (2013b). NICE quality standard 30: Supporting people to live well with dementia. London: National Institute for Health and Care Excellence.

NHS England (2014). Dementia diagnosis and care in England: learning from clinical commissioning groups. [online] Available at: <http://www.england.nhs.uk/wp-content/uploads/2014/04/learn-ccgs-rep.pdf> [Accessed 1 July 2014].

NHS England Strategic Clinical Networks (South West) (2013). Guidance to clinical commissioning groups and health and wellbeing boards on commissioning for quality in dementia care. [online] Available at: <http://dementiapartnerships.com/wp-content/uploads/sites/2/what-good-looks-like-v1.pdf> [Accessed 1 July 2014].

Nuffield Trust (2012). A decade of austerity? The funding pressures facing the NHS 2010/11 to 2021/22. London: Nuffield Trust.

Olazarán, J et al (2010). Nonpharmacological therapies in Alzheimer's disease: A systematic review of efficacy. *Dementia and Geriatric Cognitive Disorders* 30: 161–78.

Products Research Group of the Pensions and Long-term Care Working Party (2014). How pensions can help meet consumer needs under the new social care regime. London: Institute and Faculty of Actuaries.

Public Health Wales (2014). Wales National Audit: Memory Clinic and Memory Assessment Services. Cardiff: Public Health Wales.

The Rights in Community Care Group (2011). A vision for community care: Report from the 2011 seminar series run by the Rights in Community Care Group. [online] Available at: <http://www.lawcentreni.org/Publications/RICC-Report-2011.pdf> [Accessed 1 July 2014].

Royal College of Psychiatrists (2013a). English National Memory Clinics Audit report. London: Royal College of Psychiatrists.

Royal College of Psychiatrists (2013b). National Audit of Dementia Care in General Hospitals 2012-13: Second Round Audit Report and Update. London: Royal College of Psychiatrists.

Stern, Y (2012). Cognitive reserve in ageing and Alzheimer's disease. *Lancet Neurology* 11(11): 1006-12.

UK Health Forum (2014). Blackfriars Consensus on promoting brain health: reducing risks for dementia in the population. [online] Available at: http://nhfshare.heartforum.org.uk/RMAssets/Reports/Blackfriars%20consensus%20%20_V18.pdf [Accessed 1 July 2014].

UK Homecare Association (2012). Care is not a commodity. Wallington: UK Homecare Association.

UK Homecare Association (2013). UKHCA Dementia Strategy and Plan, February 2013. Wallington: UK Homecare Association.

UNISON (2012). Time to care. London: UNISON.

Warren, JD et al (2013). Frontotemporal dementia. *BMJ* 347: f4827.

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

YouGov Survey Information:

Total sample size was 2,347 adults. Fieldwork was undertaken between 29–29 May 2014. The survey was carried out online. The figures have been weighted and are representative of all UK adults (aged 18+).

Appendix 1:

UK spend on dementia research

Estimating government and charitable spend on dementia research

The following table shows estimates for the amount spent on dementia research per financial year between 2009/10 and 2012/13. Calculations show that investment in research has increased by about £10 million year on year, from around £45 million in 2009 to £75 million in 2013.

It can be difficult to classify research as specifically focused on dementia. For instance, research into fundamental neuroscience; mechanisms of ageing; the development of new technologies; and investment in wider infrastructure can generate knowledge that benefits a wide range of diseases including dementia. Equally, applied research into frailty, geriatrics or social care can also contribute to improvements in dementia care. The estimates below are for research that specifically addresses the disease processes of dementia, or that primarily aims to benefit people with or at risk of dementia.

Estimated annual spend from government and charitable organisations (£ million)

	2009/10	2010/11	2011/12	2012/13
NIHR, MRC, ESRC	28.2	36.5	43.8	52.2
EPSRC	2	0.4	1.6	0.7
Total government	30.2	36.9	45.4	52.9
Alzheimer's Research UK	4.5	5.1	5.5	6.8
Alzheimer's Society	2.3	2.8	3.6	5.3
BRACE	0.3	2	1	0.5
Wellcome Trust	3.7	3.1	6.4	5.4
Stroke Association*	0.6	0.7	0.7	0.7
Parkinson's UK*	1.2	1.3	1.2	1.4
Age UK*	0.08	0.4	0.2	0.3
MND Association*	0.7	0.9	0.6	0.5
Total charity	13.4	16.3	19.2	20.9
Total (government and charity)	43.6	53.2	64.6	73.8
NCRI cancer spend	504.3	521.4	507.3	502.8
Cancer spend/dementia spend	11.6	9.8	7.9	6.8

*estimated figure based on 25% of the organisation's total annual spend on research.

How the figures were calculated

A pragmatic approach was taken to estimating these figures and they should primarily be used to show trends in dementia research funding. Given the changing landscape individual organisations were not contacted for submission of data, but numbers were derived from published grant portfolios and annual accounts. Significant government and national charities that fund dementia research were included.

Spend for National Institute for Health Research (NIHR), Medical Research Council (MRC) and Economic and Social Research Council (ESRC) were taken from government figures. Engineering and Physical Sciences Research Council (EPSRC) figures were calculated from an analysis of their 'healthcare' portfolio. Figures for Alzheimer's Research UK, Alzheimer's Society and BRACE – three dementia-specific research charities in the UK – were taken from annual accounts. Figures for Wellcome Trust were estimated from an analysis of their annual published grants portfolio. For other health charities that may fund a proportion of research relevant to dementia, a conservative estimate was made that 25% of their research portfolios could be classified as dementia and this was proportioned to the total accordingly.

For comparison to cancer research, the annually published figure from the National Cancer Research Initiative (a collection of 22 government and charity organisations that fund significant levels of cancer research) was taken (see www.ncri.org.uk).

Comparing these figures to the Dementia 2010 report

The Dementia 2010 report compiled by the Health Economics Research Centre at the University of Oxford, gathered data on the research spend in 2007/8 by asking 200 of the largest organisations in the Association of Medical Research Charities membership to self-report their annual spend on a number of health conditions. The report found that approximately £50 million was spent on dementia research in 2007/8 compared to £590 million on cancer. The different methodologies and depth of coverage likely explain the differences between the figures above and this report, but the relative spend on cancer and dementia (approximately £12 to £1) was relatively consistent between 2007/8 in Dementia 2010 and the figures for 2009/10 in this analysis.

Appendix 2: Summary of statistics

Statistics used in this report are presented below. Those in bold indicate latest figures for 2014.

Prevalence



835,000 people with dementia in 2014
(Alzheimer's Society, 2014a).

England – 700,000 (84%)

Scotland – 70,000 (8%)

Wales – 45,000 (5%)

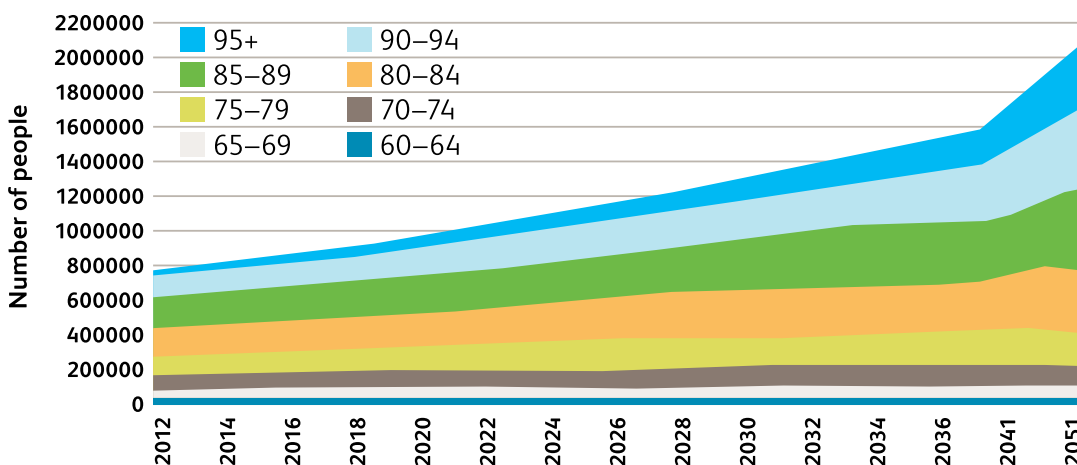
Northern Ireland – 20,000 (2%)

40,000 younger people with dementia in 2013
(Alzheimer's Society, 2014a).

25,000 people from black, Asian and minority ethnic communities with dementia in 2013
(APPG, 2013).

Projected increases

Projected increases in the number of people with dementia in the UK by age group



According to these projections, there will be over 850,000 people with dementia in the UK by 2015 (856,700), over 1 million by 2021 (1,007,485) and 2 million by 2051 (2,092,945).

Costs

Dementia costs the UK £26 billion a year (Alzheimer's Society, 2014a).

This includes over **£4 billion in healthcare costs** and over **£10 billion in social care costs**.

Unpaid carers save the UK economy **£11 billion per year** (Alzheimer's Society, 2014a).

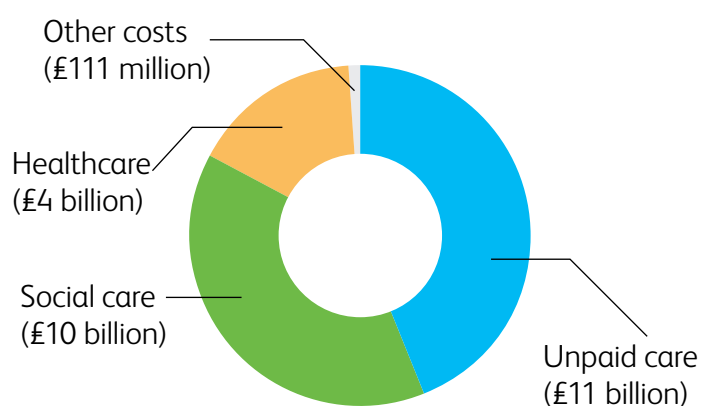
Dementia costs **£1.6 billion to UK businesses per year**

(Centre for Economics and Business Research, 2014).

37% of people don't know they have to pay for their own social care costs (YouGov poll).

Cost of dementia care by location and type

- Unpaid care – £11 billion (44%)
- Social care – £10 billion (39%)
- Healthcare – £4 billion (16%)
- Other costs – £111 million (1%)



The total annual cost per person with dementia in different settings is estimated as follows:

People in the community with mild dementia	£25,723
People in the community with moderate dementia	£42,841
People in the community with severe dementia	£55,197
People in care homes with dementia	£36,738

Quality of life

58% of people say they are living well (Dementia 2014).

28% of people are not able to make decisions about how they spend their time (Dementia 2014).

60% of people leave the house every day (Dementia 2014).

44% of people feel a part of their community (Dementia 2014).

40% of people with dementia felt lonely recently (Dementia 2014).

61% of people with dementia felt anxious or depressed recently (Dementia 2014).

Hospital care

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

People with dementia stay in hospital, on average, **five days longer** than people in a comparable situation without dementia (Alzheimer's Society, 2009).

Homecare

Over 60% of people receiving homecare have some form of dementia (UKHCA, 2013).

60% of local authorities now commission 15-minute visits (Leonard Cheshire, 2013).

More than 75% of people with dementia who receive support at home in England are not using direct payments or other personal budgets (Alzheimer's Society, 2011).

More than half of homecare workers receive between the **national minimum wage (£6.08) and £8 an hour** (UNISON, 2012).

74% of providers say that the councils they have contracts with have become more interested in securing a low price than they are in the quality of service delivered (UKHCA, 2012).

Nearly 80% of homecare workers reported that their work schedule resulted in them being rushed or leaving clients early to get to their next visit on time (UNISON, 2012).

Care homes

Up to 70% of people in a care home have a form of dementia (Alzheimer's Society, 2014a).

Over 30% of people with dementia living in care homes may be suffering from unidentified and untreated pain (NAPP Pharmaceuticals, 2014).

Support

Only 18% of people with dementia said that they thought they received enough support from the government (Dementia 2014).

27% are not involved in decisions about their care and support (Dementia 2014).

Less than half of carers (47%) receive support in their caring (Dementia 2014).

Less than 1 in 5 people think they receive enough support from the government (Alzheimer's Society, 2014a).

36% of older and disabled people who would have received social care in England five years ago now receive no support (Fernandez et al, 2013).

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

Less than 40% of people with dementia have been offered a direct payment or other personal budget and 15% of those offered them turned them down (Alzheimer's Society, 2011).

Co-morbidity

72% of people are living with another medical condition or disability as well as dementia (Alzheimer's Society, 2014).

Research

Investment in dementia research is increasing with **approximately £75 million spent by government and charities in 2012/13** (Dementia, 2014).

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

alzheimers.org.uk