



## BRIEFING PAPER

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# Dementia: policy, services and statistics

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3. Government policies to improve dementia care, support and research in England
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## Summary

There are an estimated 850,000 people with dementia in the UK. By 2040, the number of people with the condition is expected to double.

The UK Government has set an objective for England to be a world leader in fighting dementia and has committed to improving diagnosis, care and support, and research.

The [Challenge on Dementia 2020](#), published in February 2015, sets out what the UK Government wants to see in place by 2020 in order for England to be:

- the best country in the world for dementia care and support and for people with dementia, their carers and families to live
- the best place in the world to undertake research into dementia and other neurodegenerative diseases

Some of the key objectives of the Challenge are:

- Equal access to diagnosis for everyone
- GPs playing a lead role in ensuring coordination and continuity of care for people with dementia
- Every person diagnosed with dementia having meaningful care following their diagnosis
- All NHS staff having received training on dementia appropriate to their role.

In February 2019, the Government published [Dementia 2020 challenge: 2018 review phase 1](#). This review reflects on what has been achieved so far and what more needs to be done to meet its objectives. The [NHS Long Term Plan](#), published on 7 January 2019, also commits the NHS in England to continuing to improve the care provided to people with dementia and their carers.

This Library briefing provides an overview of dementia prevalence and diagnosis, as well as statistics on current rates and expected rises of dementia prevalence. It outlines UK Government policy over the last 10 years and considers recent developments such as the publication of the All-Party Parliamentary Group (APPG) on Dementia report [Hidden no more: Dementia and disability](#) in June 2019, and [Fix Dementia Care](#), published by the Alzheimer's Society in May 2019.

This briefing also outlines guidance on health and social care services for people with dementia, and covers the development of the Dementia Discovery Fund and the Dementia Research Institute.

Health and social care are devolved matters, and so each of the devolved administrations are largely responsible for setting their own dementia policies. While this Library briefing focuses on policies in England, dementia strategies in Scotland, Wales and Northern Ireland are briefly outlined in section 5.



# 1. Dementia prevalence and diagnosis

## 1.1 What is dementia?

Dementia UK note that dementia is an umbrella term for a range of progressive conditions<sup>1</sup>, which are all associated with an ongoing decline of brain functioning. This may include problems with:

- memory loss
- thinking speed
- mental sharpness and quickness
- language
- understanding
- judgement
- mood
- movement
- difficulties carrying out daily activities<sup>2</sup>

There are over 200 subtypes of dementia, but the most common are Alzheimer's disease and vascular dementia. Alzheimer's disease is thought to be caused by an abnormal build-up of proteins in the brain. Amyloid deposits form plaques around brain cells, and deposits of the protein 'tau' form tangles within brain cells. These changes also lead to a decrease of important chemicals that help with the transmission of messages within the brain. Alzheimer's disease can affect concentration, decision making and everyday living skills.<sup>3</sup>

Vascular dementia is the second most common type of dementia. It is caused by problems in the supply of blood to the brain, commonly due to, narrowing of small blood vessels in the brain, strokes or a series of small strokes, known as Transient Ischemic Attacks (TIAs), which cause areas of cell damage in the brain. The signs and symptoms of vascular dementia depend on which area of the brain has been affected.<sup>4</sup>

The Government note that there is a growing body of evidence to suggest that it is possible to reduce an individual's risk of dementia. The evidence suggests that smoking, excessive drinking, high blood pressure, lack of physical activity and diabetes all contribute to a higher risk of an individual getting dementia later in life. With this in mind, healthcare practitioners and public health bodies can aid the population to reduce or mitigate their risk of developing dementia, along with other conditions such as diabetes.<sup>5</sup>

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<sup>1</sup> [Dementia UK website, what is dementia?](#)

<sup>2</sup> [NHS website, about dementia](#)

<sup>3</sup> [Dementia UK website, what is dementia?](#)

<sup>4</sup> *Ibid.*

<sup>5</sup> Department of Health and Social Care, [Dementia 2020 Challenge: 2018 Review Phase 1](#), 22 February 2019

## 1.2 Prevalence and cost

There are estimated to be around 850,000 people with dementia in the UK. This includes an estimated 676,000 people with dementia in England. Over 450,000 people in England have been diagnosed with dementia.<sup>6</sup>

Dementia mainly affects people over the age of 65 (one in 14 people in this age group have dementia), and the likelihood of developing dementia increases significantly with age.<sup>7</sup> This is why as people are living longer the number of people with dementia is increasing. There are also around 40,000 people under the age of 65 living with dementia.<sup>8</sup>

There are around 540,000 carers of people with dementia in England. It is estimated that one in three people will care for a person with dementia in their lifetime. Half of them are employed and it's thought that some 66,000 people have already cut their working hours to care for a family member, whilst 50,000 people have left work altogether.<sup>9</sup>

It has been estimated that dementia costs the UK economy £23 billion a year, more than the costs of cancer, heart disease or stroke. By 2040, the number of people with the condition is expected to double and predicted costs are expected to treble.<sup>10</sup>

## 1.3 Dementia diagnosis

There is a national commitment for two-thirds of the estimated population living with dementia in England to have a formal diagnosis. This was originally met in November 2015 and has been maintained since.<sup>11</sup> The [Government's Mandate to the NHS 2018-19](#) includes the objective to maintain this minimum of two-thirds diagnosis rate for people with dementia.

Dementia diagnosis rates are included in the clinical commissioning group (CCG) Improvement and Assessment Framework, which enables CCGs to assess their performance and deliver longer-term improvements to dementia diagnosis services. At the end of April 2018, 116 of 195 CCGs had met the two-thirds national standard.<sup>12</sup> NHS England provides support to CCGs that do not meet the national standard.<sup>13</sup>

The *Challenge on Dementia 2020* set out future work to improve diagnosis rates, including reducing variation in rates across the country, improving waiting times for assessments, and improving the diagnosis

<sup>6</sup> Department of Health, [Challenge on dementia 2020](#), February 2015, page 10

<sup>7</sup> [Alzheimer's Society website, who gets dementia?](#)

<sup>8</sup> *Ibid.*

<sup>9</sup> [NHS England webpage on dementia](#)

<sup>10</sup> Department of Health, [Challenge on dementia 2020](#), February 2015; see also Centre for Economic and Business research, [Cost of dementia to business](#), May 2014

<sup>11</sup> NHS England, [Dementia](#)

<sup>12</sup> [PO 146969 \[on Dementia\], 25 May 2018](#)

<sup>13</sup> NHS England, [Dementia](#)

of dementia for people of Black, Asian and Minority Ethnic origins, for whom the evidence shows that diagnosis rates are worse.<sup>14</sup>

NICE has published a guideline on the [assessment, management and support of people living with dementia and their carers](#) (June 2018) which contains recommendations to assist diagnosis. A PQ response in July 2018 set out some of the other measures being taken to support early diagnosis, including the NHS health check programme for people aged 65 to 74 and the Dementia Core Skills Education and Training Framework for health and social care staff:

As part of the NHS health check programme, people aged 65 to 74 are provided with information on the signs and symptoms of dementia, the availability of memory services in their locality, as well as on health and lifestyle factors which may increase the risk of developing dementia.

Awareness and recognition of the symptoms of dementia is one of the areas covered in the Dementia Core Skills Education and Training Framework, which sets out the skills and knowledge required by all staff working with people with dementia in health and social care settings.<sup>15</sup>

NHS England is currently developing an access and waiting time standard for dementia, to try and ensure people have equal access to diagnosis for dementia as for other conditions. There will be a national average waiting time for an initial assessment of six weeks.<sup>16</sup>

## 2. Statistics on dementia prevalence in England

Figures for May 2019 show that 0.8% of people registered with a GP practice in England are diagnosed with dementia (1 person in 127), and around 4.3% of those aged 65+ (1 person in 23).<sup>17</sup> Nationally, it is estimated that two-thirds of those with dementia have been diagnosed with the disease. This section uses GP practice-level data on dementia diagnoses to produce estimates for variation across the country in dementia prevalence.

The following chart shows how recorded dementia prevalence varies between age groups. Only older age groups are shown since dementia is uncommon under the age of 65, with only 1 case for every 3,019 people. 1 in 71 people aged 70-74 are diagnosed with the disease, growing to 1 in 13 aged 80-84 and almost 1 in 5 people aged 90+.<sup>18</sup>

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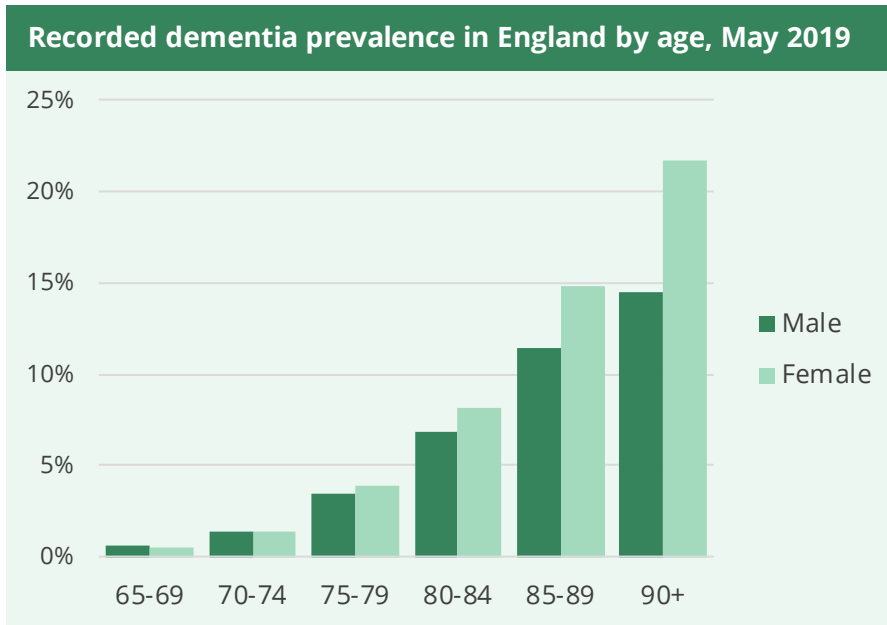
<sup>14</sup> Department of Health, [Challenge on dementia 2020](#), February 2015, page 23

<sup>15</sup> [HC Written Question – 157097, 3 July 2018](#)

<sup>16</sup> NHS England, [Dementia](#)

<sup>17</sup> NHS Digital, [Recorded Dementia Diagnoses May 2019](#)

<sup>18</sup> NHS Digital, [Recorded Dementia Diagnoses May 2019](#)



The tables below show the highest estimated rates of dementia prevalence in England by constituency. The left table shows the estimated percentage of the whole population diagnosed with dementia. As expected, these prevalence rates correlate highly with the age profile of constituencies – the constituencies with the highest prevalence are also some of the constituencies with the most older people. The right-hand tables show the estimated percentage of people aged 65+ in each constituency who have been diagnosed with dementia. This is not a raw measure of dementia levels, but it helps to detect areas where dementia rates are higher or lower than one would expect given the age structure of the population.

Note that differences between constituencies is likely to reflect variation in dementia diagnosis rates as well as variation in the prevalence of dementia.

<b>Highest recorded dementia prevalence by constituency, 2017/18</b>			
<b>Estimated prevalence among all ages</b>		<b>Estimated prevalence among 65+</b>	
Christchurch	1.6%	Sheffield, Brightside & Hillsborough	6.5%
Worthing West	1.5%	Gateshead	5.8%
New Forest West	1.4%	Bradford East	5.7%
Southport	1.4%	Stoke-on-Trent Central	5.6%
Bexhill and Battle	1.3%	Nottingham North	5.6%
Ludlow	1.3%	Epping Forest	5.6%
Fylde	1.3%	Newcastle-under-Lyme	5.6%
North Norfolk	1.3%	Bromley and Chislehurst	5.5%
Isle of Wight	1.2%	Stockport	5.5%
Eastbourne	1.2%	Stockton South	5.4%
Blackpool North and Cleveleys	1.2%	Islington North	5.4%
Louth and Horncastle	1.2%	Stoke-on-Trent North	5.4%



## 9 Dementia: policy, services and statistics

You can view more detailed estimates for your area on our [constituency health dashboard](#).

These estimates are calculated using GP practice-level dementia diagnosis statistics<sup>19</sup> and LSOA-level estimates of GP practice populations.<sup>20</sup> They are not precise counts and involve a process of estimation. The method is described on our dashboard (linked above).

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<sup>19</sup> NHS Digital, [Quality and Outcomes Framework 2017/18](#)

<sup>20</sup> NHS Digital, [Patients Registered at a GP Practice](#)

## 3. Government policies to improve dementia care, support and research in England

### 3.1 The National Dementia Strategy 2009

The Government's first National Dementia Strategy, [Living well with dementia](#), was published in 2009. The Strategy outlined three key ambitions to improve the quality of life for people with dementia and their carers in England:

- Raising awareness of dementia, and removing the stigma that surrounds the condition
- Improving diagnosis rates for people with dementia
- Increasing the range of services for people with dementia and their carers

### 3.2 The 2012 Dementia Challenge

In March 2012, the then Prime Minister, David Cameron, launched a challenge on dementia - [Dementia 2012: A national challenge](#). The challenge aimed to deliver major improvements in dementia care and research by 2015. It focused on delivering change in three key areas:

- *Creating dementia friendly communities that understand how to help* – including improving awareness among the public; and the establishment of recognised dementia-friendly communities, led by the Alzheimer's Society.
- *Driving Improvements in health and care* – including better diagnosis; improving care in hospitals; improving standards in care homes; more information for patients and families; and more support for carers.
- *Better research* – including increased funding for research into care, cause and cure, with a commitment to more than double funding for dementia research to over £66 million by 2015.

Three 'challenge groups' were responsible for leading change in each of the areas. The 2012 Challenge also detailed the achievements the Government had made since the 2009 National Dementia Strategy, such as reducing the use of anti-psychotic medication for people with dementia:

The NHS and Social Care, working together with wider partners, have taken forward initiatives to reduce the prescribing of antipsychotic drugs for people with dementia to improve quality of life with a view to achieving overall a two thirds reduction in the use of antipsychotic medicines. However, more needs to be done.<sup>21</sup>

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<sup>21</sup> Department of Health, [Challenge on dementia 2020](#), February 2015. This document also reported that antipsychotic prescriptions for people with dementia had reduced by 52 per cent between 2008 and 2011.

In February 2015, the Government outlined the progress that has been made towards achieving the objectives of the 2012 Challenge. This included increases in diagnosis, boosting research funding, and the training of health workers, social care staff, and 'dementia friends' in the community:

- Introducing the first-ever World Dementia Envoy, spearheading a global approach to the fight against dementia, driven through the G8 dementia summit in 2013
- Over 437,920 NHS staff have already received dementia training and more than 100,000 social care workers have received dementia awareness training, more than any other country worldwide
- There are now 1 million dementia friends and 82 areas across England have signed up to become [dementia friendly communities](#)
- Diagnosis rates are the highest in the world, increased from 42% to 59% and on track to reach two thirds, ensuring more people than ever before get the care and support they need.
- Research funding has doubled since 2009 to over £66m in 2015. This investment includes major research on issues that matter to people with dementia and their carers, such as the world's largest – £20 million – social science research programme on dementia. It also includes Dementias Platform UK (DPUK), a 5-year £53 million public private partnership led by the Medical Research Council, the world's largest dementia population study.
- Achieving a world-leading 52% fall in the level of prescribing of antipsychotic medication to people with dementia.<sup>22</sup>

### 3.3 The Challenge on Dementia 2020

In February 2015, the Government published the successor to the 2012 challenge on dementia. [The Challenge on Dementia 2020](#) focused on boosting research, improving care and raising public awareness about the condition in England.

The then Prime Minister, David Cameron, sets two key objectives for the *Challenge on Dementia 2020*:

By 2020 I want England to be:

- The best country in the world for dementia care and support and for people with dementia, their carers and families to live; and
- The best place in the world to undertake research into dementia and other neurodegenerative diseases.

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<sup>22</sup> Gov.uk, [PM launches next phase of Britain's fight against dementia](#), 21 February 2015

The Government also committed to invest over £300 million into dementia research and medical innovation.<sup>23</sup>

The actions contained in the challenge aim to support those who are currently affected by dementia, and look at how the Government can improve the health of the population in order to minimise the number of people who develop dementia.

The challenge sets a number of objectives that the Government wishes to see by 2020. These include:

- Increased public awareness and understanding of the factors that increase the risk of developing dementia;
- Equal access to dementia diagnosis as for other conditions, with a national average for an initial assessment of 6 weeks following a referral from a GP;
- Every person diagnosed with dementia to have meaningful care following their diagnosis, in accordance with NICE Quality Standards;
- All NHS staff to have training on dementia appropriate to their role;
- All hospitals and care homes to become dementia friendly health and care settings;
- Alzheimer's Society to deliver an additional 3 million Dementia Friends in England;
- Over half of people living in areas that are recognised as Dementia Friendly Communities;
- All businesses encouraged and supported to become dementia friendly;
- Funding for dementia research on track to be doubled by 2025;
- Cures or disease modifying therapies on track to exist by 2025; and
- Increased numbers of people with dementia participating in research.<sup>24</sup>

The 2020 Challenge also announced that an international dementia institute would be established in England within 5 years, helping to make the UK a world leader for research on dementia and medical trials – see section 3.5 below.

In March 2016, the Department of Health published an [Implementation Plan](#) which details how the Challenge on Dementia 2020 would be met. The plan sets out priority actions across four themes:

- risk reduction
- health and care
- awareness and social action
- research

In February 2019, the Government published phase 1 of its review of the implementation of the Challenge on Dementia 2020. This review reflects on what has been achieved so far and what more needs to be

<sup>23</sup> Gov.uk, [PM launches next phase of Britain's fight against dementia](#), 21 February 2015

<sup>24</sup> Department of Health, [Challenge on dementia 2020](#), February 2015, pages 5 - 6

done to meet its objectives.<sup>25</sup> The Government has stated that this progress review shows they are “largely on track” to meet its commitments to improve the lives of those living with dementia, and their families and carers:

Examples of progress we have made so far with our delivery partners include more than two thirds of people with dementia receiving a diagnosis, over 2.8 million people becoming Dementia Friends and 365 areas in England committing to being Dementia Friendly Communities. In the £250 million Dementia Discovery Fund we have the largest venture fund in the world aimed at discovering and developing novel pre-clinical therapies for dementia.<sup>26</sup>

### 3.4 Dementia Friends and dementia-friendly communities

In May 2014, Public Health England and the Alzheimer’s Society launched a campaign to recruit one million “Dementia Friends” by March 2015, who are able to recognise the symptoms and support people with dementia.

In February 2015, the Government reported that over one million Dementia Friends had been recruited, and pledges have been made by businesses, NGOs and public sector organisations to recruit more.<sup>27</sup> As of January 2019 there are, there are 2.78 million Dementia Friends.<sup>28</sup>

The Government and the Alzheimer’s Society are also encouraging communities to become “dementia-friendly”. This initiative is funded by the Alzheimer’s Society and the Government’s ambition is that over half of people will be living in dementia-friendly communities by 2020. As of January 2019, there were 412 such communities in England.<sup>29</sup>

The Government is also encouraging organisations that have regular contact with people with dementia to pledge to become more dementia-friendly. Organisations that have pledged include Lloyds Bank, Marks & Spencer and Lloyds Pharmacy.<sup>30</sup>

### 3.5 Dementia research

A May 2019 Parliamentary Question response provides information about Government funding for dementia research:

The Government remains strongly committed to supporting research into dementia and the United Kingdom research community is playing a significant role in the global effort to find a cure or a major disease-modifying treatment by 2025.

The Department funds research on health and social care through the National Institute for Health Research (NIHR). The usual practice of the NIHR is not to ring-fence funds for expenditure on particular topics such as dementia. Research proposals in all areas

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<sup>25</sup> Gov.uk, [Dementia 2020 challenge: 2018 review phase 1](#), 22 February 2019

<sup>26</sup> [HL Written Question – 15918, 6 June 2019](#)

<sup>27</sup> Department of Health, [Challenge on dementia 2020](#), February 2015, page 16

<sup>28</sup> Gov.uk, [Dementia 2020 challenge: 2018 review phase 1](#), 22 February 2019

<sup>29</sup> *Ibid.*

<sup>30</sup> Department of Health, [NHS to tackle long waits for dementia assessments](#), 28 February 2014

compete for the funding available. The NIHR welcomes funding applications for research into any aspect of human health including dementia. These applications are subject to peer review and judged in open competition, with awards being made on the basis of the importance of the topic to patients and health and care services, value for money and scientific quality. In all disease areas, the amount of NIHR funding depends on the volume and quality of scientific activity.

NIHR funding for dementia research was £43.0 million in 2017/18, having increased from £27 million in 2013/14. Government spending overall on dementia research is running ahead of the Government's 2020 Dementia Challenge commitment to maintain this at £300 million over five years. The total in 2017/18 was £82.5 million (£43 million via the NIHR, £36.3 million via the Medical Research Council and £3.2 million via the Economic and Social Research Council).<sup>31</sup>

## The Dementia Discovery Fund

In March 2015, the Government announced a \$100 million "Dementia Discovery Fund" at the World Health Organization's [First Ministerial Conference on Global Action Against Dementia](#). The then Prime Minister, David Cameron, said:

If we are to truly defeat this devastating disease, there must be a bold and determined global effort to invest in medical research.

This fund is a major step forward in this effort. And it is thanks to the growing strength of our economy that the UK is able to lead the way – investing in pioneering research and drug development to tackle this condition once and for all.<sup>32</sup>

The aim of the fund is to finance dementia research, and will include investment from the Government, Alzheimer's Research UK and major pharmaceutical companies. In March 2016, the Government said that the target for the Fund was £130 million.<sup>33</sup> In June 2018 Alzheimer's Research UK noted that due to private investment the Fund had exceeded its initial aim of £130 million and had met a new £250 million target.<sup>34</sup>

## Dementia Research Institute

As noted above, the Challenge on Dementia 2020 announced that an international dementia institute will be established in England, helping to make the country a world leader for research on dementia and medical trials. It set a target for research to identify treatments for dementia by 2025.

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<sup>31</sup> [HC Written question – 251428 \[Dementia: research\] 15 May 2019](#)

<sup>32</sup> Department of Health, [Health secretary announces \\$100m Dementia Discovery Fund](#), 17 March 2015

<sup>33</sup> [PQ 904267 \[on Dementia\], 22 March 2016](#)

<sup>34</sup> Alzheimer's Research UK, [Dementia Discovery Fund exceeds funding target to help find a cure for dementia](#), 25 June 2018

The Spending Review and Autumn Statement 2015 confirmed that up to £150 million would be invested to launch a competition for a Dementia Institute.<sup>35</sup>

In October 2016, the Medical Research Council, Alzheimer's Society and Alzheimer's Research UK announced that they had jointly invested £290million for the establishment of the UK Dementia Research Institute (UKDRI).<sup>36</sup> The Institute has centres at six universities throughout the UK, University of Cambridge, Cardiff University, University of Edinburgh, Imperial College London, King's College London and UCL.<sup>37</sup> Foundation research at these centres started in autumn 2017.

The UKDRI provides information about the work it undertakes on its website:

Working together to understand the complex mechanisms of dementias

Centred on the need for innovative, early-stage science to advance our understanding of how dementias develop and progress, the UK DRI's research will bring new therapies to patients faster. The institute's mission is to find new ways to diagnose, treat and prevent dementias, whilst finding better ways to provide care for people with dementia.

The success of the UK DRI depends on the people in it. The institute is structured so that its researchers are connected, wherever their labs are based. Having centres located across the UK allows the institute to bring people together for shared scientific inspiration, whilst making the most of cutting-edge tools and infrastructure locally.

Our hub and each centre has an associate director, and every person working in the UK DRI contributes towards achieving the institute's vision. Care research will also be integrated into the institute in 2018.<sup>38</sup>

### 3.6 Recent policy developments

The NHS Long Term Plan, published on 7 January 2019, commits the NHS to continuing to improve the care provided to people with dementia and their carers.<sup>39</sup> A National Implementation Framework, to be published shortly, is expected to provide further information on how the Long Term Plan will be implemented. Additional details, based on local health system five-year plans, are also expected to be brought together in a National Implementation Programme in the Autumn of 2019.

Chapter 1 of the NHS Long Term Plan sets out progress, and commitments to improve care to people with dementia:

Over the past decade the NHS has successfully doubled the dementia diagnosis rate and halved the prescription of

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<sup>35</sup> HM Treasury, [Spending Review and Autumn Statement 2015](#), November 2015, para 2.38

<sup>36</sup> MRC, [UK Dementia Research Institute](#), [accessed 12 June 2019]

<sup>37</sup> UKDRI, [Our centres](#), [accessed 12 June 2019]

<sup>38</sup> UKDRI, [About us](#), [accessed 12 June 2019]

<sup>39</sup> [NHS Long Term Plan](#), 7 January 2019

antipsychotic drugs. We have continued to improve public awareness and professional understanding. Research investment is set to double between 2015 and 2020, with £300m of government support. We will provide better support for people with dementia through a more active focus on supporting people in the community through our enhanced community multidisciplinary teams and the application of the NHS Comprehensive Model of Personal Care. We will continue working closely with the voluntary sector, including supporting the Alzheimer's Society to extend its *Dementia Connect* programme which offers a range of advice and support for people following a dementia diagnosis.<sup>40</sup>

Further information on the Dementia Connect programme, mentioned above, can be found in section 4 of this briefing, on services for people with dementia.

In May 2019 the Alzheimer's Society published, [Fix Dementia Care](#), which set out the case for a new 'Dementia Fund', to give people with dementia access to affordable and high quality care. The report's key recommendations are set out below:

1. Improve dementia care by investing in a new £2.4 billion Dementia Fund in the 2019 budget.
2. Publish the Green Paper on Social Care with proposals for long term funding reform that shares the cost of dementia care more fairly across society.
3. Address the Dementia Penalty to ensure that the costs associated with a health condition like dementia are covered by the NHS.

In June 2019 the All-Party Parliamentary Group (APPG) on Dementia published [Hidden no more: dementia and disability](#). The APPG report looked at the societal barriers that prevent people with the condition living independently and provided a framework for action based on disability rights. It made recommendations for local and national government to take action in 6 key areas to improve the lives of people with dementia:

In this report we focus on six of these key areas which have a direct impact on people's daily lives. We identify opportunities for action, based on what respondents told us they found challenging in each area. These are listed below.

### **Employment**

- There must be more awareness of the employment rights of people with dementia among both employers and employees.
- People need to feel empowered to tell their employers about their diagnosis.
- Employers should feel supported to fulfil their responsibilities to make reasonable adjustments to ensure people with dementia can continue to make a meaningful contribution in the workplace.

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<sup>40</sup> *Ibid.*



### **Social protection**

- People with dementia and their carers often need support to know what financial help they are entitled to, as well as how to make a successful claim. They deserve to be assessed by professionals who understand the condition, without having to undergo unnecessary reviews or reassessments.
- Assessment processes must be clear and appropriate for people with cognitive impairments.

### **Social care**

- The medical and social care support available to people with dementia is inadequate and inaccessible.
- The forthcoming Green Paper on social care reform must recognise and reflect the needs of people living with dementia, now and in the future.

### **Transport**

- People with dementia face a lack of alternatives to driving. It is imperative that any changes to bus and community transport services are reviewed in the context of the Public Sector Equality Duty (PSED).
- Reasonable adjustments must be made that enable people to continue to use public transport.
- There must be an increase in societal awareness to reduce the stigma and discrimination that people with dementia feel while using public transport.

### **Housing**

- People with dementia have the right to personal choice over where, and how, they live. Our evidence found that people want to live independently for longer, but limited availability of appropriate housing means they are faced with a lack of personal choice. They must have access to adaptable housing, trained home-care staff, and specialised supported housing schemes.

### **Community life**

- Communities must increase their awareness and understanding of dementia and people need to be supported through the development of inclusive communities where no one is excluded or has to face dementia alone.<sup>41</sup>

The Dementia APPG's co-chair Debbie Abrahams is leading a general debate on improving the lives of people with dementia in Westminster Hall on Tuesday 25 June 2019.

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<sup>41</sup> APPG on Dementia, [Hidden no more: dementia and disability](#), June 2019, Executive Summary

## 4. Services for people with dementia in England

### 4.1 NHS and social care services

There are a range of NHS and social care services to support people with dementia. When someone is diagnosed with dementia, a care plan should be drawn up that sets out which services will be provided. Further information about the services available can be found on the NHS webpage on [Dementia, social services and the NHS](#).

In general, social and personal care will be provided by social care services, and healthcare services will be provided by the NHS. Individuals may be expected to pay for some social care services, whilst NHS services are largely free.

Some people are eligible for NHS Continuing Healthcare. This is a package of care arranged and funded solely by the NHS to meet physical and/or mental health needs that have arisen because of disability, accident or illness. Eligibility decisions for NHS continuing healthcare rest on whether someone's need for care is primarily due to health needs. For example, people who are eligible may have complex medical conditions that require highly specialised nursing support. The scheme funds healthcare outside of hospital, such as a residential care home; hospice; or someone's own home. Further information can be found in the Library briefing on [NHS Continuing Healthcare in England](#).

NHS England has published an evidence-based treatment pathway for dementia to improve access to services, timely diagnosis and post diagnostic support – the [Well Pathway for Dementia](#).

In June 2018, NICE published a clinical guideline on '[Dementia: assessment, management and support for people living with dementia and their carers](#)'. This guideline covers preventing, diagnosing, assessing and managing dementia in health and social care. The guidelines are not mandatory but provide best-practice advice for commissioners and providers of healthcare in England.

The Dementia Action Alliance updated its [Dementia-Friendly Hospitals Charter](#) in 2018. It provides guidelines for hospitals to work by to try and make the experience of visits better for people living with dementia. The charter has been endorsed by a selection of professionals from across the healthcare sector.

The [National Audit of Dementia](#) (NAD) is a clinical audit programme commissioned by the Healthcare Quality Improvement Partnership on behalf of NHS England (and the Welsh Government) looking at quality of care received by people with dementia in general hospitals. The NAD measures the performance of general hospitals against criteria relating to care delivery, including NICE guidance, the Dementia Friendly

Hospitals charter, and reports from the Alzheimer's Society, Age Concern and Royal Colleges.<sup>42</sup>

The Government has stated that wherever possible, it wants to avoid people with dementia going into hospitals by improving the provision of local community services, education and training. By 2020, the Government wishes to see all hospitals and care homes meeting agreed criteria to becoming dementia-friendly health and care settings.<sup>43</sup>

## 4.2 Domiciliary care (care at home)

There are a range of support services that can enable someone with dementia to be cared for at home. Eligibility and funding arrangements for home care are determined by each local authority's policy. Further information on the criteria that local authorities will apply to determine eligibility for social care services is set out in the Library briefing on [Social care: paying for care home places and domiciliary care \(England\)](#).

A YouGov poll in June 2014 found that 85 per cent of people would rather want to stay living at home if diagnosed with dementia, rather than be admitted to a care or nursing home.<sup>44</sup>

The Government has stated that by 2020 it wants to see an increase in the numbers of people with dementia being able to live at home. It wants to see a greater provision of innovative and high-quality dementia care provided at home, suitable to the individual's needs of the person with dementia, their carers and families. In order for this to be possible, the Government has stated that there must be greater efforts to make homecare an attractive profession. The Government also encourages greater integrated working between health, social care and housing services, and the provision of housing for people who need more support, such as sheltered and extra care housing.<sup>45</sup>

## 4.3 Care homes

Some people with dementia will spend time in a care home. Care homes may be run by voluntary organisations; private organisations or individuals; or local authorities.

In October 2014, the Care Quality Commission (CQC) found that whilst many hospitals and care homes deliver excellent care, the quality of care for people with dementia varied greatly. The CQC found that some hospitals and care homes did not comprehensively identify all of a person's care needs, and there was variable or poor staff understanding and knowledge of dementia care.<sup>46</sup>

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<sup>42</sup> The NAD reports are hosted on the [website of the Royal College of Psychiatrists](#) and are aimed at people with dementia and their carers, and for staff involved in providing, commissioning and regulating care.

<sup>43</sup> Department of Health, [Challenge on dementia 2020](#), February 2015, page 31

<sup>44</sup> Alzheimer's Society, ['Most people want to stay at home if diagnosed with dementia but less than half know how'](#), June 2014

<sup>45</sup> Department of Health, [Challenge on dementia 2020](#), February 2015, page 30

<sup>46</sup> Care Quality Commission, ['Cracks in the pathway: People's experiences of dementia care as they move between care homes and hospitals'](#), October 2014

Information on care homes; eligibility for help with care home costs; and advice on choosing a care home is on the NHS webpage on [Dementia and care homes](#).

## 4.4 Funding social care in England

Whether a care home resident or recipient of social care in another setting (such as in their home) must contribute in part or in full towards the cost of their care principally depends on two factors: whether their primary need for a care home place is health related (in which case they should qualify for NHS Continuing Healthcare, see above); and, if not, their financial means to contribute. Further information on local authority care home charging, including the means-test, can be found in the Library briefing [Social care: paying for care home places and domiciliary care \(England\)](#).

At present, recipients of social care, including those with dementia, can face unlimited lifetime bills for social care. Even if their capital is diminished to the point that they pass the means-test and become eligible for local authority funding support, they are still required to contribute almost all of their income towards the cost of social care.

While legislation has been passed to allow lifetime social care charges to be capped, it has not been brought into force, its introduction having twice been postponed, first from April 2016 to April 2020, and then indefinitely.<sup>47</sup>

The Government said in March 2017 that it would publish a Green Paper on how social care is paid for, but it has missed five publication dates. The current position is that it will be published at an unspecified “earliest opportunity”.<sup>48</sup> During the last General Election, the Prime Minister said that the Green Paper would include proposals for a cap.<sup>49</sup>

The Alzheimer’s Society’s May 2019 report, [Fix Dementia Care](#), identified what it called a “dementia penalty” (due to the higher social care costs, and limited access to NHS care, faced by people with dementia). The report called for long term funding reform to share the cost of dementia care more fairly across society. In response to a PQ on the Alzheimer’s Society report, the Minister for Care, Caroline Dinenage set out commitments to improve NHS care in the Long Term Plan. She also noted the forthcoming Green Paper on adult social care:

The Government has committed to publishing a Green Paper on adult social care at the earliest opportunity, setting out proposals for reform and will bring forward ideas for including an element of risk pooling in the system, which will help to protect people from the highest costs. We are committed to ensuring everyone

<sup>47</sup> For more information, see the House of Commons Library briefing papers, [Social care: Announcements delaying the introduction of funding reforms \(including the cap\) \(England\)](#) and [Social care: how the postponed changes to paying for care, including the cap, would have worked \(England\)](#).

<sup>48</sup> [PQ 212355 29 January 2019](#)

<sup>49</sup> For more information, see the House of Commons Library briefing paper, [Social care: the Conservative Party’s 2017 General Election pledges on how individuals pay for care \(England\)](#).

has access to the care and support they need, based on a principle of shared responsibility.<sup>50</sup>

Further background on the proposed Green Paper can be found in the Library briefing [Social care: forthcoming Green Paper \(England\)](#).

## 4.5 Sources of advice and support

Advice and support is available from charities for people with dementia and their carers. The [Alzheimer's Society](#) runs the [National Dementia Helpline](#) on 0300 222 11 22 for information and advice about dementia. [Dementia UK](#) also offers advice and support to families who are living with dementia through its Admiral Nurses, who are registered nurses and dementia experts. Admiral Nurses can be contacted via the Admiral Nurse Dementia Helpline on 0800 888 6678 or email [helpline@dementiauk.org](mailto:helpline@dementiauk.org).

The Alzheimer's Society is also piloting a programme called [Dementia Connect](#), which offers a range of advice and support for people following a dementia diagnosis. This new service is being piloted in East Lancashire, Blackburn with Darwen, Birmingham and Solihull (it is also available throughout Wales). People with dementia will need to live in these areas to use this service.

The NHS provides a [Dementia Information Service](#), a weekly email that people can sign up to, to guide them through the 6 weeks after a dementia diagnosis.

# 5. Scotland, Wales and Northern Ireland

Health and social care are devolved matters, and so each part of the UK is responsible for setting their own policies with regard to dementia care. Brief information and links to dementia strategy documents for Scotland, Wales and Northern Ireland can be found below. Further information on dementia strategies in different parts of the UK are also available from the [Alzheimer's Society website](#).

## 5.1 Scotland

[Scotland's National Dementia Strategy 2017-2020](#) was published in June 2017. The third national strategy maintains a focus on improving the quality of care for people living with dementia and their families through work on diagnosis, including post-diagnostic support; care co-ordination during the middle stage of dementia; end of life and

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<sup>50</sup> [HC Written Question – 252497, 16 May 2019](#)

palliative care; workforce development and capability; data and information; and research.<sup>51</sup>

For further information, see the Scottish Government's webpage on [dementia](#).

## 5.2 Wales

The Welsh Government has set an ambition to provide support to people in Wales with dementia and their families, including:

### **Dementia risk reduction**

Our revised "Dementia: reduce your risk guidance" sets out the lifestyle choices individuals can take which could lessen the risk of developing dementia.

### **Dementia diagnosis rates**

We are taking action to improve dementia diagnosis rates in Wales, including extra training and support for primary care and care home staff.

### **Post-diagnostic support**

We will be funding new support workers across Wales to help those who have received a dementia diagnosis.

### **Care in general hospital settings**

We are supporting NHS Wales staff to ensure they have the knowledge and skills they need to provide the best care for patients with dementia.

### **Public awareness and support**

We will be providing further funding to the Alzheimer's Society in Wales for their Dementia Friends/Dementia Supportive Communities campaigns.<sup>52</sup>

The Welsh Government's [Dementia Action Plan for Wales 2018-2022](#) was published in February 2018. It aims to create new ways of caring, training and increasing the number of support workers, increasing rates of diagnoses and strengthening collaborative working between social care and housing. The plan is supported by an extra £10 million a year.<sup>53</sup>

## 5.3 Northern Ireland

The Northern Ireland Executive's Dementia Services Programme, *Dementia Together NI*, ran for four years from 2013 to 2017. It aimed to raise awareness, information and support for people living with a dementia; deliver training and development for those in the caring professions, both formally and informally; and provide respite, short breaks and support for carers.

<sup>51</sup> [Scotland's National Dementia Strategy 2013-2016](#) focused on continuing to improve diagnosis rates and post-diagnostic support; ensuring the highest quality of care and support for people with dementia at every stage of the illness; improving service response in acute care and supporting the growth of dementia-friendly communities. Scotland's first [National Dementia Strategy](#) was published in June 2010 and focused on improving the quality of dementia services through more timely diagnosis and on better care and treatment.

<sup>52</sup> Welsh Government, [Dementia](#)

<sup>53</sup> Welsh Government, [New Plan to transform dementia care in Wales](#), 14 February 2018

The Office of the First Minister and Deputy First Minister provided further information:

### **Dementia Services Programme**

With an investment of £6.25million by the Executive and The Atlantic Philanthropies over a three year period to 2017, the Delivering Social Change Dementia Services Signature Programme aims to transform the commissioning, design and delivery of dementia services into the future and improve the quality of care and support for people living with dementia. The programme will also promote better awareness, reduce the stigma attached to the condition and improve the skills and competency of those working in dementia care services.

The projects will address three key strategic themes:

- awareness raising, information and support;
- training, including delirium; and
- short-breaks, respite and support to carers.

These themes have been selected on the basis that they will make the greatest contribution to improving the quality of life, care and treatment for people living with dementia, their carers and staff working in the field of dementia.

In addition to these three strands above, the programme will:

- create a website providing information to public and professionals alike on dementia, including available services by locality and training;
- seek to identify 250-300 Dementia Champions. These will be key individuals within a dementia care setting with the skills, knowledge and understanding to enhance current practice; and
- based on feedback from people with dementia and carers, create two Dementia Navigator posts in each Health and Social Care Trust. Staff in these roles will, as the title suggests, assist people with dementia and carers to 'navigate' their way through what can be a complex and daunting system. The Navigator will provide a point of contact, providing help and support at any stage throughout the individual's care journey. The project team is working with colleagues across the statutory and voluntary sectors to promote greater collaboration between those who are engaged in providing this service. This will facilitate a more joined-up approach to service delivery.<sup>54</sup>

A previous Northern Ireland strategy, [Improving Dementia Services in Northern Ireland](#), was launched in November 2011 and set out a holistic model for supporting people with dementia.

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<sup>54</sup> Office of the First Minister and Deputy First Minister, [Delivering Social Change - Signature Programmes](#)





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