



Department  
of Health

# Dementia

A state of the nation report on dementia  
care and support in England



November 2013

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## Foreword

We are facing one of the biggest health challenges ever, a challenge as big as the fights against cancer, heart disease and HIV. Dementia steals lives. It also imposes a huge emotional and financial cost. It is time to fight back.

Around 670,000 people in England have dementia and this number is set to double in the next 30 years.<sup>1</sup> Dementia costs £19 billion a year, and this is going to increase massively. The cost in heartbreak is incalculable.

Already an estimated twenty-one million people in our country have a close friend or family member with dementia. Directly or indirectly, it will soon affect every one of us.

As a nation, we need to wake up to what is fast becoming one of the greatest pressures on families, carers, and health and care systems.

In March 2012, the Prime Minister launched his Dementia Challenge – a national programme of action to deliver sustained improvements in health and care, create dementia friendly communities, and boost dementia research.

This Dementia report, with its accompanying map of variation, available at <http://dementiachallenge.dh.gov.uk/map/>, shines a light on the quality of dementia care in England. The very best services are excellent and show what is possible. But the worst show that we still have some way to go. The message is clear: we can and must do better.

There has been some major progress. We are better at identifying and assessing people with dementia in hospitals and have responsibly reduced the prescription of antipsychotic medication.<sup>2</sup>

But it is unacceptable that less than half of people with dementia receive a diagnosis and that there is such variation across the country in how long people wait before being seen by a memory service. The availability of post-diagnosis support varies far too much as well.

47 percent of people with dementia do not feel part of their community. They often experience anxiety and depression and three quarters do not feel society is geared up to deal with dementia.<sup>3</sup> 62 percent of people with dementia living alone are lonely and it can sometimes be hard to access services, which only adds to this isolation.<sup>4</sup>

I am determined we make our fight against dementia global, so I am delighted the UK is hosting the first G8 dementia summit in December. The summit will be unprecedented in bringing together G8 governments, the World Health Organisation (WHO) and the Organisation for Economic Co-operation and Development (OECD), along with pharmaceutical companies, philanthropists, academics, research funders and industry.

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<sup>1</sup> [Prime Minister's challenge on dementia](#)

<sup>2</sup> [National Dementia and antipsychotic prescribing Audit, 2012](#)

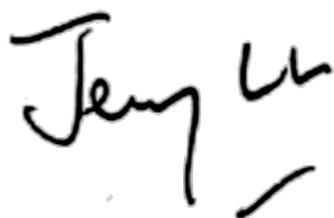
<sup>3</sup> [Dementia 2012: A national challenge, Alzheimer's Society, 2012](#)

<sup>4</sup> [Dementia 2013: The hidden voice of loneliness, Alzheimer's Society, 2013](#)

It will give us a tremendous chance to make real progress much faster. The planned follow-up events next year mean there is a great opportunity to forge a major lasting legacy.

While we continue to pursue a cure, it is vital we look at how we can help people manage dementia better, support them to lead healthier lives, and deliver real improvements in care.

We have a moral responsibility to fight dementia – and together we will.

A handwritten signature in black ink, appearing to read "Jeremy". The signature is written in a cursive, fluid style with a long horizontal stroke at the end.

# The scale of the challenge

## Our vision

We want a society where people with dementia and their carers receive high quality, compassionate care, whether at home, in hospital or in a care home. We want the person with dementia – with their family and carer – to be at the heart of everything we do. We want their wellbeing and quality of life to be first and foremost in the minds of those commissioning and providing services.

We want people to feel confident that we are making real progress towards preventing and treating dementia, and that we are relentless in our search for a cure.

The health and care system has a vital role to play in improving support for people with dementia. But it can't do it alone. This is a call to the whole of society. We want to create communities where people are more aware of dementia, understand it and know how to help. We want communities where people with dementia and their carers are encouraged to seek help and support and feel able to go about their daily lives safely and free of stigma.

We want a society where people with dementia can honestly say:

- I was diagnosed in a timely way.
- I know what I can do to help myself and who else can help me.
- Those around me and looking after me are well supported.
- I get the treatment and support, best for my dementia, and for my life.
- I feel included as part of society.
- I understand so I am able to make decisions.
- I am treated with dignity and respect.
- I am confident my end of life wishes will be respected. I can expect a good death.
- I know how to participate in research.

## What is dementia?

Dementia is a syndrome that can be caused by a number of progressive disorders. It can affect memory, thinking, behaviour and the ability to perform everyday activities. Alzheimer's disease is the most common type of dementia. Other types include vascular dementia, dementia with Lewy bodies and frontotemporal dementia.

Dementia mainly affects older people, although there is a growing awareness of cases starting before the age of 65. After 65, the likelihood of developing dementia roughly doubles every five years.<sup>5</sup>

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<sup>5</sup> LSE, King's College London, Alzheimer's Society. Dementia UK: The Full Report, 2007

Dementia is progressive, which means the symptoms will gradually get worse and the condition is currently incurable. However, medicines and other interventions can lessen symptoms and people may live with their dementia for a further 7-12 years after diagnosis.

**‘I don’t let dementia over take me, it will do one day but for now I enjoy my life.’<sup>6</sup>**

Contrary to common perceptions, there is a great deal that can be done to help people with dementia. For example, if diagnosed in a timely way, people with dementia and their carers can receive the treatment, care and support (social and psychological, as well as pharmacological) enabling them to live well with the condition. It is often about the simple things, things that most of us take for granted, like making a cup of tea, that – without support – someone with dementia can find practically impossible.

Around 60 percent of people with dementia have Alzheimer’s disease, around 20 percent have vascular dementia and many people have a mixture of the two. There are other less common forms of dementia.<sup>7</sup> Vascular dementia results from problems with the blood supply to the brain – without enough blood, brain cells can die. The effects of vascular dementia can be minimised or prevented altogether through a healthy lifestyle. Smoking and obesity, for example, affect many types of dementia, in particular vascular dementia.<sup>8</sup>

## Why is dementia important?

### A global challenge

Dementia is a growing, global challenge. It is one of the most important health and care issues the world faces as the population ages.

**‘Globally there is a new case of dementia every four seconds, and by 2020 we will see nearly 70 million people living with the condition.’<sup>9</sup>**

The worldwide cost of dementia care is around \$600 billion. If dementia care were a country, it would be the world’s 18th largest economy, ranking between Turkey and Indonesia. If it were a company, it would be the biggest in the world by annual revenue, exceeding Wal-Mart (US\$414 billion) and Exxon Mobil (US\$311 billion). An estimated 28 million people with dementia worldwide haven’t received a formal diagnosis.<sup>10</sup>

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<sup>6</sup> [Brainwaves Newsletter October 2013, Innovations in Dementia](#)

<sup>7</sup> [Dementia resources, NHS Health Check](#)

<sup>8</sup> [The Lancet Vol 377 March 19, 2011](#)

<sup>9</sup> [UK to host G8 dementia summit, GOV.UK news story](#)

<sup>10</sup> [Alzheimer’s Disease International \(2011\), World Alzheimer’s report 2011, ADI, London](#)

## Dementia in England

There are approximately 670,000 people in England living with dementia. This number will double in the next 30 years. Dementia in England costs £19 billion a year and there are an estimated 550,000 carers of people with dementia.<sup>11</sup>

## The impact of dementia

Dementia has a huge impact on people living with the condition, their families, carers and society more generally. The statistics are compelling:

### Mortality

- Of the top 25 causes of years of life lost in the UK due to premature mortality between 1990 to 2010, a study<sup>12</sup> found Alzheimer's disease and other dementias had risen from 24th place to 10th, accounting for 2.6 percent of total years of life lost across the top 25 causes.

### Diagnosis

- Currently less than half of people with dementia in England (48 percent) have a formal diagnosis or have contact with specialist services. The diagnosis rate varies from 39 percent in the worst performing areas to 75 percent in the best. This variation is unwarranted and needs to be addressed.

### Hospital care

- An estimated 25 percent of hospital beds are occupied by people with dementia.<sup>13</sup> People with dementia also stay in hospital for longer, are more likely to be re-admitted and more likely to die than patients admitted for the same reason.<sup>14</sup>

### Care homes and care at home

- An estimated one third of people with dementia live in residential care with two thirds living at home.
- Approximately two thirds of care home residents are currently estimated to have dementia.

### Economy

- Dementia costs society an estimated £19 billion a year, more than the costs of cancer, heart disease or stroke.<sup>15</sup>

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<sup>11</sup> Prime Minister's challenge on dementia, based on Alzheimer's Society (2007), Dementia UK, Alzheimer's Society, London

<sup>12</sup> Global Burden of Disease Study (GBD 2010)

<sup>13</sup> Counting the cost – caring for people with dementia on hospital wards, Alzheimer's Society, 2009

<sup>14</sup> Care Quality Commission, Care update, CQC, London

<sup>15</sup> Prime Minister's challenge on dementia, based on Alzheimer's Society (2007), Dementia UK, Alzheimer's Society, London

## Carers

- An estimated 21 million people in our country know a close friend or family member with dementia – that is 42 percent of the population.<sup>16</sup>
- There are around 550,000 carers of people with dementia in the England.<sup>17</sup> It is estimated that one in three people will care for a person with dementia in their lifetime.

## Fear

- People fear dementia more than any other disease.<sup>18</sup> 39 percent of over 55s fear getting Alzheimer's the most, compared to 25 percent who worry most about cancer.

## The prevalence of dementia

The Dementia 2007 Report<sup>19</sup> used a method known as the Expert Delphi Consensus to produce the best possible estimates of how many people living in England with dementia – diagnosed or not. The report showed that the prevalence of both early onset and late onset dementia increases with age. Between the ages 30 and 95 years, the number of people with dementia doubles every five years.

The following table shows the population prevalence of late onset dementia<sup>20</sup>. Early onset dementia is higher in men than in women aged 50–65, while late onset dementia is marginally more common in women than in men.

NHS England, with Alzheimer's Society, is working to update and improve the data on dementia.

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<sup>16</sup> Prime Minister's challenge on dementia – delivering major improvements in dementia care and research by 2015, March 2012

<sup>17</sup> Prime Minister's challenge on dementia, based on Alzheimer's Society (2007), Dementia UK, Alzheimer's Society, London

<sup>18</sup> YouGov research

<sup>19</sup> [Dementia UK 2007 report materials, Alzheimer's Society](#)

<sup>20</sup> [Dementia UK 2007 report materials, Alzheimer's Society](#)

## The consensus estimates of the population prevalence of late onset dementia

<i>Age (years)</i>	<i>F (%)</i>	<i>M (%)</i>	<i>Total (%)</i>
65–69	1.0	1.5	1.3
70–74	2.4	3.1	2.9
75–79	6.5	5.1	5.9
80–84	13.3	10.2	12.2
85–89	22.2	16.7	20.3
90–94	29.6	27.5	28.6
95+	34.4	30.0	32.5

The number of people with dementia from black, asian and minority ethnic (BAME) groups in the UK is expected to rise significantly as the BAME population ages. The All-Party Parliamentary Group on Dementia reported, in July 2013, an estimate of nearly 25,000 people living with dementia from BAME communities in England and Wales. This number is expected to grow to nearly 50,000 by 2026 and over 172,000 by 2051. This is nearly a seven-fold increase in 40 years. It compares to just over a two-fold increase in the number of people with dementia across the whole UK population in the same time period.<sup>21</sup>

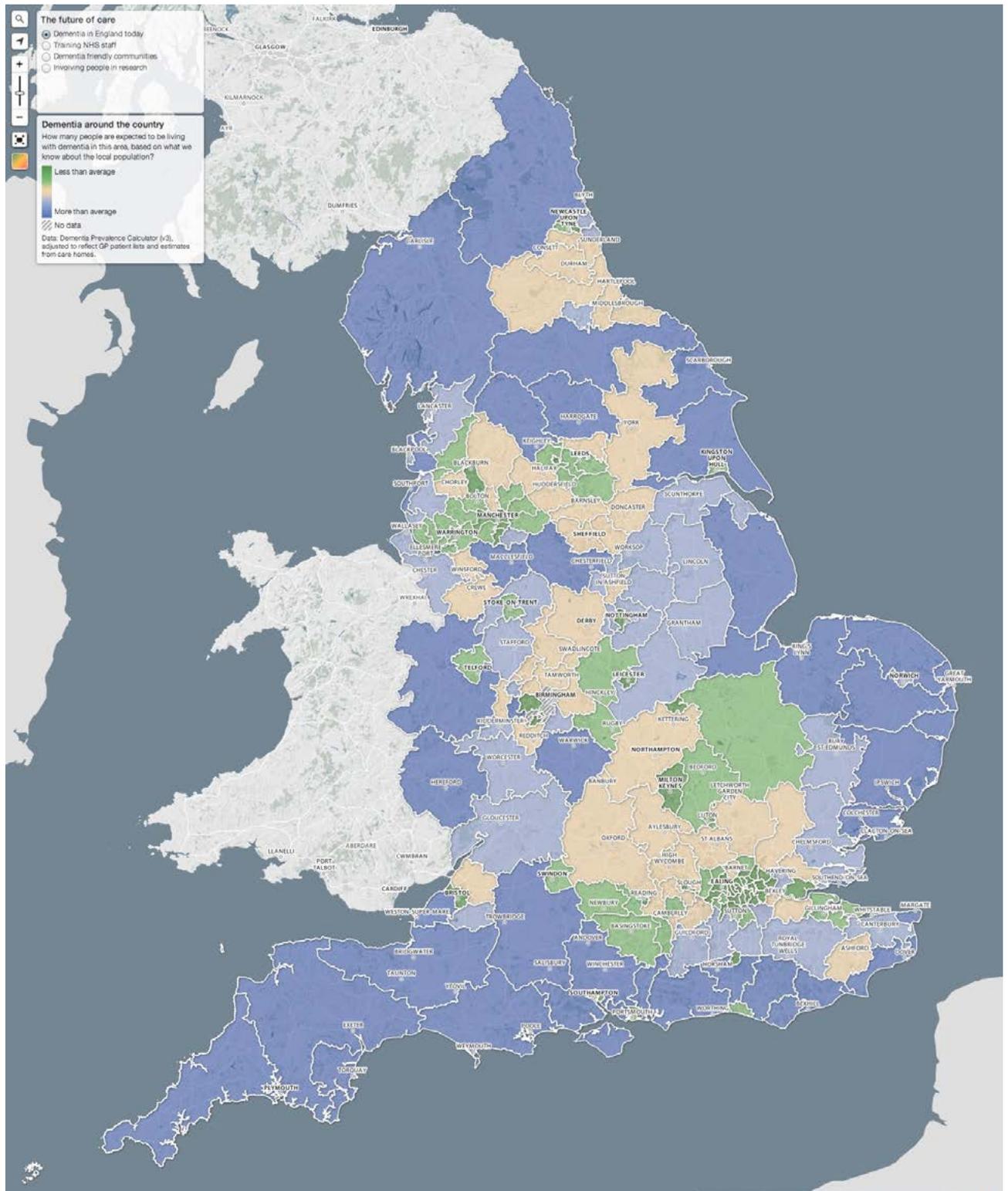
The All-Party Parliamentary Group on Dementia found that many people from BAME communities did not receive a diagnosis of dementia, preventing them from having access to support and treatments that could help them live well with the condition. In addition to this, stigma surrounding the condition meant people with dementia and their families faced social isolation, feeling unable to reach out for support. Amongst those who did seek help, there was generally felt to be a lack of culturally sensitive dementia services.

People with learning disabilities have an increased risk of developing dementia than other people and usually develop the condition at a younger age. This is particularly true of people with Down's syndrome, one in three of whom will develop dementia in their 50s.<sup>22</sup>

<sup>21</sup> Dementia does not discriminate, All-Party Parliamentary Group on Dementia, July 2013

<sup>22</sup> [Alzheimer's Society, 2011, Learning disabilities and dementia factsheet](#)

## The prevalence of dementia in England



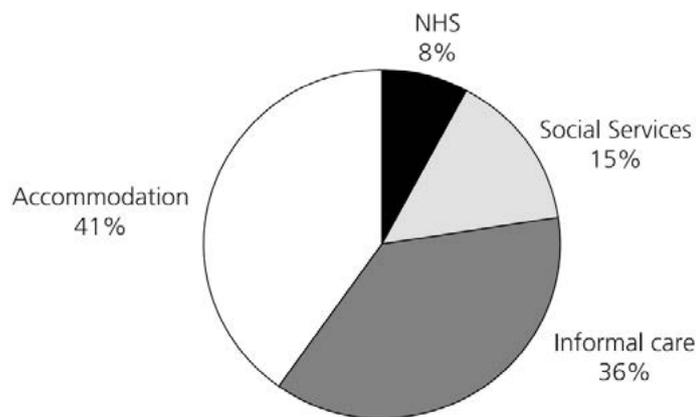
## Diagnosing dementia

In richer countries around the world, a review of recent studies conducted by Alzheimer’s Disease International found the median diagnosis rate was 39 percent, ranging from 25 percent to as high as 50 percent.<sup>23</sup> The diagnosis rate for England is currently 48 percent, but by 2015 we want this to rise to two thirds of people with dementia being diagnosed and receiving appropriate support. Across all countries in the world an estimated 28 million of the 35.6 million people with dementia worldwide do not have a formal diagnosis.<sup>24</sup>

## The costs of dementia

About 70 percent of the total worldwide cost of dementia – around \$600 billion – is in Western Europe and North America. These costs account for around 1 percent of the world’s gross domestic product.<sup>25</sup>

Alzheimer’s Society’s 2007 Dementia UK report<sup>26</sup> estimated the cost of dementia to the UK economy. The breakdown of costs is illustrated below:



Distribution of dementia service costs

It is estimated the costs of dementia are higher than cancer, stroke or heart disease.<sup>27</sup>

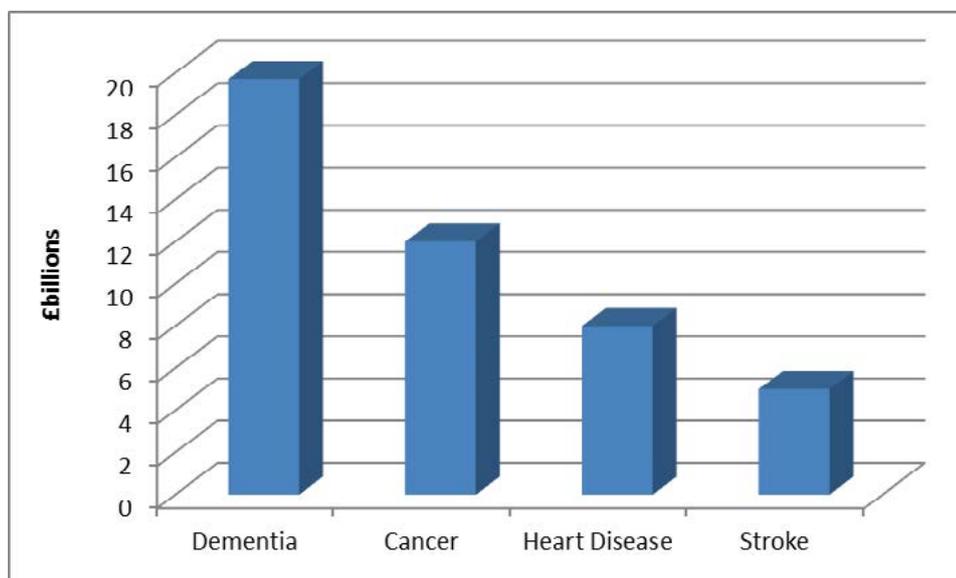
<sup>23</sup> [World Alzheimer’s Report 2011](#)

<sup>24</sup> [World Alzheimer’s Report 2011](#)

<sup>25</sup> [World Alzheimer’s Report 2010](#)

<sup>26</sup> Alzheimer’s Society (2007), Dementia UK, Alzheimer’s Society, London

<sup>27</sup> Prime Minister’s challenge on dementia – delivering major improvements in dementia care and research by 2015, March 2012



As the population grows and ages, the economic burden of dementia is expected to rise significantly. According to The King's Fund,<sup>28</sup> total annual spending on dementia is projected to reach £35 billion in 2026.

## Prevention

As well as helping people who already have dementia, we need to look at how we can do more to prevent people getting it in the first place.

Around 60 percent of people with dementia have Alzheimer's disease. Approximately 20 percent have vascular dementia and many people have a mixture of the two. There are other less common forms of dementia.<sup>29</sup> Vascular dementia results from problems with the blood supply to the brain – without enough blood, brain cells can die. The effects of vascular dementia can be minimised or prevented altogether through a healthy lifestyle. Smoking and obesity, for example, affect many types of dementia, in particular vascular dementia.<sup>30</sup> Helping people to understand the impact of their lifestyle could help them to make better, more informed choices and reduce their risk of developing vascular dementia.

## Progress

### The NHS Health Check programme

The NHS Health Check programme, introduced in April 2009, offers advice and support to help people aged 40-74 make changes that can reduce the risk of ill health, including vascular dementia. It also offers an opportunity to identify those at risk of certain diseases or who have undiagnosed conditions such as diabetes, high blood pressure or dementia.

15 million people are eligible for the NHS Health Check. Since April 2013, people in England aged 65-74, which accounts for more than 3 million people, should be given information about dementia and the availability of memory services. This provides a huge opportunity to the health and care system to focus on prevention, timely diagnosis and treatment.

Data on the NHS Health Check is reported at local authority level and is available at <http://www.healthcheck.nhs.uk/>. 100 percent of the eligible population are to be invited for an NHS Health Check over the five years from 2013-2018. According to local authority data, in the first quarter of 2013/14, the median proportion of the eligible population offered an NHS Health Check by their Local Authority was 4.2 percent (the maximum was 14.5 percent). The median rate of NHS Health Checks received compared to the number offered was 46.6 percent (the maximum was 100 percent<sup>31</sup>).

Southwark integrated dementia awareness into NHS Health Checks in March 2013 and is now rolling this out to all GP practices and pharmacies. The outreach nurses completed both face to face and online training and commented that the “training was great. Doing both was very helpful, I didn't know very much about dementia so it gave me the confidence to be able to talk about it with my clients.” A patient commented: “I was really scared when the nurse mentioned dementia. The information was very helpful, I had no idea this was something I could influence.”

<sup>29</sup> [Dementia resources, NHS Health Check](#)

<sup>30</sup> [The Lancet, Vol 377 March 19, 2011](#)

<sup>31</sup> [NHS Health Check interactive map](#)

## Call to action

We want more people to be aware of the risk factors that can increase their chances of getting vascular dementia and how positive lifestyle changes can make a difference. The NHS Health Check programme is one way of doing this, but public awareness raising of dementia and the work to establish dementia friendly communities are also important.

We need to increase the uptake of the NHS Health Check, making the most of the opportunity to encourage people to lead healthier lives and ensure data flows smoothly around the health and care systems. This is particularly important where the risk assessment carried out as part of the check raises the need for further investigation.

We know the choices people make can affect their risk of developing dementia. We need to do more to understand these risks if we are to create an effective, coordinated approach to preventing the disease. Public Health England is leading this work with partners including the National Institute for Clinical Excellence (NICE) and the UK Health Forum.

## Diagnosis

Timely diagnosis of dementia really matters. It is the key to helping people with dementia, their families and carers get the support they need, to plan for the future and to make informed choices about how they would like to be cared for. We know that with early intervention, and access to the right services and support, people with dementia can continue to live well for many years.

**‘It was too late to get power of attorney by the time diagnosis was given, which caused problems and financial hardship as we were unable to access Dad’s savings account when he needed a ramp to get outside, and had to use a credit card for expenses which obviously cost more.’<sup>32</sup>**

**‘(If we had known) earlier in her diagnosis we could have explored support networks and taken advantage of them.’<sup>33</sup>**

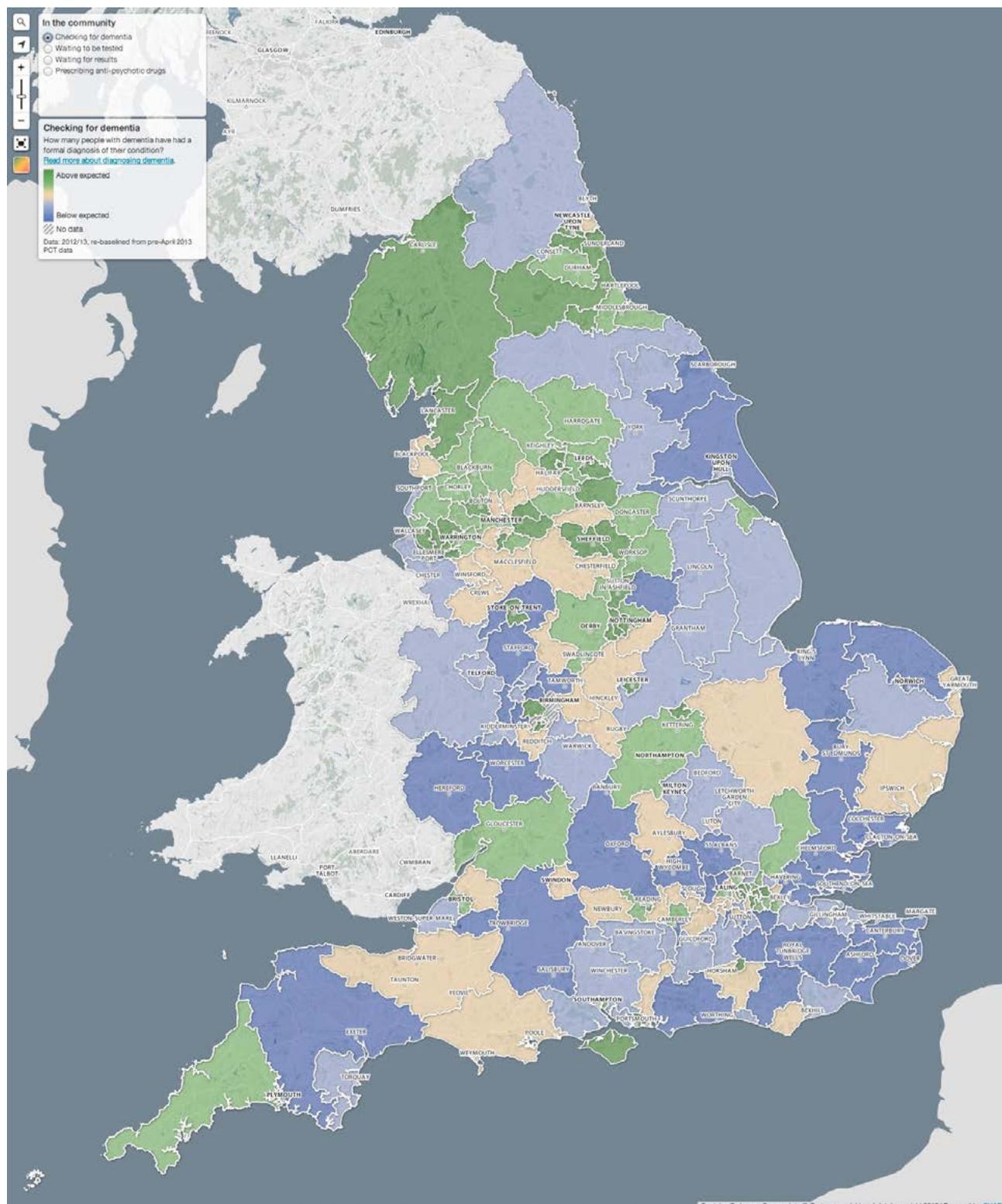
We need to do far more to increase the number of people with dementia being properly diagnosed. Currently less than half of the estimated number of people with dementia in England receive a formal diagnosis or have contact with specialist dementia services. While there has been a slight increase nationally in the diagnosis rate from 46 percent in 2011/12 to 48 percent in 2012/13, the diagnosis rate varies across the country from 39 percent in the worst performing areas to 75 percent in the best.

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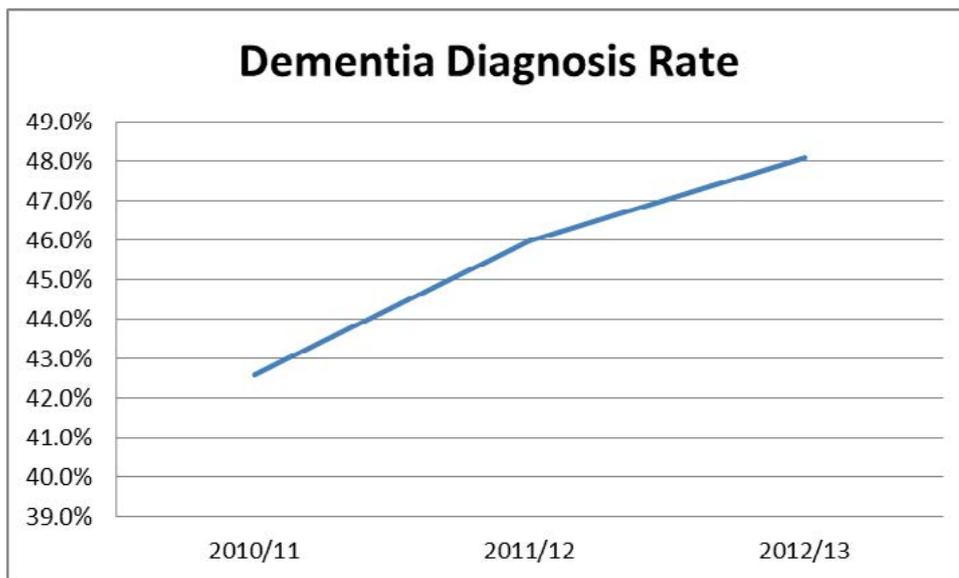
<sup>32</sup> A road less rocky – supporting carers of people with dementia, Carers Trust, 2013

<sup>33</sup> A road less rocky – supporting carers of people with dementia, Carers Trust, 2013

## Diagnosis rates in England



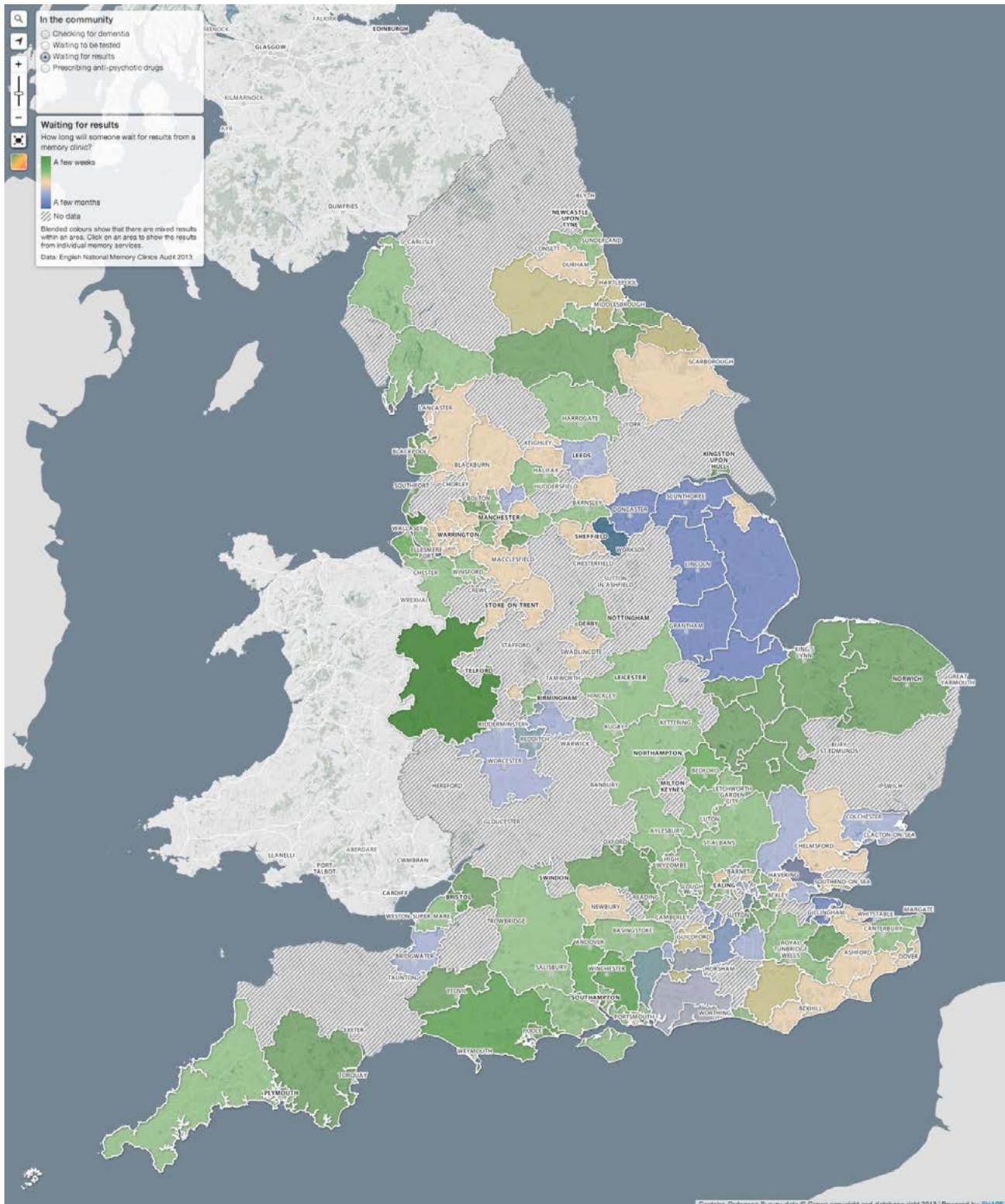
Much more needs to be done to make people aware of the signs and symptoms of dementia so they can seek help and get access to timely treatment and support.



According to the Royal College of Psychiatrists,<sup>34</sup> the number of people being assessed by memory clinics has risen four-fold since 2010/11, with just under half of the people diagnosed with dementia over the last 12 months being in the early stages of the condition. This is encouraging. However, in some parts of the country people are waiting too long before being seen by memory services. For example, the audit reported an average time period of 5.2 weeks from the point of referral to assessment by a memory clinic and an additional 8.4 weeks from that point to receiving the diagnosis.



## Waiting times in England for a diagnosis of dementia following assessment by a memory clinic



## Progress

### Timely diagnosis

NHS England has set the first ever national goal to improve dementia diagnosis rates. The goal is that by March 2015, two thirds of the estimated number of people with dementia should receive a formal diagnosis, with appropriate support, for example being given information about locally available services.

Local NHS bodies – Clinical Commissioning Groups (CCGs) – are working with their local councils and other partners to better understand how widespread dementia is in their communities, including among people living in local care homes. This will mean they can identify and support people with dementia in a timely way.

“My mother Pauline was diagnosed with Alzheimer’s disease in 2006. Her practicality and creative spirit helped her deal with this traumatic news. Afterwards, Mum told other people about it, so sharing this information was clearly important. We were advised to establish Power of Attorney and arrange Mum’s Will and legal affairs while she still had capacity to make decisions.

“Since her partner’s death four years ago, Mum has remained at home with live-in carers. Her speech has changed, words slip, and she confuses people, places and time easily. The carers provide the physical care and support Mum needs, while helping her maintain her independence where possible. A family friend keeps an eye on things, and I visit regularly. She has a weekly timetable of events to provide stimulation and activity, including an Alzheimer’s Society art group and a choir, organised by Dementia Compass.

“Early diagnosis helped my mum to make the right legal arrangements and to establish a system of care, which gradually evolved along with her needs. The care package has enabled her to stay in her own home. Her GP has provided great support throughout. Did early diagnosis help us access services earlier? Yes. Financial arrangements to provide care for someone in their home are complicated and it takes perseverance to understand what is needed, and what is available.”

The Prime Minister’s challenge on dementia – delivering major improvements in dementia care and research by 2015: [A report on progress, November 2012](#)

The South Manchester Memory Service is based on the Gnosall model where a memory specialist spends a session in a local GP practice in South Manchester. The initiative has been very well received by patients and their families and has facilitated the early referral and diagnosis of people with dementia who otherwise would not have been seen. Referrals can be more easily directed toward the appropriate specialist within the memory service and the diagnosis can be made in primary care. In addition, by examining carefully the coding of memory problems, the numbers of patients with a diagnosis of dementia can be increased.

On the Isle of Wight, a single dementia care pathway offers a fully holistic model of care focused on high quality post-diagnostic support. All patients are offered an assessment and care plan, named coordinator and individual or group education sessions to help understand the disease, symptoms, treatment and to learn more about the financial, legal and other support services available. Short and long term cognitive stimulation therapy is available and people are encouraged to join community and voluntary led groups and access e-learning modules. The island has four thriving dementia cafés.

Overseen by the ‘Dementia Challenge Steering Group’ the team has seen diagnosis rates improve by almost 10 percent since the pathway was introduced.

In Dudley, the development of a dementia gateway including a multidisciplinary care pathway aims to improve early diagnosis, integrate health and social care, and to keep people independent for as long as possible.

People living with dementia are initially assessed by dementia nurses (with specialist support). They are offered activities and interventions designed to maintain and develop their abilities and reduce:

- unplanned admissions and re-admissions
- antipsychotic medication use in residential settings
- discharges directly to care homes as new residences.

These activities aim to increase positive patient and carer experiences. A community enablement team offers advice and help to support the continuance of hobbies and interests. The service also provides short and long term respite for carers.

### Supporting people to recognise the signs and symptoms of dementia

At the end of 2012, a nationwide campaign raised dementia awareness by encouraging people to visit their doctor if they were worried or if they wanted more information, to visit [NHS Choices](#). The campaign reached over 27 million people. Three-quarters of people asked agreed the campaign would help people with dementia and their families.

### Supporting GPs to identify people with dementia

Some doctors do not diagnose dementia in their patients because they feel that “nothing can be done” to help them. This is not right in our view. Every person with dementia has the right to be diagnosed and to be offered the relevant information and help, regardless of the severity of their condition. GPs play a vital role in not only timely diagnosis of dementia but also in ensuring that well-planned and co-ordinated community services are in place to help the person once they have been diagnosed.

From 2013/14, GPs will be able to use a contract called an enhanced service to improve the diagnosis of dementia by asking people in certain at risk groups about their memory, for example, those with cardiovascular risk factors, people with long term neurological conditions and people with learning disabilities.<sup>35</sup> This pro-active approach should help to identify patients who are showing the early signs of dementia.

Penny cares for her husband David who was diagnosed with dementia in his late 50s. His problems first showed up at work where issues were raised about performance but they soon became apparent at home too. David saw his GP who referred him for an MRI scan and an appointment with a psychiatrist (who carried out the Addenbrooke's Cognitive Examination).

David was diagnosed with Pick's disease and prescribed Aricept. Initially, this appeared to help but the side-effects were a problem. In addition, David was being treated for stomach ulcers and the interaction of the medicines caused problems. After two years of taking a number of medicines, David's GP did a full review and suggested they should stop them all and then gradually build them up again, as needed.

Penny explained that David had a really good relationship with his GP and this made a huge difference, not just in relation to the diagnosis and medication, but also in getting access to other services (for example, regular community psychiatric nurse support) and making difficult decisions such as persuading David to give up driving.

A road less rocky – supporting carers of people with dementia, Carers Trust

## Call to action

We call for support from CCGs and local authorities, working with their partners and local communities, to fulfil the ambition that two thirds of people with dementia have a diagnosis and access to appropriate post-diagnosis support by 2015.

The benefits of a timely, high quality diagnosis of dementia for the person, their families and carers are compelling. Diagnosis is not an end in itself, but a gateway to making informed personal life choices. It should provide access to a full range of treatment, including medical and psycho-social interventions, and importantly, post-diagnosis support and services.

While there are many examples of excellent practice, there is regional variation across England. People with dementia, their families and carers, wherever they live, have the right to information that supports a timely diagnosis, enabling them to receive the best possible treatment, support and care.

We wish to create a culture in society where anyone who thinks they may have dementia can speak openly about it, facilitating access to a diagnosis and appropriate post-diagnosis support. We aspire to have the best dementia care in Europe.

<sup>35</sup> [Facilitating timely diagnosis and support for people with dementia, NHS England, 2013](#)

# Living with dementia

## Support after diagnosis

Once someone has received a diagnosis of dementia there will be a range of different types of support they and their families will need. If the condition is already advanced, some will be in need of health and care support straight away, while others may not have reached that point yet. However, everyone will need support, advice and help to understand what it means to have dementia, what they can do to live as well as possible with the condition and to enable them to plan for the future.

Examples of post-diagnosis help and support include:

- information about available services and sources of support
- a dementia adviser to facilitate easy access to appropriate care and advice
- peer support, such as befriending services, to provide practical and emotional support, reduce isolation and promote self-care.

Helping communities to become dementia-friendly – as discussed later in this report – is an important part of what we as a society can do to help support people after they have been diagnosed with dementia.

**‘The group I go to...it’s made my life a lot more simple. It’s put dementia on the map.’<sup>36</sup>**

The availability of diagnostic processes, treatment, care and support varies significantly across the country. Indeed, many people said they felt nothing happened after a diagnosis. This shows more immediate support and information is needed.<sup>37</sup>

**‘Information about the condition and what to expect all the way through – a roadmap of sorts – would have been helpful in making the right decisions about my husband’s care. Instead, I have muddled through and provided his care by instinct rather than informed help. [This] has caused a great deal of stress on me and inevitably on him.’<sup>38</sup>**

**‘We needed a ‘what now’ pack of essential information.’<sup>39</sup>**

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<sup>36</sup> A road less rocky – supporting carers of people with dementia, Carers Trust, 2013

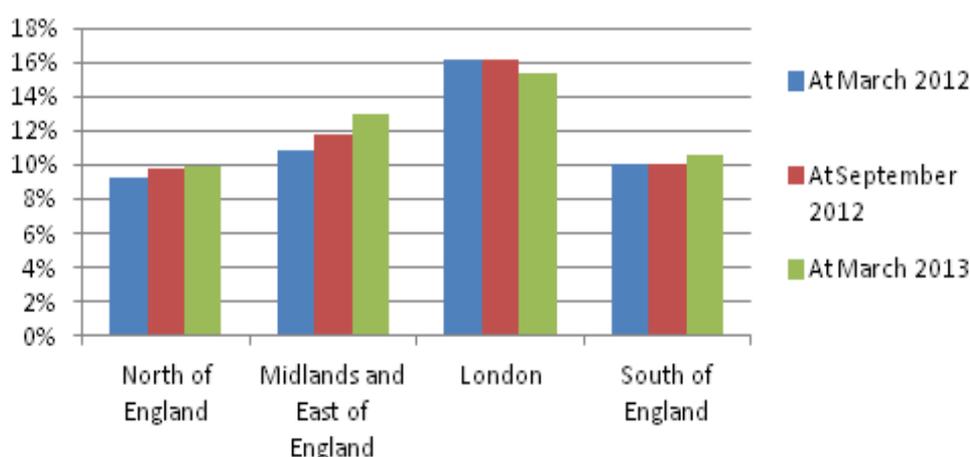
<sup>37</sup> Unlocking diagnosis: the key to improving the lives of people with dementia. All-Party Parliamentary Group on Dementia report 2012, [Brainwaves Newsletter, October 2013](#), [Innovations in Dementia](#)

<sup>38</sup> A road less rocky – supporting carers of people with dementia, Carers Trust, 2013

<sup>39</sup> A road less rocky – supporting carers of people with dementia, Carers Trust, 2013

In 2011/12, 79 percent of dementia patients had their care reviewed over the last 15 months. Further analysis of GP Patient Survey data<sup>40</sup> found an increase in the proportion of those with dementia who felt they had not had sufficient support from local services and organisations in managing their dementia (an increase of 7 percent between March 2012 and March 2013).

The diagram below illustrates the percentage of patients with dementia who felt they did not have sufficient support from local services/organisations.



## Progress

By 2015, we want two thirds of people with dementia to have been diagnosed and receiving appropriate post-diagnosis support.

An implementation plan is being developed by Public Health England, NHS England, the Association of Directors of Adult Social Services (ADASS), the Local Government Association (LGA), NHS Improving Quality, NHS Choices and other partners to support areas to improve post-diagnosis support. This work aims to make clear 'what good looks like' in terms of post-diagnosis care and improve our understanding of the level of care currently available. It will also seek to understand the support local commissioners need, and enable clearer expectations for patients and carers.

There is currently no national measure of the provision of post-diagnosis support. Therefore, to track progress, work is underway to develop an indicator as part of the NHS outcomes framework which will aim to measure the effectiveness of post-diagnosis support in helping people with dementia to live independently for longer and improve their quality of life.

<sup>40</sup> The GP Patient Survey is a postal survey; therefore patients with dementia who completed the questionnaire are unlikely to be representative of the whole dementia population. In the 2013 survey, only 0.5 percent of respondents (5851 patients) responded to the question regarding sufficient support managing their dementia.

Over the past two years, the Tower Hamlets Partnership, a coalition including users and carers, health and social care, the voluntary sector, commissioners and providers, has been reaping the benefits of an entirely integrated health and social care dementia pathway. The pathway design was the result of working together to provide better and more inclusive services.

Within a year, referrals to the memory service doubled, with a particular proportionate increase in the black and minority ethnic community. In 2012, the diagnosis rate increased by 9.6 percent to 50 percent. A reduction of 11,000 assessment bed days has enabled a reduction of inpatient beds from 44 to 21.

In Norfolk, a formal diagnosis of dementia is given by their memory service (at a location of the patient's choice) which is provided by the mental health trust. Following diagnosis, the memory service offers all patients an introductory programme of cognitive stimulation therapy.

Norfolk has commissioned an Information, Advice and Advocacy Service (IAA) specifically for people with dementia and their carers. The service is provided jointly by Age UK and the Alzheimer's Society and deals with the more specialist areas of the service. The memory service provides referrals into the IAA elements of the pathway.

The basic level of support is provided through a dementia helpline. A new website to help guide people to services and support is also in development. However, most people want someone to talk to in person (face-to-face) to get their advice, so Norfolk has jointly commissioned with social care partners, a Dementia Advisor service. This is now in its third year of operation and is provided by the Alzheimer's Society.

On initial contact with the Alzheimer's Society team, people are assessed as to their suitability for the Dementia Advisor Service. Those with a later stage diagnosis, in need of more hands-on support, may be directed to the Dementia Support Worker Service.

Norfolk is now developing an expanded network of community dementia hubs across the region. They are working in a new partnership of third sector and social care providers that will see some independent sector facilities made available to the general public. This includes a dementia café manned by volunteers from across the third sector working as a dementia partnership. These hubs will form the nucleus of a developing network of local dementia friendly communities, with the aim of delivering a dementia friendly county.

## Call to action

We call for support from CCGs and local authorities to achieve the ambition that at least two-thirds of people diagnosed with dementia and their carers are supported after diagnosis to exercise choice and control over their lives and are helped to manage the condition so they can live independently for longer.

## Carers

When someone is diagnosed with dementia, it has a profound impact, not just on them but also their family and others in their life. As a person's needs increase, family carers can become the most important source of support for them. It is vital those carers are supported throughout their journey.

There are around 550,000 people in England acting as the primary carers for people with dementia. Carers for people with dementia save the nation nearly £7 billion every year.<sup>41</sup>

Given the nature of dementia, and the effect it can have, such as changing a person's personality, carers can experience distress over many years of caring.<sup>42</sup> They can care for over 10–15 years, with the person with dementia needing a great deal of physical and emotional support 24/7 from the carer, often with little outside help.

Most family carers want to be able to support the person they are caring for at home, but they sometimes need more assistance in terms of information and advice on caring for someone with dementia while also looking after their own health.<sup>43</sup>

**'I needed one person from the beginning who understood what I was going through and how I could deal with it all. To be referred to as the carer when my life had suddenly been torn up, was being shattered, and I didn't feel any security in any role that I was doing, couldn't make any sense of what was going on – this was the hardest thing to cope with. Someone to help me steer through all those sickening peaks and troughs would have been invaluable.'**<sup>44</sup>

In spring 2013, a survey of carers of people with dementia<sup>45</sup> found that:

- over half (52 percent) of the carers reported difficulties in obtaining a diagnosis of dementia for the person they cared for.
- less than half said they had not been given information on legal issues and managing money. Many had learned about Lasting Power of Attorney too late.

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<sup>41</sup> PM's challenge on dementia, March 2012

<sup>42</sup> Moise, Schwarzinger and Um, 2004

<sup>43</sup> Difficult conversations, National Council for Palliative Care and Dying Matters Coalition, 2011

<sup>44</sup> A road less rocky – supporting carers of people with dementia, Carers Trust, 2013

<sup>45</sup> A road less rocky – supporting carers of people with dementia, Carers Trust, 2013

- many carers, particularly those caring for someone in the later stages of the illness, felt ill equipped to deal with more agitated behaviours that might develop. More than two thirds (68 percent) said they had not received training or advice on this issue
- 82 percent of carers said that caring had adversely affected their ability to work

The survey also asked carers if, during the process of getting a diagnosis, they felt their concerns had fully been taken in to account. Only 21 percent of respondents felt they had.

## Progress

The Personal Social Services Survey of Adult Carers in England is a biennial survey, undertaken by councils, which took place in its current format for the first time in 2012-13. 57,860 people out of a sample of 126,755 carers of social care users, including carers of people with dementia, responded to the survey, a response rate of 46 percent.

The survey found that carers of people with dementia are most likely to have had some sort of interaction with support, services and information resources, and that carers were more able to take a break from caring at short notice or in an emergency, where the person they cared for had dementia, a learning disability or difficulty, or a terminal illness.

The average score for carer related quality of life was 8.1 out of a maximum possible score of 12. The equivalent score for a carer of a person with dementia is 7.8.<sup>46</sup> This is a composite measure, calculated using a number of questions, which cover six different outcome domains relating to quality of life.

## Call to action

Supporting carers must become an integral part of the care and support package for people with dementia. When carers are well supported, they can provide better care for the person with dementia, leading to better outcomes for all.

The Dementia Action Alliance launched a 'Carers Call to Action' on 20 November 2013 setting out goals to bring about real change for carers. It calls for a society where carers of people with dementia:

- have recognition of the unique experience of caring for someone with dementia
- are recognised as essential partners in care – valuing their knowledge and the support they provide to enable the person with dementia to live well
- have access to expertise in dementia care for personalised information, advice, support and co-ordination of care for the person with dementia

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<sup>46</sup> Even after controlling for the different age and gender structure of carers of people with dementia compared to all carers, their average quality of life score was less (8). The difference is statistically significant at a 99 percent level.

- have assessments and support to identify the on-going and changing needs to maintain their own health and wellbeing
- have confidence they are able to access good quality care, support and respite services that are flexible, culturally appropriate, timely and provided by skilled staff for both the carers and the person for whom they care.

We ask for support from the NHS, social care, voluntary and independent sector organisations to help achieve these goals so we can improve the way people with dementia and family carers are treated and thereby enhance the quality of their lives.

## Care at home

In order to provide better care for people, we need to tailor services to the needs of people with dementia, including training staff to have a better awareness and understanding of the condition. It would mean people with dementia can stay at home for longer, avoid crisis situations such as hospital admissions and, if they do need to go to hospital, only stay as long as they need to and have a better overall experience.

Two thirds of people with dementia live in the community, one third of whom live on their own, often relying on support from home care agencies.<sup>47</sup> Alzheimer's Society's 'Support, Stay, Save' report found 83 percent of people with dementia want to stay in their own home. However, at present, too often people are unable to do so and end up in crisis, necessitating moves into care and avoidable admissions to hospital. 'Support, Stay, Save' found that one in ten respondents said the person with dementia was admitted early into care because of lack of support in the community and a similar number said the person ended up going into hospital unnecessarily because of lack of access to community support.<sup>48</sup>

The homecare sector is often the first to care for people who are showing signs of cognitive impairment, many of whom have not been diagnosed. Homecare workers can help prompt timely diagnosis and treatment, accompany people to hospital appointments and act as a valuable liaison with healthcare professionals. They can also facilitate hospital discharge by providing a viable alternative to a move into residential care.

In a recent survey, conducted by the Guardian Social Care Network on behalf of the Department of Health on attitudes to homecare, which covered all homecare and not just homecare for people with dementia, the top three most important factors in offering good homecare were: sufficient time for care (59 percent), friendly, respectful, capable care workers (58 percent) and choice about services (43 percent). This feedback is echoed in other surveys.<sup>49</sup>

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<sup>47</sup> Alzheimer's Society (2011), Support, Stay, Save, Alzheimer's Society, London

<sup>48</sup> Alzheimer's Society (2011), Support, Stay, Save, Alzheimer's Society, London

<sup>49</sup> [UKHCA Care is not a commodity, report](#)

Some 44 percent of homecare providers said they did not think councils worked well with others to arrange good quality homecare. With approximately 72 percent of homecare in England commissioned by councils,<sup>50</sup> this is clearly an area for improvement.

46 percent of people reported a positive experience with individual care staff, compared with 15 percent who said their experience was negative. But 39 percent said their experience of local councils assessing their needs and arranging care was poor or very poor, compared with just 17 percent who thought it was good or very good.

56 percent of people said it was quite or very difficult to change care provider or care worker if they were not happy with their care.

Overall, two thirds said it was quite difficult or very difficult to choose how homecare services are delivered, for example, time of visits, who visits and what care workers do during a visit. When broken down by those who are involved in homecare, friends and family, councils, care workers and care providers all agreed giving meaningful choice to people with care needs is very difficult to do.

Alzheimer's Society's 'Support, Stay, Save' report found that, of the 535 respondents who said the person with dementia received home care help with personal care tasks, 71 percent rated it satisfactory or very satisfactory and 26 percent rated it as unsatisfactory or very unsatisfactory.<sup>51</sup>

## Progress

There are examples of local innovation from commissioners, providers and others focussing on remodelling services, improving pay and conditions, using new technology and ensuring staff have an appropriate understanding of dementia. The Homecare Innovation Challenge was launched this year with the aim of sharing this innovation and good practice and to improve its adoption more widely. The following are examples:

[Homeinstead](#) have rolled out a dementia training programme to their staff. This programme has reached 1000 staff and has external accreditation. It is not focussed on making individuals experts, but about giving them the necessary skills and understanding to deliver good dementia care. They are now providing an abridged version of this training for family members to provide them with the skills and understanding to support their loved ones.

Alzheimer's Society homecare and dementia roundtable, 26 September 2013

<sup>50</sup> Information Centre for Health and Social Care Community Care Statistics, PSS-EX1 return Relevance (Figure also based on only figures available for private market, from Laing & Buisson report in 2009)

<sup>51</sup> Alzheimer's Society (2011), Support, Stay, Save, Alzheimer's Society, London

James has worked with the [Good Care Group](#) since mid-2012 and worked for two weeks with a gentleman called Doug, who is living with dementia.

James understands that people with dementia rely heavily on past memories, so reminiscing can be a very positive and healthy activity. James noted that Doug often seemed 'lost' during the day and struggled to maintain conversations about things that were happening here and now. James found a drawer full of old photographs and discovered that when he brought these out, Doug was able to talk animatedly about some of the people or places in the pictures.

James spoke to Doug's family, who were able to fill in even more of the blanks, naming people and places that were captured in the photographs, and prompting Doug's memory of these treasured past events.

James bought a photograph album, and spent an hour each evening with Doug, gluing the photographs in place and giving them labels which were meaningful to Doug. James found that Doug had particular favourites which seemed to spark 'glory stories' about the 'good old days'.

James put gold star stickers next to these very special photographs, so that other carers or family members could guide Doug to them and elicit these wonderful stories which made him come back to life.

UK home care Association members, The Good Care Group

## Call to action

The homecare survey highlights that the things people value most are really basic – respect, time and control. We call for:

- Commissioners to build their service specifications from the perspective of what each person values most, spending limited resources on making sure those priorities are protected first.
- People being given more control over how they spend the resources allocated to their care so that they can access the services they value most.
- More homecare providers giving a higher level of training to staff, having in place well developed specialist training in dementia care and enhancing the status of workers so that homecare is a career to aspire to and be proud of.

## Care in hospitals

Wherever possible, we want to avoid people with dementia having to go in to hospital. And when people are admitted, we want them to receive high-quality compassionate care.

A quarter of all hospital beds are occupied by someone with dementia and people with dementia stay longer in hospital. Some hospitals struggle to provide the high quality care needed by people with this condition.

In a 2012/13 review,<sup>52</sup> the Care Quality Commission (CQC) found in almost a quarter of hospital admissions there was no record of the person's dementia. The review also confirmed that people with dementia have longer stays in hospital, more re-admissions and higher mortality rates than similar people without the condition.

In July 2013, the Royal College of Psychiatrists<sup>53</sup> reported some progress and found that dementia champions are now in place in most hospitals, and that more hospitals have begun to collect personal information about people with dementia to help improve their care than in previous audits. More people with dementia are now having their essential health needs assessed and dementia care features more prominently in hospital training strategies.

However, there is still room for improvement. For example, too few patients are being assessed for delirium risk and for cognitive function, and may therefore fail to receive vital care. Despite more systematic collection of personal information about patients' needs, preferences and communication requirements, this is often not recorded in the patient notes, so staff remain unaware of how best to care for the individual. Half the hospitals participating in the audit did not have a system in place to ensure ward staff are aware that a person has dementia. Furthermore, only 41 percent hospitals said they provided training to new and support staff.<sup>54</sup>

Discharge plans often fail to record important details about on-going health needs. The audit found that only 36 percent of hospitals had a fully developed care pathway in place, but many others had pathways in development. The audit report recommended hospitals address this urgently. In terms of dementia awareness, the audit found there remains a huge need for better staff training and support in order to provide comprehensive, safe and dignified dementia care.

## Progress

### Dementia friendly hospitals

Since October 2012, 143 acute trusts and 24 non-acute trusts have committed to becoming dementia friendly, working in partnership with their local Dementia Action Alliance. This work is aimed at positively changing the way in which people with dementia experience care, change the outcomes of care and change the way local communities view caring for people with dementia.

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<sup>52</sup> CQC State of Care 2012/13 Technical Annex 3, November 2013

<sup>53</sup> National audit of dementia care in general hospitals, 2012-13

<sup>54</sup> National audit of dementia care in general hospitals, 2012-13

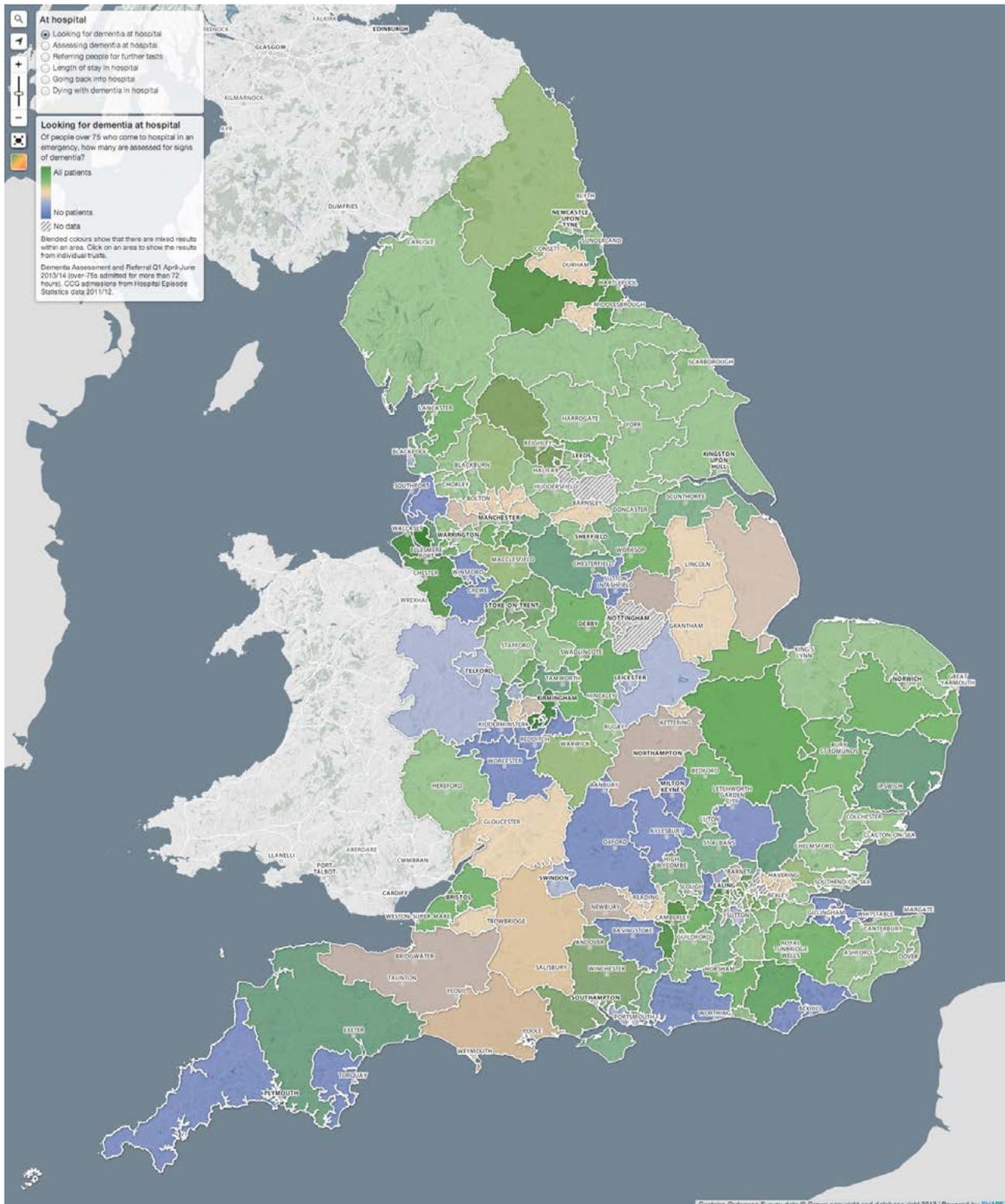
### Detecting and diagnosing dementia in hospital settings

Given the high number of people with dementia who are admitted to hospital, hospitals provide a real opportunity to detect and diagnose dementia and to therefore improve the overall quality of care people receive.

The Dementia Commissioning for Quality and Innovation (CQUIN) payment is a financial incentive in acute hospitals, which was introduced in April 2012. It is for all patients over the age of 75 admitted to hospital for more than three days and involves finding people who may have dementia, assessing their risk and referring them for further investigations. As part of the CQUIN for 2013/14, hospitals must confirm they have a named lead clinician for dementia and an appropriate staff training programme. They must also undertake a monthly audit of carers of people with dementia, including how supported carers feel and the findings must be reported to the Trust Board at least twice per year.

In the first quarter of 2013,<sup>55</sup> 71 percent of admitted patients were initially assessed for potential dementia. Of those assessed and found as potentially having dementia, 86 percent were further assessed. And of those diagnosed as potentially having dementia, 87 percent were referred on to specialist services. 59 trusts achieved 90 percent in all three measures of the CQUIN.

## Proportion of people investigated for dementia in hospitals in England



We use a computerised system to achieve and monitor the 90 percent target. Training and support is required to ensure that there is a process that works across the hospital, including surgical wards. We don't want this to be a tick box exercise and the CQUIN is part of a major programme of improvements in care for people with dementia, including coordinators, a seven day a week mental health liaison service and a clear care pathway (see figure).

Patients with prior cognitive impairment or dementia have up to a 50 fold increased risk of delirium and worse outcomes in hospital – and if we identify those at risk we know that we can substantially reduce rates of delirium. Prior to the CQUIN, patients were identified more haphazardly. Currently, for those eligible for the CQUIN question on admission to us, just under 20 percent already had dementia, 5 percent were recognised to be delirious, and 4 percent were positive for the dementia question. This equates to an extra 300 patients per year or one per GP for our area. Unfortunately, we have seen several cases of rather late stage diagnosis, but the CQUIN has certainly led to better informed patients and families.

Chris Dyer, Consultant Geriatrician, Royal United Hospital Bath NHS Trust

### Improving the care environment

Adapting hospitals and care home environments to make them dementia friendly can help people live well with their condition for longer. Currently, 116 projects are underway across health and care organisations in England, supported by a share of £50 million funding from the Department of Health. These projects are expanding the range of dementia friendly environments. The lessons learned will help the growing number of people with dementia get the best possible care.

The Royal United Hospital Bath received £500,000 in funding from the Department of Health as part of the Dementia Friendly Environments Capital Programme. The Combe Ward was converted into a unique holistic environment for dementia patients.

The dementia ward in the RUH aims to help people feel more at home and includes domestic-feel furniture, wood-effect flooring, a fireplace, living area, natural artwork and even the sound of running water, birdsong and a garden shed in the courtyard.

The use of clear signage, sensitive lighting and a clock which not only tells the time but what day it is, are set to help patients with dementia feel calmer and safer.

“It has made an incredible difference to the ward ambience and a very busy ward now seems very calm. The nursing pod in each bay has massively improved observation of patients eradicating the main nurse station.” (Chris Dyer)

## Call to action

We would like to see all hospitals commit to being dementia friendly so that greater improvements can be made in the:

- environment in which care is given
- knowledge, skills and attitudes of the workforce
- ability to identify and assess cognitive impairment
- ability to support people with dementia to be discharged back home
- use of a person centered care plan which involves families and carers.

Making improvements in these areas has the potential to reduce readmission rates, prevent falls across the country, and reduce the mortality rate of people with dementia in acute care, as well as improving the sense of pride and wellbeing in staff who care for people with dementia in acute hospitals.

## Care in care homes

About one third of people with dementia live in residential care, while about two thirds of people who live in care homes are thought to have dementia.

While many care homes offer excellent support, some are not doing enough to provide high quality, personalised care that helps individuals to live as fulfilling a life as possible. Alzheimer's Society's 'Low expectations' report on care in care homes found that, while 74 percent respondents would recommend their loved ones' homes to others, only 41 percent said the quality of life of the person with dementia was good.

Research in 2012/13 by the Care Quality Commission (CQC) found that people with dementia living at a care home are more likely to go into hospital with avoidable conditions (such as urinary infections, dehydration and pressure sores) than similar people without dementia. Once in hospital, people with dementia (not just those admitted from a care home) are more likely to stay there longer, be readmitted and die there. It also found the number of multiple emergency admissions to hospital of people with dementia living in at a care home was 10 percent higher for those with dementia than similar patients without dementia.

## Progress

The Dementia Care and Support Compact was launched in March 2012 to encourage care homes and providers to improve the quality of dementia care. To date, 165 organisations have signed the compact representing nearly 3,000 services.

**'We received excellent advice from a very skilled music therapist who helped us to explore ways of communicating with my dad when he was very distressed and anxious.'**<sup>56</sup>

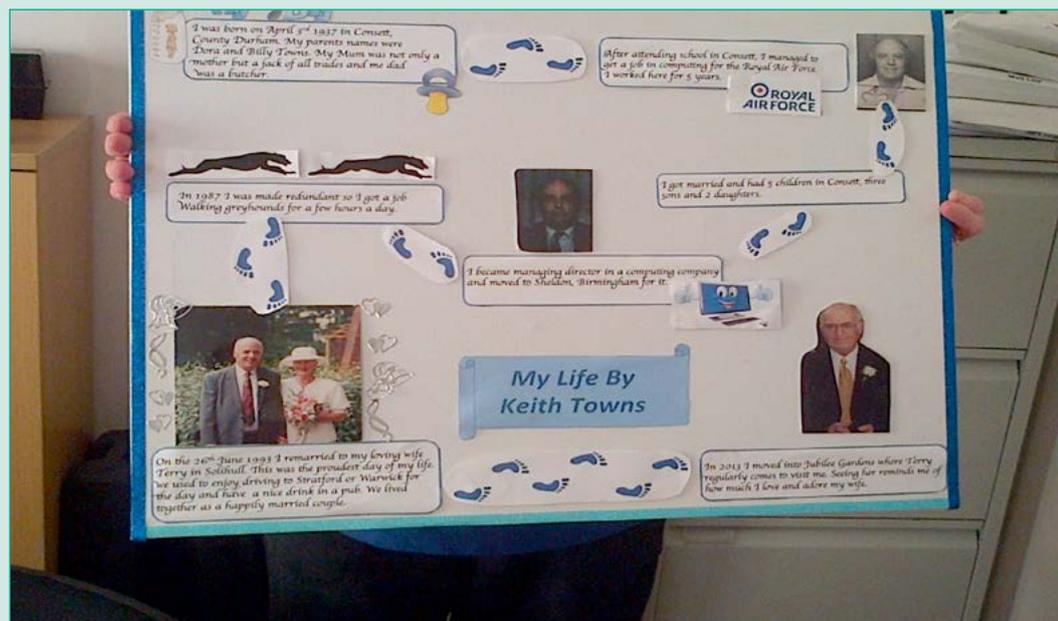
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<sup>56</sup> A road less rocky – supporting carers of people with dementia, Carers Trust, 2013

At Amore Care, our creative minds approach, through small changes, is having a big impact. For example, one of our handymen now pushes the wheelchair of a resident who pushes the lawn mower to cut the lawn. During one of our intergenerational art classes, we show a clip of an American man with dementia using an Ipad and listening to his favourite music. The music made him sit up tall and eventually he was able to sing his favourite song.

Staff from one of our homes who saw this recognised a male resident who might benefit from a similar approach. He now uses an Ipad regularly to listen to his favourite songs.

Another example is Life Stories, where we bring information about the person to life.



We are delivering to all our teams, a learning and development programme which supports them to change the way they deliver care and enables our residents to have a better life. Through our dementia lead and their team of regional coaches and care home based coordinators we are supporting our staff to translate that learning into practice.

Amore Care

## Call to action

We want more care providers to sign the compact and take tangible action to improve the experience and care of people with dementia and their families. For example, engaging and involving the wider community to improve their support for people with dementia, including GPs and healthcare professionals.

## Reducing the inappropriate prescribing of antipsychotic medication

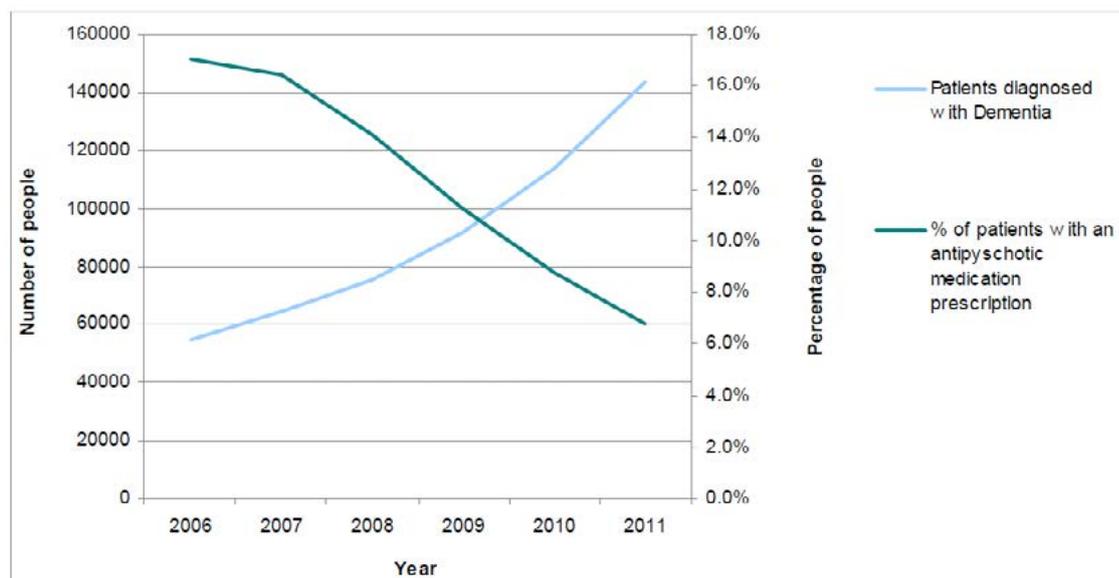
Antipsychotic drugs should only be prescribed to people with dementia in exceptional circumstances and if prescribed, the person should be reviewed on a regular basis.

### Progress

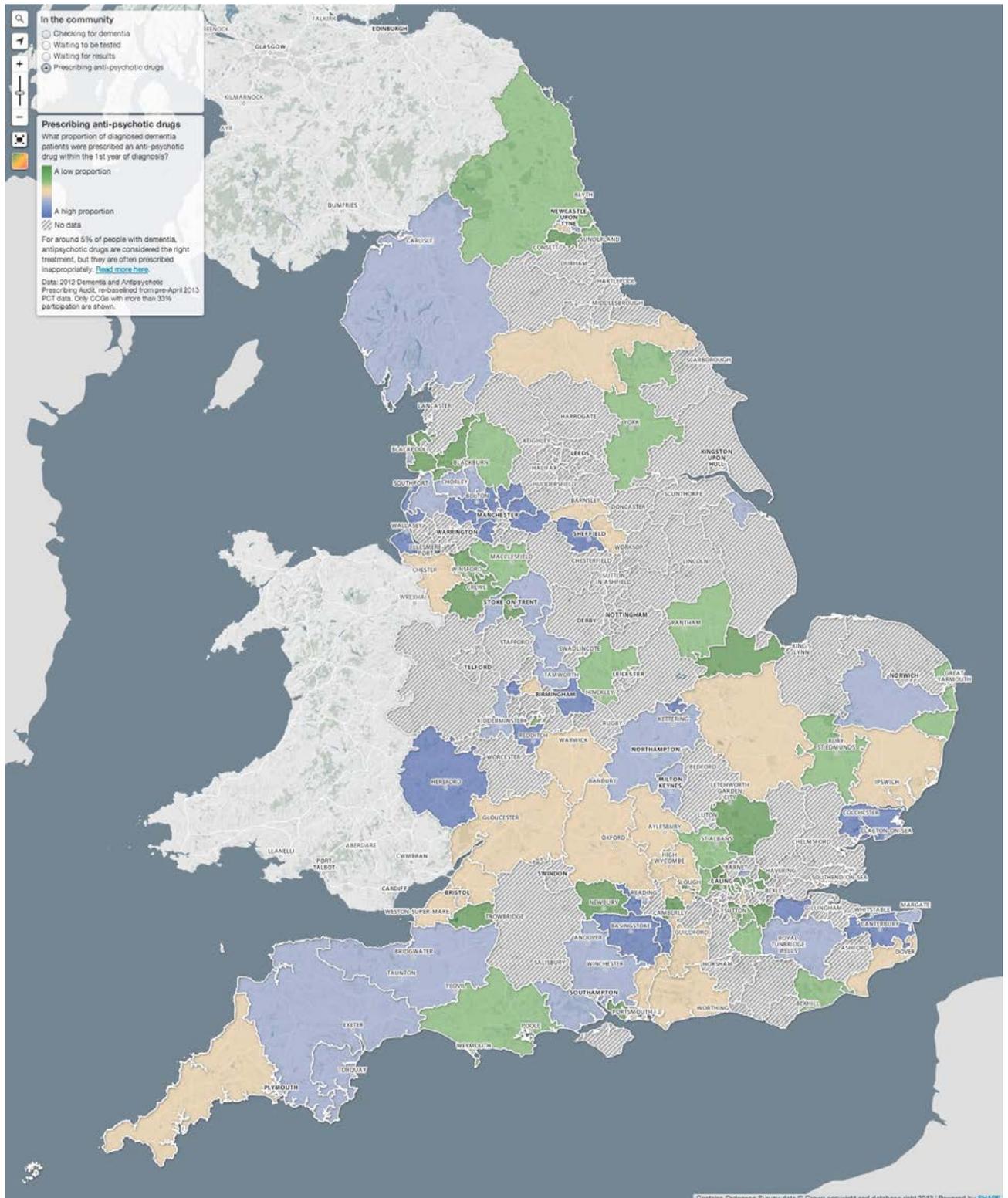
To support progress on reducing antipsychotics use, the NHS Institute for Innovation and Improvement and the Dementia Action Alliance led a call to action on reducing antipsychotics. This brought together care home managers, GPs, pharmacists, hospital doctors and others to spread good practice.

In July 2012, the National Dementia and Antipsychotic Prescribing Audit<sup>57</sup> of 3,850 GP practices, covering 196,695 people with a diagnosis of dementia, reported a 52 per cent reduction in the prescribing of antipsychotic medication for people with dementia between 2006 and 2011.

**Chart 4: Number of people with dementia and the percentage of those receiving an antipsychotic medication prescription, time trend, England**



## Prescribing of antipsychotic medication for people with dementia in England



Four Seasons Health Care homes have piloted a model of specialised dementia care called PEARL (Positively Enriching and Enhancing Residents Lives), which includes resident experience training. On average, antipsychotic use has fallen by 48 percent in the 16 homes involved in the study, with the highest reduction being 84 percent in one home. Wellbeing has increased among residents by 26 percent; depression reduced in 30 percent of residents and falls reduced by 32 percent on average.

A two day, person centred course for staff provides an understanding of the needs of people with dementia and how symptoms might affect them. It looks at communication, signs of wellbeing and how we can reduce the negative impact the care home might have on people by the things staff say or do. The PEARL programme re-defines 'challenging behaviour' as 'distress reaction' – a response to a distressing situation, such as pain or fear. People with dementia often find it hard to communicate and resort to shouting or aggression. Staff are trained to recognise body language and verbal and non-verbal cues to establish the resident's needs.

Home design has also played a big part in the PEARL programme. Corridors are painted in different colours and have different themes to give residents two cues to remember where rooms are, including their bedroom.

Four Seasons has 180 homes for people with dementia and each year about 50 go through PEARL training. The process takes up to a year and homes have to be validated before calling themselves a PEARL specialised dementia services. In April 2010, 25 were validated and now the programme includes 100 care homes.

Four Seasons Healthcare

**'My husband had been in bed for 16 months. In a matter of weeks at the home he was up and about. On the next visit we sat in the lounge having breakfast together and he is much more aware and alert. The only medication he is on now is blood pressure tablets. It's remarkable.'**<sup>58</sup>

## Call to action

While the National Dementia and Antipsychotic Prescribing Audit reported a reduction in the prescribing of antipsychotic medication nationally, overprescribing is still a problem with wide regional variation. NHS and social care organisations are working together with their partners to reduce inappropriate prescribing for people with dementia. We want to reduce the use of antipsychotic medication by two thirds.

The Department of Health is re-running the national audit to monitor the level of prescribing and regional variation. The audit results are expected to be available in spring 2014.

<sup>58</sup> PEARL specialised dementia service: Phase 2 report, Four Seasons Healthcare

## End of life care

Early conversations with people with dementia are important so that people can plan ahead for their future care, including palliative and end of life care.

One in three people over the age of 65 will die with dementia.<sup>59</sup> Dementia is now one of the top five underlying causes of death. Dementia is the second leading underlying cause of death for women and the fifth for men, identified on one in 10 and one in 20 death certificates respectively.<sup>60</sup>

We know that too many people with dementia are not supported to have early discussions and make plans for their end of life care.<sup>61</sup> This means difficult, emotional decisions are often made in crisis and the wishes of the person with dementia, including for example where they want to die, cannot be taken into account.

**‘No-one discussed end of life until he was in the first care home and we had a meeting with the manager about various issues I had, and it was raised out of the blue at the end of the meeting. With five minutes to go to the end of the meeting it was raised as an “oh, by the way”. I was sat there thinking “Excuse me? What is this all about?” It was very, very badly handled, sort of thrown in as an afterthought and it took me by surprise. It was something which hadn’t really crossed my mind until they threw it in at the end of the meeting and I thought “my goodness, this is not the way to handle relatives.” (Daughter of a person with dementia)<sup>62</sup>**

**‘How people die remains in the memory of those who live on.’<sup>63</sup>**

Findings from a national survey of bereaved people, of which one fifth of the responses were related to dementia, found that one in 10 responses relating to dementia rated their end of life care in the last three months of life as ‘poor’. Less than half (46 percent) of bereaved relatives of people with dementia rated the overall quality of care received by the deceased person across all settings as outstanding or excellent. It also highlighted marked variation in different areas of the country and gives us something clear to aim for in terms of improving dementia services.<sup>64</sup>

<sup>59</sup> Brayne C et al, Dementia before death in ageing societies – the promise of prevention and the reality, PLoS Med 2006;3; 10

<sup>60</sup> [Office of National Statistics; 2012; Deaths registered in England and Wales 2011 Accessed 14 November 2013.](#)

<sup>61</sup> Difficult conversations, National Council for Palliative Care and the Dying Matters Coalition, 2011

<sup>62</sup> Alzheimer’s Society (2012) My life until the end: dying well with dementia

<sup>63</sup> First national VOICES survey of bereaved people: key findings report, July 2012

<sup>64</sup> First national VOICES survey of bereaved people: key findings report, July 2012

## Progress

There are examples of best practice around the country, but more needs to be done to ensure all areas offer high quality end of life care for people with dementia.

The St Christopher's Hospice Namaste research project, with six local nursing homes, is the first of its kind in the UK. It explores ways in which quality of life for people with end stage dementia can be significantly improved. Namaste, an Indian term which means 'to honour the spirit within', is a programme pioneered in the USA and designed to create a peaceful end to life by reducing anxiety and agitation through calming yet meaningful activity, comfort and pleasure. It uses simple techniques that can be delivered in nursing care homes, both by staff and family members. When people with advanced dementia enter the programme, a family conference is held to discuss disease progression and peaceful end of life care, as well as how the programme can help their relatives. The technique involves creating a Namaste room where the five senses are gently stimulated through soft music or birdsong, colour from paintings or voile curtains, pleasurable aromas, interesting tastes, and touch through hand or head massages. Residents spend all day (in between meals and care routines) in comfortable chairs in the Namaste room, where they are helped to interact with their surroundings. Staff build a 'biography' of the sensory things that are most meaningful for each resident.

Difficult conversations, National Council for Palliative Care and the Dying Matters Coalition, 2011

## Call to action

Every person with dementia should receive excellent care at the end of their life and be treated with dignity and respect. We want to see more health and care professionals aware of the possible alternatives to hospitalisation and having 'planning ahead' conversations with people with dementia and their families. This should help people to have more choice and control over their care, an improved experience and their needs and wishes respected.

# Dementia education and training

All health and social care staff involved in the care of people who may have dementia should have the necessary skills to provide the best quality of care. This should be achieved through effective training and continuous professional and vocational development in dementia.

The Prime Minister's Challenge on Dementia calls on the Royal Colleges to ensure all their members are capable and competent in dementia care.

## Progress

### Training on dementia

Health Education England (HEE) is the organisation responsible for overseeing education and training within the health and care system. The Government's Mandate to Health Education England states all NHS staff looking after patients with dementia will go through foundation level dementia training, with HEE ensuring 100,000 staff have foundation level training by March 2014. This training will enable staff to spot the early symptoms of dementia, know how to interact with those with dementia and signpost staff to the most appropriate care.

Health Education England national returns show that, by October 2013, 108,888 staff had received foundation level training as defined by the Mandate.

By November 2013, HEE will have plans to roll out dementia awareness training across the country to all staff who have contact with people with dementia. They will collect evidence as to the difference this is making for patients, carers and staff alike. In addition, a national network of dementia local education and training board leads will identify the best training available in their areas and make this training available to others.

HEE will work with Skills for Health and Skills for Care to produce high quality training that can be used by people across health and social care. HEE also plans to complete research looking at the changes made in organisations and their people as a result of education and training.

Christine has provided care for her widowed mother, who lives alone, since 2009. She explained that when she started to get really concerned about her mother, the GP undertook initial tests, informed the family about power of attorney, and referred her mother to a psychiatrist for further tests. This took place within three weeks and following this she was prescribed medication and referred to a community psychiatric nurse. The community psychiatric nurse explained the medication, offered equipment (such as a commode), made a referral to the continence nurse, and provided information about the local network partner where staff helped her apply for benefits for herself and her mother and provided information on carer support groups/services. Christine said she found this input invaluable. She does not have much on-going contact with the community psychiatric nurse, but she said: 'I know that there is an open door if I need to contact her, she is very approachable.'

A road less rocky – supporting carers of people with dementia, Carers Trust 2013

### The social care workforce

A recent Skills for Care report<sup>65</sup> provides a good overview of the social care workforce. Previous research carried out by Kings College London in 2010<sup>66</sup> has indicated that 42 percent of the social care workforce supports people with dementia in some way. Evidence from Alzheimer's Society reports and other sources demonstrates care home and homecare workforces very frequently work with people with dementia.<sup>67</sup>

Every person joining the social care workforce will undertake the common induction standards which include aspects of dementia awareness. In addition to this, a number of units and qualifications at vocational levels two and three have been developed by Skills for Care and Skills for Health to support the development of the social care and health workforce working with people with dementia.

<sup>65</sup> The size and structure of the adult social care sector and workforce in England (September, 2013)

<sup>66</sup> Shereen Hussein, 2010. The dementia social care workforce in England, Social Care Workforce Periodical, Issue 9

<sup>67</sup> Alzheimer's Society (2011), Support, Stay, Save, Alzheimer's Society, London, Alzheimer's Society (2013), Low expectations, Alzheimer's Society, London

The national minimum data set for social care<sup>68</sup> tells us that on average 40 percent of people working across social care services have achieved a level two qualification or above in social care. It is important to build on this so that more people are able to obtain a level two qualification which can also include a dementia pathway.

The independent Cavendish Review,<sup>69</sup> carried out in the wake of the Francis Inquiry into Mid-Staffordshire NHS Foundation Trust, makes a number of recommendations on how the training and support of healthcare assistants who work in hospitals and social care support workers who are employed in care homes and in people's own homes can be strengthened to ensure they provide care to the highest standard.

One of the key recommendations is that healthcare assistants and social care support workers undergo the same fundamental training, based on the best practice that already exists in the system. The Government has accepted Cavendish's recommendation for developing a care certificate. The care certificate will ensure staff receive quality and consistent training and that they demonstrate the behaviours needed to deliver compassionate care across health and social care. This should help to improve the care that people with dementia receive.

Skills for Care have come across many examples of the social care workforce working to support people to live well with dementia. One example is the work that Anchor Trust are doing to support meaningful activity for people with dementia, this is well illustrated by the work they have done with Etta who has dementia:

Etta was 92 years old when she moved into the care home as an emergency admission following a house fire caused by leaving a cigarette unsupervised. Etta was understandably distressed and very confused. Over the following weeks, through conversation and life story work it was discovered she had been a very competitive swimmer in her youth, winning cups and awards. As time passed and relationships grew, a team member who loves swimming suggested to Etta that she accompany her to the local swimming baths. Etta was delighted as she had not swum for 60 years. On arrival and entering the water Etta started clapping her hands with happiness and joy. Etta went swimming every month after that, until just before she passed away.

Anchor Trust

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<sup>68</sup> [Skills for Care, national minimum data set for social care](#)

<sup>69</sup> The Cavendish review: an independent review into healthcare assistants and support workers in the NHS and social care settings, Department of Health, July 2013.

The Life Story Network has worked with housing providers in Merseyside to explore how to create the conditions to develop dementia friendly communities. The project confirmed the importance of being responsive to the needs of people with dementia and their family carers, not only those living in extra care and supported housing, but also those older residents who live in general housing stock who may not be in touch with support services or who may withdraw due to lack of confidence and support as their condition progresses. This situation can be self-perpetuating and can result in isolation and loneliness, which impact on physical and mental health. In addition to housing support staff, tenants play an important role in identifying neighbours who may be exhibiting the early signs of dementia or other mental health difficulties, and in knowing how to support and seek help for them. Our training gave them confidence to challenge their fellow tenants who may respond unsympathetically, or even with hostility, to what they perceive as anti-social behaviour. Our work demonstrated that through training, housing providers can play a major role in using their collateral effectively to improve health outcomes for the people who live and work in their local communities.

We are extending this approach through our joint project with Halton Borough Council, funded by Skills for Care, to improve the skills of the workforce in sectors beyond health and social care (such as leisure, transport and housing) in how to support people with dementia and their carers.

The Life Story Network

## Call to action

HEE wants all NHS staff to be aware of the signs of dementia, ensuring that across the workforce people know how to point patients and their carers to the necessary expert services and support available. HEE want to exceed the government target of 100,000 staff completing foundation level dementia training by March 2014, to make a real and lasting impact for patients, carers and staff leading to safer, dignified and more compassionate services.

With respect to the social care workforce we want to see more social care staff trained in high quality dementia care, personalised to meet the needs of people with dementia and their carers.

# Dementia Friendly Communities

## Public attitudes to dementia

One of the first steps towards creating dementia friendly communities involves raising public understanding and challenging attitudes which may inhibit people with dementia living life to the full. Dementia is the condition people over the age of 55 fear most - more than cancer or heart disease (YouGov 2011) – and it continues to be surrounded by fear and stigma.

**‘Treat us properly and with respect. We’re not mad; this is just something that has happened to a part of my brain.’**

Nearly half of UK adults acknowledge that public understanding of dementia is limited, and 73 percent of them do not believe society is geared up to deal with the condition.<sup>70</sup> Research shows avoidance is the dominant reaction in many people. While they are sympathetic to people with dementia, they do not always feel comfortable or able to engage with them or to help.

It is commonly reported that people with dementia lose friends after diagnosis.<sup>71</sup> Nearly two thirds of people with dementia who live alone report feeling lonely and do not want to be a burden on others.<sup>72</sup> Even people with dementia who describe themselves as living well with the condition say they feel anxious and depressed at times.<sup>73</sup>

These perceptions of dementia stifle the ability of people with the condition to live well. Promoting understanding of the condition and a living well message, showing how people with dementia can continue to make choices in their lives, is critically important.

**‘We need people to tell other people about dementia. Nobody, anywhere in the world knows if they’re going to get dementia and we need to make people aware.’**

## Progress

Previous national campaigns have helped to reduce stigma and encourage timely diagnosis. We now need to use marketing to get people, communities and society squarely behind the issue and deliver dramatic change – to create a social movement.

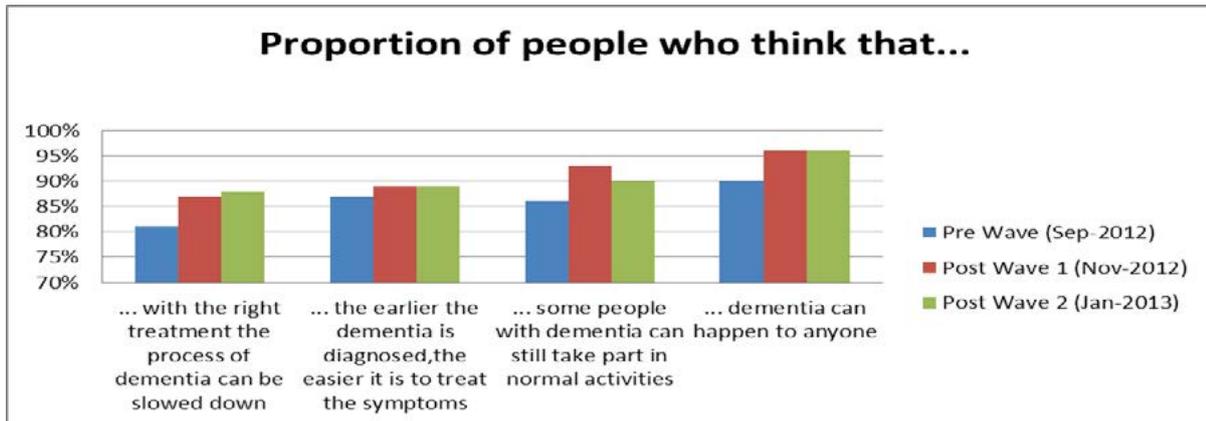
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<sup>70</sup> Building dementia friendly communities: a priority for everyone, Alzheimer's Society, 2013

<sup>71</sup> Dementia 2013: The hidden voice of loneliness, Alzheimer's Society, 2013

<sup>72</sup> Dementia 2013: The hidden voice of loneliness, Alzheimer's Society, 2013

<sup>73</sup> Dementia 2013: The hidden voice of loneliness, Alzheimer's Society, 2013



Next year the government, working with Alzheimer’s Society, the creative industry and the business community, will launch a ‘Dementia Movement’ aimed at:

- reducing fear, through activity that improves public attitudes towards dementia and gives more people the confidence to engage with people with dementia
- increasing social connectedness, for example by prompting and supporting conversations between people in the early stages of dementia and their families, friends and neighbours.
- improving skills so more people know how to help those with dementia, by recruiting people into the Dementia Friends programme and inviting communities and businesses to become dementia-friendly organisations.

## Call to action

We want the public to change how it thinks and feels about dementia and to understand how to help people with the condition. This means having the confidence to engage with people who have dementia and the skills to interact in a way that is both useful and welcome. To achieve this, individuals and organisations will be encouraged to join the Dementia Friends programme<sup>74</sup> to gain an understanding of dementia and the things they can do to make a difference to people living with the condition.

## Supporting the establishment of Dementia Friendly Communities

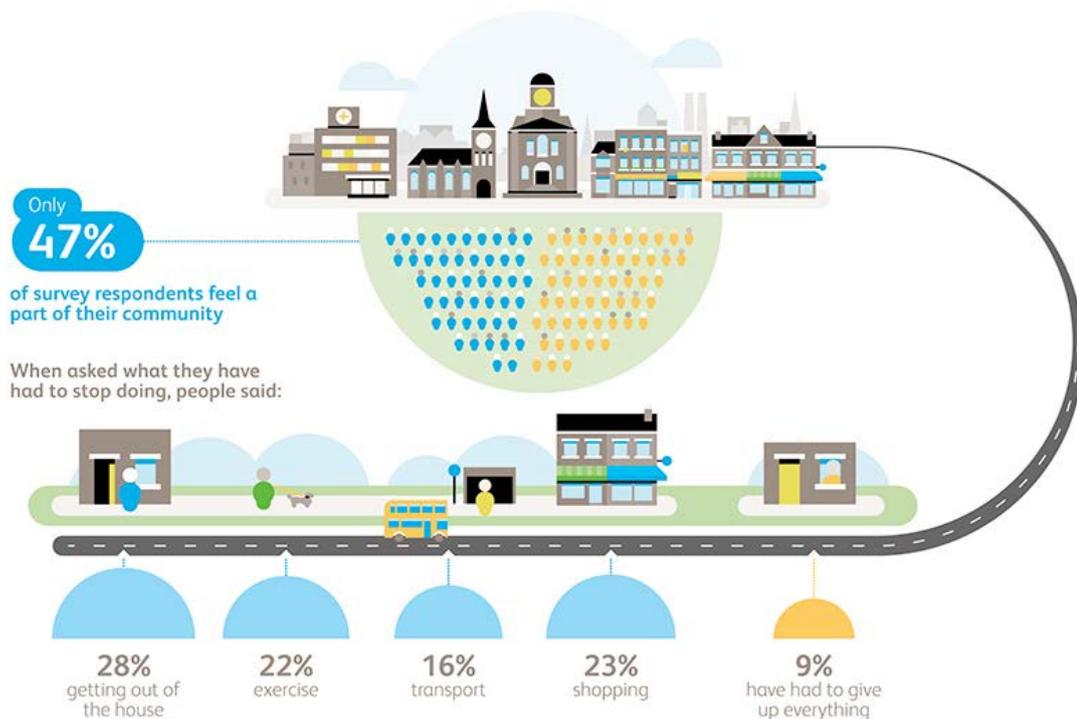
**A dementia friendly community is one in which people with dementia are empowered to have high aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them**<sup>75</sup>

<sup>74</sup> [Dementia Friends](#)

<sup>75</sup> Building Dementia Friendly Communities: a priority for everyone’, Alzheimer’s Society, September 2013

Establishing dementia friendly communities has the potential to transform the lives of people with dementia in England. Two thirds of people with the condition live in the community, close to a third of whom live on their own. Health and care services, while fundamental, cannot alone ensure people with dementia live good quality lives. Support from wider communities, services and organisations is needed, utilising the untapped potential of communities to help people with dementia and their carers.

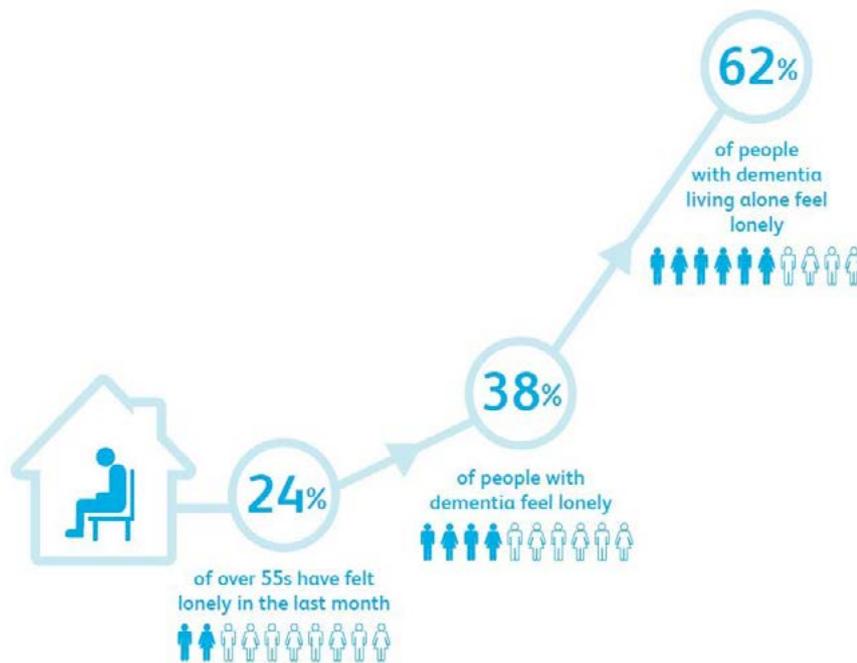
Alzheimer's Society's 'Building dementia friendly communities: a priority for everyone'<sup>76</sup> report outlined evidence from people with dementia about how they want to be engaged in their communities, the support they need to do so and what barriers they face. The report found that many people with dementia do not currently feel part of communities, as illustrated in the infographic below.



Alzheimer's Society (2013). Building dementia friendly communities: a priority for everyone. Alzheimer's Society, London.

<sup>76</sup> Building Dementia Friendly Communities: a priority for everyone, Alzheimer's Society, September 2013

The Alzheimer’s Society report, ‘Dementia 2013: the hidden voice of loneliness’, shows some progress has been made towards improving the quality of life for people with dementia and carers since 2012. However, progress has been slow, and there is still much to be done to improve the day to day experiences of people with dementia as illustrated below:



Alzheimer’s Society (2013). Dementia 2013. Alzheimer’s Society, London.

Based on the evidence from people with dementia and the progress already underway across communities, Alzheimer's Society set out the key elements of Dementia Friendly Communities. These are outlined in the infographic below.

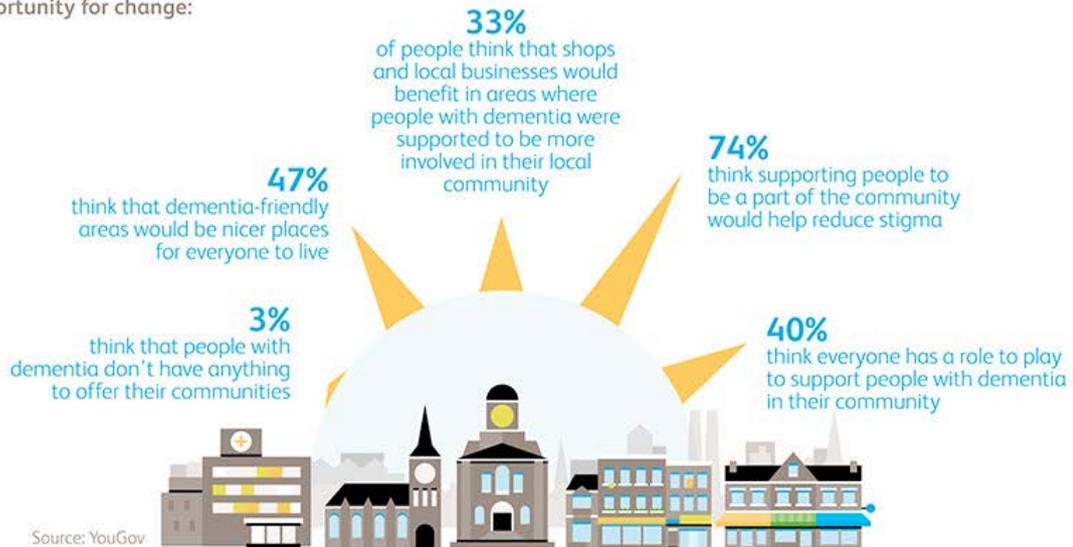


Alzheimer's Society (2013). Building dementia friendly communities: a priority for everyone. Alzheimer's Society, London.

The Alzheimer's Society report 'Building dementia friendly communities: a priority for everyone' found there is a strong sense of goodwill in the community to help people with dementia live well. Evidence from polling of attitudes of the general public found strong support, both for dementia friendly communities and the benefits these could bring to people with dementia and communities more widely. These are outlined in the infographic below:<sup>77</sup>

<sup>77</sup> Building dementia friendly communities: a priority for everyone, Alzheimer's Society, 2013

The opportunity for change:



Alzheimer's Society (2013). Building dementia friendly communities: a priority for everyone. Alzheimer's Society, London.

## Progress

### Communities working towards becoming dementia friendly

The Dementia Friendly Communities programme was started by the Alzheimer's Society in September 2013. This allows communities to be recognised for their work through a process, which sets out expected criteria for communities who wish to be recognised as working to become dementia friendly, such as involving people with dementia, raising awareness of dementia and setting achievable goals. Communities meeting the criteria can use the recognition symbol to identify those businesses or organisations are committed to become dementia friendly.

Action and interest to develop dementia friendly communities is gathering momentum. 25 communities – from York to Plymouth – have now signed up to become dementia friendly communities. A further 50 communities have expressed an interest in doing so.

We want to see even more communities and organisations become dementia friendly, with the aim of having at least 75 communities signed up by the end of the 2015. Details of the criteria, the application process and the symbol can be found at

[http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=2136](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2136)

## Communities that have signed up to the recognition process for working towards becoming dementia friendly

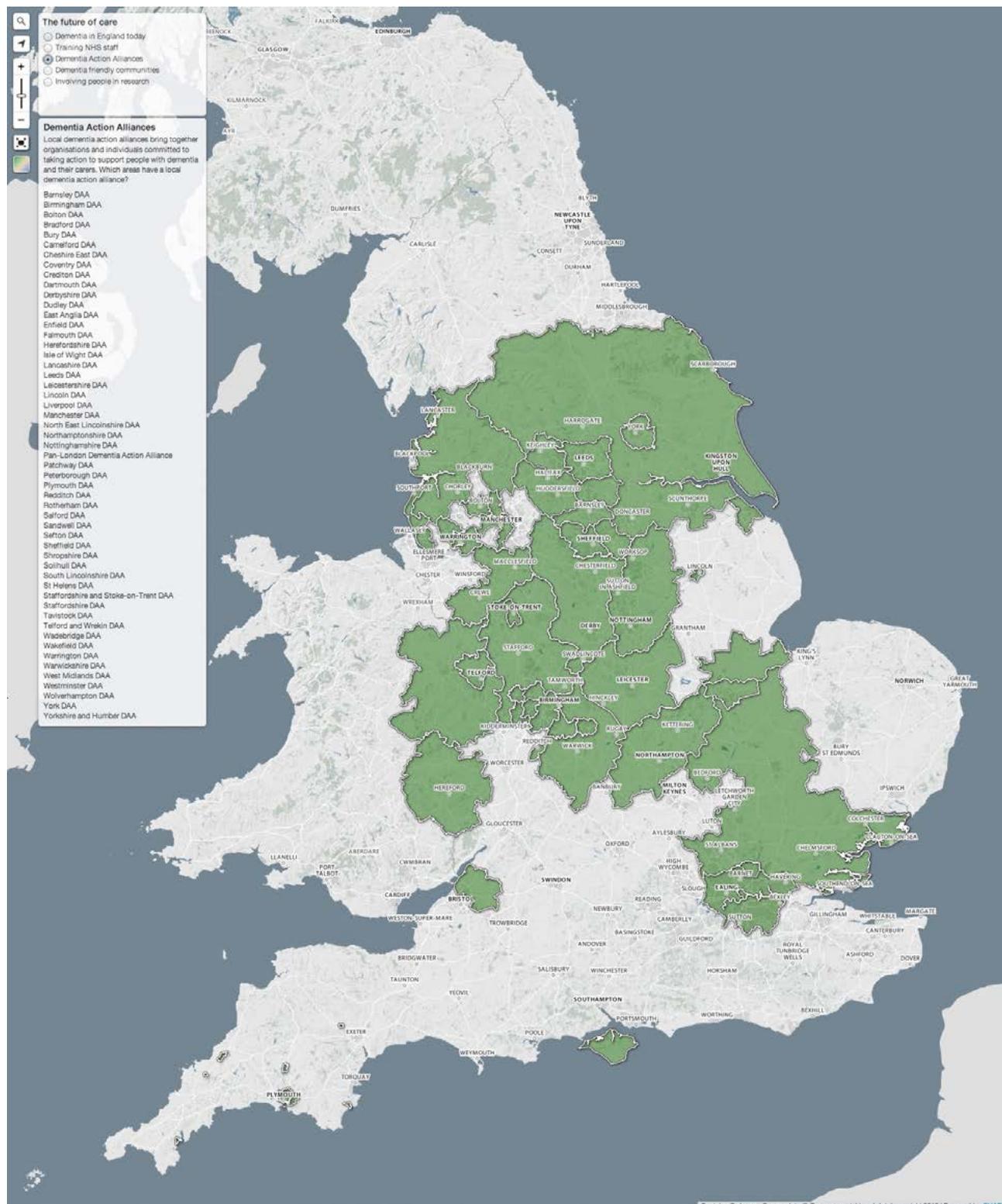


### Establishment of dementia action alliances

The establishment of a national Dementia Action Alliance (DAA) in 2010 has acted as a catalyst for national action and collaboration on dementia. The DAA now has over 130 members across England, drawn from charities, government bodies, royal colleges, care providers and businesses. It has coordinated action on cross cutting issues affecting people with dementia and has ensured members have committed to action plans around improving the lives of people with dementia.

Local dementia action alliances have the potential to be similarly transformative in their communities, bringing together organisations and individuals committed to taking action to support people with dementia and their carers. There are now 51 local Dementia Action Alliances across the country in communities such as London, Plymouth, Shropshire, Norfolk and Suffolk, York and Crawley. A wide variety of organisations and bodies are involved with local alliances ranging from local authorities and acute trusts, to corner shops and solicitors. Details of local alliances can be found at [http://www.dementiaaction.org.uk/local\\_alliances](http://www.dementiaaction.org.uk/local_alliances).

## Local Dementia Action Alliances in England



Crawley Dementia Alliance is reaching out to new networks to make Crawley a dementia friendly community. Bringing together a range of players across government, health, business and community, the Alliance aims to make Crawley:

**‘a town where people living with dementia and their families are able to live well and are supported ...to get the help they need to ensure everyday life and [the] pursuit of leisure and cultural activities are made easy.’**

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

**‘Every meeting we have, people are brimming with ideas and just getting on with things.’ Malcolm Bray, Chair of the Crawley Dementia Alliance.**

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

### Reaching out to different sectors

Businesses, organisations and services all have a role to play in helping understand and respond to the needs of people with dementia. Simple things, like changing the layout of a shop, improving or using different signs and training staff so that they are more aware of dementia can make a big difference. Below are some examples of work underway:

- Work has already begun across England to engage local faith groups, including the Church of England, in increasing awareness of dementia to help develop a guide on dementia friendly parishes.
- In some areas shops, restaurants and other retail organisations are taking action on dementia, including improving awareness among staff and providing support to people with dementia to overcome any potential barriers to using their services and having a positive experience.
- Leading firms in the financial services sector have come together to develop a Dementia Friendly Communities financial services charter.
- Work is progressing in schools to improve awareness of dementia among children and young people.<sup>78</sup>

<sup>78</sup> The Prime Minister’s challenge on dementia: annual report of progress, Department of Health, London, 2013

The 'Dementia Friendly Financial Services Charter' has been designed to help financial services organisations recognise, understand and respond to the needs of customers living with dementia and their carers.

Together, Lloyds Banking Group and Alzheimer's Society, working with 24 other financial organisations, are appealing to banks, building societies, insurance companies and other financial institutions across the sector to join them in making a commitment to families affected by the condition, so that people with dementia can plan ahead, access financial services and get help to remain independent for as long as possible.

The charter lays out a number of ways financial services organisations can work towards becoming more dementia friendly, such as appointing a 'Champion' to drive forward the initiative in each branch. Customers with the condition will also be given more choice, including the option to flag to the bank they have dementia so customer services can be tailored appropriately.

## Dementia Friends

The Dementia Friends initiative is run by the Alzheimer's Society, with funding from the Department of Health and Cabinet Office. If you are a Dementia Friend, you have a better understanding about what it is like to live with dementia and have the knowledge, confidence and skill to engage with people who have the condition. You may have turned that understanding into action, for example by giving time to a local service such as a dementia café, by campaigning or fundraising for a dementia charity, or by raising awareness amongst colleagues, friends and family about the condition.

Dementia Friends was launched in February 2013 and there are now 2,242 Dementia Friends Champions. These champions deliver short information sessions through networks of friends, workplaces and communities. On average, champions run over 70 public information sessions every month, and to date have created a total of 34,775 Dementia Friends through these sessions.

We want to have one million Dementia Friends by 2015. To deliver this reach, we will make the programme more accessible and flexible – for example by delivering online interactive learning experiences – so that people can find out about dementia and supportive actions in ways that suit them. We will also facilitate wider corporate and community participation in the programme.

The following case study sets out the work of one Dementia Friend Champion in her community:

Dementia Friends Champion, Helen Morris has reached an amazing 849 Dementia Friends in her local community. Helen started running Dementia Friends information sessions in her local village pub, with the landlords letting her use the facilities free of charge. This model has been so successful she has replicated it in other pubs nearby. In total Helen has run 27 information sessions, including two at a local school, creating a new generation of Dementia Friends.

Alzheimer's Society

## Call to action

There is now an unprecedented opportunity to become more ambitious and go faster and further towards the creation of Dementia Friendly Communities. They should be commonplace, not exceptional. To achieve this we would like to see:

- local leaders and elected representatives committing to making their communities dementia friendly.
- all communities in England signing up to the Dementia Friendly Communities recognition process, with the aim of over 75 communities signing up by the end of 2015.
- national businesses encouraged to work with the Alzheimer's Society and local dementia action alliances to look at how they can become dementia friendly and encourage their local branches to take this forward in local communities.
- people across England sign up to become Dementia Friends and Dementia Friends Champions and take actions to raise awareness of dementia in their communities.

# Research

While there is a great deal we can already do to help people to live well with dementia, there is still a great deal we need to discover. The government is determined to constantly push the boundaries of what is possible: earlier diagnosis, more effective treatments and, one day, even a cure. World leading research is critical to all of this.

The NHS has a unique set of characteristics that make it a natural global centre for dementia research. Because the NHS is the single dominant provider of healthcare, it has access to vast amounts of patient data that can, with the application of technology, be mined for information about what works.

Our world leading universities and scientists are at the cutting edge of medical science and technology. We lead the world in areas such as genetics, cognitive neuroscience and neuroimaging, each essential to furthering dementia research.

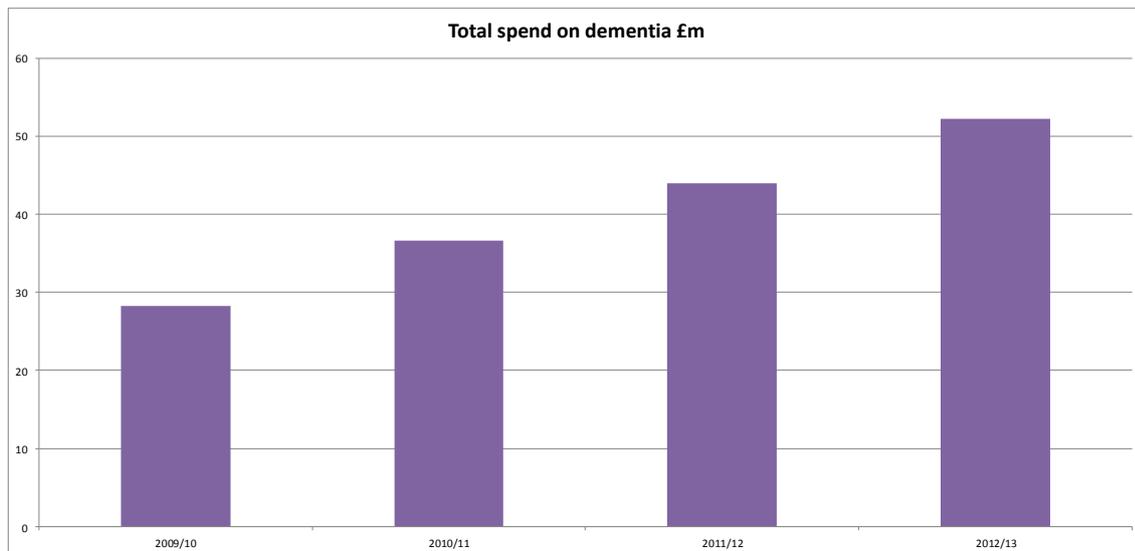
The British life science industry, with its strong academic partnerships, large scale investment and dynamic global companies, make this country a centre for commercial development.

This strength in depth is fully supported by a government dedicated to furthering dementia research. Since 2009/10, government funded dementia research in England has almost doubled, from £28.2 million to £52.2 million in 2012/13. At the same time, funding by the charitable sector has increased, in the case of Alzheimer's Research UK from £4.2 million to £6.8 million, and Alzheimer's Society from £2 million to £5.3 million over the same period.

In July 2012, a call for research proposals received a large number of applications, the quality of which exceeded expectations. Six projects, worth a combined £20 million, will look at areas including:

- Living well with dementia
- Dementia associated visual impairment
- Understanding community aspects of dementia
- Promoting independence and managing agitation in people with dementia.

## Government spending on dementia research



Each annual figure represents the sum of expenditure on dementia research by the Department of Health, the Medical Research Council (MRC) and the Economic and Social Research Council (ESRC)

## Estimated number of studies in dementia

	2012/13
Studies	194

Number of studies on the NIHR Clinical Research Network 'portfolio' supported by DeNDRoN (the NIHR Dementias and Neurodegenerative Diseases Research Network)

## Estimated number of people recruited to studies in dementia

	2012/13
Recruits	11,859
Diagnosed	319,000
Rate	3.7 %

Number of people recruited into studies on the NIHR Clinical Research Network 'portfolio' for which DeNDRoN is the main network. The number of diagnosed individuals was estimated by taking recent prevalence estimates (670,000) and applying the current estimated diagnosis rate for dementia (NHS England) of 48 percent.

## Case studies of completed research with the potential to make a real difference to those with dementia and their families

### Research towards new types of treatments

#### **Preventing neurodegenerative disease in mice**

Research at the Medical Research Council's Toxicology Unit in Leicester has shown for the first time that it is possible to prevent neurodegeneration in mice. A common feature of disorders such as Alzheimer's disease is the accumulation of specific 'misfolded' proteins in the brain. This ultimately leads to the death of neurons and the development of symptoms associated with dementia.

The work focused on mice with prion disease, an animal equivalent of human neurodegenerative disorders. A new drug compound given to the mice orally, successfully halted neuro-degeneration and disease-like symptoms. That a treatment was able to be administered orally, reach the brain and inhibit the death of nerve cells, makes it a promising avenue of investigation towards eventual treatments in humans.

#### **Reducing cognitive decline**

Giving patients the drug Donepezil in the moderate to severe stages of Alzheimer's disease significantly reduces cognitive decline. While Donepezil is one of the most commonly prescribed dementia drugs, it was only recommended in the earliest stages of Alzheimer's as it was not believed to be effective as the disease progresses.

A multi-centre trial by the Institute of Psychiatry, Kings College London and funded by the MRC and the Alzheimer's Society, has assessed the effects of prolonging prescriptions of Donepezil for patients with moderate to severe dementia. The DOMINO-AD trial has produced clear evidence of the benefits in extending the period of drug treatment for dementia patients. It is the first trial to demonstrate the value of continued drug use for patients who have deteriorated beyond the point where Donepezil is presently recommended.

## Living well with Dementia

### **People with dementia can engage in decisions that affect their lives**

Research funded by the Economic and Social Research Council suggests that people with dementia can still make decisions in their everyday lives and, with support from partners, can continue to do so as their condition advances.

A study conducted by the Universities of Bradford and Sheffield looked into how married couples living with dementia make decisions ranging from what to eat or wear to more complex decisions like who manages the finances and whether or not to attend a day centre.

The researchers found that spouses generally involved their partners with dementia in decision-making processes. However, wives tended to help their husbands with dementia with minor decision-making (such as what to wear or eat) more than husband carers. Also, spouses did not always involve their partners with dementia in major decision-making if additional disabilities such as communication made it more challenging.

The research showed that having dementia doesn't mean automatically losing your decision-making ability – this needs to be considered on a decision-by-decision basis. Professionals and carers need to facilitate the involvement of people with dementia in decision-making as much as possible.

### **Reduced use of anti-psychotics in vascular dementia**

The National Institute for Health Research's (NIHR) Biomedical Research Centre and Unit at the Maudsley Hospital in London are developing international best practice on the use of antipsychotics on people with dementia. Working with Alzheimer's Society and the Department of Health, they created a best practice guideline and resource for the treatment of behavioural and psychological symptoms in dementia, building on the unit's evolving understanding of non-drug interventions, the treatment of pain and the use of antipsychotics.

## Understanding the disease

### **Genetic risk**

A gene which nearly triples the risk of Alzheimer's disease has been identified by an international team of scientists, part funded by the MRC, the Wellcome Trust the NIHR and Alzheimer's Research UK. The gene, TREM2, is the most potent genetic risk factor for Alzheimer's disease to be identified in the past 20 years.

TREM2 was previously known to be involved in the immune system, which fits well with previous evidence linking faults in the immune system to Alzheimer's disease.

## Prevention

### **Gain in quality of life depends on tackling preventable non-dementia disease**

A team at the London School of Economics, supported through the Research Councils' New Dynamics of Ageing programme, undertook wide ranging research to understand population statistics and trends in relation to ageing and the costs of care. The research showed that a shorter period of disability at the oldest ages seems attainable, but only through halving the prevalence of major diseases which would require significant advances in prevention and treatment. Halving dementia-related disability could reduce the size of the disabled older population by 10 percent. This has significant implications – both in terms of understanding the needs and costs linked to dementia but also in terms of formulating priorities for intervention. The project has been very influential in terms of policy and important in terms of getting a handle on the future possibilities.

## Case studies of current research

### Faster diagnosis

#### **Speeding up diagnosis**

Currently, the diagnosis of dementia can take 12 months or more to complete. The MRC and the Technology Strategy Board have recently invested £2.2 million in a £3.4 million project – a collaboration between Imperial College London and Ixico Ltd, a UK company focused on advancing technologies for evaluating neuro-degenerative diseases. This project aims to develop a faster, more cost-effective diagnosis system that can be used earlier in the course of the disease.

This system uses portable, computer-based tests that assess memory and thinking, and combines this with analysis of MRI brain scans. The aim is to reduce the length of time taken for diagnosis down to three months and to make early dementia diagnosis widely available. This will allow more people living with dementia to be diagnosed accurately and to receive the necessary care. Some of the funding goes towards a feasibility study for developing a version of the system tailored towards the Chinese market. Presently, China is estimated to have 25 percent of the world's dementia cases, yet about 80 percent of these cases remain undiagnosed.

### **Blood proteins as biomarkers of disease**

Research undertaken by the NIHR Biomedical Research Centre at the Maudsley Hospital with Merck Millipore and Proteome Sciences suggest blood proteins could act as biomarkers to help identify pre-clinical dementia or to predict the progression of disease in the early stages. These biomarkers have significant potential to form the basis of a series of simple blood tests for the diagnosis and management of Alzheimer's. Analysis of the study data will determine whether individual markers and defined marker panels have diagnostic and prognostic utility.

## **Towards a cure**

### **Hypertension drug may reduce risk of dementia**

The MRC has recently invested £2 million into a clinical trial aiming to determine whether Losartan, a drug typically prescribed to patients with high blood pressure that affects the renal system, could be used in the treatment of Alzheimer's disease. The RADAR trial (Reducing pathology in Alzheimer's Disease Through Angiotensin Targeting) aims to recruit 230 participants from across the UK over two years.

The trial is based upon recent research demonstrating that people who were previously administered Losartan have a reduced likelihood of developing Alzheimer's disease when compared to people taking other drugs for blood pressure. The trial aims to use brain imaging to determine whether Losartan is able to reduce neurodegeneration associated with dementia and to measure whether it affects memory and quality of life in these patients. Losartan is well tolerated by patients, and if the trials are successful, the drug could easily complement current treatments for Alzheimer's disease.

## **Call to action**

As part of its G8 presidency, the UK is hosting a Summit on Dementia in London on 11 December 2013. The summit aims to develop coordinated global action. It will provide a forum for G8 nations to identify and agree a new international approach to dementia research and to secure a new level of cooperation to enable nations to reach shared goals faster than each nation acting alone.

The summit will bring together health ministers from each of the G8 nations, along with the OECD Deputy Secretary-General and the WHO Director General. It will also draw on the expertise of industry, national research organisations, civil society, key opinion leaders, researchers and physicians.

- Social investment and financing
- New care models
- Industry harnessing academic research

We are also seeking for one of the G8 countries to undertake a review of progress so far in December 2014.

**We want to see faster progress** towards achieving earlier diagnosis, improved assessment, more effective treatment, and better management and care. Research on how best to help those with dementia to live well with the condition remains as important a priority as research into new drugs.

**We want more dementia research and more people participating** in dementia research. To achieve this, research funders will strive to get the best from the excellent research ideas, people and resources available in the UK. Working in collaboration with other countries will accelerate progress.

**We will use** the UK's strengths in health informatics and in data sharing technology to link different sets of clinical and care data with biomedical investigations and research data, bringing together industry and academia in this activity.

**We will build** on research funders' investments in basic and translational research to identify better disease models, new biomarkers of early disease and progression, and novel therapeutic targets.

**We will promote** health and social research that will enable those with dementia to live longer, more fulfilling lives.

## The Future

We want England to be the best country in Europe for people to live with dementia. This requires more than just a great NHS and effective social care. It needs every part of our society to respond to this challenge as one. We each have a part to play and it is up to every one of us to make it happen.

This dementia report, with its accompanying map of variation, available at <http://dementiachallenge.dh.gov.uk/map> shines a light on the current quality of dementia care in England. The very best services are excellent and show what is already possible. But the worst show just how far we have to go. The message is clear: we can do better. Much better.

This report also highlights the many areas where data is either poor or entirely absent. We need more and better data and we need to place it in the hands of those most able to act on it – local councils, local doctors, patients and the public. Only with greater transparency can people know which services are available and where they can go for help and advice.

With better data and a clearer understanding of the quality of local services, we want to encourage a dialogue between health and care professionals and the people they care for. We want to support people to hold their local council or NHS Clinical Commissioning Group to account for the quality of local dementia care. We also want to support councils and the NHS to improve their services, sharing their experiences and best practice.

The Department of Health is currently looking at how dementia care has improved since 2009. Its report is expected in spring 2014 and will add further detail to the current picture of dementia care in England.

In the meantime, the evidence presented in this report points to ten priorities for action:

- **Prevention:** Because the choices we make affect our risk of developing vascular dementia, we need to support people to make healthy choices to help them to avoid getting the condition.
- **Diagnosis and support after diagnosis:** Local NHS Clinical Commissioning Groups and local councils need to work together to ensure that, by 2015, two thirds of people with dementia have a proper diagnosis and get appropriate support.
- **High quality, compassionate care everywhere:** We need to give people with dementia and their carers care and support that is flexible, appropriate, timely and provided by skilled staff whether at home, in hospital or in a care home.
- **Greater personal control:** We need to enable people with dementia and their carers to exert control over their care and over their lives throughout all stages of their dementia.
- **Cutting inappropriate medication:** NHS and social care organisations must continue to reduce the inappropriate prescribing of antipsychotic medication for people with dementia.
- **End of life care:** Health and care professionals must be made aware of the alternatives to dying in hospital. Everyone with dementia and their families should have ‘planning ahead’ conversations with their doctor. End of life care should be excellent with every person treated with dignity and respect.

- **Dementia education and training:** All NHS and Social Care staff should be aware of the signs of dementia and how best to support people with the condition, their families and carers.
- **Dementia Friendly Communities:** We need to create a dementia friendly society. We urge national businesses to become dementia friendly and to encourage their local branches to take this forward in their communities. We ask everyone to become a Dementia Friend so that more people know how they can help to support people with dementia and their families.
- **Research:** We need more dementia research and more people taking part in clinical trials. We ask those who fund research to strive ever harder to get the most from the excellent ideas, people and resources this country has to offer.
- **Better data and evidence:** We call on national health and care organisations – such as NHS England, Public Health England, Health Education England, the Care Quality Commission and the Health and Social Care Information Centre – to work with the academic and research communities, the voluntary sector, industry and central government to improve the availability and quality of data on dementia care and support.

Of course, dementia is not confined to England. Dementia is a global problem that demands global solutions. We are working with our partners in the UK and around the world, sharing our knowledge and pooling our talents to find new, creative approaches to fighting the disease. Together, we are pushing the boundaries of research to better understand, prevent and treat dementia, even to find a cure.

If we are to create a society where people can live well with dementia, we need to think and act differently. We need greater global collaboration and leadership. December's G8 dementia summit presents a unique opportunity to lead a world-wide effort to improve the lives of all those affected by dementia. The G8 countries will hold specific events throughout 2014 focused on social investment and financing, finding new models of care and helping industry to harness academic research.

By taking action today – in our communities, across our country and across the world – we have an opportunity make that vision a reality.



Department  
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