

# Prime Minister's challenge on dementia

Delivering major improvements in  
dementia care and research by 2015



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# PRIME MINISTER'S CHALLENGE ON DEMENTIA

*Delivering major improvements in dementia care  
and research by 2015*

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# Prime Minister's foreword

Imagine feeling confused and afraid because close friends and relatives seem like strangers; being unable to leave the house alone because you might not be able to find your way back; or seeing the fear in your loved one's face, as they struggle to make sense of familiar surroundings.

For many people in this country, this is the reality of everyday life. 670,000 people in England are living with dementia. An estimated twenty one million people in our country know a close friend or family member with dementia – that's 42% of the population. One in three people aged over 65 will have dementia by the time they die. And as life expectancy increases, more and more people will be affected.

Dementia is one of the biggest challenges we face today – and it is one that we as a society simply cannot afford to ignore any longer. We have made some good progress over the last few years, but there's still a long way to go.

Our research knowledge on dementia lags behind other major diseases such as cancer or heart disease. People with dementia and their carers still face a lack of understanding from public services, businesses and society as a whole. And as many as half of all dementia sufferers in this country are unaware that they have the condition, meaning that they cannot get the help that they and their families need.

So I am determined that we will go further and faster on dementia – making life better for people with dementia and their carers, and supporting the research that will ultimately help us slow, stop and even prevent the condition. Of course the Government doesn't have all the answers, and we can't fix everything overnight. But with a sustained and concerted effort from all parts of society, I believe we can make a real difference – and we are determined to do so.

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

# Introduction

After a century of advances in medical science, sanitation and nutrition, people today are living longer than ever before. This is an extraordinary success story, but one that presents challenges as well as opportunities.

One in three people over the age of 65 will develop dementia. In England in 2012, 670,000 people have dementia – equivalent to the combined populations of Bristol and Leicester. This number will double in the next 30 years.

Among the over-55s, dementia is feared more than any other illness. And at an estimated £19 billion a year, the cost to our economy is huge. It is estimated that this is higher than the costs of cancer, heart disease or stroke. We have not only a moral imperative to improve dementia care – there is a strong financial one too.

*Living Well with Dementia – A National Dementia Strategy* (2009), was one of the first strategies of its kind in the world. It set the standard for improving the lives of people with dementia, for their families and their carers, through raising awareness, encouraging earlier diagnosis and providing high-quality treatment and care.

Three years on, and we've made progress (see Box 1). But we need to do more. We need to push further and faster to improve radically the quality of life for people living with dementia, their families and carers by 2015.

## Box 1: Progress on improving dementia care

- **94% of primary care trusts (PCTs) now have a dedicated memory service for dementia**, and a further 4% are planning to set up a memory service in the future, according to the first national audit of memory services published in September 2011. The average number of people using memory services per PCT increased by 57% between 2008/9 and 2010/11 (from 605 to 951).
- **The NHS and Social Care, working together with wider partners, have taken forward initiatives to reduce the prescribing of antipsychotic drugs for people with dementia to improve quality of life** with a view to achieving overall a two thirds reduction in the use of antipsychotic medicines. However, more needs to be done.
- **More than 90 leading organisations have joined the Dementia Action Alliance (DAA) since October 2010**. Organisations from health, social care, and the voluntary and commercial sectors are working together to help improve the quality of life for people with dementia, their carers and families.
- **A Dementia Commissioning Pack was launched in July 2011**, to guide NHS commissioners in getting the best possible outcomes for people with dementia and the best value for money.

## **The ambition**

We want to make a real difference to the lives of people with dementia. Building on the National Dementia Strategy, we believe that the UK can be a world leader in dementia care and research.

People with dementia, their families and carers have told us what is important to them and what will help them to live well with dementia. They say they want to receive an early diagnosis and timely, good-quality information that will help them make informed choices about their care. They want the treatment and support they receive to be the best for their dementia and life, regardless of whether they are cared for at home, in hospital or in a care home.

The Health and Social Care Bill will improve quality and choice of care for people with dementia and their carers. GPs and other clinicians who come into regular contact with people with dementia and their carers will have the primary responsibility for commissioning health and care services, which should ensure that they get the care that they need and want.

The forthcoming Care and Support White Paper will benefit people with dementia and their carers too, giving them more choice and control over their care, better information, and better-quality care.

But we will need to do more. The PM's Challenge on Dementia is a challenge to the whole of society as well as government. It will focus on three key areas:

- **Driving improvements in health and care**
- **Creating dementia friendly communities that understand how to help**
- **Better research**

As well as driving up the quality of care, work in these three areas should help to reduce future pressures on the NHS and social care.

Annex A sets out the full list of the actions being taken forward across the three areas.

# Key commitments

## Driving Improvements in health and care

- 1. Increased diagnosis rates through regular checks for over-65s.** We will ensure that GPs and other health professionals will make patients aged 65 and older aware of memory clinics and refer those in need of assessment. From April 2013, there will be a quantified ambition for diagnosis rates across the country, underpinned by robust and affordable local plans.
- 2. Financial rewards for hospitals offering quality dementia care** From April 2012, £54m will be available through the Dementia Commissioning for Quality and Innovation (CQUIN) to hospitals offering dementia risk assessments to all over-75s admitted to their care. From April 2013, this will be extended to the quality of dementia care delivered. Also for April 2013, access to all CQUIN rewards will be dependent on delivering support for carers in line with the National Institute for Health and Clinical Excellence (NICE)/Social Care Institute for Clinical Excellence (SCIE) guidelines.
- 3. An Innovation Challenge Prize of £1m** NHS staff can win up to £1m for innovative ideas for transforming dementia care.
- 4. A Dementia Care and Support Compact signed by leading care home and home care providers** Ten leading organisations have set out their commitment to deliver high-quality relationship-based care and support for people with dementia, and to engage and involve the wider community in this work.
- 5. Promoting local information on dementia services** We will promote the information offer pioneered by NHS South West, which will be launched on 28 March 2012 and rolled out across the south by the end of 2012. From April 2013, similar information will be available in all other parts of the country. We will also be setting out in the Care and Support White Paper further steps to ensure that all people receiving care and support get better information to support their care choices.

## Creating dementia friendly communities that understand how to help

- 6. Dementia-friendly communities across the country** By 2015, up to 20 cities, towns and villages will have signed up to become more dementia-friendly.
- 7. Support from leading businesses for the PM's Challenge on Dementia** Leading national organisations have already pledged to look at how they and others can play a part in creating a more dementia friendly society and raising awareness of dementia.
- 8. Awareness-raising campaign** From autumn 2012, we will invest in a nationwide campaign to raise awareness of dementia, to be sustained to 2015. This will build on lessons learned from previous campaigns and will inform future investment.
- 9. A major event over the summer, bringing together UK leaders from industry, academia and the public sector,** to take forward the PM's Challenge on Dementia.

## Better research

- 10. More than doubling overall funding for dementia research to over £66m by 2015**  
The combined value of the National Institute for Health Research (NIHR), Medical Research Council (MRC) and Economic and Social Research Council (ESRC) funding

for research into dementia will increase from £26.6m in 2009/10 to an estimated £66.3m in 2014/15.

- 11. Major investment in brain scanning.** MRC will make a major additional investment in dementia research using the BioBank. MRC anticipates piloting the brain scanning of a subset of this national cohort, with a view to rolling out to 50,000–100,000 participants.
- 12. £13m funding for social science research on dementia (NIHR/ESRC).**
- 13. £36m funding over 5 years for a new NIHR dementia translational research collaboration to pull discoveries into real benefits for patients. Four new NIHR biomedical research units in dementia and biomedical research centres which include dementia-themed research will share their considerable resources and world-leading expertise to improve treatment and care.**
- 14. Participation in high-quality research** Offering people the opportunity to participate in research will be one of the conditions for accreditation of memory services.

# Driving improvements in health and care

The implementation of the National Dementia Strategy is beginning to improve the lives of people with dementia, but we need to do more to improve the quality of care. Failure to act will mean our health and social care services will struggle under the pressure of increasing numbers of people with dementia. **We must ensure that every person gets the treatment and support which meets their needs and their life.**

The NHS reforms will improve quality and choice of care for people with dementia and their carers. GPs and other clinicians who come into regular contact with people with dementia and their carers will have the primary responsibility for commissioning health care, which should ensure that they get the care that they need and want. The forthcoming Care and Support White Paper will set out a range of proposals that will benefit people with dementia and their carers, giving them more choice and control over their care, better information, and a greater assurance of quality. Our reforms will enable a much more integrated approach with health and social care services centred around people's needs.

## **Better diagnosis**

Currently only 42% of people with dementia in England have a formal diagnosis. The diagnosis rate varies – from 27% in the worst-performing areas to 59% in the best. Too often, diagnosis comes too late – during a crisis or beyond the point where people can plan for the future and make informed choices about how they would like to be cared for. This is not good enough.

Surveys show us that people with dementia would like early diagnosis. And 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.

The people most at risk of developing dementia (the over-75s) see their GP at least once, if not several times, a year. Around 97% of people aged over 75 go to their GP surgery at least once a year, and around 87% at least once every six months.

### Key commitment 1

***Increased diagnosis rates through regular checks for over-65s*** We will ensure GPs and other health professionals make patients aged 65 and older aware of memory clinics and refer those in need of assessment. From April 2013, there will be a quantified ambition for diagnosis rates across the country, underpinned by robust and affordable local plans.

Clinical commissioning groups and local health and wellbeing boards will be encouraged to work with wider local partners to improve diagnosis rates. We will incentivise improved diagnosis rates by including a new indicator in the NHS Outcomes Framework 2013/14.

## Improving care in hospitals

A quarter of all hospital beds are occupied by someone with dementia, and many hospitals struggle to provide the high-quality care that meets the needs of people with dementia. But others get it right. There are examples of excellent and innovative practice across care settings. We need to support this good practice and encourage it to develop and spread.

### Key commitment 2

***Financial rewards for hospitals offering quality dementia care*** From April 2012, £54m will be available through the Dementia CQUIN to hospitals offering dementia risk assessments to all over-75s admitted to their care. From April 2013, this will be extended to the quality of dementia care delivered. Also for April 2013, access to CQUIN rewards will be dependent on delivering support for carers in line with NICE/SCIE guidelines.

### Key commitment 3

***An Innovation Challenge Prize of £1m*** NHS staff can win up to £1m for innovative ideas for transforming dementia care.

## Improving standards in care homes and domiciliary care

While many care homes and care-at-home services offer excellent support for people with dementia, some are not doing enough. We need to make sure that whether people are being cared for in their own home, or in care homes, the staff who work with them have the knowledge and skills to help them lead as fulfilling a life as possible.

### Key commitment 4

***A Dementia Care and Support Compact signed by leading care home and home care providers.*** Ten leading organisations have set out their commitment to deliver high-quality relationship-based care and support for people with dementia, and to engage and involve the wider community in this work.

## Better information for people with dementia and their carers

People with dementia and their families and friends would like better information about health and care services. They want to know what they are entitled to, so that they can be sure they are getting all the support they need. Greater transparency in health and care services can also drive up quality and empower people with dementia and their carers.

But currently, the quality of advice and information which people receive is variable. In all too many areas, it is extremely difficult for people with dementia to find out what support is available and to what they are entitled to.

In 2011/12, primary care trusts were asked to work with their local authorities to publish dementia plans which set out the progress they were making locally towards implementing the National Dementia Strategy. We will do preparatory work that will mean that clinical commissioning groups, working with health and wellbeing boards, are able to go further and provide a transparent local information offer to support people with dementia and, crucially, their carers.

#### Key commitment 5

***Promoting local information on dementia services*** We will promote the information offer pioneered by the NHS South West, which will be launched on 28 March 2012 and rolled out across the south by the end of 2012. From April 2013, similar information will be available in all other parts of the country. We will also be setting out in the Care and Support White Paper further steps to ensure that all people receiving care and support get better information to support their care choices.

In the South West, the local NHS, local authorities and the Alzheimer's Society have produced a web-based information service called Our Health. This uses the NICE quality standards and other evidence to provide information on the support people with dementia should expect to receive. Our Health describes the different services available across the South West, how they can be accessed, and the quality of care they are likely to receive. People also have the opportunity to give feedback on their experience.

#### **Better support for carers**

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. Research shows that carers of people with dementia experience greater strain and distress than carers of other older people.

We want to see better support for carers. The NHS is now required to work closer than ever before with local carers' organisations and councils to agree plans, pool their resources and make sure that carers get the support and break they deserve. We have provided an additional £400m to the NHS between 2011 and 2015 to provide carers with breaks from their caring responsibilities to sustain them in their role. The NHS should also ensure that a range of psychological therapies and support is available to carers of people with dementia in line with NICE/SCIE dementia guidelines.

The NHS and Social Care working together with wider partners should continue to reduce inappropriate prescribing for people with dementia to improve quality of life with a view to achieving overall a two-thirds reduction in the use of antipsychotic medication.

#### **CHAIR OF THE CHAMPION GROUP**

Co-chair: Sir Ian Carruthers

Co-chair: Sarah Pickup

### **Case study: A personal experience of early diagnosis**

**I was diagnosed with dementia six years ago at the age of 50. Although I struggled for three years to get my diagnosis because of my young age, I was still able to receive my diagnosis while in the early stages. I first noticed symptoms 10 years ago when I started to struggle in my job as a teacher – I was forgetting things and struggling to organise classes. I also lost my mathematical ability. I was put on Aricept straight after my diagnosis, which made a huge positive difference to my quality of life. Life doesn't have to end after receiving a diagnosis; you just have to start making choices. I have a very positive outlook and think it is extremely beneficial to have an early diagnosis as it enables you to make important choices and decisions that can help you live life well. I still enjoy playing tennis and regularly go on holiday.**

***Person with dementia***

# Creating dementia-friendly communities that understand how to help

The health and care system has a vital role to play in improving support for people with dementia. But alone it cannot combat the stigma attached to dementia. Lack of awareness among the public and poor understanding in communities has a major impact on the experience of people with dementia. This is a call to action across the whole of society. **We would like people living with dementia to be able to say that they know what they can do to help themselves and who else can help them, and that their community is working to help them to live well with dementia.**

## **Dementia-friendly communities**

People living with dementia want to remain independent for as long as possible, and they want to have choice and control over their lives through all stages of their dementia. With an early diagnosis and the right support they can achieve this.

But this is not the experience of the vast majority of people living with dementia. Not only do they frequently have to battle for diagnosis and support, but everyday things we all take for granted – getting to the shops, spending time with friends and family, getting money from the bank, and going on holiday – are made difficult because of the limited understanding of dementia in their communities.

People with dementia talk about stigma and social isolation. They report losing friends following their diagnosis, seeing people cross the street to avoid them, feeling lonely, and struggling to use local services. Research with the general public has shown that this is often down to the fear, misunderstanding and helplessness people feel in the face of dementia. They simply do not understand enough to support someone to live well with dementia.

The common misunderstandings about dementia – that it's an inevitable part of ageing and that nothing can be done to improve people's lives – prevents our communities and society from becoming more dementia-friendly and meeting the needs of people with dementia and their families. As a society, we must make sure that people with dementia, their carers and families can be active citizens with the potential to live well with dementia at every stage of the condition.

Building more dementia-friendly communities will take time. The Alzheimer's Society will take the lead, working with members of the Dementia Action Alliance to create a formal dementia-friendly recognition process that will make villages, towns and cities accountable to people with dementia and their carers through local Dementia Action Alliances. They will identify what villages, towns and cities need to do to be recognised as dementia-friendly. Only villages, towns and cities that meet their criteria will be granted dementia-friendly community status.

Key commitment 6

***Dementia-friendly communities across the country*** By 2015, up to 20 cities, towns and villages will have signed up to become more dementia-friendly.

Key commitment 7

***Support from leading businesses for the PM's Challenge on Dementia.*** Leading national organisations have already pledged to look at how they and others can play a part in creating a more dementia-friendly society and raising awareness of dementia.

**Public understanding**

Despite the rising numbers of people living with dementia, public understanding of the condition is limited and populated with misconceptions. Poor understanding of dementia has a fundamental impact on the health and well-being of people with dementia. It can lead to their rights not being recognised and families and the economy being put under serious strain. People with dementia, their carers and families struggle to remain independent in a society that does not understand dementia or how to support those affected by dementia to live well with it.

Key commitment 8

***Awareness-raising campaign*** From autumn 2012, we will invest in a nationwide campaign to raise awareness of dementia, to be sustained to 2015. This will build on lessons learned from previous campaigns and will inform future investment.

Key commitment 9

***A major event over the summer, bringing together UK leaders from industry, academia and the public sector, to take forward the PM's Challenge on Dementia.***

**CHAIR OF THE CHAMPION GROUP**

Co-chair: Angela Rippon

Co-chair: Jeremy Hughes

### **Case study: A dementia-friendly city – York**

**In York, the Joseph Rowntree Foundation is funding a year-long project exploring how local partners, including people who are living with dementia and their families, can make the city of York a better place for those affected by the condition. The Dementia Without Walls project will use the experiences of people with dementia, and those who support and care for them, to consider how life can be lived to the full. Also, drawing on examples of current best practice locally, nationally and internationally, the project will challenge people to think afresh, not only about health and social care services, but housing, shopping, leisure and transport. In other words, the everyday amenities that most people take for granted, but which can create enormous challenges for people with dementia. A core aim will be creating opportunities for people with dementia to experience different kinds of services. This will be done through ‘seeing is believing’ visits (to see different places and services where innovative approaches are being tried) and by sharing their experiences with other service users.**

# Better research

While the UK is considered one of the top five countries for dementia research, there are still major challenges, including significantly increasing dementia research capacity and capability; understanding better the mechanisms of the disease and likely targets for intervention; and translating research into practice that affects quality of life. **We would like people to feel confident that we are making significant progress towards prevention, treatment and cure in the UK, and to be able to say that they wanted to take part in research and were able to do so.**

## **Funding more high-quality research into care, cause and cure**

Delivering on the commitment to enable people with dementia and their carers to participate in research will involve work to raise the volume of high-quality studies in the system – across the fields of care, cause and cure.

While it is important to ensure that all areas of scientific work are covered, consultation with experts in the field indicates that some of the greatest opportunities for further scientific progress – for finding the causes and cures for this devastating condition – lie at the early stage 'discovery' end of the scientific spectrum. There are also opportunities for social science research focused on living well with dementia and on the delivery of dementia care services.

### Key commitment 10

***More than doubling overall funding for dementia research to over £66m by 2015. The combined value of the NIHR, MRC and ESRC funding for research into dementia will increase from £26.6m in 2009/10 to an estimated £66.3m in 2014/15.***

### Key commitment 11

***Major investment in brain scanning*** MRC will make a major additional investment in dementia research using the BioBank. MRC anticipates piloting the brain scanning of a subset of this national cohort, with a view to rolling out to 50,000–100,000 participants.

Note: The UK Biobank is the largest study in the world to determine the environmental and genetic factors that influence how we age, including the risks of developing dementia. This long-term programme has already recruited 500,000 people between the ages of 40 and 69.

### Key commitment 12

***£13m funding for social science research on dementia (NIHR/ESRC)***

### Key commitment 13

***£36m funding over 5 years for a new NIHR dementia translational research collaboration to pull discoveries into real benefits for patients. Four new NIHR biomedical research units in dementia and biomedical research centres which***

***include dementia-themed research will share their considerable resources and world leading expertise to improve treatment and care.***

## **Participation in research**

Compared with other conditions such as cancer, the level of public engagement in research, by donation or by direct participation in studies, is low. When people are offered the opportunity to take part in the research, they are often keen to do so. However, people with dementia and their carers are not routinely offered the opportunity to participate in high-quality research and there is no nationally consistent system to enable them to do so, should they wish.

### Key commitment 14

***Participation in high-quality research*** *Offering people the opportunity to participate in research will be one of the conditions of accreditation for memory services.*

## **CHAIR OF THE CHAMPION GROUP**

This work will continue to be led by the Ministerial Advisory Group on Dementia Research (MAGDR) on behalf of Paul Burstow MP, Minister of State for Care Services. The group itself will be co-chaired by Dame Sally C Davies and Sir Mark Walport.

## **Case study: Living Well with Dementia research**

**Topic: Living Well with Dementia: the contribution of dementia advisers and peer support networks**

**Funded by: DH Policy Research Programme: £650,000**

**Research team: School of Health in Social Science, University of Edinburgh**

### **Background**

The National Dementia Strategy (NDS) stresses the importance of promoting the quality of life and well-being of those living with dementia and their carers. As part of the implementation of the NDS, dementia advisers and peer support networks were established in 40 demonstrator sites across England. These have developed a range of different methods and approaches for enhancing the well-being and increasing the resilience of those living with the disease. Evaluation was built into the developments of the new service models from the beginning, both at a local level and nationally.

### **The study**

The study's aims are threefold:

- to describe the range of dementia adviser and peer support organisational models developed; and their evolution, management and governance;
- to evaluate the impact of the new service models in terms of:
  - the well-being of patients and carers;
  - their contribution to the objectives of the NDS;
  - the integration, sustainability and transferability of the organisational models involved.
- to examine in depth the patient/carer experience of the new service models, in respect of increasing accessibility, improving involvement and information, enhancing support for making choices, and increasing independence.

### **Progress**

The study began on 1 April 2010 and is due to complete in September 2012. Interim findings indicate:

- strengthened partnership working;
- increased awareness of dementia on the part of providers;
- support provided being seen to fill a 'gap' in existing provision;
- a perceived reduction in carer stress;
- appreciation from other providers of the value of the new services;
- a reduction in demand for statutory services; and
- a network built on the commonality of experience.

# Next steps

The commitments set out in the Prime Minister's Challenge on Dementia will be taken forward by a range of partners across health and social care, the research and industry sector, and broader society. Three **champion groups** will bring together leading organisations and groups with an interest, to support the delivery of the commitments and to mobilise wider engagement. The champion groups will report on progress to the Prime Minister through Department of Health (DH) ministers. Each will comprise co-chairs and 10–15 members drawn from key sectors, including health and social care, industry and the third sector.

## **Champion groups**

### ***Driving improvements in health and care***

Co-chairs: Sir Ian Carruthers (NHS South West) and Sarah Pickup (ADASS)

### ***Creating dementia-friendly communities that understand how to help***

Co-chairs: Jeremy Hughes (Alzheimer's Society) and Angela Rippon

### ***Better research***

Led by the existing Ministerial Advisory Group on Dementia Research (MAGDR), with the work co-chaired by Dame Sally C Davies and Sir Mark Walport (Wellcome Trust)

## **Measuring progress**

Progress will be reported to the Prime Minister in September 2012. Thereafter progress will be reported to the Prime Minister in March 2013 and the Department of Health will review future reporting arrangements.

# Conclusion

Dementia is undoubtedly one of the major health and social care issues of our time. Until recently it was also one of the most ignored. The National Dementia Strategy has made a good start in addressing the needs of people with dementia, but we need to make more rapid progress. The wide range of new measures in this document demonstrate the Government's commitment on tackling dementia. By 2015, we intend that every person with dementia will be able to say the following:

"I get the treatment and support which are best for my dementia and my life."

"I know what I can do to help myself and who else can help me. My community is working to help me to live well with dementia."

"I wanted to take part in research and was able to do so."

Through research, we will in time find a cure. But until we do, every effort must and will be made to improve the lives of people with dementia and their families and carers.

# Annex A: List of actions

## Driving improvements in health and care

- **Increased diagnosis rates through existing checks for over-65s** We will ensure that GPs and other health professionals make patients aged 65 and older aware of memory clinics and refer those in need of assessment. From April 2013, there will be a quantified ambition for diagnosis rates across the country, underpinned by robust and affordable local plans.
- **Financial rewards for hospitals offering quality dementia care** From April 2012, £54m will be available through the Dementia CQUIN payment framework to hospitals offering dementia risk assessments to all over-75s admitted to their care. From April 2013, this will be extended to the quality of dementia care delivered. Also, for April 2013 access to all CQUIN rewards will be dependent on delivering support for carers in line with the NICE/SCIE guidelines.
- **An Innovation Challenge Prize of £1m** NHS staff can win up to £1m for innovative ideas for transforming dementia care.
- **A Dementia Care and Support Compact signed by leading care home and home care providers** Ten leading organisations have set out their commitment to deliver high-quality relationship-based care and support for people with dementia, and to engage, involve the wider community in this work.
- **We will promote the information offer pioneered by the NHS South West, which will be launched on 28 March 2012 and rolled out across the south by the end of 2012** From April 2013, information will be available in all other parts of the country. We will also be setting out in the Care and Support White Paper further steps to ensure all people receiving care and support get better information to support their care choices.
- **We will work with the profession to identify how best to improve early diagnosis of dementia through improvements in awareness, education and training and through potential improvements to the GP contract.**
- **We will ask NICE to consider ways of improving the dementia indicators in the Quality and Outcomes Framework.**
- **We will call on the Royal Colleges to respond to the challenge of dementia by bringing forward plans to ensure that all their members are capable and competent in dementia care.** The Royal Colleges have committed to driving this forward.
- **We will ensure that memory clinics are established in all parts of the country, and will work with the Royal College of Psychiatrists to drive up the proportion of memory services that are accredited, through publication of their national Memory Services Accreditation Programme, so that individual organisations can benchmark and report their own performance to drive improvement.**

- **The NHS will guarantee a written integrated personalised care plan to people with dementia.**
- **There will be better support for carers** The NHS is required to work closer than ever before with local carers' organisations and councils to agree plans, pool their resources, and make sure that carers get the support and break they deserve and that young carers do not take on excessive or inappropriate caring roles. We have made available an additional £400m to the NHS between 2011 and 2015 to provide carers with breaks from their caring responsibilities to sustain them in their role.
- **Carers have the right to be assessed and their needs met** In addition we know carers can take their support as a personal budget and they are encouraged to do so. The NHS should also ensure that a range of psychological therapies are commissioned and made available to carers of people with dementia in line with NICE/SCIE guidelines, as well as ensuring services are made available to support the couple relationship where one person is caring for a partner with dementia.
- **By September 2012 we will launch pilots of dementia clinical networks aimed at spreading clinical expertise.**
- **We welcome the Nursing and Care Quality Forum's forthcoming views on what should be done to address the needs of people with dementia as part of its work to spread best practice in nursing and care in all care settings.**

### **Creating dementia friendly communities that understand how to help**

- **Dementia-friendly communities across the country** By 2015, up to 20 cities, towns and villages will have signed up to become more dementia-friendly.
- **Support from leading businesses for the PM's Challenge on Dementia** Leading national organisations have already pledged to look at how they and others can play a part in creating a more dementia-friendly society and raising awareness of dementia.
- **Awareness-raising campaign** From autumn 2012, we will invest in a nationwide campaign to raise awareness of dementia, to be sustained to 2015. This will build on lessons learned from previous pilot campaigns and will inform future investment.
- **A major event over the summer, bringing together UK leaders from industry, academia and the public sector, to take forward the PM's Challenge on Dementia.**
- **We will work with the Alzheimer's Society to develop local Dementia Action Alliances to bring together people with dementia, their carers and key organisations, funded by £537,000 from the Department of Health over three years.**
- **We will make sure that people with dementia and carers on diagnosis have an information pack about dementia produced in conjunction with the Alzheimer's Society.**

- **The Dementia-friendly Communities Programme working in partnership with the Dementia Action Alliance will develop evidence on what a dementia-friendly community is.**

## **Better research**

- **More than doubling overall funding for dementia research to over £66m by 2015.** The combined value of the NIHR, MRC and ESRC funding for research into dementia will increase from £26.6m in 2009/10 to an estimated £66.3m in 2014/15.
- **Major investment in brain scanning** MRC will make a major additional investment in dementia research using the BioBank. MRC anticipates piloting the brain scanning of a subset of this national cohort, with a view to rolling out to 50–100,000 participants.
- **£13m funding for social science research on dementia (NIHR/ESRC)** including £3m for public health research.
- **£36m funding over 5 years for a new NIHR dementia translational research collaboration to pull discoveries into real benefits for patients. Four new NIHR biomedical research units in dementia and biomedical research centres which include dementia themed research will share their considerable resources and world leading expertise to improve treatment and care.**
- **Participation in high-quality research** Consent to participate in research will be one of the conditions of accreditation for memory services.
- **The MRC will spend over £3m in supporting the UK brain bank network, which connects all the UK brain banks for the benefit of donors, researchers and future patients** This includes £500k a year to improve the process for donation of brain tissue by meeting the costs of collecting brain tissue through the NHS, so smoothing the pathway to donation.
- **A major event will be staged for pharmaceutical and biotech companies to showcase the benefits of conducting dementia research in the UK, and to assess how best to remove the barriers to doing so.**
- **We will work towards recruiting 10% of patients into clinical trials.**
- **Up to £9m of DH funding will be made available for research into ‘living well with dementia’ and the delivery of dementia care.**
- **The DH will increase its support for capacity-building in dementia research, focusing on nurses as well as doctors.**
- **The MRC is a leading partner in two international initiatives in the area of neurodegeneration research: the European ‘Joint Programming’ initiative which aims to coordinate national efforts in this area; and the Centres of Excellence Network in Neurodegeneration (CoEN) which seeks to add value to existing investments in excellence.**

- **The world-leading MRC Laboratory of Molecular Biology (LMB) is moving to its new £200m facilities in Cambridge in the autumn** Within this, the Neuroscience Research Division has been provided with an expanded budget of £29m over the next three years, with a major part of its research dedicated to dementia/neurodegeneration.
- **The NIHR has also just completed a first-ever themed call for proposals in dementia research** Some £17m will be committed to new research projects through this call, exceeding original expectations. The 18 projects to be funded range from work on better diagnosis to improving care in a wide range of settings, from individual's own homes, through residential care to specialist hospitals.

# Annex B: Dementia Care and Support Compact

## Introduction

This Dementia Care and Support Compact is our response to the Prime Minister's Challenge on Dementia. It sets out our commitment to supporting the delivery of the National Dementia Strategy and improving care and support for people with dementia, their carers and families.

## Our challenge

We challenge the perceptions surrounding social care services for people with dementia. Our services will provide the right care, in the right place, at the right time.

People with dementia using our services will be able to say:

- I am respected as an individual.
- I get the care and support which enables me to live well with my dementia.
- Those around me and looking after me are well supported and understand how to maximise my independence.
- I am treated with dignity and respect.
- I know what I can do to help myself and who else can help me.
- I can enjoy life.
- I feel part of a community and I am inspired to participate in community life.
- I am confident that my end-of-life wishes will be respected. I can expect a good death.

## Our commitment

We will:

- focus on quality of life for people with dementia, as well as quality of care. By knowing the person, their life history and their personal culture, our staff will deliver a personalised package of care and support;
- set a benchmark for high-quality relationship-based care and support for people with dementia. We will inspire and encourage our sector to take responsibility for delivering this, building on existing good practice;
- engage and involve the wider community to improve their support for people with dementia, including GPs and healthcare professionals;
- play our part in supporting the wider community, sharing the knowledge and skills of our staff, and inviting people into our care settings;
- work with commissioners of care for people with dementia to ensure they commission quality care services appropriately; and
- clearly set out how we have delivered on this Compact to make a difference for people with dementia, their carers and families. This will link into the work on quality and transparency being taken forward as part of the Care and Support White Paper.

## **Signatories**

Martin Green, Chief Executive, English Community Care Association and DH Independent Sector Dementia Champion

Jane Ashcroft, Chief Executive, Anchor

Mike Parsons, Chief Executive, Barchester Healthcare

Stuart Fletcher, Chief Executive, BUPA

Mike Parish, Chief Executive, Care UK

Miranda Wixon, Executive Committee Member, CERETAS

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