

# Transforming the Quality of Dementia Care

*Consultation on a National Dementia Strategy*



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# Foreword by Alan Johnson MP Secretary of State for Health



Dementia can be a devastating disorder for both those who develop the illness and the families who care for them. It is also very common, with over 570,000 people already living with dementia in England. This is a daunting number. It has been estimated that the cost of dementia care exceeds that of cancer, heart disease and stroke combined. Given our ageing population, this is a challenge that will only grow in size, with the number of people with dementia projected to double in the next 30 years. This is not an illness that we can shut our eyes to, and a strategic approach is vital.

The Government has identified dementia as a national priority. In August last year, we announced a one-year programme to develop a National Dementia Strategy and implementation plan for England. The work undertaken has concentrated on three key themes:

- improving awareness of dementia, both among the general public and among health and social care professionals;
- ensuring that the condition is diagnosed as early as possible to allow for early intervention; and
- delivering a high quality of care and support for both those with dementia and their carers.

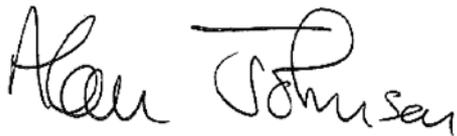
The biggest mistake we can make is to assume that nothing can be done for dementia, and that it is just a natural consequence of getting older. This is a common misunderstanding, not just among the public but often among those providing and commissioning health and care services as well. In practice, a great deal can be done to delay the onset and progression of the condition, and to improve the quality of life of all involved.

We must remove the stigma attached to dementia, which is similar in many ways to the stigma that cancer used to carry in the past. Getting these messages across is vital if we are to ensure early diagnoses and the delivery of the best-quality services.

I am enormously grateful to all those who have contributed to developing this draft strategy. My thanks go to Neil Hunt of the Alzheimer's Society for chairing the External

Reference Group of stakeholders, which has provided invaluable advice to the Department of Health. I am also grateful to Professor Sube Banerjee and Jenny Owen for leading the work of the project working group. They have achieved a great deal in a short space of time.

The aim of this document is to stimulate debate on how we can develop the final strategy, and ensure a better life in the future for all those affected by dementia. I hope that you will add your voice to the debate after considering the draft strategy and its recommendations.

A handwritten signature in black ink that reads "Alan Johnson". The signature is written in a cursive style with a prominent horizontal line above the "J" in Johnson.

Alan Johnson MP  
Secretary of State for Health

# Foreword by Ivan Lewis MP Parliamentary Under- Secretary of State for Care Services



In August last year, I announced a one-year programme to develop the first National Dementia Strategy for England. This consultation is one of the most important stages in the development of that strategy. It gives people with dementia, their families and carers, and those involved professionally in health and social care, a chance to tell us what they think needs to be done to improve dementia care.

We can no longer ignore dementia, or pretend that it is just an inevitable consequence of the ageing process. A strategic, cross-cutting approach is vital if we are to deal with the challenges and consequences of dementia as a society. We are not just asking you to consider how services for dementia can be improved, but also how we might make services as a whole work better for people with dementia and their families. Improving dementia care is part of our broad health and social care agenda, and it is also part of the personalisation agenda, the recently published Carers' Strategy, the review of care services and Lord Darzi's review of the NHS. These initiatives will all improve care for people with dementia.

During the last year I have met many hundreds of people involved with the care of people with dementia and it has brought home to me the catastrophic impact that the illness has – not only on those who develop it, but also on the families who care for them and on society as a whole. I have also been made aware of the immense amount of positive work that can be done to help people with dementia and their carers to lead good-quality lives. There are already over half a million people with dementia in England, and this number will rise significantly as our population ages.

People with dementia, their families and carers all want – and have the right to expect – services that have dignity and respect at their heart. The vast majority of people with dementia want to live in their own homes for as long as possible, and when it is no longer possible, there need to be care homes with well-trained staff, offering good-quality care.

There is no need for me to reiterate the key themes of this consultation, as they are covered in detail elsewhere. Instead I would like to pass on my gratitude to those who have brought us from a germ of an idea last August to this consultation in just 10 short months. An enormous amount of work has taken place, and I would like to thank specifically the Alzheimer's Society and the External Reference Group for their input, as well as the Department of Health's working group for developing this document.

The next key step in the development of the National Dementia Strategy is for you to add your voice to the debate and help us to improve the care of people with dementia.

A handwritten signature in black ink, appearing to read 'Ivan Lewis'. The signature is fluid and cursive, with a large initial 'I' and a long, sweeping underline.

Ivan Lewis MP  
Parliamentary Under-Secretary of State for Care Services

# Introduction by Sube Banerjee and Jenny Owen, joint leads of the National Dementia Strategy



Our vision is for the positive transformation of dementia services over the next five years. What would that look like? It would be a system where all with dementia have access to the care and support they need. Where public and professionals alike are well informed; where the fear and stigma associated with dementia have been abolished; and the false beliefs that dementia is a normal part of ageing and that nothing can be done have been corrected. It would be a system where families affected by dementia know where to go for help, what services to expect, and one where the quality of care is high and equal wherever they might live.

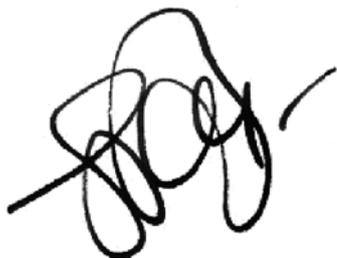
We have a unique chance here to help this to happen. In the next five years we can build an environment where people are encouraged to seek help early for problems with memory, and do so. Where they receive a prompt and competent specialist assessment, followed by an accurate diagnosis, sensitively given. Where the care and support needed is given immediately.

We have had the clearest of messages that people affected by dementia need to be supported in a seamless manner from the point of diagnosis onwards. This means health and social care services for dementia that enable:

- access to continuity of support for people with dementia and their carers (“someone to turn to if I am worried or when things go wrong”);
- access to good-quality information about dementia and the local help that is available (“I want to know where I can find help”);
- access to good-quality care at home, in hospital or in a care home – provided by people with an understanding of dementia (“they need to know how dementia changes things”); and
- access to peer support (“I don’t feel embarrassed, they really understand”).

One of our key objectives is to empower people to make choices about what they want and to control their care. This consultation document sets out a series of recommendations that put people with dementia and their carers at the heart of planning their lives, ensuring that they are informed and supported to make choices.

We present here recommendations for a programme of transformational change; now we need your views on how we can achieve these goals. The challenge is to generate services that provide people with dementia and their family carers with the help and support they need throughout the course of the illness, enabling them to lead lives of the best quality possible. We would therefore very much value your thoughts and ideas on what is proposed, and on how you think we can improve the quality of life and quality of care for people with dementia and their families.

A handwritten signature in black ink, appearing to read 'S. Banerjee', with a stylized, overlapping loop structure.

Professor Sube Banerjee  
Professor of Mental Health and Ageing, Institute of Psychiatry, King's College London, and  
Department of Health Senior Professional Adviser in Older People's Mental Health

A handwritten signature in black ink, appearing to read 'J. Owen', with a simple, cursive style.

Jenny Owen  
Association of Directors of Adult Social Services, and  
Executive Director, Adults, Health and Community Wellbeing, Essex County Council

# Executive summary

## Our aim

Our aim is to ensure significant improvements across three key areas in relation to dementia services: improved awareness, earlier diagnosis and intervention, and a higher quality of care. This document is intended to help people contribute to our consultation by summarising, using best evidence, outlining the priorities for change that we have identified and setting out what kinds of interventions and models of care might help to bring this about.

## The opportunity

Important advances in our understanding of dementia and its impact in the last two years mean that we are now able to take a strategic approach to service development for people with dementia and their family carers. The Alzheimer's Society's *Dementia UK* report has given us clear estimates of the number of people with dementia now, as well as projections of future growth. The National Institute for Health and Clinical Excellence (NICE)/Social Care Institute for Excellence (SCIE) clinical guideline on dementia provides a clear summary of the immense amount that can be done to enhance the quality of life of people with dementia at all stages of the illness through the provision of good-quality care. Finally, analyses completed by the National Audit Office identified shortcomings in our current systems but they also highlight the likelihood that investing in improving the quality of services for people with dementia to address current shortcomings would lead not only to substantial improvements in the quality of life of people with dementia, but also to savings in terms of acute hospital use and admission to care homes.

## The issue

There can be no doubt about the current and future challenge posed by dementia. There are an estimated 24.3 million people with dementia worldwide, while in the UK, best estimates suggest that the number is currently 700,000, of whom approximately 570,000 live in England. Dementia costs the UK economy £17 billion a year, and in the next 30 years the number of people with dementia in the UK will double to 1.4 million, with the costs trebling to over £50 billion a year.

While the numbers and the costs are daunting, the impact on those with the illness and on their families is also profound. Dementia results in a progressive decline in multiple areas of function, including memory, reasoning, communication skills and skills needed to carry out daily activities. Alongside this decline, individuals may develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering, which complicate care and can occur at any stage of the illness. Family carers of people with dementia are often old and

frail themselves, with high levels of depression and physical illness, and a diminished quality of life. Dementia is a terminal condition, but people can live with it for 7–12 years after diagnosis.

## The context

The size of the population affected by dementia and the pervasiveness of the condition mean that the development of policy and services for people with dementia and their families is also affected by the wider policy context. This currently includes initiatives, guidance and policy statements such as ‘Our NHS, Our Future’, *Putting People First: A shared vision and commitment to the transformation of adult social care*, the current public debate on the future of the care and support system, the NICE commissioning guide on memory assessment services, the Carers’ Strategy and the National End of Life Care Strategy. Getting services right for people with dementia would make a positive contribution to all of these.

## Work to date

We have a unique opportunity to review our current services and generate a system that can work for people with dementia for the next generation – one that empowers people with dementia and their carers, putting them at the centre so that they are in control, and one that delivers the outcomes they need. This consultation is part of a one-year programme, launched in August 2007, to generate a National Dementia Strategy and implementation plan.

We have identified three main aims:

- improved public and professional awareness of dementia;
- early diagnosis and intervention; and
- high-quality care and support.

The work has been jointly led by health and social care professionals (Professor Sube Banerjee and Jenny Owen) working with an External Reference Group of stakeholders (including people with dementia and their carers) and chaired by the Chief Executive of the Alzheimer’s Society, Neil Hunt.

## The consultation

We have framed the proposals for consultation around the outcomes – and therefore the service models – that, based on best evidence, we think will enable us to reach our five-year goal of significant improvements in the care and support available for people with dementia. This document contains suggestions on which we are seeking comments from the public, from those affected by dementia, and from those commissioning and providing services of all kinds. This document is not intended as a prescription for local commissioners – on the contrary, it presents a digest of possible priorities and actions that might improve the quality of life of and the quality of care for people with dementia and their family carers. Commissioning decisions

will depend on local analyses and prioritisation, including a consideration of how best to use existing resources. The system supporting implementation would include the world-class commissioning programme, joint commissioning by local authorities, primary care trusts (PCTs) and voluntary bodies, the Department of Health providing support for system change, and the regulator measuring success. We invite your views on whether the outcomes we have identified are the correct ones, and how they might be achieved.

## **Outcomes we want to achieve**

### ***Improved awareness***

#### **Recommendation 1: Increased public and professional awareness of dementia**

Outcome: Public and professional awareness and understanding of dementia to be improved and the stigma associated with it addressed. Individuals should be informed of the benefits of timely diagnosis and care, the prevention of dementia should be promoted, and social exclusion and discrimination should be minimised.

#### **Recommendation 2: An informed and effective workforce for people with dementia**

Outcome: All health and social care staff involved in the care of people with dementia to have the skills needed to provide the best-quality care in the roles and in the settings where they work. To be achieved through effective basic training, and continuous professional and vocational development in dementia.

### ***Early diagnosis and intervention***

#### **Recommendation 3: Good-quality early diagnosis and intervention for all**

Outcome: All people with dementia to have access to a pathway of care that delivers:

- a rapid and competent specialist assessment;
- an accurate diagnosis that is sensitively communicated to the person with dementia and their carers; and
- immediate treatment, care and support following diagnosis.

The system needs to have the capacity to see all those with dementia.

#### **Recommendation 4: Good-quality information for those with dementia and their carers**

Outcome: People with dementia and their carers to be provided with good-quality information on the illness and on the services available – both at diagnosis and throughout the course of their care.

#### **Recommendation 5: Continuity of support and advice**

Outcome: Continuous support and advice to be provided for those diagnosed with dementia and their carers.

### ***High-quality care and support***

#### **Recommendation 6: Improved quality of care in general hospitals**

Outcome: An improved quality of care to be provided in general hospitals for people with dementia.

#### **Recommendation 7: Improved home care for people with dementia**

Outcome: Home care services to better meet the needs of people with dementia and their carers.

#### **Recommendation 8: Improved short breaks for people with dementia and their family carers**

Outcome: Short break services to better meet the needs of people with dementia and their family carers.

#### **Recommendation 9: A joint commissioning strategy for dementia**

Outcome: Commissioning and planning mechanisms to be established to determine the services needed for people with dementia and their carers, and how best to meet their needs.

#### **Recommendation 10: Intermediate care for people with dementia**

Outcome: Intermediate care to be made accessible to people with dementia and to meet their needs.

#### **Recommendation 11: Improved dementia care in care homes**

Outcome: Quality of care in care homes to be improved for people with dementia.

#### **Recommendation 12: Improved registration and inspection of care homes**

Outcome: Inspection regimes for care homes to better assure the quality of the dementia care provided.

### ***Delivering the National Dementia Strategy***

#### **Recommendation 13: Clear information on the delivery of the National Dementia Strategy**

Outcome: Good-quality information to be available on the development of dementia services as the strategy is delivered.

#### **Recommendation 14: A clear picture of research evidence and needs**

Outcome: Evidence to be available on the existing UK research base on dementia, and on the gaps that need to be filled.

#### **Recommendation 15: Effective support for implementation**

Outcome: Appropriate national support to be available in support of local implementation of the strategy.

# Purpose and scope of this document

The Department of Health is developing a national strategy for dementia services. This document is consulting on evidence drawn from a wide range of reports and stakeholders, a series of preliminary listening events involving over 3,000 people and the recommendations of an External Reference Group (ERG).

## The National Dementia Strategy

The final strategy is intended to:

- provide a strategic framework within which local services can deliver quality improvements to dementia services, recognising the need to ensure that services are accessible to all whilst being responsive to the specific needs of communities who usually experience disadvantage – eg. people with a disability, and those who are socially excluded (black and minority ethnic communities; lesbian, gay, bisexual and transgender communities etc) – thus leading to a reduction in health inequalities;
- provide advice and guidance to health and social care commissioners, strategic health authorities (SHAs), local authorities, hospitals and PCTs on the planning, development and monitoring of services; and
- provide a guide to high-quality health and social care services to inform the expectations of those affected by dementia and their families.

## General principles

The final strategy will aim to deliver services for everyone with dementia and their families that:

- are based around the needs of individuals and their families;
- are consistent with the evidence base, where this exists, or with national consensus guidelines;
- are consistent with the relevant National Service Frameworks, and address the recommendations of both the National Audit Office report *Improving services and support for people with dementia* and the subsequent Public Accounts Committee report;
- are integrated across health, social care and the third sector;
- address health inequalities related to dementia; and

- enable local health and social care communities to respond to local needs and circumstances.

## **Developing the strategy**

This draft strategy has been developed under the auspices of a Department of Health Programme Board, which has provided the strategic oversight and determined the governance of the whole project; a working group, which was responsible for the writing of this document; and an ERG, which was convened and chaired by Neil Hunt, the Chief Executive of the Alzheimer's Society.

Three ERG sub-groups were appointed – one to work on each theme of the strategy, which were improving public and professional awareness; early diagnosis and intervention; and high-quality care and support. The ERG and its sub-groups had a broad inclusive membership – a full list of members can be found at Appendix 1. The ERG generated a comprehensive report on improving dementia care, which informed the work of the Department of Health working group responsible for developing the strategy. This is available on the Alzheimer's Society website at [www.alzheimers.org.uk](http://www.alzheimers.org.uk), and on the Department of Health website at [www.dh.gov.uk/dementia](http://www.dh.gov.uk/dementia).

In addition to the work of the ERG, a wider initial stakeholder consultation was also undertaken. This included regional listening and engagement events organised jointly by the Care Services Improvement Partnership (CSIP) and the Alzheimer's Society. Thanks to these events, more than 3,000 people have been able to contribute to and engage with the strategy to date. The Alzheimer's Society also ran similar events especially for people with dementia and their carers, and distributed questionnaires through its branches and online. Feedback from all of these sources was reviewed to ensure that everyone's views had been captured, and those involved in the process were struck by the consistency of the messages that were returned. However, a screening of the evidence available has suggested that there are gaps in our understanding of the provision of and access to services for particular groups. The Department of Health is committed to addressing these issues through the Equality Impact Assessment of the strategy. We will be highlighting some of these issues in a partial equality impact assessment, to be published in early July on the dementia website at [www.dh.gov.uk/dementia](http://www.dh.gov.uk/dementia), as part of this consultation.

## **The consultation document**

This consultation document is based on the work of the ERG (informed by the nationwide listening and engagement exercise), discussions with stakeholders and a thorough review of the evidence. It sets out an analysis of the main challenges currently facing services for people with dementia and their families in England, and how these can be met.

The recommendations at the beginning of each chapter summarise outcomes that have been identified as priorities for delivery, while the text that follows discusses potential ways to achieve these outcomes in the context of the evidence that is available. In order to aid readability, we have not presented extensive referencing or details of specific interventions, or a full review of the evidence base. The reader is instead signposted to the relevant literature.

A full and detailed consideration of the options for dementia care can be found in documents such as the National Institute for Health and Clinical Excellence/Social Care Institute for Excellence clinical guideline on dementia.<sup>1</sup> The consultation document is accompanied by a partial impact assessment, which looks at the broad economic and social costs and benefits of making the recommended changes (available on the Department of Health website, at [www.dh.gov.uk/dementia](http://www.dh.gov.uk/dementia)). A full impact assessment will accompany the final strategy.

All interested stakeholders are invited to comment on the recommendations outlined in this document. When commenting, stakeholders may wish to consider the feasibility, priorities and the broad economic and social costs and benefits of recommendations – as well as their effectiveness.

The consultation period began on 19 June 2008 and will end on 11 September 2008. Details of how to respond are included in Appendix 2. The Department of Health will use the responses to this consultation in the development of the National Dementia Strategy.

An easy-access version of this document is also available on the Department of Health website, at [www.dh.gov.uk/dementia](http://www.dh.gov.uk/dementia), and hard copies can be obtained by calling the Department of Health Orderline on 08701 555 455 (see back cover for the reference number and further details).

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<sup>1</sup> National Institute for Health and Clinical Excellence/Social Care Institute for Excellence (2006). *Dementia: Clinical guideline*. London: NICE/SCIE.

# Setting the scene

## The story of one person with dementia

I had been an engineer for 28 years when I realised that things were getting out of hand. One day I had gone to do some safety checks on an electrical distribution board, and on opening the cabinet door and removing the covers, I realised that all the cables looked the same – I had no idea what was what. I began to realise that all my electrical training had gone, so I returned to my office to have a cup of tea while I gathered my thoughts.

The telephone rang. It was a lady who wanted to speak to me, but I did not know what she wanted and put the phone down. After a few moments it rang again, and the same lady said, “Dad, it’s me, your daughter. Why won’t you talk to me? What’s wrong?”. I then realised that I did not remember what my daughter sounded like.

I saw a locum doctor who said that I was just stressed, and signed me off for a month. I knew that it was not stress, but the doctor refused to listen to me. Three weeks later I went back to the doctor and was told that I was depressed. After my wife spoke to the doctor, she agreed to send me to hospital to see a specialist. I was signed off for another month. I received an appointment with the Neurology Department and had an MRI scan three months later. Two months after that I returned to see the neurologist for the results of the scan, only to find that he had forgotten to send me for other tests. Two weeks later I had an appointment with a neuro-psychologist from 10am to 4pm, after which he said that I was lazy and had not tried to do the tests. I went home in tears – I had tried my best but just could not understand or cope with the tests.

I had an EEG and a blood test, and a month later an appointment had been arranged at the hospital so that I could be given my diagnosis. But at 8.30am the consultant’s secretary rang to say that the consultant had gone to a conference in Vancouver, and she had to cancel all of his appointments. There was no one else available to do his clinic. I really could not believe this – we hear of so many people who don’t turn up for their hospital appointment, and yet here was a consultant doing just that.

The next day I returned to the health centre, where the GP said that she was going to arrange for a different consultant to take over as she was not happy with the way the hospital was treating me. A week later the consultant returned and said that he now wanted me to have a lumbar puncture and an appointment would be made. We rang back to be told that the consultant was going on holiday the following week, but that we should ring the ward the following Monday. My wife rang, and was told that they knew nothing about me or my lumbar puncture. The consultant's secretary was also contacted, but she didn't know anything either. I then received a phone call from the consultant to ask why I had rung, and an appointment was made for two weeks later.

I went to the hospital in the morning for the lumbar puncture, and stayed there until the doctor came to do the work at 2.30pm – the ward hadn't been able to find a doctor. A month later my wife went to the hospital to find out what was happening, as we had heard nothing about my next appointment. It appeared that my notes had been sent off somewhere, but no one knew where. After waiting one-and-a-half hours, we had a call to say that I had an appointment the next week. At my final appointment I was told that I have Lewy Body dementia, but was not classed as ill enough to get the medication under the guidelines, and would be re-assessed in six months. This was done by a different consultant, and I was not told anything about Lewy Body dementia.

I had to retire, which also meant that I lost my home (which went with my job). My mother died so we decided that we should move back to the North East and live in the family home. The hospital consultant, our GP and the occupational health doctor all gave us letters explaining what had happened, in the hope that this would speed things up in the future. The letters were handed over to our new GP, who then arranged for me to see a neurologist at our local hospital. Four months later I saw the neurologist, who said that he would refer me to see a psychiatrist who dealt with dementia in this area.

A month later I had a home visit by the psychiatrist, who told us that she had sent off for my notes, but that they seemed to have been lost somewhere. I was referred to have a brain scan. A week later I went for an appointment with a neuro-psychologist for the first of three assessments, which were monitored to ensure that I was well enough to carry on. I then had an appointment at the outpatient clinic, where I was given my diagnosis again and was told what it meant. I was also offered medication, but before I was allowed to take it, I was sent home with all of the information about the drug and its side effects to think about it. An appointment was arranged for two weeks later so that I could be put on a trial course of the medication.

Since then my life has improved so much that I now realise that this was building up long before I knew that I had a real problem. I now have some control over my life, and in many ways I feel as though the fog has totally lifted, allowing me to see and think for myself again.

In conclusion, I can only say that the procedure at the first hospital was the most stressful experience I have ever been through – it bore no comparison with my experience with the psychiatrist. It felt as though the first doctors really did not care about this illness or about the patients, and that is very wrong in this health service. The reason I say this is because of the doctors' cavalier attitudes, and the number of times that they forgot to send me for the specified tests. This all proves that there is such a thing as a postcode lottery in this country. Please do not allow this to happen to anyone else. Having this illness is bad enough without being messed around by specialists who do not care.

## What is dementia?

The term dementia is used to describe a clinical syndrome that results in a progressive decline in multiple areas of function, including memory, reasoning, communication skills and the skills needed to carry out daily activities. Alongside this decline, individuals can develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering, which complicate care and can occur at any stage of the illness.

The causes of dementia are not entirely understood, but they result in structural and chemical changes in the brain. The main sub-types of dementia are Alzheimer's disease, vascular dementia, mixtures of these two pathologies ('mixed dementia'), and rarer types such as Lewy Body dementia and fronto-temporal dementia. The term 'Alzheimer's disease' is sometimes used to cover all forms of dementia.

All types of dementia have the same devastating impact on those affected and their family carers. Dementia affects everyone in society – irrespective of gender, ethnicity or class. It can affect adults of working age as well as older adults, and people with learning disabilities are a particular risk group. This strategy is designed to address the needs of everyone with dementia, no matter what type of dementia they have, what age they are, or what their ethnic origin or social status are.

## What is the impact of dementia?

Dementia is one of the most severe and devastating illnesses we face. It is also very common: there are approximately 570,000 people with dementia in England.<sup>2</sup> Dementia is

<sup>2</sup> Knapp, M, Prince, M, Albanese, E, Banerjee, S, Dhanasiri, S et al (2007). *Dementia UK: The full report*. London: Alzheimer's Society.

predominantly a disorder of later life, but at least 15,000 people under the age of 65 have the illness. Its incidence (the number of new cases per year) and prevalence (the number of cases at any one time) rise exponentially with age, and it affects men and women from all social and ethnic groups. Around 15,000 people from minority ethnic groups have some form of dementia, but this number is set to rise sharply as their populations age.

The *Dementia UK* report estimates the cost of dementia for the UK as a whole to be about £17 billion per year, and projects that the number of people with dementia will double to 1.4 million in the next 30 years. In the same brief period, the costs associated with dementia are set to treble to over £50 billion per year.<sup>3</sup> Dementia has a devastating impact on those with the disorder, but it also has profound, negative effects on the family members who provide the majority of all care. Family carers are often old and frail themselves, and suffer high levels of care burden, depression and physical illness, and a diminished quality of life. Dementia is a terminal disorder, but people can live with it for 7–12 years after diagnosis. The challenge we have is how to enable people with dementia and their carers to live as well as possible, maximising their quality of life.

The National Audit Office has identified problems in the current systems of health and social care for dementia. Its report *Improving services and support for people with dementia* estimates that approximately two-thirds of people with dementia don't receive a formal diagnosis – or have contact with specialist services – at any time in their illness.<sup>4</sup> It is also of concern that such diagnosis and contact, when made, often only occurs late in the illness and when the person with dementia is in crisis – so the opportunities for harm prevention and maximising quality of life are limited. If dementia is not diagnosed, the person with the illness and their family carers are denied the possibility of making choices themselves. They are unable to plan for their future and don't have access to the help, support and treatments (social and psychological, as well as pharmacological) that are available.

Contrary to popular belief, a great deal can be done to provide help for people with dementia and their carers (this has been well summarised in the NICE/SCIE clinical guideline on dementia). While there are undoubtedly potential negative reactions to diagnoses,<sup>5</sup> the balance is very much in favour of making these early – the earlier they are made, the better.<sup>6</sup> There is clear evidence that providing people with a diagnosis decreases their levels of depression and anxiety.<sup>7</sup>

3 Comas-Herrera, A, Wittenberg, R, Pickard, L and Knapp, M (2007). 'Cognitive impairment in older people: future demand for long-term care services and the associated costs.' *International Journal of Geriatric Psychiatry*, 22, 1037–45.

4 National Audit Office (2007). *Improving services and support for people with dementia*. London: TSO.

5 Iliffe, S, Manthorpe, J and Eden, A (2003). 'Sooner or later? Issues in the early diagnosis of dementia in general practice: a qualitative study.' *Family Practice*, 20, 376–81.

6 NICE/SCIE (2006). *Dementia: Clinical guideline*. London: NICE/SCIE.

7 Carpenter, BD, Xiong, C, Porensky, EK, Lee, MM, Brown, PJ, Coats, M, Johnson, D and Morris, JC (2008). 'Reaction to a dementia diagnosis in individuals with Alzheimer's disease and mild cognitive impairment.' *Journal of the American Geriatrics Society*, 56, 405–12.

The data available is limited, but UK activity in terms of the diagnosis and treatment of people with dementia is generally low. There are also significant variations between areas that are not explained by the numbers of people with dementia in those areas. International comparisons suggest that the UK is in the bottom third of European performance,<sup>8</sup> with less than half the activity of France, Sweden, Ireland and Spain. The National Audit Office's report recommended that services need to be redesigned so that dementia is diagnosed early and well, and people with dementia and their family carers can receive the treatment, care and support that will enable them to live as well as possible with dementia.

This consultation document sets out the significant role that the health and social care community needs to play in supporting people who are affected by dementia. However, a clear message from the listening exercises has been that transforming the quality of life of people with dementia is also about empowering those people to make choices about what they want, and enabling them to care for themselves. This strategy therefore sets out a series of recommendations to put people with dementia and their carers at the heart of planning their lives. It seeks to ensure that – in addition to adequate services being in place – people are informed and supported to make choices. One of the central principles underpinning the strategy will be that, in addition to providing formal services, statutory and non-statutory bodies also need to provide people with the means to support themselves.

Formal means of putting people in control will be developed through the use of individual budgets and rights under the Mental Capacity Act. The human rights of people with dementia need to be safeguarded and a set of ethical issues related to the care of people with dementia needs to be debated. However, self-care and systems that support self-care are crucial, so this document talks specifically about the importance of access to information (written, online and face-to-face) and peer support networks. People with dementia and their carers have already made it very clear that one of the things they value most is being in contact with other people who have experience of dementia and who can provide support.

## The policy framework

Services for people with dementia are complex, and include primary health care, specialist services in mental health (eg old-age psychiatry), care provided in general hospitals (eg geriatrics and neurology), as well as social care commissioned and provided by both local authorities and the voluntary and independent sectors. There are examples of excellent dementia care provided by all of these agencies, and this document is informed by them.

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<sup>8</sup> Waldemar, G, Phung, TT, Burns, A et al (2007). 'Access to diagnostic evaluation and treatment for dementia in Europe.' *International Journal of Geriatric Psychiatry*, 22, 47–54.

The last decade has seen a growing acknowledgement of the challenge posed by dementia and the need for service improvement. Details of relevant reports and initiatives are provided in Appendix 3, but key documents include:

- the Audit Commission's report *Forget me not*;<sup>9</sup>
- the *National Service Framework for Older People*;<sup>10</sup>
- the Care Services Improvement Partnership (CSIP) service development guide *Everybody's business*;<sup>11</sup>
- the National Institute for Health and Clinical Excellence (NICE) and Social Care Institute for Excellence (SCIE) joint clinical guideline on the management of dementia;
- the Alzheimer's Society *Dementia UK* report; and
- the National Audit Office's report and the subsequent report of the Public Accounts Committee.<sup>12</sup>

In response to this increasing clarity on the nature of the health and social care challenge posed, the Government has made improving dementia care a national priority. A one-year programme to develop a National Dementia Strategy and implementation plan was announced by Ivan Lewis, the Parliamentary Under-Secretary of State for Care Services, in August 2007. It has three main objectives:

- to improve awareness of dementia among the public and professionals;
- to ensure that the condition is diagnosed as early as possible to allow for early intervention; and
- to deliver a high quality of care and support for both those with dementia and their carers.

## Wider policy context

The size of the population affected by dementia and the pervasiveness of the condition in health and social care settings mean that the development of policy and services for people with dementia and their families is also affected by the wider policy context. This currently includes initiatives, guidance and policy statements such as:

9 Audit Commission (2000). *Forget me not: Mental health services for older people*. London: TSO.

10 Department of Health (2001). *National Service Framework for Older People*. London: TSO.

11 CSIP (2005). *Everybody's business: Integrated mental health services for older adults: a service development guide*. London: Department of Health.

12 Public Accounts Committee (2008). *Improving services and support for people with dementia*. London: TSO.

- ‘Our NHS, Our Future’;
- *Putting People First: A shared vision and commitment to the transformation of adult social care*;
- the current public debate on the future of the care and support system;
- the NICE commissioning guide on memory assessment services;
- the Carers’ Strategy; and
- the National End of Life Care Strategy.

Getting services right for people with dementia would make a positive contribution to all of these.

## Issues for commissioners and service providers

Dementia presents key challenges to commissioners in terms of how to commission services that can meet the needs identified, starting from the current generally low level of service provision. These commissioning challenges have their counterpart for service providers in the health and social care community. This document is not intended as a prescription for local commissioners – quite the opposite. What it presents is a digest of possible priorities and actions that we believe could improve the quality of life of and the quality of care for people with dementia and their family carers. Commissioning decisions will depend on local analyses and prioritisation, including a consideration of how best to use existing resources. Nothing in this consultation document is designed to inhibit local discretion – rather it is designed to trigger regional and local consideration of the issues, and to generate responses to inform the development of the strategy.

It is clear from *Everybody’s business* and the NICE/SCIE clinical guideline that dementia care is an issue for the health and social care system as a whole, rather than simply being the responsibility of specialist older people’s mental health services. These specialist services have a role that extends beyond dementia alone – they have responsibility for older adults with schizophrenia, depression and mania, as well as for those with dementia that is complicated by mental and/or behavioural disorders. These specialist services are, however, an important part of service provision for people with dementia, and it is not the intention of the strategy to minimise the importance of the non-dementia work carried out by these services.

The nature of risk and need in older people with mental disorders means that, in order to provide services that are of equivalent quality to those available to adults of working age, specific provision needs to be made in terms of specialist community mental health teams and inpatient services for older people that can deliver good-quality care that is attuned to their specific needs. The natural history of dementia means that a substantial proportion of those affected will develop challenging behaviour, and symptoms such as depression,

hallucinations and delusions. These are likely to require care from specialist older people's mental health services: for the system as a whole to work for people with dementia and their carers, these services need to be effective and available.

Service redesign and innovation will be needed to achieve the transformational change required to ensure that all those with dementia have a chance of receiving high-quality diagnosis and care, rather than just a minority receiving it. Such change will not be simple, but it is what the people who use the services want, and what the evidence base indicates will be most effective.

## Implementation plan

The Department of Health will draft an implementation plan to accompany the final strategy, which are expected to be issued together in October. The plan will rely on using existing levers to drive forward the strategy:

- Local commissioning procedures and decision making.
- The regulatory regime of the Care Quality Commission – used to review the success of the quality of dementia services commissioned.
- The commissioning framework, with an example of how to commission dementia services being part of world-class commissioning guidance.
- Support from the Department of Health for system change in dementia.
- Lord Darzi's 'Our NHS, Our Future' initiative.
- Public Service Agreement and local government indicators relating to older people.
- Local area agreements, including for dementia services.
- Evidence from the Partnerships for Older People Projects, LinkAge Plus and Invest to Save project, and from the current social care pilots for individual budgets.

**Figure 1: The vision of the National Dementia Strategy**



# Chapter 1 – Improved awareness

“Awareness is very mixed. A much more ‘hidden’ disease than, for example, cancer. I think it is difficult for a carer to explain that a partner, relative or close friend has dementia. Stigma remains strong.” *Carer*

“Professionals are almost non-existent in comprehension, knowledge or understanding except for a few individuals.” *Person with dementia, previously a carer*

“This condition is not openly talked about. Some people seem to feel ashamed if someone in their family has this condition. Many people still refer to people with dementia as ‘mental’, ‘doolally’, ‘off with the fairies’ or similar terms. Most people don’t regard themselves as at risk of developing this condition.” *Voluntary sector worker*

“It’s all hidden away in houses. People do not discuss it, and at the moment wider society is not discussing it either.” *Full-time carer*

“Everyone knows it exists, of course, but it is often seen as a bit of a joke. When I tell people about my nan with Alzheimer’s, they always ask ‘does she still recognise you?’. I reply no and then try to explain how badly she is suffering in so many other ways. The fact that she doesn’t recognise me is the tip of the iceberg. People think that Alzheimer’s is when you go a bit bonkers in an amusing and sweet way. Not so!” *Nan has Alzheimer’s, mother involved in her care*

“I think people know the names [of these illnesses] but do not understand what they represent. It is complex to convey what they mean – especially without alarming people and stigmatising people with dementia.” *Husband and wife caring for 87-year-old mother*

“GPs appear aware, but I believe they sometimes lack the confidence to diagnose and/or refer on to specialists for further investigation. Probably because of the mistaken belief that nothing much can be done and that the diagnosis comes with a significant social stigma.” *Clinical psychologist*

**Recommendation 1: Increased public and professional awareness of dementia**

Outcome: Public and professional awareness and understanding of dementia to be improved and the stigma associated with it addressed. Individuals should be informed of the benefits of timely diagnosis and care, the prevention of dementia should be promoted, and social exclusion and discrimination should be minimised.

## Objectives

The objectives of this element of the strategy are that:

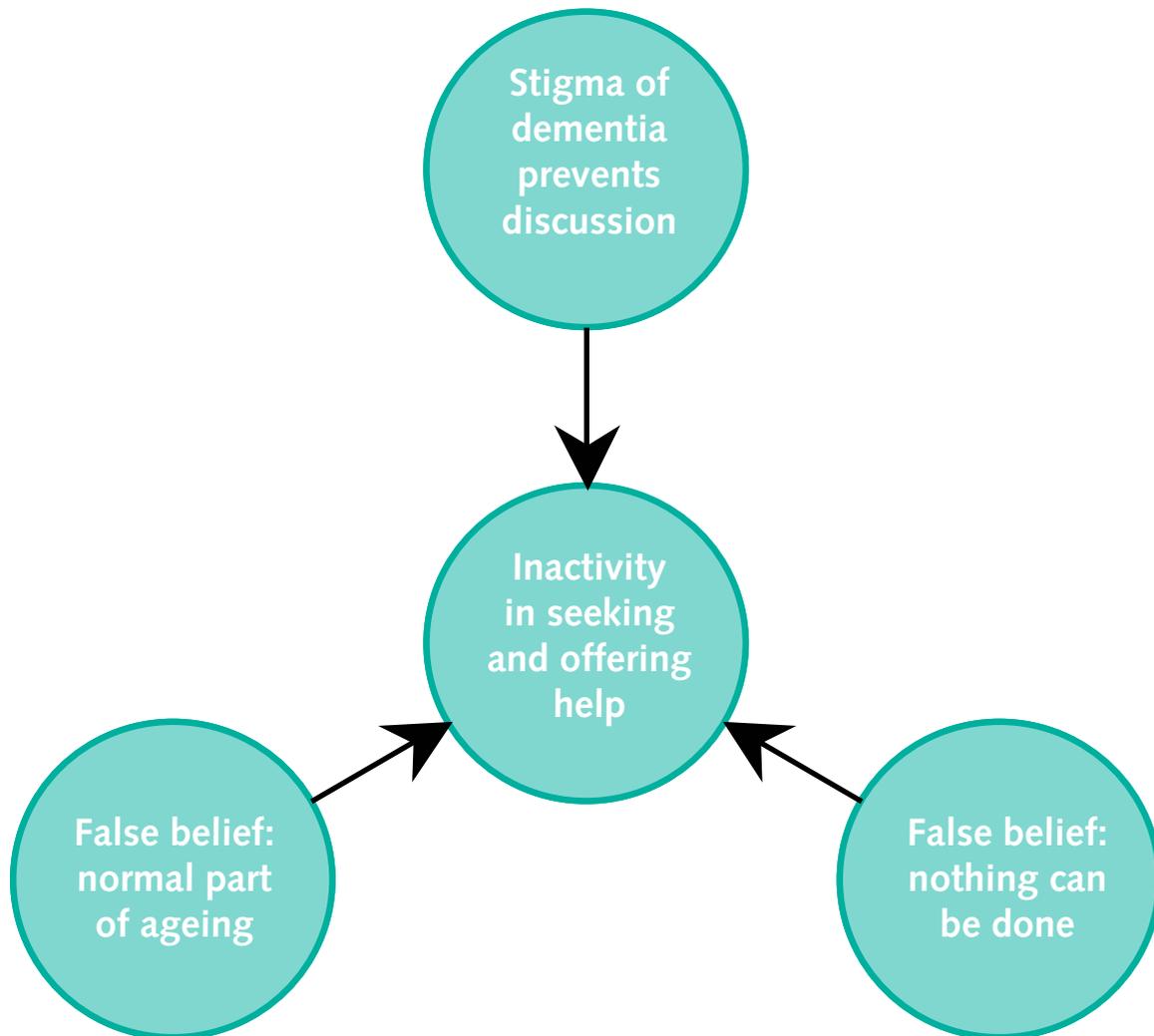
- members of the public should understand that dementia is a common condition, and that it is not an inevitable part of ageing;
- they should be able to recognise the symptoms of dementia;
- they should understand that there are many things that can be done to improve outcomes and quality of life if dementia is diagnosed;
- they should understand that the earlier the diagnosis is made, the better;
- the stigma of dementia should be diminished so that people with dementia and their carers are treated with dignity and respect, and do not experience discrimination, isolation, neglect or abuse in their communities or in health and social care settings; and
- positive messages should be communicated to the public about the health and lifestyle choices that might reduce the risk of some forms of dementia.

## Background

People with dementia and their carers are prevented from accessing diagnosis and treatment by a counter-productive cycle of stigma and misapprehension, leading to inactivity. There is a generally low level of public and non-specialist professional understanding of dementia. The stigma of dementia means that both the public and professionals find it hard to talk about the illness, and seek to avoid addressing the possibility of an individual being affected. The stigma associated with dementia also acts within professional groups to mean that the development of the skills needed to identify and care for people with dementia is accorded a low priority.

The second part of the cycle is a widespread mistaken attribution of symptoms to old age resulting in an unwillingness to seek or offer help, and the final element is the false view that there is little or nothing that can be done to assist people with dementia and their carers. Again, this is a view shared by the public and professionals alike. These factors act together to delay diagnosis and access to good-quality care.

**Figure 2: Public and professional knowledge and attitudes are a barrier to both the diagnosis of dementia and the receipt of good-quality care**



In the current system:

- people wait up to three years before reporting symptoms of dementia to their doctor;<sup>13</sup>
- 70% of carers report being unaware of the symptoms of dementia before diagnosis;<sup>14</sup>
- 64% of carers report being in denial about their relative having the illness;<sup>15</sup>
- 58% of carers believed the symptoms to be just part of ageing;<sup>16</sup> and

13 Alzheimer's Society (2002). *Feeling the pulse*. A report for Alzheimer's Awareness Week 2002. London: Alzheimer's Society

14 *Facing dementia* (2004). A pan-European survey commissioned by Eisai Inc and Pfizer Inc conducted among more than 2,500 people including those with Alzheimer's disease, caregivers, physicians, policy makers, and the general population in France, Germany, Italy, Poland, Spain and the UK. See [www.alz.co.uk/media/dementiasurvey.html](http://www.alz.co.uk/media/dementiasurvey.html)

15 Ibid

16 Ibid

- only 31% of GPs believe they have received sufficient basic and post-qualification training to diagnose and manage dementia, a decrease since the same question was asked in the *Forget me not* report.

The aim of this element of the National Dementia Strategy is therefore to:

- develop a better understanding of dementia among both the public and professionals;
- ensure that better information is provided on how to seek help, and what help and treatments are available; and
- tackle the stigma and misunderstandings that currently exist.

As well as helping the large (and growing) number of people who already have dementia, we need to look at ways of preventing new cases of dementia occurring if at all possible. The current evidence base suggests that up to 50% of dementia cases may have a vascular component (ie vascular dementia or mixed dementia), meaning that it might be possible to prevent or minimise a significant number of cases of dementia by promoting better cerebrovascular health. There is evidence that some communities such as those from South Asian and African/Caribbean backgrounds have a higher incidence and prevalence of cardiovascular disease which may render them more prone to dementia. Health checks, health promotion, the National Stroke Strategy and the recent Government commitment to vascular checks for all people aged over 40 should all have a significant impact on reducing the risk.

The programme of work for this element focuses on:

- delivering a public education campaign;
- making dementia part of core professional and vocational training; and
- improving continuing staff education in dementia.

Those who have analysed our current dementia care systems have stated clearly that there is a need for a public information campaign to change awareness and understanding about dementia. People with dementia, carers, health and social care professionals and, most recently, the Public Accounts Committee have all supported the need for such a campaign.

The potential for positive change is supported by data from a pilot awareness campaign by the Alzheimer's Society in 2007. Some 78% of GPs said that they believed that an awareness campaign would lead to people reporting symptoms earlier.<sup>17</sup> A public information campaign could be created with a phased approach, developing and continuing over time. The campaign would need to be crafted carefully to ensure that it was clear and honest, while at the same time worked to reduce anxiety and promote understanding. In the

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<sup>17</sup> Alzheimer's Society (2007). *Worried about your memory? campaign evaluation*. London: Alzheimer's Society.

words of a person with dementia, “[the information campaign] must not frighten people with dementia or their carers”. It should take account of the fact that the needs of some groups (eg those with a learning disability and dementia, younger people with dementia, and those from particular ethnic groups) may be different to and those of the rest of the population, and the fact that some groups may require specifically tailored approaches.

The campaign should inform the public about what dementia is, including its signs and symptoms, what is normal and what is not, that while some abilities are compromised, many remain, and the fact that a person with dementia is no less of a person simply because they have the illness. The campaign’s key messages should include:

- that dementia is a disease;
- that dementia is common;
- that dementia is not an inevitable consequence of ageing;
- that the social environment is important, and that quality of life is as related to the richness of interactions and relationships as it is to the extent of brain disease;
- that dementia is not an immediate death sentence – there is life to be lived with the illness, and it can be of good quality;
- that there are many positive things that we can do – as family members, friends and professionals – to improve the quality of life of people with dementia;
- that people with dementia make, and can continue to make, a positive contribution to their communities;
- that most of us will experience some form of dementia – either ourselves or through someone we care about;
- that we can all play a part in protecting and supporting people with dementia and their carers;
- that what is good for your heart is good for your head; and
- that the risk of dementia may be reduced if people protect their general health, for example by eating a healthy diet, stopping smoking, exercising regularly, drinking less alcohol and generally protecting the brain from injury.

Local services could deploy strategies for community engagement, to increase levels of understanding and to build supportive social networks. Attention should be paid to the potential of inter-generational engagement for positive and lasting improvements in community acceptance. An information campaign could be targeted at major employers and representative bodies whose workforces have significant interaction with the public (eg

public utilities companies, financial services companies, post offices, trades unions, older people's groups, transport providers and a wide range of public sector organisations).

The campaign would inform public-facing employees of the symptoms and special needs of people with dementia, and where to go if they are concerned about someone. Content would need to be developed in consultation with employers, but could include a team briefing pack, employee training materials, posters for staff noticeboards, and media materials for staff magazines and leaflets. Such a campaign could also target the human resources and occupational health departments of organisations, so that staff are aware of the early signs of dementia and of its impact on carers. Finally, making materials available to schools so that children and young people learn about dementia could also form an important strand of an effective public information campaign.

**Recommendation 2: An informed and effective workforce for people with dementia**

Outcome: All health and social care staff involved in the care of people with dementia to have the skills needed to provide the best-quality care in the roles and in the settings where they work. To be achieved through effective basic training, and continuous professional and vocational development in dementia.

## Objectives

The objectives of this element of the strategy are that:

- by means of their core training, all professional and vocational staff working with older people should have a culturally sensitive understanding of dementia which allows them to meet the needs of all people with dementia and their carers effectively; and
- continuing professional and vocational development should enable such skills to be developed and sustained.

## Background

The need for improved training runs across all of the themes in this draft National Dementia Strategy. We focus on it here as this is the first time it has been relevant to do so, and to emphasise its central importance. This addresses two fundamental complaints from people with dementia and their carers: first, that professionals who should have been there to help them get a diagnosis did not seem to have the skills and knowledge needed to do so, and second, that professionals often seem unable to understand that what works for people without dementia may well not work for people with the condition. Professionals are often unable or unwilling to adapt their practices to make them work for people with dementia.

Two-thirds of people with dementia live either in their own homes or in those of carers, and a third live in care homes. People with dementia access all services, so awareness is

needed by all sections of the workforce and society (eg housing, emergency services, employers, benefits agency staff and GP receptionists) – not just by those directly involved with care. A lack of understanding of dementia in the workforce – whether in mainstream or specialist services – can lead to care practices that can make the situation worse for both the person with dementia and their carer.<sup>18</sup> So people with dementia and their carers need informed understanding and support from all of the services they come into contact with.

People with dementia and their carers need to be supported and cared for by a trained workforce, with the right knowledge, skills and understanding to offer the best-quality care and support. PCTs and local authorities, in particular, need to commission a trained and competent workforce – through the development of core competencies and an improved career structure for dementia care workers and other professionals working with people with dementia, as well as through fulfilling regulatory requirements. Providing adequate training and support is likely to improve staff morale, and ease the recruitment and retention problems in dementia care. The top challenges in terms of providing good dementia care from a care home manager’s point of view are developing a staff team with the right attributes and skills, and then keeping them motivated.<sup>19</sup> Training should mean that younger people with dementia, those with dementia and a learning disability, and those from black and minority ethnic backgrounds are all better understood. There is currently a range of training and education providers in dementia care, but there is no nationally recognised system of quality assurance. Some form of ‘kite-marking’ of good practice would assist commissioners and care providers in selecting effective training.

To initiate positive change, the Department of Health could convene a discussion group made up of representatives of the bodies that are involved in professional and vocational training and continuing professional development. The aim would be to come to an agreement on the core competencies required in dementia care. These bodies would then be able to adapt their curricula and requirements to include these core competencies in pre- and post-qualification training. Such changes would also inform any review of national health and social care standards.

An agreed set of core competencies would help care organisations to identify learning and development needs, would focus learning providers on producing courses that are useful to the sector, and would assist regulators and commissioners in identifying quality in dementia care.

18 Ballard, C, Powell, I, James, I, Reichelt, K, Myiut, P et al (2002). ‘Can psychiatric liaison reduce neuroleptic use and reduce health service utilization for dementia patients residing in care facilities.’ *International Journal of Geriatric Psychiatry*, 17, 140–45. Turner, S (2005). ‘Behavioural symptoms of dementia in residential settings: A selective review of non-pharmacological interventions.’ *Aging and Mental Health*, 9 (2), 93–104.

19 Sharp, S (2007). *Home from home: A report highlighting opportunities for improving standards of dementia care in care homes*. London: Alzheimer’s Society.

## Summary propositions for consultation

### **Recommendation 1: Increased public and professional awareness of dementia**

Proposition for consultation 1: Public information campaigns at the national and local level, making use of the personal narratives of people with dementia and their carers.

### **Recommendation 2: An informed and effective workforce for people with dementia**

Proposition for consultation 2: Those responsible for professional and vocational education ensuring that the core curriculum and training for all those who work with older people and anyone with dementia enables them to work effectively with people with dementia and their carers. Care providers auditing dementia training and competencies. Commissioners including training and competencies in dementia care as part of the specification for services commissioned.

## Consultation questions

1. Are these outcomes, recommendations and the suggested means of achieving them the right ones?
2. Is there anything that has been missed to help us improve public and professional awareness of dementia?
3. What can you or your organisation do to help implement these recommendations?

## Chapter 2 – Early diagnosis and intervention

“I can only say from my grandmother’s experience, no, she did not get an early diagnosis. It was a long process to actually receive a diagnosis, and when we did, it was just written in a clinic letter, not told to us or discussed. By the time she was diagnosed, it was too late to say goodbye.” *Carer*

“Some GPs still consider confusion and memory loss as just being part of old age.” *Carer support group*

“The GP did not react favourably when I took my mother along with problems that I had recognised. It was six months later – when I stressed that I was suffering severe stress – that we were referred to the memory clinic, where the people were very helpful.” *Carer*

“My experience with the GP pre-diagnosis was extremely difficult – the first reaction was to offer antidepressants. Post-diagnosis, the reaction of the GP has been very different, but we have encountered various doctors and consultants who do not consider the needs of somebody with dementia – we have found them to be rude and lacking understanding.” *Carer*

“The specialist examined my father twice – the first time was two years before the diagnosis. We suspected dementia, but the specialist said he would re-examine my father in a year. Maybe a diagnosis of some kind would have enabled my parents to be better equipped for what came later. Also, maybe access to drugs in the early stages would have been beneficial. The second examination took place around 18 months later, and the diagnosis didn’t come for another six months! By this time my father was becoming quite difficult, but my mother couldn’t get him accepted into day care because there was no diagnosis.” *Carer*

“A diagnosis of Alzheimer’s disease was one of the hardest things I’ve had to deal with. But now I know what it is, I’ve found a way of coping and living with dementia. I thought it would be the end of my life, but with support it hasn’t been.” *Person with dementia*

**Recommendation 3: Good-quality early diagnosis and intervention for all**

Outcome: All people with dementia to have access to a pathway of care that delivers:

- a rapid and competent specialist assessment;
- an accurate diagnosis that is sensitively communicated to the person with dementia and their carers; and
- immediate treatment, care and support following diagnosis.

The system needs to have the capacity to see all those with dementia.

## Objectives

The objectives of this element of the strategy are that:

- good-quality services are available for early diagnosis and intervention in dementia; and
- there is enough capacity to assess all of the new cases in each area.

## Background

According to the National Audit Office's report, less than half of people with dementia ever receive a formal diagnosis, and when diagnoses are made, it is often too late for those suffering from the illness to make their own choices. Further, diagnoses are often made at a time of crisis – a crisis that could potentially have been avoided if the diagnosis had been made earlier. The National Dementia Strategy needs to ensure that effective services for early diagnosis and intervention are available for everyone across the country. There is evidence that such services are cost-effective – when established they can release substantial funds back into health and social care systems – but they will require extra initial local investment to be established.

In generating this consultation document, we have developed the detailed cost-effectiveness case for such services, and this is included at Appendix 4. It sets out clearly that a 'spend to save' approach (as advocated by the National Audit Office) can both increase quality of care and save hundreds of millions of pounds in expenditure over a five-year period. These services are clinically effective and cost-effective using any accepted measure.

The literature points strongly to the value of early diagnosis and intervention in terms of improving quality of life and delaying or preventing admissions into care homes. According to the *Dementia UK* report, putting people with dementia into care homes costs the UK £7 billion per year, with two-thirds paid by social services and a third by older people and their families themselves.

Evidence suggests that:

- early provision of support at home can decrease institutionalisation by 22%;<sup>20</sup>
- even with complex co-morbidity and where the comparison group is served by a highly skilled multidisciplinary team, case management can reduce admissions to care homes by 6%;<sup>21</sup>
- older people’s mental health services can help with behavioural disturbance, hallucinations and depression associated with dementia, thus reducing the need for institutional care;<sup>22</sup>
- carer support and counselling at diagnosis stage can reduce care home placements by 28%;<sup>23</sup>
- early diagnosis and intervention have positive effects on the quality of life of people with dementia;<sup>24</sup> and
- services that enable early intervention have positive effects on the quality of life of family carers.<sup>25</sup>

There is also a strong argument that increased quality can help to prevent institutionalisation. People with dementia generally want to stay in their own homes, as do their carers, and their quality of life is higher at home than in a care home. All PCTs currently commission a number of services that might diagnose dementia, including GPs, old-age psychiatric community teams, geriatric medical services and neurology services. The current systems are non-prescriptive and lack clarity about where and by whom diagnoses of dementia should be made. There is, however, a marked reluctance on the part of primary care services to be directly involved in the diagnosis of dementia because of a belief that nothing can be done for people who have it, because of risk avoidance, because of concerns about competency and because of concerns about the availability of resources.<sup>26</sup> The current focus of old-age psychiatric services is on the severe and complex end of the spectrum, leaving early diagnosis and intervention largely unaddressed.

20 Gaugler, JE, Kane, RL, Kane, RA and Newcomer, R (2005). ‘Early Community-Based Service Utilization and Its Effects on Institutionalization in Dementia Caregiving.’ *The Gerontologist*, 45, 177–85.

21 Challis, D, von Abendorff, R, Brown, P, Chesterman, J and Hughes, J (2002). ‘Care management, dementia care and specialist mental health services: an evaluation.’ *International Journal of Geriatric Psychiatry*, 17, 315–25.

22 Gilley, DW, Bienias, JL, Wilson, RS, Bennett, DA, Beck, TL and Evans, DA (2004). ‘Influence of behavioral symptoms on rates of institutionalization for persons with Alzheimer’s disease.’ *Psychological Medicine*, 34, 1129–35.

23 Mittelman, MS, Roth, DL, Clay, OJ and Haley, WE (2007). ‘Preserving health of Alzheimer caregivers: impact of a spouse caregiver intervention.’ *American Journal of Geriatric Psychiatry*, 15, 780–9.

24 Banerjee, S, Willis, R, Matthews, D, Contell, F, Chan, J and Murray, J (2007). ‘Improving the quality of dementia care – an evaluation of the Croydon Memory Service Model.’ *International Journal of Geriatric Psychiatry*, 22, 782–8.

25 Mittelman, MS, Roth, DL, Clay, OJ and Haley, WE (2007). ‘Preserving health of Alzheimer caregivers: impact of a spouse caregiver intervention.’ *American Journal of Geriatric Psychiatry*, 15, 780–9.

26 Iliffe, S, Wilcock, J and Haworth, D (2006). ‘Obstacles to Shared Care for Patients with Dementia: A qualitative study.’ *Family Practice*, 23, 353–62.

From our consultation, and based on a successful Department of Health pilot<sup>27</sup> and the cost-effectiveness case made at Appendix 4, it appears that new specialist services need to be commissioned to deliver good-quality early diagnosis and intervention. These services would provide a simple single focus for referrals from primary care, and would work locally to stimulate understanding of dementia and referrals to the service. They would provide an inclusive service, working with all diverse communities using appropriate cultural and linguistic tests. Their sole focus would be on early diagnosis and intervention for people with dementia. This would include making the diagnosis well, breaking the diagnosis well to the person with dementia and their family, and providing direct and immediate care and support after diagnosis. There is value in considering such a service being a joint health and social care team venture, with core involvement from local voluntary sector organisations.

The provision of such services locally would have the effect of simplifying the care pathway and locating responsibility, enabling easy referral, simple communication and clear performance monitoring. A core set of assessment tools (eg for cognition, behaviour, activity limitation and quality of life in dementia patients) could be agreed and specified to enable the services to be directly monitored and compared.

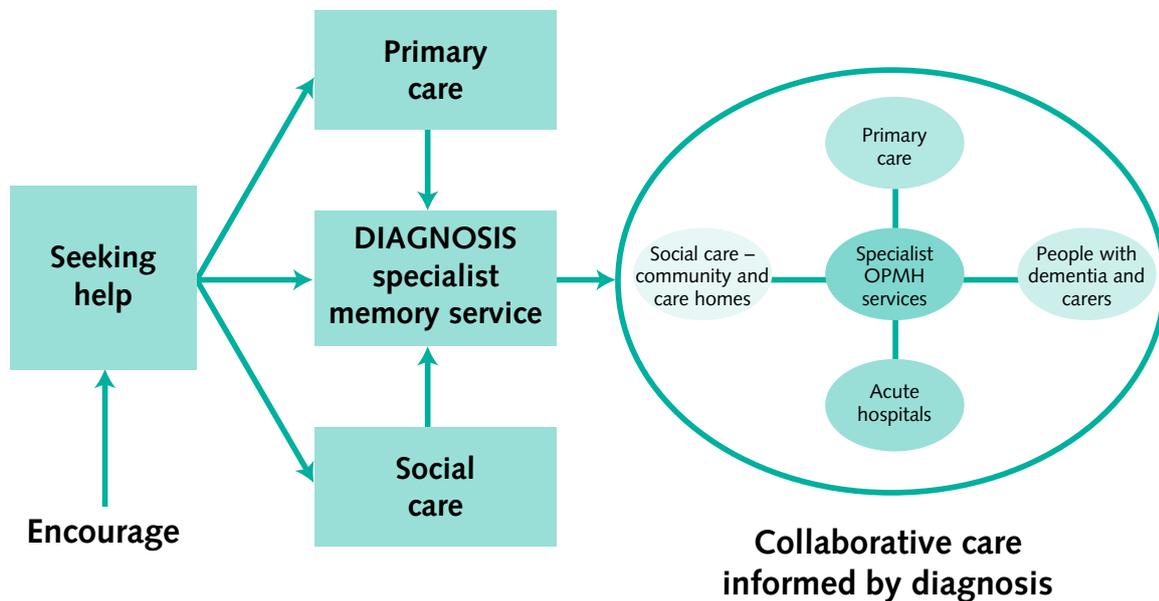
**Recommendation 4: Good-quality information for those with dementia and their carers**

Outcome: People with dementia and their carers to be provided with good-quality information on the illness and on the services available – both at diagnosis and throughout the course of their care.

Everyone diagnosed with dementia and their carers need to be provided with good-quality, relevant information on the illness and on the availability of local services. This could take the form of an information prescription, consisting of an individually tailored, comprehensive package of high-quality information for dementia, to be given out on diagnosis and as needed. This information would best be developed nationally and adapted locally to include information on the nature of the condition, its treatment and the support available. Different materials might be needed as the disease progresses, and to cover the evolution and management of different symptoms and situations. They could also be available as a resource to other services involved in the care of people with dementia.

27 Banerjee, S, Willis, R, Matthews, D, Contell, F, Chan, J and Murray, J (2007). 'Improving the quality of dementia care – an evaluation of the Croydon Memory Service Model.' *International Journal of Geriatric Psychiatry*, 22, 782–8.

Figure 3: Simplifying the care pathway for dementia

**Recommendation 5: Continuity of support and advice**

Outcome: Continuous support and advice to be provided for those diagnosed with dementia and their carers.

One of the most clear and consistent messages to date from people with dementia and their carers has been a desire for access to a named and known individual for them to approach for help and advice at any stage of the illness. Current health and social care services normally discharge individuals once they are stable and the care package is being delivered. But this is almost always perceived negatively by people with dementia and their carers: faced with a serious illness involving an inevitable long-term decline and an increase in dependency, they want continuing support – even if this is at a low level.

This support needs to be provided without removing health and social care professionals from front-line care. One suggestion that has emerged from consultation so far is for a nominated individual to be in a position to act as a point of contact, advice and signposting to other services if needed. This individual – the ‘dementia care adviser’ – would have a mixture of navigator, brokerage and support worker responsibilities. Such new posts might well be provided by voluntary sector agencies, but might be usefully placed within the early diagnosis and intervention service described above. All those diagnosed with dementia could then be given the contact details of their local dementia care adviser, whose advice would be available in addition to whatever active clinical and social care contacts were required. At the end of an episode of care, individuals with dementia and their carers would therefore not be discharged from services, but instead transferred to the care of the dementia care adviser.

Dementia care advisers would not be responsible for intensive case management, but would provide a single identifiable point of contact with knowledge of and direct access to the whole range of local services available. Their responsibilities would be to enable people with dementia and their carers to obtain the help, care and support needed quickly and easily. This would allow dementia care advisers to work with high numbers of people diagnosed with dementia in their area, in collaboration with both social care and health care services. Dementia care advisers could be jointly commissioned by local authorities and PCTs.

## Summary propositions for consultation

### **Recommendation 3: Good-quality early diagnosis and intervention for all**

Proposition for consultation 3: Commissioning a specific service to carry out early diagnosis and intervention, working in a way that complements existing services.

### **Recommendation 4: Good-quality information for those with dementia and their carers**

Proposition for consultation 4: Development of a comprehensive package of high-quality information, to be given out following diagnosis and during care as needed. To include details of the nature of the condition, its treatment, and the support available nationally and locally.

### **Recommendation 5: Continuity of support and advice**

Proposition for consultation 5: Development of a dementia care adviser role. Not responsible for the provision of services themselves, these individuals would act as a single point of contact for people with dementia and their carers, providing advice and signposting them to the care needed.

## Consultation questions

1. Are these outcomes, recommendations and the suggested means of achieving them the right ones?
2. Is there anything that has been missed to help us enable early diagnosis and intervention?
3. Do you agree that the diagnosis of dementia should be made by a specialist?
4. How open should referral systems to a memory service be? Should people be able to refer themselves, or should they have to go to their GP first?
5. How would the dementia care adviser be able to ensure continuity of care?
6. What can you or your organisation do to help implement these recommendations?

# Chapter 3 – High-quality care and support

“I have just had my friend in hospital. She was sent to the discharge lounge, put in an ambulance and sent back to the care home in a nightdress, thin dressing gown, soaking wet and terrified – no one was informed of her discharge.” *Carer*

“From my experience, sadly to say, professionals do not have much insight into black and minority ethnic group people and dementia. They tried to fit us in the traditional model, and this did not work for us .... We are an Asian family. When the consultant assessed my father, the test was totally inappropriate for him. He does not understand British culture or the English language, and the questions he was being asked were in English and about British culture.” *Carer*

“Understanding and stimuli are not available in many care homes. I take my friend out to try and keep her in touch with the outside. Others in care homes are not as fortunate.” *Carer*

“The carers who came to the house were very mixed in terms of quality of care and experience. Some knew how to deal with an Alzheimer’s patient while some clearly didn’t. The weekend staff were the worst. Overall the home carers were not actually much help. They were often late, so I would sometimes get him washed and dressed myself. Also, they weren’t allowed to bath him but I wasn’t capable – so he never had a bath. They didn’t even wash his feet.” *Carer*

“What works is high-quality awareness training. What tends not to work is criticism of sincere professionals without a full understanding of the challenges that they face in delivering quality dementia care.” *Dementia care worker*

## Objectives

The objectives of this element of the strategy are that:

- the quality of general hospital care for people with dementia improves;
- the quality of care at home for people with dementia improves; and
- the quality of care in care homes for people with dementia improves.

## What needs to change?

In many ways this is the most complex of the three themes that we have considered as part of the National Dementia Strategy. The scope for improving the quality of care and support is very broad, with room for improvement in almost every area from diagnosis to the end of life. Here we have chosen to focus on the four settings where the greatest need has been identified to date: general hospitals, home care, intermediate care and care homes.

People with dementia often have a troubled time in general hospital settings with some evidence that their human rights may be infringed. We need to improve both the general and specialist care provided, including considering liaison services that would enable the effective care of people with dementia.<sup>28</sup> Successive reports have emphasised the need to ensure that joint health and social care mental health teams work better together in the community, and the need for better home care.<sup>29</sup> A third of people with dementia live in care homes, and yet the care they receive for their dementia is frequently poor, according to the Public Accounts Committee's report.

We know that people with dementia are an 'at risk' group in terms of abuse, particularly (although not exclusively) through financial exploitation, fraud and theft. Reliance on others for support to manage finances can expose people with dementia to the risk of abuse. Additionally, the complex dynamics of caring relationships mean that people do not always report abuse or mistreatment. This becomes even more problematic if the individual lacks the capacity to be able to complain. Managers and staff in all settings need to be alert to the possibility of abuse of all kinds, and be familiar with the local arrangements for reporting allegations of abuse and safeguarding people with dementia and their carers and protecting their human rights. Services should make sure that there is clear information available on how to complain about poor standards of care or report concerns about possible abuse.

Although the problems are well documented, there is little evidence of effective interventions – not because they do not work, but because the research has often not been done. In the National Dementia Strategy, to be published later in the year, we will include cost-effectiveness metrics equivalent to those in Appendix 4 for the provision of services in both general hospitals and care homes, bringing together the best available evidence on clinical and economic costs and benefits.

### **Recommendation 6: Improved quality of care in general hospitals**

Outcome: An improved quality of care to be provided in general hospitals for people with dementia.

<sup>28</sup> CSIP (2005). *Everybody's business*. London: Department of Health.

<sup>29</sup> National Audit Office (2007). *Improving services and support for people with dementia*. London: TSO.

Up to 70% of acute hospital beds are currently occupied by older people<sup>30</sup> and up to a half of them may be people with cognitive impairment, including those with dementia and delirium.<sup>31</sup> Many of these people are not known to specialist health services and many are undiagnosed. General hospitals are particularly challenging environments for people with memory and communication problems – cluttered ward layouts, poor signage and other issues all cause problems. People with dementia in general hospitals have worse outcomes in terms of length of stay, mortality and institutionalisation,<sup>32</sup> but this is not widely appreciated by clinicians, managers or commissioners.

There is a lack of leadership for and ownership of dementia in most general hospitals. There are also marked deficits in the knowledge and skills of the general hospital staff who care for people with dementia. Often, not enough information is sought from relatives and carers, meaning that person-centred care is not delivered, and delirium and dementia can go unrecognised. Currently, families are often excluded from discharge planning, meaning that false assumptions may be made about it not being possible for people with dementia to be cared for at home. The National Audit Office report found that some general hospital services worked hard not to make the diagnosis of dementia, for fear that it would delay discharge.

Poor care can lead to malnutrition and dehydration. There is often a lack of co-ordination between hospitals and care providers at the point of discharge, delaying access to care packages (such as home care and intermediate care) that might enable successful discharge. There is, therefore, a clear need to improve the quality of care and support provided for people with dementia in general hospitals. The proposed improvements to core and continuing professional training set out in Chapter 1 should improve the quality of care, but there are three further ways of delivering improvements:

- the identification of a senior clinician within the general hospital to take the lead for quality improvement in dementia in the hospital;
- the development of an explicit care pathway for the management and care of people with dementia in hospital, led by that senior clinician; and
- commissioning specialist older people’s mental health liaison teams to work in general hospitals.

A policy for the better management of people with dementia, written in consultation with local social services and user and carer organisations, could specify the arrangements for local leadership and accountability for dementia in general hospitals. Core competencies for all general hospital staff who have contact with people with dementia (including the Patient

30 Department of Health (2001). *National Service Framework for Older People*. London: TSO.

31 Royal College of Psychiatrists (2005). *Who cares wins: Improving the outcome for older people admitted to the general hospital*. London: RCPsych.

32 Ibid

Advice and Liaison Service (PALS) and Local Involvement Networks (LINKs)) could be included, and the relevant training could be delivered by experts in dementia care.

Specialist older people's mental health liaison teams are already advocated by the NICE/SCIE clinical guideline on dementia services, and can provide rapid and high-quality specialist assessments as well as input into care planning for those admitted to general hospitals. These teams can provide input into ongoing care and discharge planning. They will generally consist of three to four members of staff (part-time consultant, staff-grade doctor, nurse and psychologist/therapist) with administrative support and a base in the general hospital. These teams can work closely with the designated general hospital lead to build skills and improve care throughout the hospital, and need to have good links with the social work assessment teams based in or linked to the hospital. Such teams are already provided in some – but by no means all – hospitals.

**Recommendation 7: Improved home care for people with dementia**

Outcome: Home care services to better meet the needs of people with dementia and their carers.

**Recommendation 8: Improved short breaks for people with dementia and their family carers**

Outcome: Short break services to better meet the needs of people with dementia and their family carers.

**Recommendation 9: A joint commissioning strategy for dementia**

Outcome: Commissioning and planning mechanisms to be established to determine the services needed for people with dementia and their carers, and how best to meet their needs.

These three recommendations can usefully be considered together.

## Objectives

The objectives of this element of the strategy are that people with dementia and their carers should have services available at home that are:

- seamless and continuous;
- simple to access and use;
- responsive in a crisis; and
- sensitive to the needs and preferences of the person with dementia.

## What needs to change?

Two-thirds of all people with dementia live at home. Apart from family members and friends, who provide the vast bulk of care and support at home, home care is probably the single most important service involved in supporting people with dementia in their own homes. The Commission for Social Care Inspection (CSCI) has found that good-quality, flexible home care services contribute significantly to maintaining people's independence, reducing social isolation, preventing admissions to care homes and hospitals, and supporting carers.<sup>33</sup> The CSCI report and other studies point to the importance of continuity, reliability and flexibility in home care services, and of people having more choice and control over the services they receive. These are important messages for commissioners of home care services – both for mainstream home care services and for specialist dementia services for people with more complex needs.

Specifying tasks rather than outcomes, not having the time or continuity to develop relationships between individuals and care workers, and care workers being rushed and only visiting for short (15-minute) periods are all particular problems for people with dementia. As successful commissioning is key to improving home care services for people with dementia and their carers, a toolkit has been produced by the CSIP (see [www.dh.gov.uk/dementia](http://www.dh.gov.uk/dementia)). Emerging research-based evidence shows that specialist dementia home care brings considerable benefits to both people with dementia and their carers when compared with standard home care services. Improved outcomes include reduced stress and risk of crises for carers, and extended capacity for independent living for people with dementia.<sup>34</sup>

Most people want to remain in their own homes for as long as possible. This message is consistently given by the public, by older people generally and by people with dementia specifically, be they young or old. Most family carers want to be able to provide support to help the person with dementia stay at home, but they sometimes need more assistance than is currently routinely available. All too often, people with dementia (particularly older people) find themselves on a conveyor belt that takes them into long-term residential care because it appears that there are no alternatives available – this is especially the case if the person is admitted to hospital after a crisis. This is partly because a lack of knowledge and understanding about dementia leads some professionals to make erroneous assumptions that residential care is the only option. It is also due to home care staff not receiving training in dementia, and so not having the skills and competencies to provide appropriate care.

Equally, there is a clear need for short-term breaks to support families in their caring role in the community. Such services need to be able to provide valued and enjoyable experiences for people with dementia and their family carers. They can play an important role in

<sup>33</sup> CSCI (2006). *Time to care: An overview of home care services for older people in England*. London: CSCI.

<sup>34</sup> Rothera, I, Jones, R, Harwood, R et al (2008). 'An evaluation of a specialist multiagency home support service for older people with dementia using qualitative methods.' *International Journal of Geriatric Psychiatry*, 28, 65–72.

preventing institutionalisation and keeping people with dementia in the community. The arrangements for such short breaks need to be flexible and responsive to the needs of each person with dementia and their carer. Short breaks can be provided in a variety of settings, including the home of the person with dementia, and need to be available on an emergency, urgent or planned basis.

As people with dementia will live with their condition for a number of years and their care needs will change over time, their need for health and social services will also change. It is important therefore for PCTs and local authorities to consider the need for commissioning services jointly. A joint commissioning strategy will be most effective if it is based on a joint strategic needs assessment that specifies the quality outcomes required and that is developed in consultation with people with dementia and their carers. It needs to take account of the need for both mainstream and specific services, and would need:

- a community focus, linking into local area agreements and the development of sustainable communities; and
- an individual focus, drawing on the use of personal budgets and the commissioning of self-directed support.

A joint commissioning strategy should feed into the operational plans and budget cycles of PCTs and local authorities, and demonstrate how they plan to improve services for people with dementia. It can be informed by guidance in the world-class commissioning framework and specific commissioning guidance linked to this strategy. As a local priority, local authority and PCT commissioners should lead the development of an integrated pathway of care, specifying the elements of the pathway against which services will be procured and performance-managed.

A comprehensive home support service would provide:

- home care that is reliable, with staff who have received culturally sensitive basic training in dementia care;
- flexibility to respond to changing needs, not determined by rigid time slots that prevent staff from working alongside people rather than doing everything for them;
- access to personalised social activity, short breaks and day services;
- access to peer support networks;
- access to expert patient and carer programmes;
- crisis response services;
- access to supported housing that is inclusive of people with dementia;

- flexible and responsive short-term breaks that provide valued and enjoyable experiences for people with dementia as well as for their family carers, which can be provided in a variety of settings, including the home of the person with dementia;
- independent advocacy services; and
- assistive technologies such as telecare.

**Recommendation 10: Intermediate care for people with dementia**

Outcome: Intermediate care to be made accessible to people with dementia and to meet their needs.

### What needs to change?

Pathways out of hospital, such as intermediate care, often exclude people with dementia, meaning that they cannot access rehabilitation services that could enable them to return home: specialist intermediate dementia or mental health care services that enable discharge from the general hospital setting are rare. This appears to stem from a misunderstanding of the guidance in this area – staff working in intermediate care are often reluctant to offer people with dementia the opportunity to benefit from the service because they are likely to need longer than the usual six weeks, and are therefore perceived not to meet the criteria. The group developing the strategy understands that this is an erroneous interpretation of the Department of Health guidance.

Another problem is the false assumption that people with dementia cannot benefit from rehabilitation, meaning that criteria for services have often specifically excluded these people. Pressures to reduce lengths of stay in acute care, combined with risk-averse discharge planning, can mean that people with dementia are rushed into long-term residential care prematurely.

There is good clinical evidence that people with physical rehabilitation needs in addition to mild or moderate dementia do well if given the opportunity, while people with severe dementia may need specialist services better geared to meeting their mental health needs as well as providing physical rehabilitation. Like any other staff group, staff working in intermediate care need core training in dementia and access to advice and support from specialist mental health personnel. This will ensure that people with dementia are able to benefit from rehabilitation opportunities.

**Recommendation 11: Improved dementia care in care homes**

Outcome: Quality of care in care homes to be improved for people with dementia.

**Recommendation 12: Improved registration and inspection of care homes**

Outcome: Inspection regimes for care homes to better assure the quality of the dementia care provided.

These two recommendations can usefully be considered together.

## Objective

The objective of this element of the strategy is that reports on the need to improve the quality of dementia care and support provided for people in care homes are addressed.

## What needs to change?

A third of people with dementia live in care homes. The need for workforce development and training is already covered in Chapter 1, but this section focuses on:

- making dementia an explicitly owned priority within care homes;
- enabling a minimum level of input into care homes from specialist mental health services for older people; and
- using inspection regimes to drive up the quality of care.

Evidence from the Alzheimer's Society *Home from home* report<sup>35</sup> suggests that:

- 54% of carers reported that their relative did not have enough to do;
- the typical person in a home spent just two minutes interacting with staff or other residents over a six-hour period of observation (excluding time spent on care tasks);
- the availability of activities and opportunities for occupation is a major determinant of quality of life, affecting mortality, depression, physical function and behavioural symptoms; and
- staff enjoy providing opportunities for activity and occupation, and would like to be able to do more of this within their work.

The report found that maintaining good relationships between the relatives and the home – and supporting the ongoing relationship between relatives and the person with dementia – has important benefits for all parties. It reduces carers' degree of stress, improves residents' quality of life and boosts engagement in activity.

A study by CSCI has shown that the quality of staff communication with people with dementia has a major impact on their quality of life. Leadership, the ethos of the care home, staff

<sup>35</sup> Sharp, S (2007). *Home from home*. London: Alzheimer's Society.

training, and support and development are the crucial factors in supporting best practice.<sup>36</sup> Commissioners could develop service specifications with providers that include these key factors, and identify how performance will be assessed in contract monitoring and evaluation.

The mental health needs of people living in care homes are extensive and generally not well met. Up to 75% of residents in non-specialist care homes have dementia,<sup>37</sup> and the prevalence rises to between 90% and 95% in homes for the elderly mentally infirm.<sup>38</sup> In addition, an estimated half of all care home residents have depressive disorders that would warrant intervention.<sup>39</sup> Behavioural disturbance in dementia in these settings is both very common and a cause of immense stress to residents and staff. It is striking that there is very little in the way of active management of these problems in these settings, despite growing evidence of the effectiveness of old-age psychiatric intervention.<sup>40</sup> Current input from mental health services is generally on an ad hoc basis in times of crisis.

One issue that is of particular concern is the use of anti-psychotic medication in care homes for the management of behavioural and psychological symptoms in residents with dementia. (Those criticising current practice include the Public Accounts Committee, the Alzheimer's Society and the All-Party Parliamentary Group on Dementia.<sup>41</sup>) These drugs can have negative effects, and there is evidence that they are initiated too freely, that they are not reviewed appropriately following initiation, and that they are not withdrawn as quickly as they should be. Improving the quality of care in care homes requires this issue to be addressed effectively.

One means of addressing these problems could be a system of specialist mental health assessment on admission, followed by regular review. This would enhance the quality of care by providing a regular forum for discussion between nursing staff, GPs and mental health teams on how best to identify and manage the mental health problems of care home residents. Most care homes have a contract with a GP who visits once or twice a week to provide medical care for the residents. Any intervention would need to be in partnership with these GPs. In this system the quality of mental health care for residents in care homes could be improved by:

36 CSCI (2008). *See me, not just the dementia: Understanding people's experiences of living in a care home*. London: CSCI.

37 Macdonald, AJ, Carpenter, GI, Box, O et al (2002). 'Dementia and use of psychotropic medication in non "elderly mentally infirm" nursing homes in South East England.' *Age and Ageing*, 31, 58–64.

38 Margallo-Lana, M, Swann, A, O'Brien, J, Fairbairn, A, Reichelt, K, Potkins, D, Mynt, P and Ballard, C (2001). 'Prevalence and pharmacological management of behavioural and psychological symptoms amongst dementia sufferers living in care environments.' *International Journal of Geriatric Psychiatry*, 16, 39–44.

39 Ames, D (1991). 'Epidemiological studies of depression among the elderly in residential and nursing homes.' *International Journal of Geriatric Psychiatry*, 6, 347–54.

40 Proctor, R, Burns, A, Powell, HS, Tarrier, N, Faragher, B, Richardson, G, Davies, L and South, B (1999). 'Behavioural management in nursing and residential homes: a randomised controlled trial.' *Lancet* 354 (9172), 26–9.

41 All-Party Parliamentary Group on Dementia (2008). *Always a last resort*. London: Alzheimer's Society.

- detailed specialist assessments of mental health needs on admission;
- regular six-monthly mental health reviews of residents in conjunction with the GP and nursing home staff;
- providing access to specialist advice on problems arising between reviews – to prevent problems by means of a regular pattern of visiting;
- the formulation and deployment of non-pharmacological management strategies for behavioural disorders in dementia, so avoiding the initiation of anti-psychotic medication;
- specialist input into decision making concerning the initiation, review and cessation of anti-psychotic medication for people with dementia;
- rapid specialist reviews of all those with dementia who have started taking anti-psychotic medication;
- a rapid specialist response to problems as they occur within homes; and
- assessments of the residential care provided and the potential for improvement – to create a more therapeutic environment.

Commissioners should consider whether this could all be achieved by extending the existing role of the old-age community mental health teams – building existing capacity, rather than setting up a separate service. Joint commissioning of in-reach services from other professionals (such as community pharmacists, community dentists and geriatricians) could also improve the support to care homes.

Assessing the real-life experience of people with dementia is an important part of the inspection process, and listening to their views should be part of any assessment of quality. Specific efforts need to be made to ensure that all inspections include monitoring the experience of those with more advanced dementia or compromised communication needs. As well as interviewing people with dementia, inspection regimes need to include interviewing family carers, regular visitors and staff, as well as observing care and support. For example, CSCI has developed an inspection tool (SOFI) that allows inspectors to go below the surface of routine care practice.

Following the NICE/SCIE clinical guideline on dementia, SCIE's work is now focusing more specifically on the quality of dementia care provided by the independent sector. Inspectorates of care homes need to ensure that their inspection regimes include an assessment of the quality of dementia care provided. Given that the large majority of people in care homes have dementia, registration requirements might be altered to stipulate that all care homes should be able to provide good-quality care for people with dementia – unless there are specific reasons for an exemption.

## Summary propositions for consultation

### **Recommendation 6: Improved quality of care in general hospitals**

Proposition for consultation 6: General hospitals developing an explicit care pathway for the management of people with dementia on their wards, identifying a senior clinician to lead its development and delivery. Complemented by the provision of older people's mental health liaison teams for general hospitals to provide specialist assessments and expertise.

### **Recommendation 7: Improved home care for people with dementia**

Proposition for consultation 7: Commissioners and providers reviewing the specification of the services they buy, to ensure that the home care services that are commissioned are personalised, offer flexible support and meet the needs of the individual. People with more complex needs are likely to require a specialist home care service.

### **Recommendation 8: Improved short breaks for people with dementia and their family carers**

Proposition for consultation 8: Short breaks that provide valued and enjoyable experiences for people with dementia as well as their family carers. They should be flexible and responsive, and able to be provided in a variety of settings (including the home of the person with dementia).

### **Recommendation 9: A joint commissioning strategy for dementia**

Proposition for consultation 9: A joint commissioning strategy by local authorities, PCTs and others, based on a joint strategic needs assessment. It would generate a comprehensive integrated pathway of care to cover the full range of generic and specialist home support services, rehabilitation, intermediate care, residential care and nursing services. The strategy would define the specification for each element of the pathway against which services would be procured and performance-managed. It would take account of the allocation of personal budgets for people with dementia and the implications of self-directed commissioning.

### **Recommendation 10: Intermediate care for people with dementia**

Proposition for consultation 10: Updating Department of Health guidance on intermediate care to ensure that the needs of people with dementia are properly addressed. PCTs and local authorities would review services to ensure that people with dementia have access to re-ablement home care and rehabilitation services, including intermediate care.

### **Recommendation 11: Improved dementia care in care homes**

Proposition for consultation 11: Care homes developing a policy for good quality care for people with dementia; the appointment of a senior member of staff to lead the development and delivery of the policy; the policy being monitored and its provision being part of the contracting process. Commissioning specialist mental health in-reach services into care homes as well as enabling in-reach from other professionals such as community pharmacists, community dentists, optometry and geriatricians.

### **Recommendation 12: Improved registration and inspection of care homes**

Proposition for consultation 12: Introducing registration procedures requiring all care homes to demonstrate that they can provide good-quality care for people with dementia, unless there are specific reasons for exemption.

### **Consultation questions**

1. Are these outcomes, recommendations and the suggested means of achieving them the right ones?
2. Is there anything that has been missed that would help to ensure high-quality care and support for people with dementia and their families?
3. What more could be done in acute care, home care and care homes?
4. What could be done to make the personalisation of care agenda (including individual budgets) work for people with dementia and their family carers?
5. What can you or your organisation do to help implement these recommendations?

# Chapter 4 – Delivering the National Dementia Strategy

## **Recommendation 13: Clear information on the delivery of the National Dementia Strategy**

Outcome: Good-quality information to be available on the development of dementia services as the strategy is delivered.

Transforming the quality of dementia care in England is a huge challenge for all parts of the health and social care system. People with dementia, their carers, the public and professionals will all expect to see steady progress. It is therefore very important to establish the nature of current dementia services, to track them over time and to monitor the progress of the National Dementia Strategy. This will require a national baseline measurement of service content and finance, as well as local service audits. Information on the growth and activity of services for people with dementia and their carers will need to be available, as will comparisons with agreed benchmarks. These might be delivered by specifically commissioned research to support the implementation of policy, and by existing service and financial mapping activities.

The developments recommended here will need the workforce to grow if the new and improved services described are to be delivered. This has implications across the whole health and social care economy – including the voluntary sector and private providers. It is envisaged that the individual elements of the strategy could be delivered in a staged manner, possibly over a five-year period. This should mitigate the workforce effects and allow time for appropriate local prioritisation and decision making. This element of the strategy will need to feed into the operational plans and budget cycles of PCTs and local authorities, and to demonstrate how it will meet national and local targets for improving services for people with dementia. It needs to take account of guidance in the world-class commissioning framework, *Putting People First*, and specific commissioning guidance linked to this strategy.

## **Recommendation 14: A clear picture of research evidence and needs**

Outcome: Evidence to be available on the existing UK research base on dementia and on the gaps that need to be filled.

Many of those consulted have argued that there is a strong need to build the dementia research base. There has been growth in public, industrial and charity funding for dementia research, but the level of funding still lags behind those of other major health priorities such as cancer and heart disease. Further research is needed in all areas of the illness – from the basic biological process and the evaluation of new biological and non-biological treatments through to options for care and prevention.

Ministers plan to convene a summit of all relevant organisations to consider a planned programme of research and the potential for further development – because dementia is now one of the most significant challenges facing our society. The Department of Health will then generate a strategic review of national dementia research, identifying the strengths that might be built on and the gaps in the evidence base that might be filled. This will mean that we can focus on how research funders, charities and industry might work together to deliver a programme of dementia research into prevention, cause, cure and care. This work would be part of the National Dementia Strategy.

**Recommendation 15: Effective support for implementation**

Outcome: Appropriate national support to be available in support of local implementation of the strategy.

Previous implementation experiences suggest that some support will be needed to achieve delivery of the National Dementia Strategy. Areas will need help with getting started, particularly if little strategic attention has previously been given to the needs of people with dementia. The recommendations in the draft strategy set out the areas on which health and social care communities can initially focus their attention.

The Department of Health will need to support the implementation of the strategy, and as part of this will need to consider the issue of clinical leadership. Local and regional leadership will be key to driving forward service development and delivery. The Department of Health will be considering how best to provide this leadership, but the focus is likely to be on:

- helping health and social care commissioners to develop services that deliver better outcomes for people with dementia and their carers by:
  - using the world-class commissioning and *Putting People First* initiatives as frameworks, and ensuring synergy with the clinical pathways developed through the ‘Our NHS, Our Future’ review; and
  - developing an inclusive approach to personalisation that enables people with dementia and their carers to direct their own support, for example through self-assessment and personal budgets;
- identifying and using levers and incentives to improve dementia care;
- developing practical materials to encourage front-line service providers (who face a range of competing priorities) to effect change; and
- encouraging the development of clinical networks to support service improvement, share learning and spread good practice.

Implementation of the National Dementia Strategy will need to be part of a broader focus on older people's mental health services. Some localities are interpreting age equality in psychiatry services to mean a 'one size fits all ages' approach, but the improvement of services for people with dementia must not be used as an excuse for diluting specialist services for older people with other mental health needs. The final version of the strategy will include a detailed implementation plan, based on the outcome of the consultation.

The guidance on joint strategic needs assessments published by the Department of Health in December 2007 stated that these will now include a longer-term assessment (five to 10 years) to take into account anticipated changes in demography and infrastructure. People with dementia and their family carers have indicated that they want the care and support system in England to promote independence and wellbeing by helping individuals with dementia and their families to live safely at home, meet their own personal care needs and continue to be able to contribute to society. These common themes and policy objectives support the Government's programme to promote independence and wellbeing through *Putting People First*, the *Independent Living Strategy*, *Lifetime homes, lifetime neighbourhoods: A national strategy for housing in an ageing society* and the *NHS Next Stage Review*. They are also the same aspirations which people with dementia have.

In undertaking joint strategic needs assessments and in looking ahead over the next 10 years, commissioners will need to consider investing in new models of supported housing (such as extra care) and in assistive technology that takes full account of the needs of people with dementia (as recommended in this strategy). The implementation of this strategy, and the development of new care models that incentivise re-ablement and rehabilitation through the use of increasingly innovative technology and the shift of investment to a range of supported housing options, will all require considerable changes to take place in the configuration of services over the next 10 years. In the coming years, consideration will need to be given to the role that both traditional and emerging models of long-term care provision (either at home or in care homes) should play in supporting the projected increasing numbers of people with dementia.

We have not included a timetable for implementation here, but will generate one to accompany the full strategy that will be published following this consultation. We would like to seek your views on what the timetable for implementation should be: what can and should be done first? What should be the highest priorities?

This strategy is the start of a process – not an end in itself. Even if all of these recommendations are fully implemented, there will still be very much more to do. Clearly there are costs to the system in making these changes, but the cost in financial and human terms of not making them may be higher.

## Summary propositions for consultation

### **Recommendation 13: Clear information on the delivery of the National Dementia Strategy**

Proposition for consultation 13: Establishing a national baseline measurement of the content and resources of dementia services. Subsequently, completing an independent programme of assessment on a national basis on the growth and activity of services for people with dementia and their carers, comparing services against agreed benchmarks at one, three and five years.

### **Recommendation 14: A clear picture of research evidence and needs**

Proposition for consultation 14: A strategic review of UK dementia research, conducted or facilitated by the Department of Health, setting out how research funders, charities and industry can work together to deliver the programme of research into prevention, cause, cure and care.

### **Recommendation 15: Effective support for implementation**

Proposition for consultation 15: Central support from the Department of Health, with both regional and local implementation.

## Consultation questions

1. Are these outcomes, recommendations and the suggested means of achieving them the right ones?
2. Is there anything that has been missed to help us deliver the National Dementia Strategy?
3. What are your priorities for implementation? What can and should be done first?
4. What should the timetable for implementation be?
5. What can you or your organisation do to help implement these recommendations?
6. Does this draft strategy fully address issues of equality and diversity, and the needs of particular groups?

# Appendix 1 – List of project group members and stakeholders consulted

The Department of Health would like to thank the following people who gave up their time to contribute to the development of this document:

## **Core External Reference Group (ERG)**

Neil Hunt, CEO, Alzheimer's Society (Chair)

Dr Dave Anderson, Chair, Faculty of Old Age Psychiatrists

Paul Cann, Director of Policy, Help the Aged

Andrew Chidgey, Head of Policy and Campaigns, Alzheimer's Society

Gary Fitzgerald, CEO, Action on Elder Abuse

Jane Gilliard, Secretary to the ERG and its sub-groups

Philip Hurst, Policy Manager, Age Concern England

Professor Steve Iliffe, Professor of Primary Care for Older People and Associate Director, DeNDRoN National Co-ordinating Centre, University College London

Lis Jones, Executive Nurse Director, Camden and Islington Mental Health Trust

George Marshman, Divisional Director, Adult Social Care, Lambeth Adults and Community Services

Barbara Pointon MBE, Alzheimer's Society Ambassador and former carer

Sara Render, CEO, Kinross & Render, Public Relations Consultancy

Daphne Wallace, member of the Alzheimer's Society and a person with dementia

Professor Gordon Wilcock, Professor of Clinical Geratology, Nuffield Department of Medicine, University of Oxford

## **ERG raising awareness working group**

Sara Render, CEO, Kinross & Render, Public Relations Consultancy (Chair)

Heide Baldwin, Royal College of Nursing

Gary Blatch, Royal College of Nursing

Professor Carol Brayne, Professor of Public Health Medicine, Cambridge University

Professor Alistair Burns, Professor of Old Age Psychiatry, University of Manchester

Professor Murna Downs, Bradford Dementia Group, University of Bradford

Anne McDonald, Local Government Association

Ian Morgan, Head of Pharmacy, Lloyds Pharmacy

Dr David Morris, Programme Director, National Social Inclusion Programme, National Institute for Mental Health in England

Linda Seaward, Head of Marketing and Publishing, Alzheimer's Society

Keith Turner, member of the Alzheimer's Society and a person with dementia

Lillian Turner, member of the Alzheimer's Society and a carer

### **ERG early diagnosis and intervention working group**

Professor Steve Iliffe, Professor of Primary Care for Older People and Associate Director, DeNDRoN National Co-ordinating Centre, University College London (Chair)

Dr Andy Barker, Healthcare Commission

Gillian Broxholme, Helpline Supervisor, Alzheimer's Society

Janice Clasper, member of the Alzheimer's Society and a carer

Ken Clasper, member of the Alzheimer's Society and a person with dementia

Professor Peter Crome, Professor of Geriatric Medicine, Keele University, and President, British Geriatrics Society

Dr Gwyn Grout, Consultant Nurse, Hampshire Partnership NHS Trust

George Marshman, Divisional Director, Adult Social Care, Lambeth Adults and Community Services

David Matthews, Consultant Clinical Psychologist, British Psychological Society

Jackie Pool, Independent Consultant, Jackie Pool Associates

Professor Martin Rossor, Association of British Neurologists

Samantha Sharp, Alzheimer's Society

Jean Tottie, Uniting Carers for Dementia and a carer

## **ERG improving the quality of care working group**

Professor Gordon Wilcock, Professor of Clinical Geratology, Nuffield Department of Medicine, University of Oxford (Chair)

Peter Ashley, member of the Alzheimer's Society and a person with dementia

Penny Banks, Head of Information and Reporting, Commission for Social Care Inspection

Marie Barnes, Nurse Consultant, St Helens & Knowsley Teaching Hospitals

Professor Dawn Brooker, Bradford Dementia Group, University of Bradford

Rosemary England, Assistant Director of Adult Social Services, London Borough of Bexley, and nominated by the Association of Directors of Adult Social Services (ADASS)

Daren Felgate, Training Development Manager, Alzheimer's Society

Sue Garwood, Care Services Improvement Partnership, Housing Learning and Improvement Network

Dr John Holmes, Senior Lecturer in Liaison Psychiatry of Old Age, University of Leeds

Philip Jones, Practice Development Manager, Mental Health, Social Care Institute for Excellence

Barbara Pointon MBE, Alzheimer's Society Ambassador and former carer

Anne Roberts, CEO, Crossroads

Lucianne Sawyer, President, UK Home Care Association

Ian Smith, Information and Policy Manager, PRIAE (Policy Research Institute on Ageing and Ethnicity)

Dr Graham Stokes, BUPA Care Homes and South Staffordshire and Shropshire NHS Foundation Trust

## **Department of Health working group**

Professor Sube Banerjee (Co-lead, National Dementia Strategy) Professor of Mental Health and Ageing, Institute of Psychiatry, King's College London, and Department of Health Senior Professional Adviser in Older People's Mental Health

Jenny Owen (Co-lead, National Dementia Strategy) Association of Directors of Adult Social Services, and Executive Director, Adults, Health and Community Wellbeing, Essex County Council

Gill Ayling, Department of Health

Jerry Bird, Project Manager, Department of Health

Andrew Chidgey, Alzheimer's Society  
Rose Cofie, Department of Health  
David Corcoran, Department of Health  
James Davison, Department of Health  
Keith Douglas, Department of Health  
Ruth Eley, Care Services Improvement Partnership  
Jane Gilliard, Department of Health  
Andy King, Department of Health  
Claire Mills, Department of Health  
Andrew Palethorpe, Department of Health  
Ronan Segrave, Department of Health  
Helene Shaw, Department of Health  
Deborah Sturdy, Department of Health  
Helen Wiggins, Department of Health

**Contributions were also received from**

Dr Nori Graham, Emeritus Consultant, Royal Free Hospital  
Professor Barry Gurland, Stroud Center for Quality of Life, Columbia University, New York, USA  
Neil Mapes, Age Concern England  
Dr Rupert McShane, Consultant Old Age Psychiatrist, Oxfordshire and Buckinghamshire Mental Health Trust  
Professor Ajit Shah, University of Central Lancashire, and Consultant Old Age Psychiatrist, West London Mental Health NHS Trust  
Melba Wilson, Delivering Race Equality Programme, Department of Health  
Housing 21  
NHS Confederation  
Unison

## Wider stakeholders

The following stakeholder organisations will also be invited to respond to the consultation. Please contact the Dementia Team with the names of any other stakeholder groups not on the list that you feel might be able to contribute at the address given in Appendix 2.

Afiya Trust

Age Concern

Alzheimer's Research Trust

Alzheimer's Society

Ambulance Service Association

Association of British Neurologists

Association of Directors of Adult Social Services

Association of Professional Music Therapists

Black Health Agency

British Association of Art Therapists

British Association of Dramatherapists

British Association of Prosthetists and Orthotists

British Association of Social Workers

British Association of Stroke Physicians

British Cardiovascular Society

British Geriatric Society

British Pharmacological Society

British Psychological Society

BUPA

Chartered Society of Physiotherapy

College of Health

College of Occupational Therapists

Commission for Social Care Inspection

Confederation of Indian Organisations

Connect

Connecting for Health

Deaneries

Dementia Services Development Centres  
DeNDRoN  
Down's Syndrome Association  
Eastwards Trust  
English Community Care Association  
Equality and Human Rights Commission  
Faculty of Public Health  
Faith Action  
Federation of Irish Societies  
for dementia  
Foundation trusts  
Health and Social Care Advisory Service  
Healthcare Commission  
Help the Aged  
Housing 21  
Improvement and Development Agency  
Joint Royal Colleges Ambulance Liaison Committee  
King's Fund  
Local Government Association  
Medical Research Council  
Mencap  
Multi-Faith Group for Healthcare Chaplaincy  
National Audit Office  
National Care Association  
National Care Forum  
National Collaborating Centre for Chronic Conditions  
National Employment and Health Innovations Network  
National Institute for Health and Clinical Excellence  
National Institute for Health Research  
NHS Direct  
NHS Institute for Innovation and Improvement

NHS trusts  
Nuffield Council on Bioethics  
Parkinson's Disease Society  
People First  
Polari  
Postgraduate Medical Education and Training Board  
Primary care trusts  
Race Equality Foundation  
Registered Nursing Home Association  
Residents and Relatives Association  
Royal Association for Disability and Rehabilitation (RADAR)  
Royal College of General Practitioners  
Royal College of Nursing  
Royal College of Physicians  
Royal College of Psychiatrists  
Royal College of Radiologists  
Royal College of Speech and Language Therapists  
Royal Pharmaceutical Society  
Skills for Care  
Skills for Health  
Social Care Institute for Excellence  
Society of Chiropodists and Podiatrists  
Stonewall  
Strategic health authorities  
Stroke Association  
Thomas Pocklington Trust  
Voice4Change England  
Wellcome Trust  
Workforce Review Team

## Appendix 2 – Responding to the consultation

This consultation seeks views on the recommendations developed for the National Dementia Strategy, as set out in this document. Consultation questions are included in each chapter, and a response form can be downloaded from [www.dh.gov.uk/dementia](http://www.dh.gov.uk/dementia) or obtained by writing to us at the address below. An easy-read version is also available.

As a reminder, the questions raised in the draft strategy are as follows:

1. Are these outcomes, recommendations and the suggested means of achieving them the right ones?
2. Is there anything that has been missed to help us improve public and professional awareness of dementia?
3. Is there anything that has been missed to help us enable early diagnosis and intervention?
4. Do you agree that the diagnosis of dementia should be made by a specialist?
5. How open should referral systems to a memory service be? Should people be able to refer themselves, or should they have to go to their GP first?
6. How would the dementia care adviser be able to ensure continuity of care?
7. Is there anything that has been missed that would help to ensure high-quality care and support for people with dementia and their families?
8. What more could be done in acute care, home care and care homes?
9. What could be done to make the personalisation of care agenda (including individual budgets) work for people with dementia and their family carers?
10. Is there anything that has been missed to help us deliver the National Dementia Strategy?
11. What are your priorities for implementation? What can and should be done first?
12. What should the timetable for implementation be?
13. Does this draft strategy fully address issues of equality and diversity, and the needs of particular groups?
14. What can you or your organisation do to help implement these recommendations?

## How to respond

The consultation period began on 19 June 2008 and will run until 11 September 2008. As well as providing for written responses, the consultation exercise will involve a series of regional and national workshops organised by the Care Services Improvement Partnership for people to give their views on the draft strategy. Details will be available on the dementia website at [www.dh.gov.uk/dementia](http://www.dh.gov.uk/dementia) should you wish to participate in any of these events. Please ensure that your response reaches us by that date. If you would like further copies of this consultation document, it can be found at [www.dh.gov.uk/consultations](http://www.dh.gov.uk/consultations), or you can contact [dementia.strategy@dh.gsi.gov.uk](mailto:dementia.strategy@dh.gsi.gov.uk). Hard copies can be obtained by calling 08701 555 455 (see back cover for the reference number and further details).

Please send consultation responses by email to:

[dementia.strategy@dh.gsi.gov.uk](mailto:dementia.strategy@dh.gsi.gov.uk)

Or by post to:

David Corcoran  
Dementia Team  
Department of Health  
8E13 Quarry House  
Quarry Hill  
Leeds LS2 7UE

The Department of Health will use the responses to this consultation in the development of the National Dementia Strategy. The strategy will put forward a vision for the delivery of health and social care services for those at risk of or who have dementia.

When responding, please state whether you are responding as an individual or representing the views of an organisation. If responding on behalf of a larger organisation, please make it clear who the organisation represents and, where applicable, how the views of members were assembled.

Information provided in response to this consultation, including personal information, may be published or disclosed in accordance with the access to information regimes (these are primarily the Freedom of Information Act 2000, the Data Protection Act 1998 and the Environmental Information Regulations 2004).

If you want the information that you provide to be treated as confidential, please be aware that, under the Freedom of Information Act 2000, there is a statutory code of practice with which public authorities must comply and which deals, among other things, with obligations of confidence. In view of this, it would be helpful if you could explain to us why

you regard the information you have provided as confidential. If we receive a request for disclosure of the information we will take full account of your explanation, but we cannot give an assurance that confidentiality can be maintained in all circumstances. An automatic confidentiality disclaimer generated by your IT system will not, of itself, be regarded as binding on the Department of Health.

The Department will process your personal data in accordance with the Data Protection Act 1998 and, in the majority of circumstances, this will mean that your personal data will not be disclosed to third parties.

### **What will happen next?**

A summary of responses, including the next steps, will be published by October 2008 and will be available at [www.dh.gov.uk/dementia](http://www.dh.gov.uk/dementia). Printed copies will be available on request.

### **Impact assessments**

A partial impact assessment is available at [www.dh.gov.uk/dementia](http://www.dh.gov.uk/dementia). A partial equality impact assessment is currently being finalised and will be available on the same website by mid-July at the latest.

Comments or complaints (but not responses to the consultation itself) should be directed to:

Consultation Co-ordinator  
Department of Health  
Skipton House  
80 London Road  
London SE1 6LH

Email: [consultations.co-ordinator@dh.gsi.gov.uk](mailto:consultations.co-ordinator@dh.gsi.gov.uk)

## The consultation criteria

The consultation is being conducted in line with the Code of Practice on Consultation. The criteria are listed below; a full version of the criteria can be found at [www.cabinetoffice.gov.uk/regulation/Consultation/Code.htm](http://www.cabinetoffice.gov.uk/regulation/Consultation/Code.htm).

The Cabinet Office code of practice criteria are as follows:

1. Consult widely throughout the process, allowing a minimum of 12 weeks for written consultation at least once during the development of the policy.
2. Be clear about what your proposals are, who may be affected, what questions are being asked and the timescale for responses.
3. Ensure that your consultation is clear, concise and widely accessible.
4. Give feedback regarding the responses received and how the consultation process influenced the policy.
5. Monitor your department's effectiveness at consultation, including through the use of a designated consultation co-ordinator.
6. Ensure your consultation follows better regulation best practice, including carrying out an impact assessment if appropriate.

# Appendix 3 – The policy context for the National Dementia Strategy

## ***Forget me not***

In 2000 the Audit Commission published its *Forget me not: Mental health services for older people* report.<sup>42</sup> Key findings included the following:

- Only a half of GPs believed it important to look actively for signs of dementia and to make an early diagnosis.
- Less than half of GPs felt that they had received sufficient training in how to diagnose dementia.
- There was a lack of clear information, counselling, advocacy and support for people with dementia and their family carers.
- There was insufficient supply of specialist home care.
- There were poor assessments and treatment, with little joint health and social care planning and working.

They found little improvement when reviewing change two years later.<sup>43</sup>

## ***National Service Framework for Older People***

The 2001 *National Service Framework for Older People* included a chapter on mental health and older people.<sup>44</sup> This included a consideration of dementia, advocating early diagnosis and intervention. It recommended that the NHS and local authorities should review arrangements for health promotion, early detection and diagnosis, assessment, care and treatment planning, and access to specialist services. Reviewing progress, this appears to have had little positive impact on services for people with dementia and their families.

## ***Everybody's business***

In 2005 the Department of Health and the Care Services Improvement Partnership (CSIP) published *Everybody's business: Integrated mental health services for older adults: a service*

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42 Audit Commission (2000). *Forget me not: Mental health services for older people*. London: TSO.

43 Audit Commission (2002). *Forget me not 2002: Developing mental health services for older people in England*. London: TSO.

44 Department of Health (2001). *National Service Framework for Older People*. London: TSO.

*development guide*.<sup>45</sup> This set out the essentials for a service that works for older people's mental health in general including memory assessment services to enable the early diagnosis of dementia for all and integrated community mental health teams whose role includes the management of people with dementia with complex behavioural and psychological symptoms.

## **NICE/SCIE clinical guideline on dementia**

The National Institute for Health and Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE) published a joint clinical guideline on the management of dementia in 2006.<sup>46</sup> Key recommendations included:

- integrated working across all agencies;
- provision of memory assessment services as a point of referral for diagnosis of dementia;
- assessment, support and treatment (where needed) for carers;
- assessment and treatment of non-cognitive symptoms and behaviour that challenges;
- dementia care training for all staff working with older people; and
- improvement of care for people with dementia in general hospitals.

## **Dementia UK report**

In February 2007 the Alzheimer's Society published *Dementia UK*.<sup>47</sup> The report's key findings on the number of people with dementia and the associated costs are discussed earlier in the report. Its recommendations included making dementia an explicit national health and social care priority and the need to improve the quality of services provided for people with dementia and their carers.

## **National Audit Office value for money study**

The National Audit Office (NAO) published the findings of its review of dementia services, *Improving services and support for people with dementia*, in July 2007.<sup>48</sup> This report was critical of the quality of care received by people with dementia and their families. It found that the size and availability of specialist community mental health teams was extremely variable and that the confidence of GPs in spotting the symptoms of dementia was poor

<sup>45</sup> CSIP (2005). *Everybody's business: Integrated mental health services for older adults: a service development guide*. London: Department of Health.

<sup>46</sup> NICE/SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care*. London: TSO.

<sup>47</sup> Knapp, M, Prince, M, Albanese, E, Banerjee, S, Dhanasiri, S et al (2007). *Dementia UK: The full report*. London: Alzheimer's Society.

<sup>48</sup> NAO (2007). *Improving services and support for people with dementia*. London: TSO.

and lower than it had been in 2000. They also commented on deficiencies in carer support. The report concluded that, overall, services are not currently delivering value for money to taxpayers or people with dementia and their families; that too few people are being diagnosed or being diagnosed early enough, and that early intervention is needed to improve quality of life; and finally that services in the community, care homes and at the end of life are not delivering consistently or cost-effectively against the objective of supporting people to live independently as long as possible in the place of their choosing. The NAO advocated a 'spend to save' approach, with upfront investment in services, for early diagnosis and intervention and improved specialist services, community services and in general hospitals resulting in long-term cost savings from prevention of transition into care homes and decreased length of hospital stay.

### **Public Accounts Committee report**

The NAO report was submitted for consideration by the House of Commons Public Accounts Committee (PAC), and at the committee's public hearing on 15 October 2007 the NHS Chief Executive and others from the Department of Health were questioned on the NAO's criticisms and recommendations. As is normal practice, following the hearing, the PAC published its own report on dementia services in January 2008. The committee's comments and recommendations (available at [www.publications.parliament.uk/pa/cm200708/cmselect/cmpubacc/228/22802.htm](http://www.publications.parliament.uk/pa/cm200708/cmselect/cmpubacc/228/22802.htm)) were consistent with those of the NAO report and with earlier reports on the changes that were needed.

The Government's response to the PAC report is available at [www.official-documents.gov.uk/document/cm73/7323/7323.pdf](http://www.official-documents.gov.uk/document/cm73/7323/7323.pdf). The response accepted virtually all the conclusions and recommendations of the committee, emphasising that their findings would be fully addressed in the National Dementia Strategy.

### **Wider policy context**

The size of the population affected by dementia and the pervasiveness of the condition in health and social care settings means that development of policies and services for people with dementia and their families is also affected by the wider policy context. Currently this includes 'Our NHS, Our Future', which shapes the vision for the NHS over the next decade by making sure it focuses on meeting rising expectations and the challenges it will face over that time. Such challenges include clinical reviews in eight key areas: maternity and newborn; children's health; staying healthy; long-term conditions; acute care (urgent and emergency); planned care; mental health; and end-of-life care. Dementia is an important factor in all but the first two of these.

*Putting People First* is a concordat signed by government departments and organisations including the Association of Directors of Social Services, the Local Government Association, the NHS Confederation, and Skills for Care. It sets out the Government's vision for public

services that enable people to live their own lives as they wish. It is underpinned by a set of values that includes “ensuring older people with chronic conditions, disabled people and people with mental health problems have the best possible quality of life and the equality of independent living”. It advocates a personalised adult social care system which will need to work for people with dementia as well as those without cognitive impairment.

There is increasing evidence that investment in social care initiatives that focus on early intervention and re-ablement can have a positive impact on people’s health. The Department of Health is making more than £500 million of funding available through the new Social Care Reform Grant, to all councils with social services responsibilities (CSSRs) over the next three years to reform social care systems including taking forward work on early intervention to promote independence and improved wellbeing.

The *Putting People First* concordat, signed up to by central and local government and the NHS, sets out the agenda to give more choice and control to people who use services. People with dementia need to be able to benefit from initiatives such as direct payments, individual budgets and personalised services as much as other people. It is important for people with dementia to have choice and control over when and what is offered, as people can be best reassured by familiar faces and responses. Following a commitment made in the 2006 White Paper *Our Health, Our Care, Our Say*, the Government is extending the availability of direct payments, defined as cash in lieu of social services, to people who lack capacity under the Mental Capacity Act 2005 in the Health and Social Care Bill currently going through Parliament. The policy allows a direct payment to be made to a ‘suitable person’ who can receive and manage the payment on behalf of a person who lacks capacity.

NICE has published a commissioning guide on memory assessment services which describes the potential benefits of commissioning effective services, which include:

- increasing the number of people seen for early diagnosis and intervention;
- reducing total care expenditure by delaying the time to nursing home admissions and other costly outcomes;
- reducing the stigma of dementia and barriers to recognition and diagnosis;
- improving the quality of life of people with dementia and their carers by promoting and maintaining their independence;
- reducing inequalities and improving access to appropriate treatment and support;
- increasing patient choice, improving partnership working, patient experience and engagement; and
- achieving better value for money.

The Carers' Strategy was published on 10 June 2008. Over 500,000 family members who care for people with dementia provide over £6 billion a year of unpaid care. A far-reaching consultation of carers has contributed to the development of the Carers' Strategy and its implementation will ensure a 10-year plan that builds on the support for carers and enables them to have a life outside caring. The Government is currently leading a public debate on the future of the care and support system for England. The debate builds on the current transformation programme set out in *Putting People First*, and aims to find an affordable, fair and sustainable way of delivering and funding a first-class care and support system for the 21st century. The findings of the debate will be used to inform the development of reform options for a Green Paper.

Finally, the National End of Life Care Strategy is in preparation, and the NAO will publish a report in the autumn of 2008 on end-of-life care. End-of-life care for people with dementia is an underdeveloped area which requires specific attention.

### **Partnerships for Older People Projects (POPPS)**

The 2004 Spending Review provided ring-fenced funding of £60 million (£20 million in 2006/07 and £40 million in 2007/08) for councils with social services responsibilities (CSSRs) to establish locally innovative pilot projects in partnership with PCTs and the voluntary, community and independent sectors. The key purpose of the pilots is to deliver and evaluate approaches aimed at creating a sustainable shift in resources and culture towards early intervention and thereby deliver improved outcomes for older people. Across the country, 29 pilot sites have been established and are delivering a wide range of interventions, including in some pilots older people's mental health services, aimed at addressing the spectrum of need from emerging mental health needs such as anxiety and depression through to dementia and the early stages of Alzheimer's disease.

### **The Dignity in Care Campaign**

The campaign was launched by the Minister for Care Services, Ivan Lewis, in November 2006. Its aim is to put dignity at the heart of care services, and the role of Dignity Champion has been created to help achieve this. These champions come from many different sectors and professions, including older people themselves and carers, and speak up for dignity, challenging practices that are inadequate and working with health and social care organisations to improve the experience of older people. Sir Michael Parkinson has recently agreed to serve as an Ambassador for Dignity. Champions receive regular newsletters, and the Dignity in Care website provides many resources such as podcasts and good practice examples to support Dignity Champions in their role. To register as a Dignity Champion, go to [www.dignityincare.org.uk](http://www.dignityincare.org.uk) or ring 020 7972 4007.

# Appendix 4 – The clinical and health economic case for early diagnosis and intervention services in dementia

## Summary

- S1 This note summarises the analysis of costs and benefits of expanding early diagnosis and intervention services for dementia.
- S2 The enhanced services would cost an estimated extra £220 million per year nationally. This consists of:
- establishment of a national network of memory services;
  - support for existing community mental health teams for older people; and
  - enhancement of social services for older people with mental health problems.
- S3 There is good evidence, summarised here, that establishing such services would lead to reduced use of residential care. As there is uncertainty about the extent of the reduction, the analysis uses three possible assumptions – ie reductions of 6%, 10% and 20% – by way of sensitivity analysis. The reduction in use of residential care by users of the service would start in the fourth year.
- S4 In the tenth year of the service's operation its estimated cost would be around £265 million (in 2007/08 prices) due to real rises in care costs. The estimated savings under the central 10% scenario would be £120 million in public expenditure (health and social care) and £125 million in private expenditure (service users and their families) which makes a total saving of £245 million to society. This means that under a 10% reduction in residential care the annual cost would be almost offset by the estimated saving to society. Under a 20% reduction, the annual cost would be almost offset by the estimated saving to public expenditure alone.
- S5 The estimated net present value (NPV) over 10 years of the costs and savings to society of the 10% scenario, with a 3.5% discount rate, would be around (minus) £950 million. This analysis, however, takes no account of the value of the increase in quality of life expected from the services.

- S6 The evaluation of the Department of Health early intervention pilot (the Croydon Memory Service) found at the six-month follow-up statistically significant improvement in self-rated and proxy-rated quality of life, representing around 4% of the interval between lowest and highest possible states.
- S7 The NPV would be positive if benefits (such as improved quality of life) could be achieved whose monetary value rose linearly from nil in the first year to around £250 million in the tenth year. This would be a gain of around 6,250 QALYs in the tenth year, where a QALY is valued at £40,000, or 12,500 QALYs if a QALY is valued at only £20,000.
- S8 We estimate that by the tenth year of the service all 600,000 people in England then alive with dementia will have had the chance to be seen by the new services. A gain of 6,250 QALYs per year would amount to only around 0.01 QALYs per person per year. A gain of 12,500 QALYs would amount to only around 0.02 QALYs per person per year. These relatively small improvements seem very likely to be achievable in view of the rise of 4% reported in the Department of Health pilot.
- S9 This analysis suggests that the service need only achieve a modest increase in average quality of life of people with dementia, plus a 10% diversion of people with dementia from residential care, to be cost-effective. The net increase in public expenditure would then, on the assumptions discussed in this paper, be justified by the expected benefits.
- S10 This modelling provides a strong case for the development of nationwide services for the early identification and treatment of dementia in both financial and quality terms.

## 1.0 Introduction

- 1.1 This note sets out the clinical and economic case for investing in services for the early identification of and intervention in dementia. The purpose of this is to present systematically the available evidence on the costs and benefits of enhancing and reconfiguring services for people with dementia and to present the results of new modelling of costs and benefits. The evidence is drawn directly from the peer-reviewed scientific literature on evaluations of service delivery for people with dementia. This evidence has been considered systematically and critically but, for the purposes of clarity, a summary is presented here. The analyses suggest that it would be clinically effective and cost-effective to invest in such services.

### What is dementia?

- 1.2 The term 'dementia' is used to describe a clinical syndrome characterised by progressive decline in multiple areas of function, including a decline in memory, reasoning and communication skills and a decline in skills needed to carry out daily

activities. Alongside this decline, individuals may develop behavioural and psychological symptoms, such as depression, psychosis, aggression and wandering, which complicate care and which can occur at any stage of the illness.

- 1.3 This syndrome has a number of causes which effect structural and chemical changes in the brain such as those characteristic of Alzheimer’s disease. The main sub-types are Alzheimer’s disease, vascular dementia, mixtures of these two pathologies (‘mixed dementia’) and rarer types such as Lewy Body dementia and fronto-temporal dementia. The term ‘Alzheimer’s disease’ is used increasingly as a shorthand term to cover all forms of dementia.

### Who gets dementia and how are they affected?

- 1.4 Dementia is predominantly a disorder of later life, with 98% of cases occurring in those over the age of 65. It affects men and women in all social and ethnic groups. Its incidence (the number of new cases per year) and prevalence (the number of cases at any one time) rise exponentially with age. The prevalence rises from around 1% at age 65 to 35% at 85.
- 1.5 It is clearly a devastating disorder for those with dementia, and it also has profound negative impacts on family members who provide the majority of all care. Family carers of people with dementia are often old and frail spouses and often have high levels of carer burden, depression, physical illness, and diminished quality of life. Dementia is a terminal disorder, but people may live with their dementia for 7–12 years after diagnosis. The challenge is how to enable people with dementia and their carers to live well rather than badly with dementia, maximising quality of life.

### What is the size and cost of the challenge of dementia?

- 1.6 The *Dementia UK* report provides the best available estimates for dementia prevalence, cost and population projections.<sup>49</sup> This report found that currently:
- there are 570,000 people with dementia in England; and
  - dementia costs the UK economy £17 billion per year.
- 1.7 With population ageing, in just 30 years it is estimated that:
- the numbers with dementia will double; and
  - the costs of dementia will treble.<sup>50</sup>

49 Knapp, M, Prince, M, Albanese, E, Banerjee, S, Dhanasiri, S et al (2007). *Dementia UK: The full report*. London: Alzheimer’s Society.

50 Comas-Herrera, A, Wittenberg, R, Pickard, L and Knapp, M (2007). ‘Cognitive impairment in older people: future demand for long-term care services and the associated costs.’ *International Journal of Geriatric Psychiatry*, 22, 1037–45.

### Why is early diagnosis and intervention important?

- 1.8 The literature strongly points to the value of early diagnosis and intervention to improve quality of life and to delay or prevent transitions into care homes. According to the best estimates available in the *Dementia UK* report,<sup>51</sup> care home placement costs the UK £7 billion per year with two-thirds paid by social services and one-third by older people and their families themselves.
- 1.9 Data suggest that early provision of in-home support can decrease institutionalisation by 22%,<sup>52</sup> and reductions of 6% even in more severe cases with a highly active control have been reported for case management in dementia.<sup>53</sup> Behavioural disturbance, hallucinations and depression in dementia are three of the most important factors in predicting institutionalisation,<sup>54</sup> and older people's mental health services are designed to treat these symptoms. The value of carer support is clearly shown by the finding that having a co-resident carer exerts a 20-fold preventative effect on entering a care home.<sup>55</sup> A brief programme of carer support and counselling at diagnosis alone has been demonstrated to reduce care home placement by 28%, with a median delay to placement of 557 days compared with those not receiving the intervention.<sup>56</sup>
- 1.10 There is also a strong quality argument for the prevention of institutionalisation; people with dementia and their carers generally want them to stay in their own homes and their quality of life is higher at home than in care homes. Finally, services that enable early intervention have been shown to have positive effects on the quality of life of people with dementia<sup>57</sup> and their family carers.<sup>58</sup>

51 Knapp, M, Prince, M, Albanese, E, Banerjee, S, Dhanasiri, S et al (2007). *Dementia UK: The full report*. London: Alzheimer's Society.

52 Gaugler, JE, Kane, RL, Kane, RA and Newcomer, R (2005). 'Early community-based service utilization and its effects on institutionalization in dementia caregiving.' *The Gerontologist*, 45, 177–85.

53 Challis, D, von Abendorff R, Brown, P, Chesterman, J and Hughes, J (2002). 'Care management, dementia care and specialist mental health services: An evaluation.' *International Journal of Geriatric Psychiatry*, 17, 315–25.

54 Gilley, DW, Bienias, JL, Wilson, RS, Bennett, DA, Beck, TL and Evans, DA (2004). 'Influence of behavioral symptoms on rates of institutionalization for persons with Alzheimer's disease.' *Psychological Medicine*, 34, 1129–35.

55 Banerjee, S, Murray, J, Foley, B, Atkins, L, Schneider, J and Mann, A (2003). 'Predictors of institutionalisation in older people with dementia.' *Journal of Neurology, Neurosurgery and Psychiatry*, 74, 1315–1516.

56 Mittelman, M, Haley, WE, Clay, OJ and Roth, DL (2006). 'Improving caregiver well-being delays nursing home placement of patients with Alzheimer's Disease.' *Neurology*, 67, 1592–9.

57 Banerjee, S, Willis, R, Matthews, D, Contell, F, Chan, J and Murray, J (2007). 'Improving the quality of dementia care – an evaluation of the Croydon Memory Service Model.' *International Journal of Geriatric Psychiatry*, 22, 782–8.

58 Mittelman, MS, Roth, DL, Clay, OJ and Haley, WE (2007). 'Preserving the health of Alzheimer's caregivers: Impact of a spouse caregiver intervention.' *American Journal of Geriatric Psychiatry*, 15, 780–9.

## 2.0 What is the problem?

- 2.1 The problem we have is that, in current systems, only around 30% of people with dementia have a formal diagnosis made, or contact with specialist services, at any time in their illness.<sup>59</sup> Such diagnosis and contact, when made, often only occurs late in the illness and in crisis, when the opportunities for harm prevention are limited.
- 2.2 If dementia is not diagnosed early, then the person with dementia and their family carers are denied the possibility of planning for their future or of availing themselves of the help, support and treatments (social and psychological, as well as pharmacological) which are available. Contrary to social misconceptions, there is a great deal that can be done to help people with dementia and their carers, and while there are undoubtedly potential negative reactions to diagnosis as well as positive outcomes,<sup>60</sup> the balance is very much in favour of early diagnosis, and the earlier such intervention is available in the illness the better.<sup>61</sup>
- 2.3 All PCTs will be commissioning a number of services which might make the diagnosis of dementia such as GPs, old-age psychiatric community teams, geriatric medicine, and neurology services. Current systems are non-prescriptive about where and by whom diagnoses of dementia should be made. There is, however, a marked reluctance on the part of primary care to be directly involved in the diagnosis of dementia for reasons that include: therapeutic nihilism; risk avoidance; concerns about competency; and concerns about resources.<sup>62</sup> The current focus is on the severe and complex end of the spectrum, leaving the issue of early diagnosis and intervention largely unaddressed.

## 3.0 The proposal for whole-system quality improvement

- 3.1 The service structures needed to provide early diagnosis of dementia and intervention for people with dementia and family carers are increasingly well understood but have not been delivered by policy and commissioning guidance to date.<sup>63,64</sup>
- 3.2 The case presented here is based on commissioning a new system to work in a complementary way with existing primary and secondary care services. This has three necessary components:

59 National Audit Office (2007). *Improving services and support for people with dementia*. London: TSO.

60 Iliffe, S, Manthorpe, J and Eden, A (2003). 'Sooner or later? Issues in the early diagnosis of dementia in general practice: A qualitative study.' *Family Practice*, 20, 376–81.

61 NICE/SCIE (2006). *Dementia: Clinical guideline*. London: NICE/SCIE.

62 Iliffe, S, Wilcock, J and Haworth, D (2006). 'Obstacles to shared care for patients with dementia: A qualitative study.' *Family Practice*, 23, 353–62.

63 Department of Health (2005). *Everybody's business: Integrated mental health services for older adults: a service development guide*. London: CSIP.

64 Royal College of Psychiatrists (2006). *Raising the standard of specialist services for older people with mental illness*. London: Royal College of Psychiatrists.

- establishment of a national network of memory services;
  - support for existing community mental health teams for older people; and
  - enhancement of social services for older people with mental health problems.
- 3.3 The best simple predictor of need for dementia care in a particular population is its age distribution, in particular the number of people over 65 years of age. The next most important factor is the number of care home beds in an area, given that up to 80% of the residents of these institutions have dementia. The 152 PCTs in England vary greatly in size, with the number of over-65s ranging between 14,000 and 220,000. The local level of need will determine the size of the teams needed (and resource allocation formulae reflect this). In some areas where the population is low, one team might service two or more PCTs; in others where the PCTs are large, two or more teams might be needed to serve different geographical areas in a PCT.
- 3.4 The costs presented here include staff costs and trust overheads. They do not cover the direct costs of those extra investigations, care packages in the community, medication, or other need for health and social care which might be uncovered by the diagnostic process and early treatment. They do cover all costs (other than investigations) for the process of diagnosis; explaining that diagnosis to the family; and the care and support needed following diagnosis by the team.
- 3.5 In the estimation of benefits, no calculation is made of the savings that might accrue from early diagnosis in terms of reduced use of acute hospital beds, by prevention of admission and the facilitation of discharge, or decreased use of community social care by the early provision of advice, treatment and support. This direct health service saving may be extensive, with the National Audit Office estimating that re-engineering systems for dementia could yield £6.5 million of acute trust savings per year in a single area (Lincolnshire).
- 3.6 The investment needed to establish early diagnosis and intervention services in all PCTs in England consists of the following (note that the system will not work without all elements being commissioned together, and all modelling in this report is based on this):
- 3.6.1 **Establishment of a national network of ‘memory services’ for early diagnosis and intervention in dementia.** These only exist in a very few areas and even then do not have the capacity to see the large number of cases that are in the community. These multidisciplinary and interagency teams would provide people with their diagnosis, so enabling choice and forward planning while people have capacity. They would also provide information, and direct medical, psychological and social help to people with dementia

and their family carers to enable them to set a different, better course in their illness. They would prevent future crises by encouraging more effective and earlier help seeking, and so reduce unwanted transition into care homes. The Department of Health has piloted this service model with positive results. Start-up costs, including training, are estimated at six months' running costs for the team. Such services could be provided by older people's mental health services, geriatricians, neurologists or GPs with a special interest. These costs are based on 10.0 whole-time equivalent (WTE) multidisciplinary team members for a population of 50,000 over 65s (indicative content: 1.5 WTE doctors, 3.0 WTE nurses, 1.0 WTE psychologist, 2.0 WTE care managers, 1.0 WTE occupational therapist, and 1.5 WTE administrators) generating a team working five days a week with flexible hours, processing 600 to 800 referrals per year, and providing diagnoses and direct care and support to those diagnosed with dementia and their family carers. The estimated cost for an average PCT is £600,000 per year, equating to £95 million per year nationally covering the costs of both health and social care staff.

### 3.6.2 **Support for existing community mental health teams for older people.**

These are the mainstay of dementia health care in the UK, providing individualised intervention for people with dementia and their family carers in their own homes. These teams need to have the capacity to work with people seen in the first instance by the early intervention teams mentioned above, but who either immediately or later in their illness require more complex and assertive models of care. The capacity to provide this is not available within these teams at present and the memory services mentioned in paragraph 3.6.1 are not constructed to provide such care. They will continue to look after those with the most complex and severe problems in dementia (as well as those with schizophrenia, depression, mania and other mental disorders in later life) and will continue to provide a diagnostic service to those referred who need their input. They are the complementary means by which much institutionalisation will be prevented or delayed and quality of life can be provided. They can also help to provide the continuity of care that is so valued by carers. Most people with dementia will not need their input, but for those that do their skills are vital. These are multidisciplinary teams which include social workers and social care staff. These costs are based on recruiting a further 7.5 WTE multidisciplinary team members into those teams serving a population of 50,000 over-65s. Case mix will be determined by the existing team composition (indicative content: 0.5 WTE doctors, 2.0 WTE nurses, 1.0 WTE psychologist, 2.0 WTE care managers, 1.0 WTE occupational therapist, and 1.0 WTE administrator). The estimated cost for

an average PCT is £460,000 per year equating to £70 million per year nationally, covering both health and social care staff.

**3.6.3 Enhancement of social care services for older people with mental health problems.** As with the community mental health teams noted above there will be a knock-on effect of early diagnosis and intervention for generic older people's social services that are responsible for assessment, and for commissioning and arranging care packages to support people at home, in respite care, in intermediate care and in the transition to residential care where necessary. Generic older people's social services also provide ongoing care management and social work support, as well as arranging care. Social services departments do not map exactly onto PCTs, and their funding is differently determined. Funding for social care staff is included in paragraphs 3.6.1 and 3.6.2 above, since they are part of integrated teams, but we estimate that extra assessment and case management in generic older people's social services will require the equivalent of 7.0 WTE care managers per average PCT population. The estimated cost for an average local authority with adult social services responsibilities is £360,000 per year, equating to £55 million per year nationally.

## 4.0 Economic model

4.1 The following is a summary explanation of the main findings of an economic model for the impact of early diagnosis and intervention. The purpose of the model is to examine the potential savings associated with delayed admissions to care homes as a result of early identification of dementia.

### Stock and flow of care home residents

4.2 Our best estimate is that some **215,000** people with dementia in England are currently resident in care homes. An unknown number will be being supported at home by families and friends – with or without the help of formal social care services. Around **85,000** people with dementia enter care homes in England every year (the assumption is that they spend on average two-and-a-half years there). In the absence of other changes, these numbers could be expected to rise by around 1.5% per year due to demographic pressures.

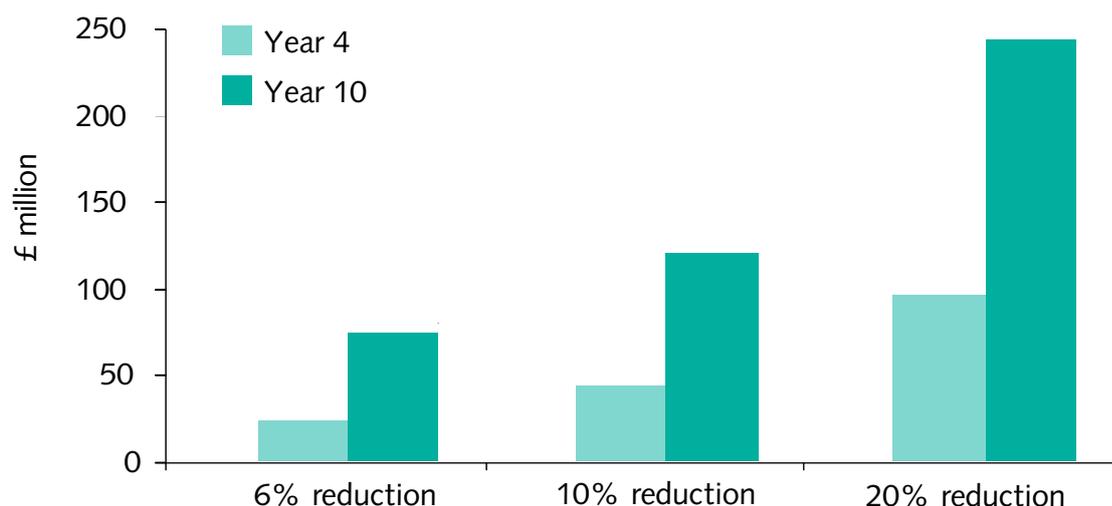
4.3 A reduction of 6% in the number of people with dementia entering care homes (as a result of investment in early diagnosis and treatment services) would translate in time to a reduction of 15,000 in the overall number of care home residents (taking account of demographic pressures). Reductions of 10% or 20% in the number of older people with dementia entering care homes would result in respective reductions of 25,000 and 35,000 in the numbers of people in care homes.

4.4 The reduction in care home admissions is assumed to commence from the fourth year following the start of a new early diagnosis service, with the resulting cost savings accruing from the fourth year onwards. (A 2% annual real rise in care costs has been incorporated into the model to allow for anticipated real rises in social care pay and prices.)

### Savings for publicly funded care home residents

4.5 Publicly funded residents account for two-thirds of the older people in care homes, so delayed or reduced admissions to care homes would result in substantial public cost savings. (These savings are only partially offset by the need for councils to provide home care support to those eligible for publicly funded home care.) Figure 1 illustrates the potential net savings to councils in year 4 and year 10, with comparisons made between a 6%, 10% and 20% reduction in care home numbers.

**Figure 1: Potential public savings from reducing admissions to care homes**



4.6 A 6% reduction in the number of people with dementia entering care homes translates into cost savings of around **£25 million** in year 4, increasing to around **£75 million** in year 10. A 10% reduction translates into cost savings of around **£45 million** in year 4, rising to around **£120 million** in year 10. A 20% stock reduction translates into cost savings of around **£95 million** in year 4, rising to around **£245 million** in year 10.

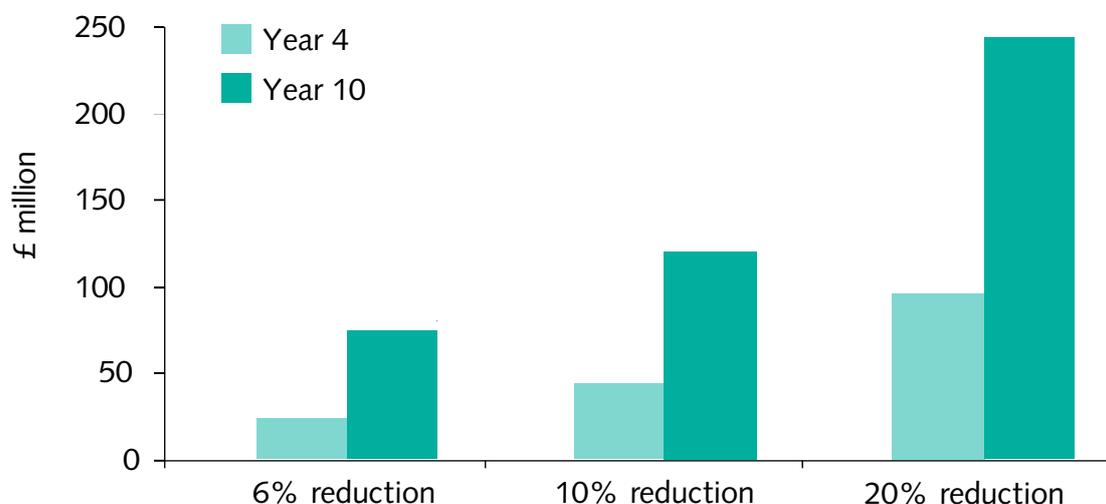
### Savings for privately funded care home residents

4.7 A third of care home residents are privately funded (by themselves or their families), and delayed or reduced admissions to care homes would result in substantial cost savings to these individuals. However, these savings are partially offset by the need for councils to provide home care support to those who are eligible for publicly funded home care, by individual user contributions to home care costs (£15 per week has been assumed) and by private home care costs for those who are not

eligible for publicly funded home care. The savings are further offset by the general living costs of people who are cared for in the community (£150 per week has been assumed). There would also be costs to carers, but these have not been quantified.

4.8 Figure 2 illustrates the potential net savings to individuals and families in year 4 and year 10, with comparisons made between a 6%, 10% and 20% reduction in the numbers of admissions to care homes.

**Figure 2: Potential family savings from reducing admissions**



4.9 A 6% reduction in the number of people with dementia entering care homes translates into cost savings of around **£25 million** in year 4, increasing to around **£75 million** in year 10. A 10% reduction translates into cost savings of around **£45 million** in year 4, rising to around **£125 million** in year 10. A 20% stock reduction translates into cost savings of around **£95 million** in year 4, rising to around **£250 million** in year 10. The cost savings presented in Figure 2 accrue to **private individuals**.

### Overall savings to society

4.10 Overall, savings accruing to public funds and private individuals are shared fairly evenly between both parties (ie a 50% split), and increase as the numbers of people prevented from entering care homes increases over the 10-year period. Total annual savings to society from 6%, 10% and 20% reductions in the numbers of people with dementia entering care homes amount to around **£150 million, £245 million and £490 million** respectively by year 10.

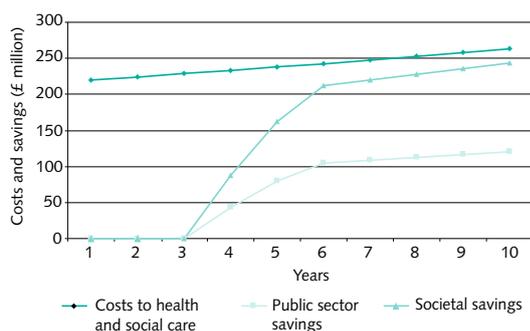
4.11 As discussed above, the analysis assumes no significant net costs or savings to the NHS or any other service except social care, and it does not include an allowance for the opportunity costs of informal care. Our estimates do take account of

demographic pressures and of estimated real rises in care costs of 2% per year, and are based on the assumptions set out in this note. They should be treated with caution.

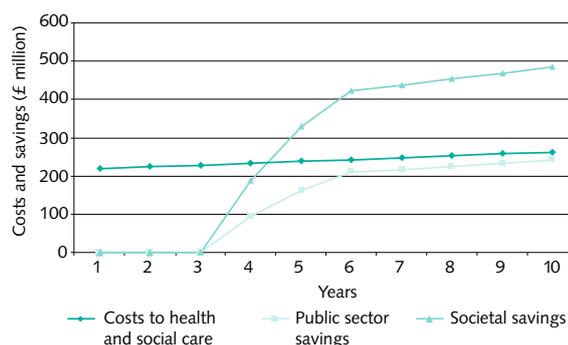
### Costs and savings

4.12 The estimated costs and savings over time are summarised in Figures 3 and 4, based on a 10% and a 20% prevention of transitions into care homes. The three lines represent the public costs of enhanced services, the savings to public funds from the reduced use of residential care, and the savings to society from the reduced use of residential care. The costs and savings to public funds are estimated to balance under the 20% variant, while the costs and savings to society are estimated almost to balance under the 10% variant. These estimates are subject to the caveats discussed above.

**Figure 3: Potential costs of enhanced services and savings from reduced care home admissions: 10% variant**



**Figure 4: Potential costs of enhanced services and savings from reduced care home admissions: 20% variant**



## 5.0 Cost-effectiveness

5.1 In the tenth year of operation of the early diagnosis and intervention service, its estimated cost would be around £265 million (in 2007/08 prices), taking account of real rises in care costs. The estimated savings under the 10% scenario would be £120 million in public expenditure (health and social care) and £125 million in private expenditure (service users), which makes a total saving of £245 million to society as a whole. If the reduction in residential care was less than 10%, the annual cost would be almost offset by the estimated saving to society.

5.2 The estimated NPV over 10 years of the costs and savings to society of the 10% scenario (with a 3.5% discount rate) would be around (minus) £950 million. This analysis, however, takes no account of the value of the increase in quality of life expected from the new service.

- 5.3 The evaluation of the Department of Health national early intervention in dementia pilot (the Croydon Memory Service) found that at the six-month follow-up stage there were statistically significant improvements in both self-rated and proxy-rated quality of life (using the DEMQOL quality of life measurement for dementia). The improvement represents around 4% of the interval between the lowest and highest states on the DEMQOL instrument. It should be recognised, however, that the evaluation did not include a control group.
- 5.4 The NPV would be positive if benefits (in terms of improved quality of life) could be achieved with a monetary value that rose in a linear way from nil in the first year to around £250 million in the tenth year. This would be a gain of around 6,250 QALYs in the tenth year where a QALY is valued at £40,000, or 12,500 QALYs if a QALY is valued at only £20,000.
- 5.5 By the tenth year of the service, it seems likely that all 600,000 people in England with dementia will have been seen by the service if they wish. The Croydon service sees around 400 to 500 new patients per year, suggesting that some 60,000 to 75,000 new patients nationally could be seen each year if a service were established in each area. These numbers are similar to the estimated incidence of new cases of dementia every year across the country.
- 5.6 If all 600,000 people in England with dementia had been seen by the service, a gain of 6,250 QALYs per year would amount to only around 0.01 QALYs per person per year. A gain of 12,500 QALYs would amount to only around 0.02 QALYs per person per year. These relatively small improvements seem likely to be achievable with ease in view of the rise of 4% achieved on the DEMQOL scale – although some caution is clearly required in comparing gains on the DEMQOL scale with gains on the EuroQoL scale.
- 5.7 This analysis suggests that the service need only achieve a modest increase in the average quality of life of people with dementia – plus a 10% diversion of people with dementia from residential care – if it is to be cost-effective. On the assumptions discussed in this paper, the net increase in public expenditure would then be justified by the expected benefits.

## 6.0 Conclusions

- 6.1 We believe that this modelling, which is based on evidence from the literature, provides a strong case for the development of nationwide services for the early identification and treatment of dementia. The financial case is strong if a strategic view of between four and 10 years is adopted.

- 6.2 There is a powerful quality argument for the prevention of institutionalisation: people with dementia and their carers generally want them to stay in their own homes. Their quality of life is higher at home than it is in a care home. Services that enable early intervention have been shown to have positive effects on the quality of life of people with dementia and their family carers.

This appendix was prepared by Sube Banerjee, Senior Professional Adviser in Older People's Mental Health, Department of Health, and Raphael Wittenberg, Economic Adviser, Social Care Strategy Unit, Department of Health.



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