

Living well with dementia: A National Dementia Strategy



Putting **People** First

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Description This strategy provides a strategic framework within which local services can deliver quality improvements to dementia services and address health inequalities relating to dementia; provide advice and guidance and support for health and social care commissioners and providers in the planning, development and monitoring of services; and provide a guide to the content of high-quality services for dementia.

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Foreword by Alan Johnson MP, Secretary of State for Health



Dementia is not an illness we can ignore. It has a devastating impact on the people who develop it, and the families who care for them. We all know someone who has been affected, be it a relative, friend or work colleague. It also affects more and more of us each year, as the numbers affected rise with an ageing population. That is why the Government has made dementia a national priority. The publication of the first National Dementia Strategy is a key step towards achieving the goal of building health and social services for dementia that are fit for the 21st century.

I am very grateful for the huge amount of work undertaken over the last year in developing the Strategy. In particular, I would like to thank Professor Sube Banerjee and Jenny Owen for the leadership they have provided. I am also grateful to Neil Hunt from the Alzheimer's Society for leading the work of the External Reference Group. The close co-operation with the Alzheimer's Society has been a key feature in undertaking an informed and expert analysis of all the issues involved.

The Strategy outlines three key steps to improve the quality of life for people with dementia and their carers. First, we need to ensure better knowledge about dementia and remove the stigma that sadly still surrounds it. The challenge of removing common misconceptions is crucial. Dementia is not a natural consequence of ageing and it is not true that nothing can be done for people with the condition. In reality, a great deal can be done to help people overcome the problems of dementia, to prevent crises 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.

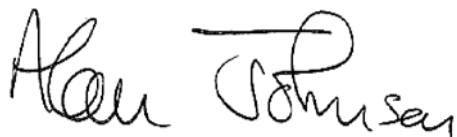
So we need to ensure that both the public and professionals have the full facts. One of the key messages in the Strategy is the need for better education and training for professionals. This will not just be for people providing dementia services. Many people in the NHS and social care come into contact with people with dementia and their carers. They need to know more about dementia and how they can best provide care that meets people's needs. Getting these messages across is vital if we are to ensure the delivery of the best quality services.

Second, we have to ensure that people with dementia are properly diagnosed. Current best estimates are that only one-third of people with dementia ever receive a diagnosis of their illness. We can't hope to address their needs fully, or those of their carers, without a diagnosis being made, appropriate information being given and effective intervention at an early stage. Some have argued in the past that it is best not to let people know. We have long accepted that this should not occur with cancer sufferers. The same should be true for those with dementia. This was one of the most consistent messages emerging from the consultation process from people with dementia.

Third, we must develop a range of services for people with dementia and their carers which fully meets their changing needs over time. The consultation on the draft strategy demonstrated widespread agreement on what these services should be. I believe the ambitions and aspirations expressed by a wide range of stakeholders are now reflected in what is an excellent strategy document.

We now need to begin the process of implementation. I don't underestimate the scale of the task ahead. The pace of implementation may vary, depending on the current level and development of services at a local level within each NHS and local authority area.

It will require a great deal of work and commitment by those responsible for commissioning and providing services. However, I have every confidence that all those involved, in the NHS, local authorities and voluntary bodies, will rise to the challenge of delivering the changes needed.

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".

Alan Johnson MP
Secretary of State for Health

Foreword by Phil Hope MP, Minister of State for Care Services



In August 2007, the Government announced a programme to develop the first National Dementia Strategy and implementation plan for England. Following an immense amount of hard work and a huge public consultation process, we have now developed that Strategy. I am confident that it will give us a solid foundation on which to build dementia services that we can all be proud of.

I would like to pass on my thanks to those thousands of individuals and organisations that have helped us get this far in such a short space of time. The Department held over 50 consultation events over the summer of 2008, and we eventually received approximately 600 written responses to the draft strategy. We also benefited enormously from the contribution made by a report from the External Reference Group of key stakeholders. What has been notable throughout the whole process has been the welcome degree of consensus on what is needed to meet fully the needs of people with dementia and their carers.

Dementia should no longer be misconstrued as an inevitable consequence of the ageing process. Nor can it be acceptable any more to pretend that nothing can be done about it. A great deal can and should be done, as the Strategy ably demonstrates. We now begin the task of delivering high-quality dementia services for all. That is not to say that there is not already good practice in both the NHS and social care. We must learn from this, and ensure that it becomes the norm rather than the exception.

I have no doubt of the challenge that implementing the strategy will provide. It won't be easy. Currently, it is estimated that there are over 570,000 people in England living with dementia. This figure is likely to double over the next 30 years in the absence of any medical breakthrough in treatment. We also have to recognise the profound effects that dementia can have on family carers. This is already being addressed by the Government's Carers' Strategy. It will require a concerted effort by the Government, the NHS, local authorities, voluntary bodies and many others to ensure that the aims of the Strategy are fully achieved.

During the last few months, I have met many people living with dementia, both those who have the illness and their family carers. I have been hugely impressed with the contribution they have made to the debate on the Strategy. They were also represented on the project's External Reference Group, and their role in developing the Strategy has been crucial. Their continued involvement should be central to the future delivery of the strategy locally. They above all are best placed to advise on what services are needed and what they find helpful, throughout their care pathway and the progression of the illness.

In launching work on the Strategy in 2007, we called for dementia to be taken out of the shadows. I believe that that is what this Strategy will achieve. Dementia and this Strategy will continue to be priorities for the Government, and we will do all we can to support those responsible in the NHS and social care in ensuring its delivery.

A handwritten signature in black ink, reading "Phil Hope". The signature is written in a cursive style with a period at the end.

Phil Hope MP
Minister of State for Care Services

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



We would first like to thank all the people who have worked with us to produce this Strategy. In particular, we must thank the people with dementia and their carers whose testimony has truly shaped this plan. Their courage and perseverance in the face of systems seemingly set up to deny them access to diagnosis, treatment and care rather than to facilitate such access has galvanised us in our work.

This is an ambitious strategy. Our aim is that all people with dementia and their carers should live well with dementia. There is no doubt that the dementias are a devastating set of illnesses and that they have profound negative effects on all those affected, be they people with dementia or their carers. However, it is also clear that there is a vast amount that can be done to improve and maintain quality of life in dementia. Positive input from health and social care services and from the third sector and carers of people with dementia can make all the difference between living well with dementia and having a poor quality of life.

This is a comprehensive strategy which requires us to transcend existing boundaries between health and social care and the third sector, between service providers and people with dementia and their carers. Our vision is for a system where all people with dementia have access to care and support that they would benefit from. As the Strategy is implemented, we look to a time when the public and professionals alike are well informed, and where the fear and stigma associated with dementia have been decreased. It will be a system where families affected by dementia know where to go for help and what services to expect, where the quality of care is high and equal wherever they might live, and where people seek help early for problems with memory and are encouraged to do so. We have heard clearly that knowledge is power with respect to diagnosis, giving those affected and their families an understanding of what is happening and the ability to make choices themselves. Making the diagnosis early on in the illness means that there is the chance to prevent future problems and crises and to benefit more from positive interventions.

We have a unique opportunity to make a true difference for those affected by dementia, but achieving our goals will not be simple. Success will require true joint planning and joint working between health and social care commissioners and providers, the third and independent sectors and people with dementia and their carers. It will require flexible and imaginative leadership at all levels along with constant vigilance and scrutiny if the delivery of the strategy is to be kept on track. It will require commitment over time and ambition in the face of the true scale of the challenge. But there has never been a better chance to improve the quality of care for dementia. The successful implementation of the Strategy will improve the quality of lives of all with dementia.

We believe that the objectives presented here, taken as a whole, will 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 live lives of the best quality possible – enabling them to live well with dementia.



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



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

Executive summary

The aim of the Strategy

1. The aim of the Strategy is to ensure that significant improvements are made to dementia services across three key areas: improved awareness, earlier diagnosis and intervention, and a higher quality of care. The Strategy identifies 17 key objectives which, when implemented, largely at a local level, should result in significant improvements in the quality of services provided to people with dementia and should promote a greater understanding of the causes and consequences of dementia. This Strategy should be a catalyst for a change in the way that people with dementia are viewed and cared for in England.

The issue

2. Recent reports and research have highlighted the shortcomings in the current provision of dementia services in the UK. Dementia presents a huge challenge to society, both now and increasingly in the future. There are currently 700,000 people in the UK with dementia, 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.



3. 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 the 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

4. 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 National Institute for Health and Clinical Excellence (NICE) commissioning guide on memory assessment services, the Carers' Strategy (Carers at the heart of 21st century families and communities) and the National End of Life Care Strategy. Getting services right for people with dementia will make a positive contribution to all of these.



The consultation

5. Over 50 stakeholder events were held throughout the country as part of the consultation exercise, attended by over 4,000 individuals, and approximately 600 responses to the consultation document were received. The draft strategy was very well received by the public and professionals alike, and the recommendations it set out were seen as being the right ones if dementia services are to fully meet the needs of people with dementia and their carers. Areas where changes have been made are: provision for people with learning disabilities; the need for better peer support networks; improved end of life care; housing for people with dementia; and the particular needs of people with early-onset dementia (people under 65 years of age). In general, however, the draft strategy recommendations were acknowledged as the right ones and welcomed. A detailed response to the consultation has been published separately.

The Strategy objectives

6. The key objectives of the Strategy, addressed in more detail in the full document, are as follows:
 - **Objective 1: Improving public and professional awareness and understanding of dementia.** Public and professional awareness and understanding of dementia to be improved and the stigma associated with it addressed. This should inform individuals of the benefits of timely diagnosis and care, promote the prevention of dementia, and reduce social exclusion and discrimination. It should encourage behaviour change in terms of appropriate help-seeking and help provision.
 - **Objective 2: Good-quality early diagnosis and intervention for all.** All people with dementia to have access to a pathway of care that delivers: a rapid and competent specialist assessment; an accurate diagnosis, sensitively communicated to the person with dementia and their carers; and treatment, care and support provided as needed following diagnosis. The system needs to have the capacity to see all new cases of dementia in the area.
 - **Objective 3: Good-quality information for those with diagnosed dementia and their carers.** Providing people with dementia and their carers with good-quality information on the illness and on the services available, both at diagnosis and throughout the course of their care.
 - **Objective 4: Enabling easy access to care, support and advice following diagnosis.** A dementia adviser to facilitate easy access to appropriate care, support and advice for those diagnosed with dementia and their carers.

- **Objective 5: Development of structured peer support and learning networks.** The establishment and maintenance of such networks will provide direct local peer support for people with dementia and their carers. It will also enable people with dementia and their carers to take an active role in the development and prioritisation of local services.
- **Objective 6: Improved community personal support services.** Provision of an appropriate range of services to support people with dementia living at home and their carers. Access to flexible and reliable services, ranging from early intervention to specialist home care services, which are responsive to the personal needs and preferences of each individual and take account of their broader family circumstances. Accessible to people living alone or with carers, and people who pay for their care privately, through personal budgets or through local authority-arranged services.
- **Objective 7: Implementing the Carers' Strategy.** Family carers are the most important resource available for people with dementia. Active work is needed to ensure that the provisions of the Carers' Strategy are available for carers of people with dementia. Carers have a right to an assessment of their needs and can be supported through an agreed plan to support the important role they play in the care of the person with dementia. This will include good-quality, personalised breaks. Action should also be taken to strengthen support for children who are in caring roles, ensuring that their particular needs as children are protected.
- **Objective 8: Improved quality of care for people with dementia in general hospitals.** Identifying leadership for dementia in general hospitals, defining the care pathway for dementia there and the commissioning of specialist liaison older people's mental health teams to work in general hospitals.
- **Objective 9: Improved intermediate care for people with dementia.** Intermediate care which is accessible to people with dementia and which meets their needs.
- **Objective 10: Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers.** The needs of people with dementia and their carers should be included in the development of housing options, assistive technology and telecare. As evidence emerges, commissioners should consider the provision of options to prolong independent living and delay reliance on more intensive services.
- **Objective 11: Living well with dementia in care homes.** Improved quality of care for people with dementia in care homes by the development of explicit leadership for dementia within care homes, defining the care pathway there, the commissioning of specialist in-reach services from community mental health teams, and through inspection regimes.

- **Objective 12: Improved end of life care for people with dementia.** People with dementia and their carers to be involved in planning end of life care which recognises the principles outlined in the Department of Health End of Life Care Strategy. Local work on the End of Life Care Strategy to consider dementia.
- **Objective 13: An informed and effective workforce for people with dementia.** Health and social care staff involved in the care of people who may have dementia to have the necessary skills to provide the best quality of care in the roles and settings where they work. To be achieved by effective basic training and continuous professional and vocational development in dementia.
- **Objective 14: A joint commissioning strategy for dementia.** Local commissioning and planning mechanisms to be established to determine the services needed for people with dementia and their carers, and how best to meet these needs. These commissioning plans should be informed by the World Class Commissioning guidance for dementia developed to support this Strategy and set out in Annex 1.
- **Objective 15: Improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers.** Inspection regimes for care homes and other services that better assure the quality of dementia care provided.
- **Objective 16: A clear picture of research evidence and needs.** Evidence to be available on the existing research base on dementia in the UK and gaps that need to be filled.
- **Objective 17: Effective national and regional support for implementation of the Strategy.** Appropriate national and regional support to be available to advise and assist local implementation of the Strategy. Good-quality information to be available on the development of dementia services, including information from evaluations and demonstrator sites.

Implementation

7. The implementation plan for the Strategy can be found on the Department's dementia website at: www.dh.gov.uk/dementia. The Strategy's economic impact assessment (also available on the dementia website) is modelled over five years. However, the pace of implementation will inevitably vary, depending on local circumstances and the level and development of services within each NHS and local authority area. Decisions on funding for subsequent years will only be made once we have had the opportunity to consider the results from the initial demonstrator sites and evaluation work. There is no expectation therefore that all areas will necessarily be able to implement the Strategy within five years.



8. The Department will provide support for all those involved in implementing the strategy locally to ensure its delivery, particularly for those areas where services are less developed. Support will be provided at a national, regional and local level. The regional teams will work with localities within the region to help implement the Strategy. A national team will co-ordinate the programme and oversee production of materials to support implementation, using web-based materials and networks as well as running workshops and conferences.

What will the National Dementia Strategy mean for people with dementia and their carers?

9. Full implementation of the Strategy will mean that all people with dementia and those who care for them would have the best possible healthcare and support. We know that early diagnosis, effective intervention and support from diagnosis through the course of the illness can enable people to live well with dementia. We also know that improving health and social care outcomes in dementia in the short and medium term can have significant benefits for society both now and in the future.
10. Our vision is for the positive transformation of dementia services. It would be a system where all people with dementia have access to the care and support they need. It would be a system where the public and professionals alike are well informed; where the fear and stigma associated with dementia have been allayed; and where the false beliefs that dementia is a normal part of ageing and 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 where the quality of care is high and equal wherever they might live.

Chapter 1: Purpose and scope of the Strategy

1. The purpose of the Strategy is to:
 - provide a strategic quality framework within which local services can deliver quality improvements to dementia services and address health inequalities relating to dementia;
 - provide advice, guidance and support for health and social care commissioners, strategic health authorities (SHAs), local authorities, acute hospital trusts, mental health trusts, primary care trusts (PCTs), independent providers and the third sector, and practice-based commissioners in the planning, development and monitoring of services; and
 - provide a guide to the content of high-quality health and social care services for dementia to inform the expectations of those affected by dementia and their families.
2. The Strategy does not act as a detailed clinical guideline – the joint National Institute for Health and Clinical Excellence (NICE) and Social Care Institute for Excellence (SCIE) guideline¹ fulfils that role. The Strategy is designed to be inclusive of dementia of all types in all groups affected. It applies to services in England only.

Defining dementia

3. The term ‘dementia’ is used to describe a syndrome which may be caused by a number of illnesses in which there is progressive decline in multiple areas of function, including decline in memory, reasoning, communication skills and the ability to carry out daily activities. Alongside this decline, individuals may develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering, which cause problems in themselves, which complicate care, and which can occur at any stage of the illness.
4. The causes of these illnesses are not well understood to date but they all result in structural and chemical changes in the brain leading to the death of brain tissue. 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,

¹ NICE/SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care*. London: TSO.

dementia in Parkinson's disease and fronto-temporal dementia. The term 'Alzheimer's disease' is used sometimes as a shorthand term to cover all forms of dementia.

5. The dementias all share the same devastating impact on those affected and their family carers. Dementias affect all in society irrespective of gender, ethnicity and class. They can affect adults of working age as well as older adults. People with learning disabilities are a group at particular risk. This Strategy is designed to address the needs of all people with dementia, no matter of what type, age, ethnic origin or social status.



The impact of dementia

6. Dementia is one of the most severe and devastating disorders we face. It is also very common. Key data for the UK as a whole include the following:²
 - There are approximately 700,000 people with dementia.
 - In just 30 years, the number of people with dementia is expected to double to 1.4 million
 - The national cost of dementia is about £17 billion per year.
 - In the same 30 years, the cost will treble to over £50 billion per year.³
 - Dementia is predominantly a disorder of later life, but there are at least 15,000 people under the age of 65 who have the illness.

² Knapp M, Prince M, Albanese E et al (2007). *Dementia UK: The full report*. London: Alzheimer's Society.

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*, 22:10, 1037–45.

- Its incidence (the number of new cases per year) and prevalence (the number of cases at any one time) rise exponentially with age.
 - It affects men and women in all social groups.
 - People from all ethnic groups are affected by dementia. The current number of people with dementia in minority ethnic groups is around 15,000 but this is set to rise sharply.
 - The level of UK diagnosis and treatment of people with dementia is generally low, with a 24-fold variation in activity between highest and lowest activity by PCT.
 - International comparisons suggest that the UK is in the bottom third of European performance in terms of diagnosis and treatment, with less than half the activity of France, Sweden, Ireland and Spain.
7. Dementia not only has a devastating impact on those with the disorder, but also has profound, negative effects on family members who provide the majority of care. Family carers are often old and frail themselves and have high levels of carer burden, depression and physical illness, and decreased quality of life. However, caring cuts across the age range and in some cases might be undertaken by children or young people under 18. Dementia is a terminal disorder, but people may live with their dementia for 7–12 years after diagnosis.
8. Contrary to social misconception, there is a very great deal that can be done to help people with dementia.⁴ Services need to be re-engineered so that dementia is diagnosed early and well and so that people with dementia and their family carers can receive the treatment, care and support following diagnosis that will enable them to live as well as possible with dementia.⁵ Currently only a third of people with dementia receive a formal diagnosis or have contact with specialist services at any time in their illness. Also, such diagnosis and contact often occur late in the illness and/or in crisis when opportunities for harm prevention and maximisation of quality of life have passed. If dementia is not diagnosed, then the person with dementia and their family carers are denied the possibility of making choices themselves. They are unable to make informed plans for their future and do not have access to the help, support and treatments (social and psychological, as well as pharmacological) which can help.

Developing the National Dementia Strategy

9. This Strategy was 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 Department of Health Working Group, led by Jenny Owen and

⁴ NICE/SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care*. London: TSO.

⁵ NAO (2007). *Improving services and support for people with dementia*. London: TSO.

Professor Sube Banerjee, was responsible for writing the consultation document and the strategy. An External Reference Group (ERG) was convened and chaired by Neil Hunt, the Chief Executive of the Alzheimer's Society. Three ERG sub-groups worked on the key themes identified – raising public and professional awareness; early diagnosis and intervention; and improving the quality of care. They generated a comprehensive report on improving dementia care which informed the development of the strategy. The ERG and its sub-groups had a broad inclusive membership and the Department is very grateful for their hard work and excellent input. Full details of the members of the Programme Board, the Working Group and the ERG (including its sub-groups) are given at Annex 3.

10. The development of the Strategy also benefited from two waves of consultation organised jointly by the Care Services Improvement Partnership (CSIP) and the Alzheimer's Society. The first, completed prior to developing the consultation document, involved a nationwide listening and engagement exercise where more than 3,000 people were able to contribute to and engage with developing the Strategy. The Alzheimer's Society also ran similar events especially for people with dementia and carers and distributed questionnaires, both through the Society's branches and online. Feedback from all these sources was reviewed to ensure that all views were captured.
11. In the second phase, between June and September 2008, the Department undertook a formal public consultation exercise on the draft proposals for the Strategy. Approximately 600 written responses were received from individuals, including people with dementia and their carers, and from a wide range of professional and other stakeholder groups. These responses have been analysed and have informed the development of the final strategy. In addition, 53 regional consultation events were held, organised by CSIP and the Alzheimer's Society with support from the Central Office of Information (COI). Over 4,000 individuals attended these meetings, which covered the whole of England, including rural and urban areas. As with the initial listening events, specific groups were targeted. This ensured that the views of diverse populations were taken into account in the development of the Strategy, including: younger people with dementia; people with learning disabilities; people from minority ethnic groups; people from rural and island communities; and older people in prisons.
12. Representatives from the Strategy Working Group attended most of these meetings. They also took part in other dementia-related conferences and meetings across the country to publicise the consultation and gather feedback. The Department plans to maintain this engagement as the Strategy is implemented. We are very grateful to all who contributed to this work and in particular to the Alzheimer's Society for ensuring the full involvement of people with dementia and their carers.

13. The Strategy is intended to promote access to services that is the same for everyone with a need. The Department has published an equality impact assessment (EIA) to accompany the Strategy, which assesses whether the Strategy will have any adverse effects on any particular group. It also alerts commissioners and service providers of health and social care of the need to monitor the Strategy's impact on all groups within society and to make changes to mitigate any inequality. Service providers and commissioners may need to produce their own EIAs to assess the Strategy's Impact locally.
14. Those involved in developing the Strategy worked closely with other emerging policy initiatives such as the NHS Next Stage Review, the Carers' Strategy, End of Life Care Strategy and *Putting People First*. For example, the Next Stage Review local clinical pathway groups and the SHA vision process were informed by the evidence that was collected for the National Dementia Strategy. The objectives of this Strategy are complementary to such programmes of work and delivering the National Dementia Strategy will help to deliver these other goals.

How the Strategy is structured

15. The Strategy is outcome focused. The outcomes are divided into three broad themes and these form the basis for Chapters 3 to 5:
 - raising awareness and understanding;
 - early diagnosis and support; and
 - living well with dementia.
16. Chapters 3 to 5 present objectives that have been identified as priorities for delivery. These objectives and the care pathway set out a vision of what a good dementia service should look like. The objectives are presented here in life course order according to a defined care pathway, rather than in priority order. This helps to make clear temporal relationships and interdependencies. Under each objective is the case for change including key objectives for commissioners to meet. Commissioners can begin by establishing a baseline, to determine where they already have plans and services in place and where they may need to do further work.
17. Chapter 6 discusses drivers and levers for change, again in terms of objectives. The objectives presented are intended to help commissioners to analyse their current commissioned services, to set local goals and to monitor progress in their own areas. Annex 1 contains guidance developed to support the world class commissioning of dementia services. The implementation plan for the Strategy can be found on the Department's dementia website at: www.dh.gov.uk/dementia.

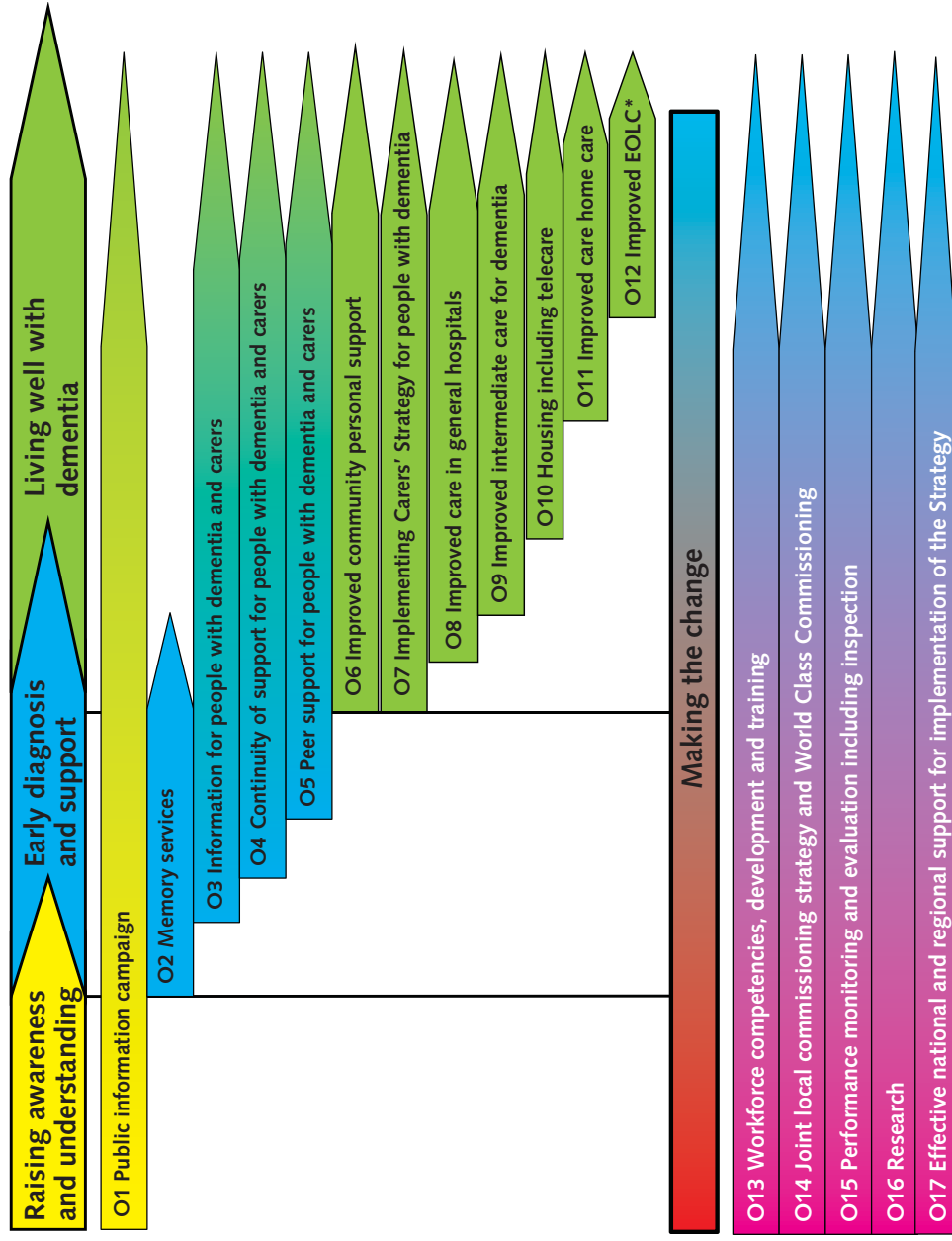
18. The strategy is accompanied by a full economic impact assessment which can also be found on the Department's dementia website. The impact assessment is modelled over five years. However, the pace of implementation will inevitably vary, depending on local circumstances and the level and development of services within each NHS and local authority area. Funding for subsequent years will only be made once we have had the opportunity to consider the results from the initial demonstrator sites and evaluation work. There is no expectation therefore that all areas will necessarily be able to implement the Strategy within five years.
19. Annex 2 sets out the wider policy context in which the Strategy is set.

Chapter 2: The vision for services for dementia

1. The Department's goal is for people with dementia and their family carers to be helped to live well with dementia, no matter what the stage of their illness or where they are in the health and social care system. The vision to achieve this is a simple one, in three parts, to:
 - encourage help-seeking and help-offering (referral for diagnosis) by changing public and professional attitudes, understanding and behaviour;
 - make early diagnosis and treatment the rule rather than the exception; and achieve this by locating the responsibility for the diagnosis of mild and moderate dementia in a specifically commissioned part of the system that can, first, make the diagnoses well, second, break those diagnoses sensitively and well to those affected, and third, provide individuals with immediate treatment, care and peer and professional support as needed; and
 - enable people with dementia and their carers to live well with dementia by the provision of good-quality care for all with dementia from diagnosis to the end of life, in the community, in hospitals and in care homes.
2. The care pathway set out in Figure 1 places the objectives identified as needed within this framework. This is a vision for the future of people with dementia and their carers shared by all – central and local government, the third sector and, most importantly, people with dementia and their family carers.



Figure 1: Delivering the National Dementia Strategy – joint commissioning of services along a defined care pathway to enable people to live well with dementia



*End of life care

Chapter 3: Raising awareness and understanding

'I used to have a very good memory and suddenly I found that words that I knew the meaning of I was not able to give their meaning...that told me something was wrong.' (person with dementia)

'I knew my brain wasn't what it used to be because I've always remembered when I gave birth to my girls and one time I thought, "I can't remember what their birthday is."' (person with dementia)

'I was having difficulty in remembering things that I knew that I knew and beginning to have arguments with the wife as to where she had told me things, asked me to do something or she had done something on my behalf and I'd say, "No you didn't."' (person with dementia)

'The worst part was telling the kids. One daughter...just doesn't want to know, the other one is in denial, and my son knows more than I do.' (person with dementia)

'My son is looking but he doesn't know me; my daughter...never mentions it.' (person with dementia)

'You don't get the same empathy that you would get if you were terminally ill.' (carer)

'It's as though that's it, you are dribbling and nodding, and that's Alzheimer's. That's the picture of Alzheimer's. But we are all sitting here talking perfectly normally. We have got Alzheimer's of some form, we are not nodding and dribbling.' (person with dementia)

'They always show them [people with dementia] in the worst state.' (carer)

'You are just as likely of getting dementia as you are getting a haematoma or lung cancer or whatever else. If there was that sort of attitude by society, then this would make the whole process of actually getting the diagnosis a lot easier. So you know it is all part of the stigma, isn't it?' (person with dementia)

'The more, as you say, it's talked about, about well known people having it, the better it's accepted as part of life.' (carer)

'More coverage of ordinary people saying what it's like a) for them to have dementia and b) for their carer/partner to say what it's like to be caring for them having dementia.' (person with dementia)

'[The GP said] when you pass 70 you can expect to lose your memory a little bit.' (person with dementia)

'I consider that I didn't get a service from, not from the doctor, my own GP. From my own GP I just got patted on the head.' (person with dementia)

'We had an appointment with the local GP anyway, over a different matter, and while I was there I said, you know, I told him the symptoms and he pooh-poohed it.' (person with dementia)

Increased public and professional awareness of dementia

Objective 1: Improving public and professional awareness and understanding of dementia. Public and professional awareness and understanding of dementia to be improved and the stigma associated with it addressed. This should inform individuals of the benefits of timely diagnosis and care, promote the prevention of dementia, and reduce social exclusion and discrimination. It should encourage behaviour change in terms of appropriate help-seeking and help provision.

How this can be delivered

- Developing and delivering a general public information campaign.
- Inclusion of a strong prevention message that 'what's good for your heart is good for your head'.
- Specific complementary local campaigns.
- Targeted campaigns for other specific groups (eg utilities, public-facing service employees, schools, and cultural and religious organisations).

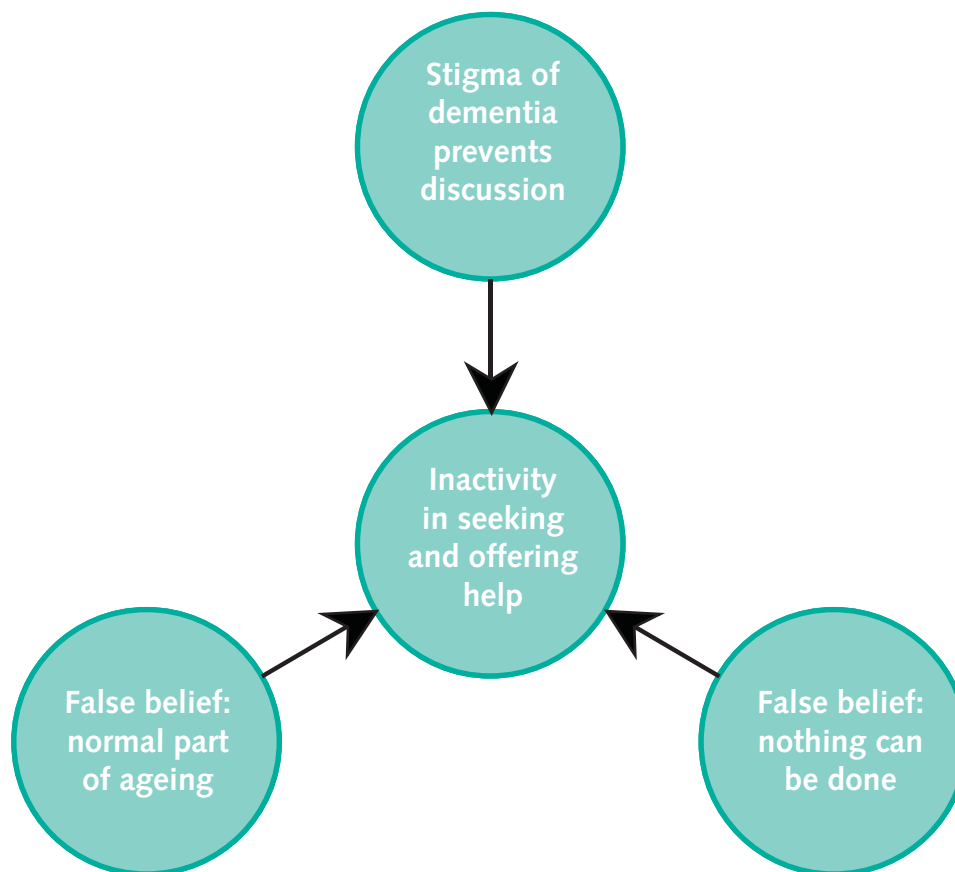
The case for change

Help-seeking and help provision

1. Currently, people with dementia and their carers are prevented from accessing diagnosis, and therefore support 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 creates a background where both the public and non-specialist professionals find it hard to talk about dementia, and seek to avoid addressing the possibility of an individual being affected. The stigma associated with dementia also acts within professional groups, resulting in low priority being accorded to the development of the skills needed to identify and care for people with dementia. Professional and vocational training are of major importance in determining professional knowledge, attitudes and behaviour. These are addressed in detail in Chapter 4.
2. The second part of the cycle is a widespread mis-attribution of symptoms to ‘old age’, resulting in an unwillingness to seek or offer help. 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. This again is a view shared by public and professionals alike. These factors are presented in Figure 2 and together they act to delay diagnosis and access to good-quality care.



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



3. The effect of these factors acting together is profoundly unproductive and means that:

- people currently wait up to three years before reporting symptoms of dementia to their doctor;⁶
- 70% of carers report being unaware of the symptoms of dementia before diagnosis;⁷
- 64% of carers report being in denial about their relative having the illness;⁸
- 58% of carers believe the symptoms to be just part of ageing;⁹
- only 31% of GPs believe they have received sufficient basic and post-qualification training to diagnose and manage dementia,¹⁰ a decrease since the same question was asked in for the Forget Me Not report¹¹ eight years ago;

6 Alzheimer's Society (2002). *Feeling the Pulse*. London: Alzheimer's Society.

7 Eisai Inc/Pfizer (2004). *Facing Dementia Survey*. London: Eisai Inc and Pfizer.

8 Ibid.

9 Ibid.

10 NAO (2007). *Improving services and support for people with dementia*. London: TSO.

11 Audit Commission (2000). *Forget Me Not*. London: TSO.

- 50% of the public believe that there is a stigma attached to dementia;¹² and
 - people over 65 are more worried about developing dementia (39%) than cancer (21%), heart disease (6%) or stroke (12%).¹³
4. The aim of the raising awareness theme of the strategy is therefore to develop a better understanding of dementia by public and professionals alike; to ensure that better information is provided on how to seek help and what help and treatment is available; and to tackle the stigma and misunderstandings that currently exist.

Positive about prevention in dementia – what's good for your heart is good for your head

5. As well as helping the large number of people who already have dementia and the predicted growth in this population, we need to look at ways of preventing new cases of dementia occurring if this is at all possible. This element of the strategy therefore also focuses on the prevention of the condition. The current evidence base suggests that up to 50% of dementia cases may have a vascular component (ie vascular dementia or mixed dementia). This holds out the possibility of preventing or minimising dementia by means of promoting better cerebrovascular health.
6. Current health promotion messages on diet and lifestyle and actions such as health checks are therefore likely to have a positive effect. Providing public education that such changes may decrease the likelihood of developing dementia can only help the overall impact of the campaigns overall.

The campaign

7. There has been a clear and consistent message from those who have analysed current dementia care systems in England, and from the strategy consultation process, on the need for a public information campaign to change awareness and understanding about dementia. This includes expert opinion from people with dementia, carers, health and social care professionals¹⁴ and the Public Accounts Committee.¹⁵ The potential for positive change is supported by data from a pilot awareness campaign by the Alzheimer's Society carried out in 2007. This achieved positive results with 78% of GPs believing that such a campaign would lead to people reporting symptoms earlier.¹⁶

12 Alzheimer's Society (2008). *Dementia: Out of the shadows*. London: Alzheimer's Society.

13 Ibid.

14 NAO (2007). *Improving services and support for people with dementia*. London: TSO.

15 Public Accounts Committee (2008). *Sixth Report of Session 2007–8: Improving services and support for people with dementia*. London: TSO.

16 Alzheimer's Society (2008). *Worried about your memory?* London: Alzheimer's Society.

8. The nature and size of the issues involved means that such a public information campaign would need a phased approach, developing and continuing over time. The campaign would need to be well planned, incorporating research evidence to build effective campaign messages, and crafted carefully to ensure that it is clear and honest. It should aim to reduce anxiety and promote understanding. In the words of one person with dementia, 'It 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, those from minority ethnic groups, or those from rural, island or traveller communities) may be different from those of the majority population, and may require specifically tailored approaches.
9. The content should inform the public what dementia is, including: its signs and symptoms; what is normal and what is not; that while some abilities are compromised, many remain; and that a person with dementia is no less a person because they have dementia. Messages about how to seek help need to be co-ordinated with the development of services, since there is a need to avoid the problems created if demand is stimulated and the supply of services is not available.



Emerging key messages for a national public information campaign

- Dementia is a disease.
 - Dementia is common.
 - Dementia is not an inevitable consequence of ageing.
 - The social environment is important, and quality of life is as related to the richness of interactions and relationships as it is to the extent of brain disease.
 - Dementia is not an immediate death sentence; there is life to be lived with dementia and it can be of good quality.
 - There is an immense number of positive things that we can do – as family members, friends and professionals – to improve the quality of life of people with dementia.
 - People with dementia make, and can continue to make, a positive contribution to their communities.
 - Most of us will experience some form of dementia either ourselves or through someone we care about.
 - We can all play a part in protecting and supporting people with dementia and their carers.
 - Our risk of dementia may be reduced if we protect our general health, eg by eating a healthy diet, stopping smoking, exercising regularly, drinking less alcohol and generally protecting the brain from injury.
10. On a more local level, services could deploy strategies for community engagement, to increase levels of understanding and build supportive social networks. Information campaigns could be targeted at major employers and representative bodies whose workforces have significant interaction with the public (eg public utilities, financial services, post office workers, the police, milkmen, trade unions, older people's groups, transport providers and a wide range of public sector workers). The campaign could inform public-facing employees of the symptoms and special needs of people with dementia, and where to go if they are concerned about someone they are providing a service to. Content would need to be developed in consultation with employers but

could include: a team briefing pack, employee training materials, posters for staff notice boards, media materials for staff magazines and leaflets.

11. Such a campaign could also target the personnel/human resources and occupational health departments of employers so that they are aware of the early signs of dementia and its impact on carers.
12. Finally, making materials available to schools for children and young people to learn about dementia as part of Personal, Social and Health Education and Citizenship Education could also form an important strand of an effective public information campaign.



Chapter 4: Early diagnosis and support

'General practitioners after all are exactly that, general practitioners, and so they can't be expert in everything, but they don't seem to have a general sensitivity to dementia as an illness.' (person with dementia)

'Surely they should be getting more training and then if [they] can't understand it...pass it on to the neurologist or psychiatrist rather than put you on tranquillisers.' (person with dementia)

'We had gone to him [the GP] for a lot of things and he was always telling [the person with dementia] that it was in his mind, he hadn't got these problems, he needed to pull himself together.' (carer)

'I've just been told "You've got Alzheimer's" and they walk out; [it] is absolutely bloody disgusting.' (person with dementia)

'I got the diagnosis on the phone by somebody I had never met telling me, "Your husband has Alzheimer's and vascular dementia." That was probably the worst possible way. That was absolutely infuriating.' (carer)

'I think they need [to be] diagnosing much earlier and take notice of it because I think there are lots of channels that could be avoided if the first time they saw you, they got down to business and meant it. Not just fob you off.' (person with dementia)

'[The GP] has been very positive in supporting both of us really. When this problem occurred he referred [the person with dementia] straight away to the memory clinic and stuff so he obviously saw something in her that he felt he should deal with straight away. When consultants and people have done tests on her and written to him he has always been in touch with us to let us know what is going on. He is very positive.' (carer)

'[The consultant] said it's dementia and I just burst into tears because I was so... I half expected it but it's still a terrible shock.' (carer)

'It was as if the thunder clouds had been taken away because they had given an answer to me why I was treating my family so like a louse that I was.' (person with dementia)

'I was relieved really that what I was trying to convince people of had been verified.' (person with dementia)

'They didn't give me enough information. I came away thinking, "What do we do now, where do we go from here?" I have a prescription in one hand and a note for blood tests in the other and nobody has said what the CAT scan showed...nobody has given me that information. I am the person who is going to deal with [my husband].' (carer)

'It was organised by various people from the Alzheimer's Society and carers, and they explained to the people what kinds of dementia there were, and what happens, and how you can help it by healthy living and all this; it was really good.' (carer)

'Be honest to yourself and to your friends because there is a lot of support if you are open. Some of them will walk away and can't deal with it but an awful lot of people will help.' (person with dementia)

'Today I have met people who are in very much the same boat as I am with things they can and can't do...so for me it's a relief, a bloody relief to find that there are other people in the same boat as me.' (person with dementia)

'I think I've been part of a group that regularly goes together and since I've got to know other people and I think of it as being "We're all in it together", and therefore I don't feel lost...and that's very helpful actually.' (person with dementia)

Good-quality early diagnosis and intervention for all

Objective 2: Good-quality early diagnosis and intervention for all. All people with dementia to have access to a pathway of care that delivers: a rapid and competent specialist assessment; an accurate diagnosis sensitively communicated to the person with dementia and their carers; and treatment, care and support provided as needed following diagnosis. The system needs to have the capacity to see all new cases of dementia in the area.

How this can be delivered

- The commissioning of a good-quality service, available locally, for early diagnosis and intervention in dementia, which has the capacity to assess all new cases occurring in that area.

The case for change

Under-diagnosis is the current norm

1. Currently only about one-third of people with dementia receive a formal diagnosis at any time in their illness.¹⁷ When diagnoses are made, it is often too late for those suffering from the illness to make choices. Further, diagnoses are often made at a time of crisis; a crisis that could potentially have been avoided if diagnosis had been made earlier. A core aim of the National Dementia Strategy is therefore to ensure that effective services for early diagnosis and intervention are available for all on a nationwide basis. There is evidence that such services are cost effective, but will require extra initial local investment to be established. When established, such services can release substantial funds back into health and social care systems.¹⁸
2. In its Operating Framework for 2008/9,¹⁹ the Department of Health summarised the situation as follows:

“...providing people with dementia and their carers the best life possible is a growing challenge, and is one that is becoming increasingly costly for the NHS. Research shows that early intervention in cases of dementia is cost-effective and can improve quality of life for people with dementia and their families...”

¹⁷ NAO (2007). *Improving services and support for people with dementia*. London: TSO.

¹⁸ Ibid.

¹⁹ DH (2007). *The NHS in England: the Operating Framework for 2008/09*. London: DH.

3. The text went on to state that the Department of Health would publish details of the clinical and economic case for investing in services for early identification and intervention in dementia which PCTs should consider when planning local services. This detailed cost-effectiveness analysis for such services was published as Appendix 4 of the Strategy consultation document.²⁰ It is available for download on the Department's dementia website at www.dh.gov.uk/dementia and also in revised form as a peer-reviewed publication.²¹ This sets out clearly that a 'spend to save' approach as advocated by the National Audit Office (NAO) in their value for money report can both increase the quality of care and save hundreds of millions of pounds of expenditure over a 10-year period. These analyses suggest that such services are clinically and cost effective using accepted measures.

The value of early intervention

4. The evidence available also points strongly to the value of early diagnosis and intervention to improve quality of life and to delay or prevent unnecessary admissions into care homes. According to the best estimates available,²² care home placement of people with dementia costs the UK £7 billion per year with two-thirds paid by social services and one-third by older people and their families themselves. While it is clearly the case that some people will need and benefit from admission to care homes, and that this can be a positive choice, there is also a strong quality argument for the prevention of unnecessary institutionalisation. People with dementia generally want to stay in their own homes, as do their carers. The evidence available indicates that:
 - early provision of support at home can decrease institutionalisation by 22%;²³
 - even in complex cases, and where the control group is served by a highly skilled mental health team, case management can reduce admission to care homes by 6%;²⁴
 - older people's mental health services can help with behavioural disturbance, hallucinations and depression in dementia, reducing the need for institutional care;²⁵

20 DH (2008). *Transforming the Quality of Dementia Care: Consultation on a National Dementia Strategy*. London: DH.

21 Banerjee S, Wittenberg R (2008). 'Clinical and cost effectiveness of services for early diagnosis and intervention in dementia.' *International Journal of Geriatric Psychiatry* (ePub in press).

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

23 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, 177–185.

24 Challis D, von Abendorff R, Brown P et al (2002). 'Care management, dementia care and specialist mental health services: an evaluation'. *International Journal of Geriatric Psychiatry*, 17:4, 315–25.

25 Gilley DW, Bienias JL, Wilson RS et al (2004). 'Influence of behavioral symptoms on rates of institutionalization for persons with Alzheimer's disease'. *Psychological Medicine*, 34:6, 1129–35.

- carer support and counselling at diagnosis can reduce care home placement by 28%;²⁶
 - early diagnosis and intervention improves quality of life of people with dementia;²⁷ and
 - early intervention has positive effects on the quality of life of family carers.²⁸
5. All PCTs currently commission a number of services which might make the diagnosis of dementia. They include general practitioners, old age psychiatric community teams, geriatric medicine and neurology services. Current systems are almost without exception non-prescriptive and lack clarity about where and by whom diagnoses of dementia should be made.

Role of primary care

6. A strong and consistent message emerged from DH's consultation process that the diagnosis of dementia, and in particular mild dementia where the diagnosis is more complex, should be carried out by a clinician with specialist skills. With a disorder as common as dementia it is tempting to assume that this should be completed by primary care. However, this is in effect the status quo which has delivered the low



26 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*, 15:9, 780–89.

27 Banerjee S, Willis R, Matthews D et al (2007). 'Improving the quality of care for mild to moderate dementia: an evaluation of the Croydon Memory Service Model'. *International Journal of Geriatric Psychiatry*, 22:8, 782–88.

28 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*, 15:9, 780–89.

levels of activity that we have summarised above. A review of the evidence confirms that there is a marked reluctance on the part of primary care to be directly involved in the diagnosis of dementia for reasons that include: the belief that nothing can be done for dementia; risk avoidance; concerns about competency; and concerns about the availability of resources.²⁹ This can be particularly problematic for people from specific groups, such as people with learning disabilities or younger people with dementia.

7. The message from those responding to the consultation exercise was that these are reasonable concerns, and that the primary care role should be that of identifying those with worrisome symptoms that might mean that their patient has dementia, excluding any other explanatory disorder, and referring on to a specialist service for that individual to receive a definitive diagnosis, not only of dementia, but also of the sub-type of dementia. This would require that such services are available for the GP to refer to and, in the large majority of the country, this is not currently the case. The focus of old age psychiatric services is on the severe and complex end of the spectrum, leaving early diagnosis and intervention largely unaddressed. Equally, geriatric and neurology services are saturated at present with their current work with those referred to them with dementia and complex physical co-morbidity and younger and atypical presentations respectively. This strategy is not intended in any way to minimise or undermine the role of primary care in the diagnosis and management of people with dementia. It is instead an acknowledgement of complexities that have become apparent in the last 10 years, and is designed to support primary care by generating services that they can use in a clear explicit care pathway. The primary care role following diagnosis can therefore be informed by the clinically important information as to whether or not that person has dementia, and of what sub-type, and treatment modified to take account of that.

The case for commissioning a specific service for early diagnosis and intervention

8. From our consultation, and based on a successful DH pilot³⁰ and the DH cost-effectiveness case,^{31, 32} it appears that new specialist services need to be commissioned to deliver good-quality early diagnosis and intervention. Such services would need to 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 for people of all ages and from all ethnic backgrounds.

29 Iliffe S, Wilcock J, Haworth D (2006). 'Obstacles to Shared Care for Patients with Dementia: A qualitative study'. *Family Practice*, 23:3, 353–62.

30 Banerjee S, Willis R, Matthews D et al (2007). 'Improving the quality of care for mild to moderate dementia: an evaluation of the Croydon Memory Service Model'. *International Journal of Geriatric Psychiatry*, 22:8, 782–88.

31 DH (2008). *Transforming the Quality of Dementia Care: Consultation on a National Dementia Strategy*. London: DH.

32 Banerjee S, Wittenberg R (2008). 'Clinical and cost effectiveness of services for early diagnosis and intervention in dementia'. *International Journal of Geriatric Psychiatry* (ePub in press).



Their sole focus would be on early diagnosis of 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 directly appropriate treatment, information, care and support after diagnosis.

9. Such services would not replace the work currently completed by old age psychiatry, geriatrics, neurology or primary care, but would be complementary to their work. The aim is to complete work not currently associated with any service. Instead such a service might be provided by any of a number of types of specialist with diagnostic skills in dementia (eg old age psychiatrists, geriatricians, neurologists, or GPs with a specialist interest) or combinations thereof. Local decisions would be based on existing service provision and where local skills and enthusiasm lie. Those referred with needs other than dementia would be referred on appropriately. There is value in considering commissioning such a service as a joint health and social care venture, with core

involvement of local third sector organisations. Such services could see people in their own homes, or in primary care settings, rather than be hospital-based. The provision of such services locally would have the effect of simplifying the care pathway for the majority, locating responsibility and so enabling easy referral, simple communication and clear performance monitoring. A core set of assessment tools (eg of cognition, behaviour, activity limitation and quality of life in dementia) could be agreed and specified to enable direct regional and national monitoring and comparison of the services provided. Where there are existing memory clinics that have resources associated with them, they may form the core of such a new service, and those resources could be used as part of this service reconfiguration.

10. Local commissioners will wish to consider the extent to which referral to such services are 'open' for the public or rely on referral through primary care or adult social care. There was a genuine divergence of opinion in those responding to the consultation on this. There will be a need to work out how services can be made to work for those from specific groups such as people with learning disabilities. Consistent feedback was received during the consultation process about how difficult it is for this group to receive a diagnosis and appropriate help and support. People with learning disabilities are likely to be in touch already with health and social care services, so close liaison and collaboration between the different professionals involved is essential.

Good-quality information for people with dementia and carers

Objective 3: Good-quality information for those with diagnosed dementia and their carers. Providing people with dementia and their carers with good-quality information on the illness and on the services available both at diagnosis and throughout the course of their care.

How this can be delivered

- A review of existing relevant information sets.
- The development and distribution of good-quality information sets on dementia and services available, of relevance at diagnosis and throughout the course of care.
- Local tailoring of the service information to make clear local service provision.

The case for change

11. The importance of good-quality information, given in such a way as to be accessible to patients and carers in enabling them to direct their own care, is clear. Every person 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. The consultation process has provided excellent examples of national and local documents

that could be adapted with ease for use across England. One such example is the booklet *Coping with dementia – a practical handbook for carers*³³ published by Health Scotland and currently available to be given out to carers across Scotland on diagnosis. Information could be made easily available in a range of settings, for example in local libraries.

12. The challenge is to generate an individually tailored comprehensive package of high-quality information. This should be developed nationally to include information on the nature of the condition, and then adapted locally to describe the 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. Equally, versions would be needed to work across the diverse populations affected by dementia (eg different language groups, minority ethnic groups, people with learning disabilities and people with early-onset dementia). Information should also be available on what options exist for planning ahead for those diagnosed with dementia, to ensure that their desires and wishes are properly considered were they to lose mental capacity. For example, by making a Lasting Power of Attorney and registering it with the Office of the Public Guardian.
13. For this element of the strategy there will therefore be a need centrally to collect the excellent sets of information that have been generated on dementia to date, rather than starting from scratch. The strategy therefore identifies the need for an initial phase involving the central collection of materials and their collation, and the development of key documents for distribution.

Enabling easy direct access to a contact who can signpost and facilitate health and social care input throughout life with dementia

Objective 4: Enabling easy access to care, support and advice following diagnosis.

A dementia adviser to facilitate easy access to appropriate care, support and advice for those diagnosed with dementia and their carers.

How this can be delivered

- This is a new role and there will be a need first for the development and generation of demonstrator projects, and the piloting and evaluation of models of service provision prior to implementation.
- Following this, commissioning a local dementia adviser service to provide a point of contact for all those with dementia and their carers, who can provide information and advice about dementia, and on an ongoing basis help to signpost them to additional help and support.

³³ Health Scotland (2008). *Coping with dementia – A practical handbook for carers*. Edinburgh: Health Scotland.

- Contact with a dementia adviser to be made following diagnosis.
- The dementia adviser not to duplicate existing ‘hands-on’ case management or care.

The case for change

14. One of the most clear and consistent messages emerging from discussions with people with dementia and their carers has been the desire for there to be someone who they can approach for help and advice at any stage of the illness – ‘someone to be with us on the journey’. Current health and social care services normally discharge individuals once the case is stable and the care package is being delivered. This is almost always perceived negatively by people with dementia and their carers, who, faced with a serious illness where there is inevitable long-term decline and increase in dependency, want to feel that there is continuing support available to them when they need it.
15. In the course of consultation it has become clear that this support needs to be provided without removing health and social care professionals from front-line care, and needs to be complementary to the other elements of the care pathway described here. There are interesting models of provision of support and signposting that are emerging, mostly from the third sector. However there is a lack of good-quality definitive studies available at present from which to choose models with the greatest likelihood of success. This is clearly an area where there is a need to invest in service model development, piloting and evaluation to generate data upon which to make commissioning decisions. A development, demonstration and evaluation phase is therefore proposed.
16. In order to stimulate debate, one possibility for testing would be a ‘dementia adviser’ who can provide a point of contact, advice, and signposting and enabling contact with other services if needed. These posts might best be commissioned from the third sector, but could be located within the early diagnosis and intervention service described above to enable professional support and advice and seamlessness of service. The volume of cases diagnosed with dementia makes this a challenging role that requires a clear remit. Contact details for the dementia adviser could be given to the person with dementia and carers at diagnosis. At the end of an episode of care, individuals with dementia and their carers would therefore not just be discharged from services, but instead continue to have access to the dementia adviser who could contact people pro-actively perhaps once or twice a year to check how things are.
17. The role of a dementia adviser would not be that of intensive case management, as carried out by members of community mental health teams or outreach workers who go into people’s homes, or Admiral Nurses. Rather they would provide a single identifiable point of contact with knowledge of and direct access to the whole range of

local services available. Their actions would therefore be to identify what the problems might be, and then to signpost and facilitate engagement with the specialist services that can best provide the person with dementia and their carers with the help, care and support they need simply and quickly. This remit would allow dementia advisers to work with the high numbers of people diagnosed with dementia in each area. They could work with both social care and health care services and be jointly commissioned by local authorities and PCTs.

Peer support and learning networks for people with dementia and their carers

Objective 5: Development of structured peer support and learning networks.

The establishment and maintenance of such networks will provide direct local peer support for people with dementia and their carers. It will also enable people with dementia and their carers to take an active role in the development and prioritisation of local services.

How this can be delivered

- Demonstrator sites and evaluation to determine current activity and models of good practice to inform commissioning decisions.
- Development of local peer support and learning networks for people with dementia and their carers that provide practical and emotional support, reduce social isolation and promote self-care, while also providing a source of information about local needs to inform commissioning decisions.
- Support to third sector services commissioned by health and social care.

The case for change

18. One clear message we have received from people with dementia and their carers is that they draw significant benefit from being able to talk to other people living with dementia and their carers, to exchange practical advice and emotional support. Structured models of peer support already exist in some parts of the country, with examples such as carer support groups and dementia cafés. However, they often cater for only a very small proportion of those who might benefit from them. In structured models of support it is possible to incorporate advice and support from health and social care professionals in an effective and efficient manner. Health and social care commissioners need to consider how to support the development of local peer support networks for people with dementia and their carers.

19. This element of the strategy is complementary to the previous one. People with dementia and their carers can obtain continuity of care and support not only from statutory services, but also in the form of peer support. If the strategy is successful in ensuring that early diagnosis of dementia becomes the norm, then this opens up the possibility for much greater levels of peer support and interaction.
20. There is much good practice in this area already, but activity is often at a relatively low level. The challenge here is first to determine which models of peer working to adopt, and then how to make them available for all who want to access them locally. What is proposed therefore is a programme incorporating investigation and analysis of current practice and the development and evaluation of new models.
21. The value of such an approach is that this can empower people to make choices about what they want, and enable them to care for themselves. Providing people with dementia and their carers with peer support can assist enormously in helping them plan their own lives. On an aggregate level, this can generate advice for commissioners and providers on the local needs of people with dementia and their carers to inform the development of services.



Chapter 5: Living well with dementia

Living well with dementia at home

'I have also lost handling things like knives and forks.' (person with dementia)

'He used to be an engineer and he was very precise in everything he did, and now when he gets problems doing things he gets very frustrated. Very frustrated. He gets angry and he'll shout at me, "I never used to be like this."' (carer)

'I rely greatly on my wife and my carers...I'd be in terrible trouble without them.' (person with dementia)

'That was a wonderful feeling: to know that there were people, in the right area, who absolutely cared for you.' (person with dementia)

'I could cope with him in the day. I couldn't cope at night. Without sleep it was hopeless. I was on the verge. I said to the doctor, "If I don't kill him, I'll kill myself". That's how bad it was.' (carer)

'The memory nurse...she was very good wasn't she. She gave us lots of information we didn't know or wouldn't even have thought of. She was excellent.' (carer)

'I need to make those decisions while I have enough mental capacity to be able to do that and to understand the implications of it before I get too far down the line. So it has given me the time to think about that. That is important.' (person with dementia)

'I think the powers that be don't realise that when someone has dementia, the partner who is caring for them also has their own mental problems.' (carer)

'Most important of all to be given all the information they need: not about what's just happened but about what is likely to happen and where you can go for assistance.' (carer)

'Sometimes they think of you as if you are gaga: [speaking slowly] "can you do this, can you do that?"' (person with dementia)

'Everybody I have met has been absolutely amazed that I can still talk and still think, even though I have a diagnosis of dementia. They do not understand it. I think that is indicative of what the public is like.' (person with dementia)

'Because we were able to have home carers, organised by the social services, my husband was able to spend the last six years of his life in our own home, where he was very happy, instead of going into residential care, which would have made us all very sad. The carers came three times a day and we also had district nurses and a respite service who looked after him when I went shopping. I was able to look after him 24 hours a day. None of this would have been possible without the carers.'

'The carers do the best they can, but they have to be in and out in 20 minutes, which doesn't really leave any time to do things properly.' (carer)



Living well with dementia in care homes

'I cannot speak highly enough about this home. My mother is 93, and before, she lived in isolation at home. She loves company and every time I visit her, she tells me how happy she is there. It is just one year since she moved there and I do not detect any deterioration in her condition.' (carer)

'Would not recommend the home to dementia sufferers, as staff would sometimes see residents as a bit of a nuisance.' (carer)

'My husband went into care in January of this year. He was there for four weeks when we were told he would have to leave. He was a bit too much trouble for them. Wasn't prepared to sit in his chair and watch TV all day. He was one who was walking around and opening doors, one thing or another.' (carer)

'My husband still has his own teeth at the age of 91! Unless I go to the home, he is not reminded to clean them – which seems a small thing I know, but it matters to me as he always took care of them previously.' (carer)

'I would say that of the last 30 residents I have assessed over the last two years, the majority were on anti-psychotic medication, and I would estimate that over 50% of dementia clients within care homes are on anti-psychotic medication.' (care home manager)

'Instead of trying to understand why my husband was getting upset and angry, they put him on sedative drugs and didn't take him off them for months. I only realised when I questioned his medication.' (carer)

'And I think my other concern is...that often, when people go into a care home, the care homes are registered and they say that they can provide the care that the person needs and they clearly can't. You're dealing with a situation where people are being moved on all the time, not through any fault of theirs but because the care homes haven't got the qualified staff to deal with the issues that come up with dementia. And if you are registered as a care home for dementia care, then you should be able to provide care.' (carer)

'I never saw evidence of any entertainments at the first home my mother was in, while all sorts of things have been done at the one she is in now. There are annual summer and Christmas parties for clients and their families, with staff and their families. It's really nice to see young children so cheerfully involved. Such a lot of effort and planning goes into these and it's lovely to participate in the party atmosphere with my Mum.' (carer)

Community personal support

Objective 6: Improved community personal support services. Provision of an appropriate range of services to support people with dementia living at home and their carers. Access to flexible and reliable services, ranging from early intervention to specialist home care services, which are responsive to the personal needs and preferences of each individual and take account of their broader family circumstances. Accessible to people living alone or with carers, people who pay for their care privately, through personal budgets, or through local authority-arranged services.

How this can be delivered

- Implement *Putting People First* personalisation changes for people with dementia, utilising the Transforming Social Care Grant.
- Establish an evidence base for effective specialist services to support people with dementia at home.
- Commissioners to implement best practice models thereafter.



The case for change

1. Two-thirds of all people with dementia live in their own homes in the community. Some will be in the early stages of their illness, and others near the end of their lives. The right support, at the right time and in the right place, is especially important for people with dementia, to give them choice and control over the decisions that affect them. Some people will just want access to services that should be available to everyone locally, such as transport, leisure, housing and information. Some will need a little more help, for example, maintaining their homes and gardens, their physical health, and peer support networks. As people's conditions progress they will want access to good-quality personal care and intensive support. People will still want to choose how and by whom that care and support is provided, regardless of who is paying for it, and will expect to be treated with dignity and respect at all times. In line with the principles set out in the Government's *Think Family* report,³⁴ they will also expect their broader family circumstances, including the needs of any dependent children, to be taken into account and for support to be provided in a holistic way.
2. Apart from family members or friends, who provide the vast bulk of care and support, 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.³⁵ Studies carried out by CSCI and others point to the importance of continuity, reliability and flexibility of home care services, in ensuring that people with dementia and their carers have 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. For people who wish to purchase care and support themselves, with the help of a carer or advocate, commissioners need to ensure there is a range of appropriate services in their area.
3. Current practices of specifying tasks rather than outcomes, not having the time or consistency of worker to develop the relationship between the individual and care worker, and care workers being rushed and visiting for short (eg 15-minute) periods are particularly problematic 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 Care Services Improvement Partnership (CSIP) and is available at www.dh.gov.uk/dementia. Emerging research-based evidence shows considerable benefits to both people with dementia and their carers from specialist dementia home care when compared with standard home care services. Improved

³⁴ Social Exclusion Task Force (2008). *Think Family: Improving the life chances of families at risk*. London: Cabinet Office.

³⁵ CSCI (2006). *Time to Care?* London: TSO.

outcomes include reduced stress and risk of crises for carers, and extended capacity for independent living for people with dementia.³⁶ Some examples of innovative practice are emerging from dedicated home care dementia teams. They ensure the provision of additional time prior to the commencement of the care package, to build a rapport, learn about the person with dementia, their family, their preferences and their life as a whole so that the service is truly person-centred.

4. A comprehensive community personal support service would provide:
 - home care that is reliable, with staff who have 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 things for them;
 - access to personalised social activity, short breaks and day services;
 - access to peer support networks;
 - access to expert patient and carer programmes;
 - responsiveness to crisis services;
 - access to supported housing that is inclusive of people with dementia;
 - respite care/breaks that provide valued and enjoyable experiences for people with dementia as well as their family carers;
 - flexible and responsive respite care/breaks that 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.
5. Services need to be able to work for the diverse groups of people who may be affected by dementia. For example, people with learning disabilities who develop dementia will generally be of a younger age group and may have needs which services designed for people 30 or 40 years older find hard to meet.
6. In order to identify, collate and evaluate the data available on existing models of generic and specialist personal support, a collation and evaluation period will be necessary to enable good-quality advice and information to be made available for commissioners.

³⁶ Rothera I, Jones R, Harwood R et al (2007). 'An evaluation of a specialist multiagency home support service for older people with dementia using qualitative methods'. *International Journal of Geriatric Psychiatry*, 23:1, 65–72.

7. People with dementia are known to be 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. Feedback from the consultation process has highlighted concerns from carers and professionals about inadequate safeguards for people with dementia. 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, 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.

Carers – the most valuable resource for people with dementia

Objective 7: Implementing the Carers’ Strategy for people with dementia. Family carers are the most important resource available for people with dementia. Active work is needed to ensure that the provisions of the Carers’ Strategy are available for carers of people with dementia. Carers have a right to an assessment of their needs and can be supported through an agreed plan to support the important role they play in the care of the person with dementia. This will include good-quality personalised breaks. Action should also be taken to strengthen support for children who are in caring roles, ensuring that their particular needs as children are protected.

How this can be delivered

- Ensuring that the needs of carers for people with dementia are included as the strategy is implemented.
- Promoting the development of breaks that benefit people with dementia as well as their carers.

The case for change

8. Most people want to remain living 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. Residential care may be the most appropriate and effective way of meeting someone's needs and providing a service of choice. But it should always be a choice. 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 the erroneous assumption that residential care is the only option. It is also due to home care staff and family carers not receiving training and advice in dementia, and so not having the skills and competences to provide appropriate care.
9. Equally there is a clear need for breaks and day services 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 the prevention of institutionalisation and the maintenance of people with dementia in the community. The arrangements for such breaks need to be flexible and responsive to the needs of each individual with dementia and their carer. Breaks can be provided in a variety of settings, including the home of the person with dementia. They need to be available on emergency, urgent and planned bases. CSIP has produced a fact sheet on different models of breaks for people with dementia, with examples and contact details, available at www.dh.gov.uk/dementia.
10. The Department's Carers' Strategy was published in 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 contributed to the development of the Carers' Strategy. Its implementation will ensure a 10-year plan that builds on the support for carers and enables them to have a life outside caring. Joint working between those implementing the dementia and carers' strategies will be needed at a local, regional and national level to help the Carers' Strategy deliver for those that care for people with dementia.

Improved quality of care in general hospitals

Objective 8: Improved quality of care for people with dementia in general hospitals. Identifying leadership for dementia in general hospitals, defining the care pathway for dementia there, and the commissioning of specialist liaison older people's mental health teams to work in general hospitals.

How this can be delivered

- Identification of a senior clinician within the general hospital to take the lead for quality improvement in dementia in the hospital.
- Development of an explicit care pathway for the management and care of people with dementia in hospital, led by that senior clinician.
- The gathering and synthesis of existing data on the nature and impacts of specialist liaison older people's mental health teams to work in general hospitals.
- Thereafter, the commissioning of specialist liaison older people's mental health teams to work in general hospitals.

The case for change

11. Up to 70% of acute hospital beds are currently occupied by older people³⁷ and up to a half of these may be people with cognitive impairment, including those with dementia and delirium.³⁸ The majority of these patients are not known to specialist mental health services, and are undiagnosed. General hospitals are particularly challenging environments for people with memory and communication problems, with cluttered ward layouts, poor signage and other hazards. People with dementia in general hospitals have worse outcomes in terms of length of stay, mortality and institutionalisation.³⁹ This impact is not widely appreciated by clinicians, managers and commissioners. The NAO has estimated the excess cost to be more than £6 million per year in an average general hospital.⁴⁰
12. There is a lack of leadership and ownership of dementia in most general hospitals. There are also marked deficits in the knowledge and skills of general hospital staff who care for people with dementia. Often, insufficient information is sought from relatives and carers. This means that person-centred care is not delivered and it can lead to under-recognition of delirium and dementia. Currently, families are often excluded

37 DH (2001). *National Service Framework for Older People*. London: TSO.

38 Royal College of Psychiatrists (2005). *Who Cares Wins: Improving the outcome for older people admitted to the general hospital*. London: RCPsych.

39 Ibid.

40 NAO (2007). *Improving services and support for people with dementia*. London: TSO.

from discharge planning, so false assumptions may be made about whether it is possible for people with dementia to be cared for at home. The NAO found that some general hospital services worked hard not to make the diagnosis of dementia, for fear it would delay discharge.⁴¹

13. Poor care can lead to malnutrition and dehydration for people with dementia, an outcome highlighted in the Age Concern England report *Hungry to be Heard*.⁴² Many examples were cited during the consultation on the National Dementia Strategy of people with dementia being left without assistance to eat or drink. As part of the Dignity in Care campaign, the Department of Health has produced a Nutrition Action Plan to which the key national organisations have signed up and which addresses issues of raising awareness, guidance, screening, training, and inspection and regulation. The action plan and supporting materials are available at www.dignityincare.org.uk.
14. There is often a lack of co-ordination between hospitals and care providers at the point of discharge, with delay in access to care packages such as home care and intermediate care that might enable successful discharge. There is a clear need therefore to improve the quality of care provided for people with dementia in general hospitals. The proposed improvements in core and continuing professional training set out in the next chapter should improve quality of care. Three ways suggested as having the potential to deliver further improvements are:
 - the identification of a senior clinician within the general hospital to take the lead for quality improvement in dementia care 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 liaison older people's mental health teams to work in general hospitals.
15. The care pathway for the better management of people with dementia, including pathways out of hospital, should be developed in consultation with local social services and user and carer organisations. It could specify the arrangements for local leadership and accountability for dementia in general hospitals. Core competencies for all general hospital staff in contact with people with dementia (including Patient Advice and Liaison Services (PALS) and Local Involvement Networks (LINKs)) could be included, and training provided around these competencies.

⁴¹ Ibid.

⁴² Age Concern England (2006). *Hungry to be Heard*. London: Age Concern.

Specialist liaison older people's mental health teams in general hospitals

16. Specialist liaison older people's mental health teams are already advocated by the NICE/SCIE guideline on dementia services.⁴³ They can provide rapid high-quality specialist assessment and input into care planning for those with possible mental health needs admitted to general hospitals, including input into ongoing care and discharge planning. They will generally consist of a multidisciplinary team 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. They can cover the whole range of mental health problems in older adults, not just dementia. These teams can then work closely with the designated general hospital lead to build skills and improve care through the hospital. They need to have good links with the social work assessment teams based in or linked to the hospital. They are already provided in some but by no means all hospitals. Mental health care in accident and emergency departments is often focused on self-harm and acute psychosis in adults of working age. There is also a clear need for services to be commissioned to work on the wards with skills in the diagnosis and management of dementia.
17. There is currently considerable diversity in the models adopted and the nature and scope of the work completed by such liaison services in general hospitals. Reviewing the available evidence, including emerging information from research, indicates that the data need to be brought together formally in order to build the case for the commissioning of such services. There would therefore be the need for an initial period of collation and synthesis of the data available on the services that currently exist in order to inform future commissioning decisions.

Intermediate care for people with dementia

Objective 9: Improved intermediate care for people with dementia. Intermediate care which is accessible to people with dementia and which meets their needs.

How this can be delivered

- The needs of people with dementia to be explicitly included and addressed in the revision of the Department of Health's 2001 guidance on intermediate care.

⁴³ NICE/SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care*. London: TSO.

The case for change

18. Pathways out of hospital and to avoid hospitalisation, such as intermediate care, often exclude people with dementia, meaning that they cannot access rehabilitation services that could enable them to return home or prevent their admission to hospital. Specialist intermediate dementia or mental health care services that enable discharge from the general hospital setting are rare. Both factors appear to stem from a misunderstanding of the Department of Health 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 feel they are likely to need longer than the usual six weeks, and are therefore perceived to not meet the criteria. This is an erroneous interpretation of the Department's guidance. Also problematic is the false assumption that people with dementia cannot benefit from rehabilitation. Local criteria for services have therefore often specifically excluded people with dementia. 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.
19. Community hospitals provide a valuable resource in a non-acute setting to enable recuperation and rehabilitation. Some of these services are specifically labelled as intermediate care. However, the same difficulties occur in community hospitals as in acute hospitals concerning staff knowledge and competences about dementia. This is particularly important as people with dementia often fall victim to the practice of moving people quickly out of acute hospitals to relieve pressure on beds. Commissioners will want to assure themselves that community hospitals are able to deliver good-quality rehabilitation and intermediate care services for people with dementia. CSIP has produced a Good Practice guide to reviews of community hospitals and intermediate care resources, available at www.dh.gov.uk/dementia.
20. There is good clinical evidence that people with mild or moderate dementia with physical rehabilitation needs do well if given the opportunity. People with severe dementia may need more specialist services geared to meeting their mental health needs as well as those providing general physical rehabilitation. Staff working in intermediate care, like any other staff group, need to have core training in dementia and access to advice and support from specialist mental health personnel to help them ensure that people with dementia are able to benefit from rehabilitation and reablement opportunities.

21. To address these concerns, the Department is reviewing and updating its 2001 guidance to reflect the new policy landscape and to correct misconceptions. It will make explicit the need to enable people with dementia to access intermediate care, whether through support to mainstream services for people with physical rehabilitation needs or by developing specialist intermediate care for people with more advanced or complex mental health needs. It will take account of the acute care pathways developed through the Next Stage Review and the prevention and early intervention agenda of *Putting People First*. The new guidance is scheduled to be available in the spring of 2009.

Housing and telecare for people with dementia

Objective 10: Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers. The needs of people with dementia and their carers should be included in the development of housing options, assistive technology and telecare. As evidence emerges, commissioners should consider the provision of options to prolong independent living and delay reliance on more intensive services.

How this can be delivered

- Monitoring the development of models of housing, including extra care housing, to meet the needs of people with dementia and their carers.
- Staff working within housing and housing-related services to develop skills needed to provide the best quality care and support for people with dementia in the roles and settings where they work.
- A watching brief over the emerging evidence base on assistive technology and telecare to support the needs of people with dementia and their carers to enable implementation once effectiveness is proven.

The case for change

22. There has been little research conducted into the role of supported housing in dementia care. Nevertheless, those studies which have been conducted demonstrate that, on the whole, people with dementia can benefit from the support offered in sheltered and extra care housing. They are not always offered this opportunity. A study in 1995⁴⁴ found that sheltered housing can offer a positive environment to people with dementia, provided that appropriate opportunities for social interaction are available. The role of housing staff was identified as critical in the integration of tenants with dementia.

⁴⁴ Kitwood T, Buckland S and Petre T (1995). *Brighter Futures: a report on research into provision for persons with dementia in residential homes, nursing homes and sheltered housing*. Oxford: Anchor Housing Association.

23. More recently the importance of flexible care packages in meeting the needs of people with dementia in extra care housing has been demonstrated.⁴⁵ Many areas are now offering this sort of flexible, responsive care package through floating support services. Many residents with dementia in sheltered or extra care housing have complex health and care needs. The Housing Corporation/Housing 21 study found that these needs could be met where health, social care and housing worked together to provide a whole system strategy, although the researchers acknowledged that this remains a key challenge in supported housing.
24. The evidence base on design principles is sparse, but there is consensus on key principles and a number of good practice checklists are available. There is a more substantial evidence base to show the opportunities offered by assistive technology and telecare to enable people with dementia to remain independent for longer, and in particular to help the management of risk. But the data on newer approaches are still sparse and inconclusive. An evaluation of one scheme demonstrated cost effectiveness and reports of improved quality of life.⁴⁶ Large-scale DH field trials of such technology are currently under way.
25. This is an evolving field, but one that is of potentially high and central importance in enabling people with dementia to live well with their condition. There is much that is being done currently that is positive in terms of housing options and assistive technologies that are part of mainstream care for people with dementia, and that contribute to their independence and safety. However, with respect to more recent innovations, this is not an area where the strategy is able at this time to make specific recommendations. Instead, central, regional and local teams should keep in touch with initiatives in the areas of housing and telecare and make appropriate commissioning decisions as data become available, for example from the Department's large-scale field trials of telecare and assistive technology.

⁴⁵ Vallely S, Evans S, Fear T and Means R (2006). *Opening doors to independence: a longitudinal study exploring the contribution of extra care housing to the care and support of older people*. London: Housing Corporation and Housing 21.

⁴⁶ Woolham J (2005). *The effectiveness of assistive technology in supporting the independence of people with dementia: the Safe at Home project*. London: Hawker Publications.

Improving care for people with dementia in care homes

Objective 11: Living well with dementia in care homes. Improved quality of care for people with dementia in care homes through the development of explicit leadership for dementia care within care homes, defining the care pathway there, the commissioning of specialist in-reach services from community mental health teams, and through inspection regimes.

How this can be delivered

- Identification of a senior staff member within the care home to take the lead for quality improvement in the care of dementia in the care home.
- Development of a local strategy for the management and care of people with dementia in the care home, led by that senior staff member.
- Only appropriate use of anti-psychotic medication for people with dementia.
- The commissioning of specialist in-reach services from older people's community mental health teams to work in care homes.
- The specification and commissioning of other in-reach services such as primary care, pharmacy, dentistry, etc.
- Readily available guidance for care home staff on best practice in dementia care.

The case for change

26. One-third of people with dementia live in care homes and at least two-thirds of all people living in care homes have a form of dementia. This state of affairs has not been planned for, either through commissioning services or through workforce planning. The need for workforce development is profound, and training in this area is covered in the next chapter. This section focuses on: making dementia an explicitly owned priority within care homes; enabling a minimum standard level of input into care homes from specialist mental health services for older people; and using the inspection regimes to drive up care quality. Following the NICE/SCIE clinical guideline on dementia, SCIE work is now focusing on supporting the independent sector in its work on dementia care. More specifically, as part of the implementation of this Strategy, the Department will be discussing with SCIE and others how to promote best practice in dementia care in care homes.

27. There is no doubt that residential care may be the most appropriate and effective way of meeting the needs of someone with dementia and a service of choice. There are care homes that provide excellent care for people with dementia. Such homes generally pay close attention to leadership and staff management, staff training and development, and person-centred care planning. They also provide a physical environment that enables people with dementia to move around the home safely. They provide purposeful activities that relate to individual preferences rather than general entertainment; actively involve relatives and friends in the care of residents; and develop strong links with and involvement in local communities. There is a growing interest in Life Story work which provides an effective vehicle for care home staff to communicate and develop relationships with residents, based on their unique life experiences. Equally the provision of therapeutic activities within care homes, such as art therapy, music therapy or dramatherapy, may have a useful role in enabling a good-quality social environment and the possibility for self-expression where the individuality of the residents is respected.
28. However, evidence from the Alzheimer's Society Home from Home report⁴⁷ on the current reality indicated that:
- 54% of carers reported that their relative did not have enough to do in a care home;
 - the typical person in a care 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, but that these activities are seldom available; and
 - staff enjoy providing opportunities of activity and occupation and would like to be able to do more of this within their work, but do not feel they have the time.
29. The report found that maintaining good relationships between relatives and the home, and supporting the ongoing relationship between relatives and the person with dementia, have important benefits for both parties, including carers' degree of stress, residents' quality of life and engagement in activity. A study by CSCI of care homes has shown the quality of staff communication with people with dementia has a major impact on their quality of life. Leadership, ethos of the care home, staff training and support and development are the crucial factors in supporting good practice.⁴⁸ Commissioners can develop service specifications with providers which include

⁴⁷ Alzheimer's Society (2008). *Home from home*. London: Alzheimer's Society.

⁴⁸ CSCI (2008). *See me, not just the dementia: Understanding people's experiences of living in a care home*. London: CSCI.

these key factors, and identify how performance will be assessed in contract monitoring and evaluation.

30. 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 for older people have dementia,⁴⁹ and the prevalence rises to between 90 and 95% in homes for the elderly mentally infirm.⁵⁰ In addition, an estimated 50% of all care home residents have depressive disorders that would warrant intervention.⁵¹ Behavioural disturbance in dementia in these settings is both very common and a cause of stress to residents and staff. It is striking that there is very little in the way of active non-pharmacological management of these problems in these settings, despite accumulating evidence of the effectiveness of old age psychiatric intervention.⁵² Current input from mental health services is generally on an ad-hoc basis or reactive with referrals at times of crisis.
31. 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 those residents with dementia. Those who have criticised current practice include the Parliamentary Accounts Committee,⁵³ the Alzheimer's Society⁵⁴ and the All-Party Parliamentary Group on Dementia.⁵⁵ It appears that there are particular risks that are serious and negative in the use of anti-psychotic medications for people with dementia. These include increased mortality and stroke. There is accumulating evidence that in care homes they are initiated too freely, they are not reviewed appropriately following initiation, and they are not withdrawn as quickly as they could be. However it is also the case that behavioural problems in people with dementia can be dangerous and disruptive, and in some cases medication is the least worst option. Improving the quality of care in care homes requires this issue to be addressed effectively.
32. In response to the widespread concern at the inappropriate use of anti-psychotic drugs for people with dementia, the then Minister for Care Services announced a review of the issue in June 2008. This is being led by Professor Sube Banerjee, the joint lead of the National Dementia Strategy. This review is expected to complete its work and issue a full public report in the spring of 2009.

49 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.

50 Margallo-Lana M, Swann A, O'Brien J et al (2001). 'Prevalence and pharmacological management of behavioural and psychological symptoms amongst dementia sufferers living in care environments'. *International Journal of Geriatric Psychiatry*, 16:1, 39–44.

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

52 Proctor R, Burns A, Powell HS et al (1999). 'Behavioural management in nursing and residential homes: a randomised controlled trial'. *Lancet*, 354(9172): 26–9

53 NAO (2007). *Improving services and support for people with dementia*. London: TSO.

54 Alzheimer's Society (2008). *Home from home*. London: Alzheimer's Society.

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

33. In the course of developing the Strategy, one means suggested to address these problems has been a system of regular specialist mental health assessment following admission, and regular specialist review for this vulnerable population. This would enhance the quality of care by providing a regular forum for discussion between nursing staff, GPs and mental health teams to identify and manage the mental health problems of care home residents. Any intervention would need to be in partnership with the GPs responsible for care within care homes. In this system the quality of mental health care for residents in care homes could be improved by:
- detailed specialist assessment of mental health needs following admission;
 - regular six-monthly mental health reviews of residents in conjunction with the GP and nursing home staff;
 - providing access to specialist advice for 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 disorder 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 review of all those with dementia initiated on anti-psychotic medication;
 - rapid specialist response to problems as they occur within homes; and
 - assessment of the residential care provided and the potential for improvement to create a more therapeutic environment.
34. All the above would act to minimise the use of such medication. Commissioners could achieve this by commissioning an extension of the existing role of the old age community mental health teams building on existing capacity, rather than by setting up a separate service. Joint commissioning of in-reach services from other professionals, such as community pharmacists, community dentists, arts therapists and geriatricians, could also improve support to care homes and enhance their environment.
35. Given demographic projections for a major increase in the number of people living with dementia in the years ahead, commissioners will need to give careful strategic consideration to local care home capacity. Some people with dementia (especially those with severe and complex needs without family carers) will continue to require residential care provision. Although it may be possible to reduce the proportion of people with dementia who live in care homes, population growth means it is likely that there will be a need for at least the current care home capacity in absolute terms.

Therefore, taking the longer view with the implementation of this Strategy, we may see a smaller proportion of people with dementia going into long-term care, but the same or a larger number of people continuing to need such care.

End of life care for people with dementia

Objective 12: Improved end of life care for people with dementia. People with dementia and their carers to be involved in planning end of life care which recognises the principles outlined in the Department of Health End of Life Care Strategy. Local work on the End of Life Care Strategy to consider dementia.

How this can be delivered

- Initiating demonstration projects, piloting and evaluation of models of service provision prior to implementation, given the current lack of definitive data in this area.
- Developing better end of life care for people across care settings which reflects their preferences and makes full use of the planning tools in the Mental Capacity Act.
- Developing local end of life care pathways for dementia consistent with the Gold Standard framework as identified by the End of Life Care Strategy.
- Ensuring that palliative care networks, developed as part of the End of Life Care Strategy, support the spread of best practice on end of life care in dementia.
- Developing better pain relief and nursing support for people with dementia at the end of life.

The case for change

36. From the consultation process the Department heard that there needed to be stronger emphasis on developing end of life care in dementia and linking service development to the Department's End of Life Strategy. In dementia, end of life planning needs to take place early, while someone has sufficient mental capacity and where decisions and preferences can be recorded consistent with the principles set out in the Mental Capacity Act. This could include the use of lasting powers of attorney, advance decisions and advance statements.
37. The End of Life Care Strategy, published in July 2008, made clear the need for the development of end of life pathways which draw on the good practice shown in the Liverpool pathway and the Gold Standard framework. Local work on end of life care needs to focus on the large numbers of people who will die with dementia. In addition, in workforce development for end of life care, commissioners and providers need to consider how to ensure that effective end of life care for people with dementia can be

made real, including the effective use of specialist liaison with palliative care providers and skilled training in pain detection, pain relief and end of life nursing care.

38. For a given disorder, people with dementia have 4–6 times the mortality than the cognitively intact.⁵⁶ There is strong evidence to suggest that people with dementia receive poorer end of life care than those who are cognitively intact in terms of provision of palliative care.⁵⁷ For example, few people with dementia have access to hospice care.
39. The subject of pain illustrates the discriminatory care provided for people with dementia. In the last year of care giving, 63% of family carers reported that the patient had been in pain either ‘often’ or ‘all the time’.⁵⁸ Yet people with dementia receive less analgesia than other older people for a given illness.^{59, 60} Dementia may impair the ability of an individual to make themselves understood, and at least some of the agitated and aggressive behaviours seen in late-stage dementia may be an expression of pain.^{61, 62} People with dementia admitted to hospital for hip fracture with the same surgical intervention received less than half the pain relief of those who were cognitively intact.⁶³ The majority of those with dementia were in severe pain post-operatively and this pain was not actively managed.⁶⁴ However, communication problems in dementia may lead staff to ‘surmise that pain not expressed is pain not experienced’, and that pain expressed as aggression or confusion may lead to labelling and management as ‘difficult’.⁶⁵

56 Morrison RS, Siu AL (2000). ‘Survival in end-stage dementia following acute illness’. *Journal of the American Medical Association*, 284, 47–52.

57 Sampson EL, Gould V, Blanchard MR (2006). ‘Differences in care received by patients with and without dementia who died during acute hospital admission: A retrospective case note study’. *Age and Ageing*, 35, 187–89.

58 Schulz R, Mendelsohn AB, Haley WE et al (2003). ‘End-of-life care and the effects of bereavement on family caregivers of persons with dementia’. *New England Journal of Medicine*, 349(20): 1936–42.

59 Scherder EJ, Bouma A (1997). ‘Is decreased use of analgesics in Alzheimer’s disease due to a change in the affective component of pain?’ *Alzheimer Disease and Associated Disorders*, 11, 171–74.

60 Horgas AL, Tsai P (1998). ‘Analgesic drug prescription and use in cognitively impaired nursing home residents’. *Nursing Research*, 47, 235–42.

61 Geda YE, Rummans TA (1999). ‘Pain: Cause of agitation in elderly individuals with dementia’. *American Journal of Psychiatry*, 156(10): 1662–63.

62 Buffum MD, Miaskowski C, Sands L, Brod M (2001). ‘A pilot study of the relationship between discomfort and agitation in patients with dementia’. *Geriatric Nursing*, 22(2): 80–85.

63 Morrison RS, Siu AL (2000). ‘Survival in end-stage dementia following acute illness’. *Journal of the American Medical Association*, 284, 47–52.

64 Morrison RS, Siu AL (2000). ‘A comparison of pain and its treatment in advanced dementia and cognitively intact patients with hip fracture’. *Journal of Pain and Symptom Management*, 19, 240–48.

65 Riesenber D (2000). ‘Hospital care of patients with dementia’. *Journal of the American Medical Association*, 284, 87–89.

40. So there are major problems in end of life care for people with dementia. One report⁶⁶ has summarised the situation as follows: “...people with dementia often die with inadequate pain control, with feeding tubes in place, and without the benefits of hospice care.” The particular issues of capacity and the impacts of dementia mean that dementia-specific approaches need to be developed if the needs of people with dementia and their families are to be addressed. This is acknowledged in the Department’s End of Life Care Strategy. The National Council for Palliative Care has been evaluating end of life care for people with dementia, and has published a series of useful publications on current best practice.^{67, 68}



66 Sachs GA, Shega JW, Cox-Hayley D (2004). ‘Barriers to excellent end-of-life care for patients with dementia’. *Journal of General Internal Medicine*, 19, 1057–1063.

67 National Council for Palliative Care (2006). *Exploring Palliative Care for People with Dementia: A Discussion Document*. London: Alzheimer’s Society/NCPC.

68 National Council for Palliative Care. *Creative Partnerships: Improving Quality of Life at the End of Life for People with Dementia* (January 2008) and *Progress with Dementia – Moving Forward: Addressing Palliative Care for People with Dementia*. (August 2007). London: NCPC.

Chapter 6: Delivering the National Dementia Strategy

1. This final chapter addresses the implementation of the Strategy. The framework outlined here acknowledges the need to dovetail work on dementia with all other important current policy and service developments in the NHS and local government. Given the growing number of people with dementia in our health and social care systems, it will need to link with and help deliver major initiatives such as *Putting People First*, the Next Stage Review (NSR), the Carers' Strategy, the End of Life Care Strategy, and others. The framework also makes clear the different roles of central and local government, the NHS and key stakeholders. The approach to implementation is that set out by David Nicholson, the NHS Chief Executive, in outlining the following guiding principles for implementing the Next Stage Review:
 - **Co-production:** implementation must be discussed and decided in partnership with the NHS, local authorities and key stakeholders.
 - **Subsidiarity:** where necessary, the Department will play an enabling role, but wherever possible, the details of implementation will be determined locally.
 - **Clinical ownership and leadership:** DH staff must continue to be active participants and leaders as the strategy is implemented and the necessary changes are made.
 - **System alignment:** the wider system needs to be aligned around the same goals, enabling combined leverage to drive up quality across the system.
2. PCTs and local authorities will be expected to demonstrate continued progress towards meeting the 17 key objectives detailed in the diagram on page 20. Priorities for improvement will be for local determination, but feedback from the consultation responses suggests that particular attention should be paid to early diagnosis and intervention, workforce development, and improving care in care homes. Prioritisation is complex and will need to take account of the existing state of local services and their readiness for change, as well as financial issues. Commissioners will want to ensure that the necessary investment in dementia required to deliver the Strategy is given appropriate priority.

Workforce competencies, development and training in dementia

Objective 13: An informed and effective workforce for people with dementia.

All health and social care staff involved in the care of people who may have dementia to have the necessary skills to provide the best quality of care in the roles and settings where they work. To be achieved by effective basic training and continuous professional and vocational development in dementia.

How this can be delivered

- Department of Health workforce strategies to take on board the implications of the dementia strategy.
- The Department to work with representatives of all bodies involved in professional and vocational training and continuing professional development to reach agreement on the core competencies required in dementia care.
- These bodies to consider how to adapt their curricula and requirements to include these core competencies in pre- and post-qualification and occupational training.
- Such changes also to inform any review of national health and social care standards.
- Commissioners to specify necessary dementia training for service providers.
- Improving continuing staff education in dementia.

The case for change

Central importance of training and workforce development

3. The need for improved training is a priority that runs across all the themes in the Strategy. It is dealt with separately here to emphasise its central importance.
4. Two major criticisms were made by people with dementia and their carers during the consultation process. First, 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. Second, professionals often seemed unable to understand that what works for people *without* dementia may not work for people *with* dementia, and that professionals are often unable or unwilling to adapt their practice to make it work for people with dementia.
5. Two-thirds of people with dementia live in their own homes or those of carers, and one-third live in care homes. People with dementia access all services and so need informed understanding and support from all the services they come into contact with, not only from specialist dementia services. Awareness and skills are therefore needed in all sections of the workforce and society (eg housing, emergency services, employers,

utilities, public sector services, GP receptionists, criminal justice system staff), not just those involved with dementia 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 carers. Providing adequate training and support is likely to improve staff morale and ease recruitment and retention problems in dementia care. The top challenges to 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 keeping them motivated.⁶⁹ Training should also cover the principles of the Mental Capacity Act 2005, to ensure that all decisions made on behalf of dementia sufferers, where they lack capacity, are in their best interests and take their wishes and desires into account.

Commissioning a trained and competent workforce

6. People with dementia and their carers need to be supported and cared for by a trained workforce, with the right knowledge, skills and understanding of dementia to offer the best quality care and support. The challenge is for professional colleges and bodies, commissioners and learning consortia to take action to ensure that we have a workforce able and supported to deliver the changes required to fully implement the strategy. For social care workers the Department of Health Adult Social Care Workforce Strategy will be a force for change. Skills for Care, Skills for Health, the General Social Care Council, the Social Care Institute for Excellence (SCIE) and the new National Skills Academy will all have a role to play in developing the standards and skills of the social care workforce required to drive forward improvements.
7. Action can also be taken in the short term. PCTs and local authorities need to commission a trained and competent workforce using regional and local workforce development resources. Core competencies could be developed to train staff who are not professionally qualified or registered. This would also help care organisations identify learning and development needs; focus learning providers on producing courses that have content the sector needs; and assist regulators and commissioners in identifying quality in dementia care.
8. In the medium and longer-term, curricula for undergraduate professional qualifications and continuing professional development for doctors, nurses, therapists, other relevant health service staff and social care staff should all contain modules on dementia care. Training should enable an understanding of the diversity in dementia, including younger people with dementia, those who have dementia and a learning disability, and those with particular needs from minority backgrounds. There is currently a range of training and education providers in dementia care but no nationally recognised system

⁶⁹ Alzheimer's Society (2007). *Home from home*. London: Alzheimer's Society.

of quality assurance. Some form of ‘kite-marking’ of good practice would assist commissioners and care providers in selecting effective training.

9. The best arrangements will be where health and social care systems work together to develop their workforce. The Eastern region has already developed a quality outcomes-based integrated commissioning strategy for dementia training and education programmes that is intended for use by a newly developed County Workforce group to commission training and education. A multi-agency approach has been used to develop this Strategy, which has the full support of the relevant local authorities and the Eastern Strategic Health Authority. The strategy aims to cover learning outcomes for all staff from all sectors including medical staff. The local agencies involved have included Skills for Care, Skills for Health, universities, NHS trusts, local authorities, the Alzheimer’s Society, the Higher Education for Dementia Network (HEDN), the medical deaneries, independent care homes, and carers.

Objective 14: A joint commissioning strategy for dementia. Local commissioning and planning mechanisms to be established to determine the services needed for people with dementia and their carers, and how best to meet these needs. These should be informed by the World Class Commissioning guidance developed to support the Strategy and set out at Annex 1.

10. 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 change. It is important therefore for PCTs and local authorities to consider the need for the commissioning of coherent joint services. A joint commissioning strategy for dementia will need to be based on the Joint Strategic Needs Assessment. The strategy needs to specify the outcomes required and should be developed in consultation with people with dementia and their carers. CSIP has produced a toolkit to strengthen the involvement of people with dementia and their carers, which is available at www.dh.gov.uk/dementia. Joint commissioning strategies will need to take account of people’s needs for both mainstream and specific services. They will 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.
11. The strategies should inform the operational plans and budget cycles of PCTs and local authorities, and demonstrate how they plan to improve services for people with dementia. They should be informed by guidance on World Class Commissioning and the specific guidance on World Class Commissioning for dementia developed to

support this Strategy at Annex 1, as well as the *Putting People First* guidance. As a local priority, local authority, PCT and practice-based 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.

Performance monitoring and evaluation including inspection

Objective 15: Improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers. Inspection regimes for care homes and other services that better assure the quality of dementia care provided.

12. The Care Quality Commission (CQC) will be operational from April 2009 to protect and promote the health, safety and welfare of people who use health and social care services and to encourage improvement, by inspecting and assessing for quality across health and social care services, and primary and secondary care. The Commission will therefore have a crucial role in driving up standards, particularly for people living with dementia who require support from across health and social care. CQC will contribute to a better understanding about the experience of people living with dementia and their carers across care pathways. It will bring together information from assessment of the outcomes from local authority and PCT commissioning with other data about the quality of the health and social care services it regulates. In this way, and through its programme of national studies and reviews, CQC will contribute understanding about the experience of people living with dementia and their carers to Comprehensive Area Assessment, and can provide independent assessment of the progress and impact of the National Dementia Strategy.
13. Assessing the real-life experience of people with dementia is an important part of the inspection process. Understanding what it is like to live in and use a service is crucial to understanding the quality of outcomes that people experience. Specific efforts will need to be made to ensure that, where relevant, inspections include monitoring the experience of those with more advanced dementia or compromised communication needs. As well as talking to people with dementia, inspections could also include talking to family carers, regular visitors and staff. Understanding people's experiences is more than getting their views. It is also crucial that inspections include observing care, support and interactions between staff and people who use services. For example, CSCI has developed an observational tool used during inspections (Short Observation Framework for Inspection (SOFI)) which allows inspectors to have a structured way of observing people's experiences and enables them to make judgements beyond routine care practice. The CQC will use this.

14. Inspectorates of care homes need to ensure that their inspections include an assessment of the quality of care that people with dementia experience. Given that the large majority of people in care homes have dementia, the inspectorate should consider how their guidance supports both providers and inspectors to identify and understand what good-quality care for people with dementia looks like.

Research

Objective 16: A clear picture of research evidence and needs. Evidence to be available on the existing research base on dementia in the UK and the gaps that need to be filled.

How this can be delivered

- The Medical Research Council (MRC) with DH to convene a summit of parties interested in dementia research.

The case for change

15. There has been a clear and consistent message from the consultation of the need to build the research base in dementia. There has been a growth in public, industrial and charity funding of dementia research, but it appears that the level of funding lags behind other major health priorities such as cancer and heart disease. The need for further research has been identified by stakeholders for all aspects of dementia from basic biological processes, to the evaluation of new biological and non-biological treatments, through to options for care and prevention ('prevention, cause, cure and care'). The potential and importance of research in this area have been clearly articulated by the Department for Innovation Universities and Skills Foresight Programme (www.foresight.gov.uk).
16. In February 2008, the MRC conducted a strategic review of neurodegeneration research. The aim of the review was to formulate strategic advice to the MRC Neurosciences and Mental Health Board on the changes in health needs, new scientific opportunities and the most important research and training questions that the MRC/UK could address. The report, available at www.mrc.ac.uk/Utilities/Documentrecord/index.htm?d=MRC004898, made three central recommendations: to strengthen biological research into disease origins and mechanisms; to improve training and enhance critical mass; and to provide support for a strategic co-coordinated network that would address the key barriers to progress in this field. MRC is also exploring the opportunities for working collaboratively with other funders at a European level within the area of neurodegeneration.

17. Following on from this, at the beginning of October 2008, the MRC and the Wellcome Trust launched a £30 million joint call for collaborative and innovative interdisciplinary proposals in neurodegeneration. The focus of the call is on advancing understanding of biological processes underpinning neurodegenerative diseases. The aims of the call are to: create consortia comprising leading UK research groups wherever based; facilitate interdisciplinary approaches to address key gaps in our knowledge of the biological basis of neurodegenerative diseases; and catalyse development of new approaches for diagnosis and interventions. Details are available at www.mrc.ac.uk/Fundingopportunities/Calls/Neurodegenerativeresearch/MRC004893
18. The Dementias & Neurodegenerative Diseases Research Network (DeNDRoN) was established in September 2005 as part of the UK Clinical Research Network. The aim of the Network is to facilitate research by bringing about focused, effective investment to enhance NHS research infrastructure, and to increase collaborative working between academics, clinicians, patients, carers and research funders. It builds on strengths already present in the UK as well as increasing general capacity in the field of dementia and neurodegeneration, and covers major diseases including the dementias, as well as motor neurone disease, Parkinson's disease and Huntington's disease (www.dendron.org.uk/index.html).
19. Between 2002 and 2006 the MRC invested £150 million in neurodegeneration research, of which 21% (£32 million) was spent on the dementias. The Biotechnology and Biological Sciences Research Council (BBSRC) funds research relevant to understanding normal human function. Neurodegeneration-related research funded by BBSRC includes neuronal damage and repair; neurogenesis; cognitive dysfunction and decline; research underpinning Alzheimer's/Parkinson's disease; and research into transmissible spongiform encephalopathies (TSE). Their estimated spend on all the above between 2004 and 2007 was £11 million. The Department of Health in 2006/07 spent £22.8m on dementia research under its national research programmes, including infrastructure support for DeNDRoN. Charitable funding includes the Wellcome Trust, the UK's largest charity funding biomedical research, which in 2007 funded £23 million across research in neurodegeneration. The Alzheimer's Research Trust spends approximately £3 million per annum on Alzheimer's/dementia-related research, and the Alzheimer's Society approximately £1.5 million per year.
20. In recognition of the importance of this area, the MRC with the Department will convene a summit of relevant organisations funding, conducting and using research into dementia to consider dementia research and the potential for further development and co-ordination. This is in recognition of the fact that dementia is now one of the most significant challenges facing our society. The summit will focus on how research

fundors, charities and industry could work more effectively together to begin to deliver the research needed on prevention, cause, cure and care.

Support for implementation of the Strategy

Objective 17: Effective national and regional support for implementation of the Strategy. Appropriate national and regional support to be available to advise and assist local implementation of the Strategy. Good-quality information to be available on the development of dementia services, including information from evaluations and demonstrator sites.

How this will be delivered

- The Department of Health will provide support for all those involved in implementing the strategy locally to ensure its delivery, particularly for those areas where services are less developed.
- Localities will need help with ‘getting started’, particularly if little attention has previously been given strategically to the needs of people with dementia.
- Regional support teams will be convened to support local implementation.
- Information will be gathered on an annual basis by the Department from both the NHS and social care services to review the extent of current services for people with dementia and their carers, and to track these over time to monitor progress on implementing the National Dementia Strategy.
- A national baseline measurement of services will be established.
- Specifically commissioned research, evaluations and data from demonstrator sites will support the implementation of the Strategy.

The case for change

21. Implementation support is required at national, regional and local level. Feedback from the consultation events suggests that many people are keen to get going. Some localities are already moving ahead as a consequence of specific pathways developed through the Darzi review. At regional level, networks of key groups are already forming, eg around commissioning. It is important to build on and develop this energy and enthusiasm.

Local delivery, regional support, nationally co-ordinated

22. The Department will provide regionally based diagnostic advice and improvement support to local health and social care economies to implement the National Dementia Strategy. The regional teams will work with the regional tier and health and social care

organisations to identify localities within the region, based on local authority areas, that require help to implement the Strategy, using agreed criteria. They will develop effective links with PCT and SHA leads for the delivery of the Darzi regional visions, some of which include specific pathways for dementia. Similarly they will make the necessary links with local authority leads to ensure coherence with the *Putting People First* agenda, working in collaboration with Joint Investment Plans (JIPs) and Regional Improvement and Efficiency Partnerships (RIEPs).

23. A national team will co-ordinate the programme and oversee the production of materials to support implementation, using web-based materials and networks as well as running workshops and conferences. They will provide additional assistance at a national level, based on particular themes in the Strategy. For example, the Strategy emphasises the need to improve the quality of residential care for people with dementia and also addresses the issue of the use of anti-psychotic medication for people with dementia. Improvement support will need to reach commissioners, care managers, specialist mental health teams, residential care staff, home managers and medical staff. While much of this will be developed and provided in the regions according to local needs, there will also be some core support materials that will be needed everywhere. Producing these nationally will avoid duplication and make best use of resources.
24. In the first six months of the Strategy, the Department will test out how this methodology works by providing support to a small number of localities around the country through its regional delivery arrangements. This will include an initial scoping of where to target further support region by region, bearing in mind that localities will be at different stages of development as far as meeting the needs of people with dementia are concerned.
25. Transforming the quality of dementia care in England is a huge challenge for all parts of the health and social care systems. People with dementia, their carers, the public and professionals will all expect to see steady progress. It is therefore very important to ascertain the nature of current dementia services, and to track these over time to monitor the progress of the National Dementia Strategy. This will require a national baseline measurement of service content and finance, and local service audits. Successive programmes of assessment will need to be completed to deliver information on the growth and activity of services for people with dementia and their carers, comparing services with agreed benchmarks. These might be delivered by specifically commissioned research to support the implementation of policy and by the use of existing service and financial mapping activities.
26. The developments recommended here will require an extension of the workforce in order to deliver the new and improved services described. 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. This should mitigate the workforce effects and give time for appropriate local prioritisation and decision making. It will need to feed into the operational plans and budget cycles of PCTs and local authorities, and to demonstrate how they will meet national and local targets for improving services for people with dementia.

27. The guidance on Joint Strategic Needs Assessment (JSNA) published by the Department in December 2007 stated that JSNA will include a longer-term assessment (five to ten 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 well-being by helping individuals with dementia and their families to live safely at home, meet personal care needs, and continue to be able to contribute to society. Their aspirations are the common themes and policy objectives that support the Government's programme to promote independence and well-being through *Putting People First*, the Independent Living Strategy, *Lifetime homes, lifetime neighbourhoods* and the NHS Next Stage Review.

Interface with older people's mental health services

28. The consultation exercise revealed strong concern about specialist older people's mental health services and how they might be affected by this Strategy. It is clear from this Strategy, as well as *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. It is also the case that 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. However, they are also a vital component part of service provision for people with dementia. An effective system of dementia care requires strong, well resourced and effective specialist older people's mental health services.
29. 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 with mental disorder. The separation of 'organic' and 'functional' disorders in terms of service provision is essentially a false dichotomy, and one that is likely to disadvantage people with dementia with complex needs and their family carers. Specialist mental health services are needed that can deliver good-quality care that is attuned to the specific needs of older people. The natural history of dementia means that a substantial proportion of

those affected will develop challenging behaviour, including 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. This means services in the community that work for older people with both functional and organic disorders and therefore a mixture of both.

30. Implementation of this Strategy will need to be part of a broader focus on older people's mental health services. Strong concerns were raised during the consultation exercise that some localities may be interpreting age equality in mental health services to mean a 'one size fits all ages' approach. This generally means using existing working-age adult services to look after older people with functional illness. With reflection, this is much more likely to increase age discrimination than it is to address it. This is because age here is a proxy for a different set of needs and therefore skills. Equivalent quality of care is likely to require enhancing current older people's mental health teams to have higher levels of functionality in terms of the capacity for assertive outreach, for example. This would benefit those with dementia as well as those older people with functional disorder. 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.

Performance monitoring and evaluation

31. During the development of the Strategy it has become apparent that the information currently available on dementia services falls well short of the ideal. In order to ensure that commissioners can assess the needs of their populations, assess their priorities and develop local services, it is vital that they have good-quality information. To be able to assess the impact of the strategy, good information on the services currently being provided and their effectiveness in meeting the needs of people with dementia and their carers will be essential from the outset.
32. This Strategy is the start of a process, not an end in itself. Even if all the 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 of not making the changes will be immeasurably higher, both in financial and human terms.

Annex 1: World Class Commissioning guidance for dementia

Living well with dementia

Securing better quality of life for people with dementia and their families through World Class Commissioning



1. Securing world class health for people with dementia and their family carers

All people with dementia, and those that care for them, have the right to the best possible healthcare and support. We know that early diagnosis, along with effective intervention and support from diagnosis through the course of the illness, can enable people to live well with dementia. We also know that improving health and social care outcomes in dementia in the short and medium term can have significant benefits for society, both now and in the future.

Commissioners from across the public sector, including primary care trusts (PCTs) and local authorities, can significantly impact the shaping of health outcomes for people with dementia and their family carers. Together, their role is to ensure that resources are used most effectively to achieve the best possible health outcomes.

Living well with dementia: A National Dementia Strategy sets out the following ambitions for people with dementia and their carers:

- World class health and social care outcomes.
- Improved public and professional attitudes and understanding.
- Early diagnosis and intervention.
- Good-quality health and social care, from diagnosis to the end of life.

The Strategy is the next phase in the Government's ambition to improve health for older people, building on initiatives including:

- **National Service Framework for Older People** – The *National Service Framework for Older People*⁷⁰ (2001) included a chapter on mental health and older people. This included a consideration of dementia, advocating early diagnosis and intervention. It recommended that the NHS and local councils should review arrangements for health promotion, early detection and diagnosis, assessment, care and treatment planning, and access to specialist services.
- **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 development guide*.⁷¹ 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

⁷⁰ DH (2001). *National Service Framework for Older People*. London: DH.

⁷¹ CSIP (2005). *Everybody's Business – Integrated mental health services for older adults: a service development guide*. London: DH.

community mental teams, whose role includes the management of people with dementia with complex behavioural and psychological symptoms.

- **NICE/SCIE dementia clinical guideline** – 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 2006.⁷² Key recommendations included: integrated working across all agencies; memory assessment services as a point of referral for diagnosis of dementia; assessment, support and treatment for carers (where needed); 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: The full report** – In February 2007, the Alzheimer’s Society published *Dementia UK: The full report*.⁷³ Its key findings were that there are 700,000 people with dementia in the UK, and that this costs society as a whole £17 billion per year. In 30 years the numbers are set to double, and the costs to triple. The report’s recommendations included making dementia an explicit national health and social care priority and improving the quality of services provided for people with dementia and their carers.
- **NAO 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 2007.⁷⁴ This report was critical of the quality of care received by people with dementia and their families. The report concluded that overall spending occurs too late – too few people are being diagnosed or being diagnosed early enough, and that early intervention is needed to improve quality of life. The NAO advocated a ‘spend to save’ approach, with upfront investment in services for early diagnosis and intervention, improved specialist community services, and in general hospitals to enable long-term cost savings from the prevention of unnecessary transition into care homes and shorter stays in hospital.
- **Public Accounts Committee report** – These findings were confirmed and summarised by the House of Commons Public Accounts Committee (PAC) report,⁷⁵ following the committee’s public hearing on 15 October 2007 where the NHS Chief Executive and others from the Department of Health were questioned on the NAO’s criticisms and recommendations. The PAC identified eight areas for action: making dementia a national priority; effective ownership and leadership; early diagnosis for all; improving public attitudes and understanding; delivering co-ordinated care; making services work

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

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

74 NAO (2007). *Improving services and support for people with dementia*. London: TSO.

75 Public Accounts Committee (2008). *Sixth Report of Session 2007–8: Improving services and support for people with dementia*. London: TSO.

for carers too; improving care in care homes; and improving care in general hospitals. The Government's response accepted the conclusions and recommendations of the Committee, emphasising that their findings would be fully addressed in the National Dementia Strategy.

- **Our NHS, Our Future: NHS Next Stage Review**⁷⁶ – The review identifies the need to secure high-quality and personalised care for all, with people with dementia cutting across all but two of the eight strategic health authority Next Stage Review pathways. Success in achieving the goals of the Next Stage Review will help to improve dementia services across all regions and, in a complementary manner, implementation of the dementia strategy will help to deliver on the goals of *Our NHS, Our Future*.

1.1 Commissioning to improve health and social care outcomes for people with dementia and their families

Living well with dementia: A National Dementia Strategy makes clear that stronger commissioning for people with dementia and their families is key to achieving improved health outcomes – this message was echoed in stakeholder engagement on the strategy, in work on the Carers' Strategy, *Putting People First* and the NAO and PAC reports discussed above. The increasing focus on personalised services requires that commissioners of health and social care together focus their efforts to ensure that this policy is applied appropriately to services for dementia, to secure better health and social outcomes.

World Class Commissioning⁷⁷ seeks to transform the way in which services are commissioned by health bodies – it is about adding life to years, and years to life. Our vision for World Class Commissioning, published in December 2007, is for better health and well-being, better care and better value for all. World Class Commissioning is not an end in itself, but provides a framework to help commissioners of health services to deliver a more strategic and long-term approach, with a clear focus on improving outcomes. A set of World Class Commissioning organisational competencies has been developed, covering the knowledge, skills and behaviours expected to become world class, and an assurance system has been developed to drive up performance and development in PCTs.

1.2 Who this document is for

This document is for anyone who is involved in commissioning for health outcomes for people with dementia and their families. Health commissioners, including practice-based commissioners, need to work with their social care counterparts to ensure that the needs of people with dementia are fully met. It is designed to help commissioners to work **together** in order to secure improved health and social outcomes for people with dementia and their families.

⁷⁶ www.dh.gov.uk/en/Healthcare/OurNHSourfuture/index.htm

⁷⁷ www.dh.gov.uk/en/Managingyourorganisation/Commissioning/Worldclasscommissioning/index.htm

If you are part of the commissioning process then this document will help you to develop as a world class commissioner, ensuring that people with dementia and their families have the best possible chances of good health.

1.3 What this document covers

This document supports commissioners to play their central role in securing improved outcomes for people with dementia and their families. It accompanies *Living well with dementia: A National Dementia Strategy* and describes what World Class Commissioning for health outcomes for people with dementia and their families looks like.

This document brings together information from across the health, social care, and third sectors, and it:

- sets out **who** is involved in commissioning related to health outcomes for people with dementia and their families (section 2);
- outlines the **World Class Commissioning competencies** in the context of outcomes for people with dementia and their families (section 3);
- expresses a **coherent care pathway** for commissioning for people with dementia and their families (section 4); and
- sets out **next steps and further support for commissioners** as part of the roll-out of the national dementia strategy (section 5).

1.4 Support for commissioners

Some of the information in this document has been published previously, but the Department of Health recognises the need to bring this together in one place. Some of the information, for example on World Class Commissioning, may be new to you.

This document is one component of a package of support to enable commissioners to deliver the vision of the *Living well with dementia: A National Dementia Strategy* agenda. To enable more effective commissioning, the Government will do the following:

- **Promote joint leadership and strengthen local accountability arrangements for dementia**, via regional support and national co-ordination of the National Dementia Strategy.
- **Provide practical support and guidance to overcome local commissioning challenges**. The programme will provide a community of practice to facilitate networking and resource exchange, and offer bespoke support including tailored workshops for commissioners.
- **Provide specific guidance** on key services, such as memory services for early intervention, community personal support, liaison services in general hospitals, dementia advisers and in-reach into care homes etc.

- **Develop dementia datasets and models for the planners and commissioners of services**, for example to improve local authorities' and PCTs' ability to understand the complex relationship between dementia care spending and outcomes.
- **Further promote the voice of people with dementia and their family carers** through commitments to ensure that people with dementia and their family's views are given prominence in future assessments of healthcare organisations.
- **Ensure that robust arrangements are in place to promote and ensure the quality of health services.**

2. Who is involved in commissioning for health outcomes for dementia and their family carers?

Effective commissioning for dementia involves a wide range of partners at strategic and operational levels. At all levels, commissioners need to take account of and appropriately prioritise:

- **clinical need** – balancing the need for universal health promotion and preventative measures through to healthcare for acute health needs and specialist support for people with dementia and complex health and social care needs; and
- **wider risk factors** – targeting support for vulnerable groups who often suffer disproportionately poorer health outcomes, such as people with learning disabilities and dementia.

The specific mix of partners and the nature of their involvement will be determined locally. However, at a minimum those involved should include the following:

- **Commissioners from the PCT and local authority** – senior leadership should ensure that the investment decisions and strategies of their own organisations support the shared priorities for dementia health outcomes. At a minimum, this should include the Director of Adult Social Services and other local authority leaders, senior management from the PCT, and the Director of Public Health and his or her senior team. Together these individuals are at the core of the systems delivering health outcomes for people with dementia and their families.
- **Technical experts** – those with relevant expertise across the commissioning cycle, including needs assessment, engagement of people with dementia and their families (particularly those that are hardest to engage), procurement/contracting staff, legal capacity, information and evidence expertise, and performance management and improvement staff.
- **Wider partners** – in addition to the PCT and the local authority, input from the wider partnership, eg people with dementia and their carers themselves, and from local third and private sector partners, is crucial.

- **Professionals, clinicians and specialist staff** – commissioning also benefits from the expertise of front-line practitioners. This includes (but is not limited to) **health service providers** (eg old age psychiatrists, geriatricians and neurologists in acute care and the community, practice and district nurses, health visitors); **social care providers** (eg staff in adult social care, home care, intermediate care and care homes, etc); **wider older people’s services** (eg staff in day centres, non-specialists in acute hospitals, etc); and **primary care providers** including general practitioners. When involving front-line practitioners, it is important to recognise their dual role in achieving health outcomes for people with dementia and their families. For example, general practitioners are both commissioners (via practice-based commissioning), and service providers.
- **Oversight and scrutiny leads** – the local strategic partnership, PCT and local authority have oversight and scrutiny structures that review strategic direction and ensure that resources are being used to deliver. They may not have detailed involvement in the commissioning process, but they can provide helpful challenge and review. These partners may include the lead member for older people’s services, the local authority health scrutiny committee, the SHA and the non-executive members of the PCT board.
- **People with dementia and their families** – while professionals, service specialists and leaders are key, it is crucial that people with dementia and their families must be fully engaged at all the phases of commissioning. This engagement should move beyond consultation to meaningful roles in priority setting, monitoring and service design. The World Class Commissioning competencies (below) promote the use of creative approaches to ensure that, where possible, people with dementia are included and that their voices are heard (as well as the voices of their family carers).

Commissioning for people with dementia’s health outcomes requires involvement from a range of partners who have their own priorities and, sometimes, different views on what success looks like. The *Living well with dementia: A National Dementia Strategy* provides a common vision for all to rally around, through which this vision can be achieved locally.

3. World Class Commissioning for people with dementia and their family carers

The World Class Commissioning programme aims to raise ambitions for a new approach to commissioning that is about delivering better health and well-being for all. By focusing on people with dementia's health and well-being outcomes, partners in dementia care will be contributing to improved outcomes for the whole population for the future.

The World Class Commissioning competencies are the knowledge, skills, behaviours and characteristics that underpin effective commissioning. When put into practice, world class commissioners can transform people's health and well-being, reduce inequalities and promote well-being.

Building on the existing articulation of the competencies, this section expresses some of the skills and behaviours needed for World Class Commissioning in order to improve health outcomes for people with dementia and their families. It is by no means exhaustive, but is rather a starting point for those working in this area to review and improve their own skills and competence.

The National Dementia Strategy identifies 17 objectives to transform the quality of dementia care. One or more of the World Class Commissioning competencies will be needed by commissioners in order to achieve these objectives. The outcomes for people with dementia and their family carers are listed down the right-hand side of the competencies in order to illustrate the important links between them. Further detail on how each competency supports the outcomes is set out in Table 1.

3.1 The competencies⁷⁸ and the National Dementia Strategy objectives

The 11 World Class Commissioning competencies represent detailed work carried out with NHS commissioners, but **are relevant to all partners contributing to commissioning for health outcomes for people with dementia and their families**. They are set out below, alongside the National Dementia Strategy objectives.

⁷⁸ www.dh.gov.uk/en/Managingyourorganisation/Commissioning/Worldclasscommissioning/index.htm

World Class Commissioning competencies	National dementia objectives
<p>1. Locally lead the NHS</p> <p>World class commissioners of dementia services provide leadership with the Director of Adult Social Services across health and social care to jointly commission a well-defined, fully integrated, locally agreed care pathway for dementia. As discussed above, this involves the definition of this care pathway through the involvement of the whole network of those involved in dementia care, including health and social services, the independent and third sector, and users of services and their carers. With this network, commissioners will generate a joint commissioning strategy for dementia, owned by local authorities, PCTs and others based on a Joint Strategic Needs Assessment. The joint commissioning strategy will define the specification for each element of the pathway against which services are 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.</p>	<p>NDS objective 1: Improving public and professional awareness and understanding of dementia. Public and professional awareness and understanding of dementia to be improved and the stigma associated with it addressed. This should inform individuals of the benefits of timely diagnosis and care, promote the prevention of dementia, and reduce social exclusion and discrimination. It should encourage behaviour change in terms of appropriate help-seeking and help provision.</p> <p>Using an open and transparent process, the world class commissioner will contract for, and performance manage, all elements of the pathway. They must clearly state the quality standards to be achieved, including staffing resources and skills.</p>

<p>2. Work with community partners</p> <p>World class commissioners of dementia services develop relationships with strategic and operational bodies, engaging them in ways that increase efficiency and effectiveness. These relationships extend beyond the public sector and its traditional partners to include businesses such as the care home industry and other local services such as the Alzheimer’s Society, as well as other third-sector organisations that have delivery and achievement of local outcomes as core to their business. World class commissioners of dementia services make particular efforts to engage with core service providers, including mental health trusts, acute trusts, adult social service departments and primary care practices, in order to commission care pathways that will deliver measurable health outcomes.</p>	<p>NDS objective 2: Good-quality early diagnosis and intervention for all. All people with dementia have access to a pathway of care that delivers: a rapid and competent specialist assessment; an accurate diagnosis 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 attend to all new cases of dementia in the area.</p> <p>NDS objective 3: Good-quality information for those with diagnosed dementia and their carers. Providing people with dementia and their carers with good-quality information on the illness and on the services available, both at diagnosis and throughout the course of their care.</p> <p>NDS objective 4: Enabling easy access to care, support and advice following diagnosis. A dementia adviser to facilitate easy access to appropriate care, support and advice for those diagnosed with dementia and their carers.</p>
<p>3. Engage with public and patients</p> <p>World class commissioners of dementia services engage with people and their families in order to prioritise outcomes and shape delivery. People with dementia and their families are not just listened to, but are fully engaged with the design and delivery of services to secure improved outcomes. Creative and innovative approaches should be used to ensure that people with dementia with multiple and complex needs and their families <i>and</i> vulnerable people with dementia and their families are at the heart of this engagement. Engagement is a two-way street in which the process itself seeks to raise individual and community aspirations for improved health outcomes, and to develop a shared vision for achieving them.</p>	

4. Collaborate with clinicians and professionals

World class commissioners of dementia services actively seek and value the expertise of local clinicians and other professionals, including professionals working with people with dementia and their families in health, social care and wider services. Where necessary, they seek independent expertise. Experts and professionals are engaged by commissioners and are confident that their input shapes decisions at every level. The process of engagement promotes the sharing of knowledge and expertise across boundaries and contributes to the development of networks locally and more widely. It also enables everyone to think radically about the way that needs are addressed and ensures that the best evidence is used to commission the most appropriate care pathways.

NDS objective 5: Development of structured peer support and learning networks.

The establishment and maintenance of such networks will provide direct local peer support for people with dementia and their carers. It will also enable people with dementia and their carers to take an active role in the development and prioritisation of local services.

NDS objective 6: Improved community personal support services.

Provision of an appropriate range of services to support people with dementia living at home and with their carers. Access to flexible and reliable services, ranging from early intervention to specialist home care services, which are responsive to the personal needs and preferences of each individual and take account of their broader family circumstances. Accessible to people living alone or with carers, people who pay for their care privately, through personal budgets, or through local authority-arranged services.

5. Manage knowledge and assess needs

World class commissioners of dementia services have (and manage) knowledge and information about the needs of their population, including *all* people with dementia and their families, and can prioritise effectively to gain optimum improvements and address health inequalities. They understand the full range of expectations and service needs for all people with dementia. They also understand current service provision and pay particular attention to those least able to influence and who are seldom heard. World class commissioners of dementia services value qualitative and quantitative information and bring the two together for a more nuanced understanding of their local circumstances. They gather information from a wide range of sources across sectors, including public health, current and potential providers, and share this information in a meaningful and transparent way with their partners, and with people with dementia and their families. This information forms the foundation of the Joint Strategic Needs Assessment and is at the heart of local strategic planning and prioritisation.

NDS objective 7: Implementing the Carers' Strategy for people with dementia.

Family carers are the most important resource available for people with dementia. Active work is needed to ensure that the provisions of the Carers' Strategy are available to carers of people with dementia. Carers have a right to an assessment of their needs and can be supported through an agreed plan, in order to support the important role they play in the care of the person with dementia. This will include good-quality, personalised breaks. Action should also be taken to strengthen support for children who are in caring roles, ensuring that their particular needs as children are protected.

NDS objective 8: Improved quality of care for people with dementia in general hospitals.

Identifying leadership for dementia in general hospitals, defining the care pathway for dementia there and the commissioning of specialist liaison older people's mental health teams to work in general hospitals.

6. Prioritise investment

World class commissioners of dementia services invest across a wide range of opportunities in order to address the full spectrum of needs. In doing so, they balance prevention of harm with intervention as well as balancing improving health outcomes with efficiencies and sustainability. They work hard to generate and grow resources from other local partners and more widely. Partners are transparent over their respective arrangements for prioritising, planning and investing. They ensure that investments can be linked back to key improvements in health outcomes for people with dementia and their families. Increasingly, world class commissioners of dementia services understand the links between investment and outcomes.

7. Stimulate the market

World class commissioners of dementia services work with others, including those in the third sector, other local authorities and regional partners, to build a robust, flexible and diverse market. Market management is based on robust information and intelligence, which is used to make assessments of current service provision and future requirements. World class commissioners of dementia services identify gaps and explore how to respond to unmet needs, which is likely to include increasing contestability, lowering barriers to market entry and exit, and developing sustainability of services and third sector capacity. They work with providers to develop services in the light of new evidence and in response to gaps between services and needs. This may include training and capacity building rather than new services, as well as decommissioning when appropriate.

NDS objective 9: Improved intermediate care for people with dementia. Intermediate care that is accessible to people with dementia and that meets their needs.

NDS objective 10: People with dementia and their carers receive the right housing support, housing-related services and telecare at the right time. People with dementia are included in housing options and assessment for assistive technology and telecare solutions. People with dementia and their carers have access from an early stage to a wide range of low-level support services to help prolong independent living and delay reliance on more intensive services.

NDS objective 11: Living well with dementia in care homes. Improved quality of care for people with dementia in care homes by the development of explicit leadership for dementia within care homes, defining the care pathway there, the commissioning of specialist in-reach services from community mental teams, and through inspection regimes.

<p>8. Promote improvement and innovation</p> <p>World class commissioners of dementia services specify outcomes and improvements that they expect from providers as part of their contracting and procuring process. They are constantly scanning the horizon for examples of emerging world class programmes, approaches and services. World class commissioners of dementia services support innovation, sharing emerging and good practice, eg improving the engagement of people with dementia and their families. They make investment decisions that enable innovation and improvement, particularly encouraging prevention of harm, and innovation to improve outcomes for vulnerable people with dementia and their family carers.</p>	<p>NDS objective 12: Improved end of life care for people with dementia. People with dementia and their carers to be involved in planning end of life care, which recognises the principles outlined in the Department of Health End of Life Care Strategy. Local work on the End of Life Strategy to consider dementia.</p> <p>NDS objective 13: An informed and effective workforce for people with dementia. All health and social care staff involved in the care of people who may have dementia to have the skills needed to provide the best quality of care in the roles and in the settings where they work. This is to be achieved by effective basic training and continuous professional and vocational development in the field of dementia.</p> <p>NDS objective 14: A joint commissioning strategy for dementia. Local commissioning and planning mechanisms to be established to determine the services needed for people with dementia and their carers, and to determine how best to meet these needs. These should be informed by the dementia World Class Commissioning guidance developed to support this Strategy.</p>
<p>9. Secure procurement skills</p> <p>World class commissioners of dementia services develop their procurement and contracting skills within the partnership, or contract together for support as necessary to ensure that they have the contracting, negotiating and legal skills and capacity to develop and manage market-shaping, as well as driving and managing outcomes-based contracts. World class commissioners of dementia services continually assess and seek to improve their capacity and capability, and invest in developing this to a high level. They focus on developing the skills to shape and manage outcomes-based contracts between the commissioning organisations and service providers. Where skills need to be contracted from outside, world class commissioners of dementia services secure these at the best possible value and ensure skills transfer to in-house resources.</p>	

<p>10. Manage the local health system</p> <p>World class commissioners of dementia services develop and champion a shared vision and strategy for the current and future pattern of services and experiences for people with dementia and their families. Based on this, they nurture a common understanding of the efforts and investment needed to achieve this vision, and have the support of the community and wider partners in order to make this happen. They are working closely with providers to manage change and improve outcomes and efficiency. They are facilitating networks and sharing good practice within and across sectors. They have a robust understanding of what is best delivered locally, and which services are most effectively commissioned or provided regionally or indeed nationally.</p>	<p>NDS objective 15: Improved registration and inspection of care homes and other health and social care services for people with dementia and their carers.</p> <p>Inspection regimes for care homes and other services that better assure the quality of dementia care provided.</p>
<p>11. Make sound financial investments</p> <p>World class commissioners of dementia services tie investments to progress against agreed local dementia-specific health priorities, as well as national ambitions. They ensure transparency in the deployment of resources, including providing clear information to people with dementia and their families.</p>	<p>NDS objective 16: A clear picture of research evidence and needs.</p> <p>Evidence to be available on the existing research base on dementia in the UK and gaps that need to be filled.</p> <p>NDS objective 17: Effective national and regional support for implementation of the Strategy.</p> <p>Appropriate national and regional support to be available to advise and assist local implementation of the Strategy. Good-quality information to be available on the development of dementia services over the course of the strategy, including information from evaluations and demonstrator sites.</p>

These competencies are applicable across the full range of commissioning activities. The detail provided above is illustrative of what effective commissioning for people with dementia's health outcomes looks like. For further detail on the World Class Commissioning competencies, please consult the Department of Health website (www.dh.gov.uk/en/Managingyourorganisation/Commissioning/Worldclasscommissioning/index.html).

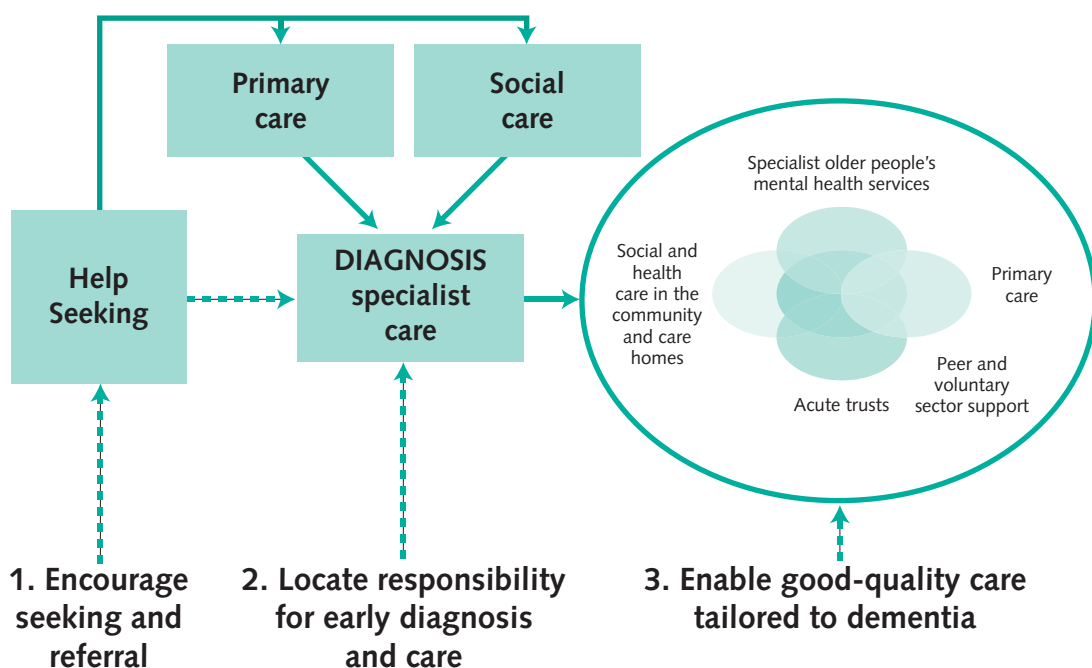
4. Commissioning a care pathway for people with dementia and their family carers

The Department of Health’s goal is for people with dementia and their family carers to be helped to live well with dementia, no matter what the stage of their illness or where they are in the health and social care system. The vision to achieve this is a simple one, in three parts, to:

- encourage help-seeking and help-offering (referral for diagnosis) by changing public and professional attitudes, understanding and behaviour;
- make early diagnosis and treatment the rule rather than the exception. This will be achieved by locating the responsibility for the diagnosis of mild and moderate dementia in a specifically commissioned part of the system that can a) make the diagnoses well, b) breaks those diagnoses sensitively and well to those affected, and c) provides individuals with immediate treatment, care and peer and professional support as needed; and
- enable people with dementia and their carers to live well with dementia by the provision of good-quality of care for all with dementia from diagnosis to the end of life, in the community, in hospitals and in care homes.

The care pathway set out below (Figure 1) illustrates a coherent system for the basis of local commissioning.

Figure 1: Care pathway summarising the three themes of the National Dementia Strategy and the commissioning challenges



5. Next steps

This document is one component of a programme of support for commissioners intended to improve health and social care outcomes for people with dementia, making England a place where people with dementia and their families can live well with dementia.

The Department of Health is making significant support available through its National Dementia Strategy. This builds on the principles of World Class Commissioning and aims to transform the commissioning of services for people with dementia and their families. The Strategy is expected to be the primary source of support for commissioning health outcomes for people with dementia and their families, and will work closely with regional and local partners to identify and agree priorities and respond to particular requests.

World class commissioners of dementia services will make use of the many examples of good practice and expertise that already exist, in order to inform the development of local plans. A community of practice will facilitate networking and resource exchange between commissioners; and a programme of bespoke support, including training and workshops for commissioners, will be available to help solve specific local commissioning challenges. The support programme will work closely with regional partners – SHAs, Government Offices and regional improvement and efficiency partners – to ensure that the support offered can be accessed by those bodies and aligned with other support as appropriate.

We welcome your input into all of these programmes, as well as any thoughts you might have about this specific document. We also welcome examples of good practice and/or tools you have developed locally to support success at each phase of commissioning and ensure that resources are used effectively and efficiently to deliver outcomes, so that we can share them more widely with other commissioners.

This commitment to support is shared by the Department of Health and other relevant Government departments. Please contact us at dementia.strategy@dh.gsi.gov.uk with any input and suggestions.

Table 1: World Class Commissioning competencies and outcomes

Below is a table summarising the detail provided in section 3, which illustrates each of the 11 World Class Commissioning competencies in the context of dementia care. It sets out the outcomes that can be achieved by each competency.

Competency	Fit with NDS objectives
1. Locally lead the NHS	1, 2, 3, 4, 5, 7, 8, 9, 11, 12, 13, 14, 15, 17
2. Work with community partners	1, 2, 3, 4, 5, 6, 7, 9, 10, 11, 12, 13, 14, 15, 17
3. Engage with public and patients	1, 2, 3, 4, 5, 6, 7, 9, 11, 14, 17
4. Collaborate with clinicians and professionals	1, 2, 3, 4, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17
5. Manage knowledge and assess needs	1, 2, 3, 4, 5, 7, 11, 13, 14, 15, 16, 17
6. Prioritise investment	1, 2, 4, 5, 6, 7, 8, 9, 11, 12, 13, 14, 17
7. Stimulate the market	1, 2, 4, 5, 6, 8, 9, 10, 11, 13, 14, 17
8. Promote improvement and innovation	1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 16, 17
9. Secure procurement skills	2, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 17
10. Manage the local health system	1, 2, 3, 4, 7, 8, 9, 11, 12, 13, 14, 15, 17
11. Make sound financial investments	1, 2, 4, 5, 6, 7, 8, 9, 11, 12, 13, 14, 16, 17

Annex 2: The policy context for the National Dementia Strategy

Forget Me Not

In 2000 the Audit Commission published its *Forget Me Not* report;⁷⁹ key findings included:

- Only one half of general practitioners (GPs) believed it important to look actively for signs of dementia and to make an early diagnosis.
- Less than one half of GPs felt that they had received sufficient training.
- 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.
- Poor assessments and treatment with little joint health and social care planning and working.

They found little improvement when reviewing change two years later.⁸⁰

National Service Framework for Older People

The National Service Framework for Older People⁸¹ (2001) included a chapter on Mental Health and Older People. This included a consideration of dementia, advocating early diagnosis and intervention. It recommended that the NHS and local councils 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 DH and the Care Services Improvement Partnership (CSIP) published *Everybody's Business – Integrated mental health services for older adults: a service development guide*.⁸²

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 teams whose role includes the management of people with dementia with complex behavioural and psychological symptoms.

79 Audit Commission (2000). *Forget Me Not*. London: TSO.

80 Audit Commission (2002). *Forget Me Not 2002*. London: TSO.

81 DH (2001). *National Service Framework for Older People*. London: TSO.

82 CSIP (2005). *Everybody's Business – Integrated mental health services for older adults: a service development guide*. London: DH.

NICE/SCIE Clinical Guideline

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 2006.⁸³ 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*;⁸⁴ its key findings on numbers of people with dementia and costs are discussed above. 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.

NAO 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 2007.⁸⁵ This report was critical about 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 confidence of GPs in spotting the symptoms of dementia was poor 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 spending is late – too few people are being diagnosed or being diagnosed early enough; and that early intervention is needed to improve quality of life. Finally it concluded 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

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

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

85 NAO (2007). *Improving services and support for people with dementia*. London: TSO.

services and care in general hospitals resulting in long-term cost savings from prevention of transition into care homes and decreased hospital stay length.

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 subsequently 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) 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. 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 policy and services for people with dementia and their families is also affected significantly by the wider policy context. Currently these include *Our NHS, Our Future*; this 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. It includes 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, 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 reablement can have a positive impact on people's health. The Department of Health is making more than £500 million of funding available, via the new Social Care Reform Grant, to all councils with social services responsibilities (CSSR) over the next three years to reform social care systems, including taking forward work on early intervention to promote independence and improved well-being.

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 through familiar faces and responses as allowed by their memories and experiences. Following a commitment made in the 2006 White Paper *Our health, our care, our say*, the Government is extending, in the Health and Social Care Act 2008, the availability of direct payments (cash in lieu of social services) to people who lack capacity under the Mental Capacity Act 2005. 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. Draft regulations were issued for consultation at the end of 2008 with a view to these coming into effect later in 2009.

NICE has published a commissioning guide on memory assessment services which describes the potential benefits of commissioning effective memory assessment 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 in June 2008. Half a million family members who care for people with dementia provide over £6 billion a year of unpaid care. A far-reaching consultation of carers 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 has been consulting in 2008 to produce a Green Paper about the future of adult social care funding. People with dementia and their carers are one of the largest groups using social care services and contribute a significant amount to the costs of care through user charges. Finally, the Department's End of Life Strategy was published in July 2008. End of life care for people with dementia is an under-developed 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. Twenty-nine pilot sites have been established across the country 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.



Annex 3: List of project group members

The Department of Health would like to thank those who gave up their time to contribute to the development of the Strategy, including:

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