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To: Adult Social Services Policy Overview Committee –  
1 April 2009

Subject: **LIVING WELL WITH DEMENTIA: A NATIONAL  
DEMENTIA STRATEGY**

Classification: Unrestricted

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Summary: This paper outlines the main points of the above Strategy. The Strategy identifies three key areas, first, **improved awareness**, second, **earlier diagnosis and intervention**, and third, a **higher quality of care**. Attached is a table that describes the 17 key objectives together with resources information where available and some of the main actions associated with the objectives. The Kent and Medway Dementia Collaborative will be instrumental in driving the delivery of strategy across the local social and health care economy.

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## Introduction

1. (1) The Department of Health (DH) published the “Living well with dementia: A National Dementia Strategy” on 3 February 2009. The 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.

(2) The purpose of the Strategy is to:

- provide a strategic quality framework within which local social care, health care, voluntary sector support and housing 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, local authorities, acute hospital trusts, mental health trusts, primary care trusts, 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.

(3) The purpose of this report is to inform Members of the Policy Overview Committee (POC) on the key aspects of the Strategy. The outline action plan is attached as Appendix 1. The Kent and Medway Dementia Collaborative with liaise with all the stakeholders on the implementation steps.

## **Policy Context**

2. (1) A number of national reports and research have highlighted weaknesses in the current provision of dementia services in the UK that the Strategy seeks to address. It is known that dementia presents a huge challenge to society, currently and increasingly in the future. The current estimate is that around 700,000 people in the UK have dementia, of whom approximately 570,000 live in England.

(2) It is reported that 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) The Department of Health has stated that the aim of the Strategy is to ensure that considerable 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, should result in significant improvements in the quality of services provided to people with dementia and their families, promote a greater understanding of the causes and consequences of dementia.

(4) The Strategy will undoubtedly be a catalyst for change in the way that people with dementia are viewed and cared for in Kent. This is important for a number of reasons. Amongst other things, it shines a torch on raising awareness and understanding, good quality early diagnosis and intervention, good quality information for those with dementia and their carers, support and advice following diagnosis, improved community personal support services. Furthermore, there is a clear link to the implementation of the Carers and the End-of-Life Care strategies. It also calls for improvements in the quality of care in hospitals, intermediate care, housing support and housing-related services and telecare. Members should note that work is in progress to complete the Kent and Medway Dementia Strategic Needs Assessment which was one of the development areas identified in the overarching Adult Strategic Needs Assessment which was produced last year.

## **The Essential Summary of the Strategy**

3. (1) The Strategy is divided into six chapters:

**Chapter 1:** Purpose and scope of the Strategy - sets out the purpose of the Strategy as well as defining what is meant by the term dementia. This chapter describes how the condition affects people with dementia and their families.

**Chapter 2:** The vision for services for dementia - this section deals with the DH's goal for people with dementia and their families and how they are supported live well with dementia, no matter what the stage of their illness or where they are in the health and social care system.

**Chapter 3:** Raising awareness and understanding – focuses on improving public and professional awareness and understanding of dementia. The aim is to improve on the stigma associated with dementia through better understanding. This should inform individuals of the benefits of timely diagnosis and care, promote the prevention of dementia, and reduce social exclusion and discrimination. It is expected that this would encourage a change in behaviour in terms of people having the confidence to seek appropriate help and support.

**Chapter 4:** Early diagnosis and support - this chapter is concerned with how good-quality early diagnosis and intervention for all. It calls for all people with dementia to have access to a pathway of care that delivers: a quick and competent specialist assessment; an accurate diagnosis that is sensitively communicated to the person with dementia and their families; and treatment, care and support provided as needed following diagnosis.

**Chapter 5:** Living well with dementia - sets out the kinds of improvement in community personal support services required. This includes the provision of a range of services to support people with dementia living. It also considers the approach to flexible and reliable services, which are responsive to the personal needs and preferences of individuals and take account of their broader family circumstances. It notes that access for people living alone or with carers, people who pay for their care privately, through personal budgets, or through local authority-arranged services merits equal consideration.

**Chapter 6:** Delivering the Strategy – The final chapter addresses the implementation of the Strategy. The framework recognises the need to joined up work on dementia with all other important current policy and service developments in local government and the NHS such as *Putting People First*, the Next Stage Review , the Carers' Strategy, and the End of Life Care Strategy.

## **Implementation**

4. (1) The DH has stated that the pace of implementation will vary, depending on local circumstances and the level and development of services in each local authority and NHS area. Decisions on funding for subsequent years will only be made once the DH has had the opportunity to consider the results from the initial demonstrator sites and evaluation work. Therefore there is no expectation that all areas will necessarily be able to implement the Strategy within five years.

## **Recommendation**

5. (1) Members are asked to NOTE and COMMENT on the contents of the attached draft outline action plan.

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*Background documents:*

Living well with dementia: A National Dementia Strategy, Department of Health,  
3 February 2009

Copies of the full document are attached separately to the papers for Members of  
the POC. Further copies are available via the following link:

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_094058](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094058)

Objective	Resource	Action
<p><b>Objective 1: Improving public and professional awareness and understanding of dementia.</b></p> <p>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><b>£1 million a year in Year 1</b> and then <b>£3.5 million in Year 2.</b></p> <p>Funding beyond Year 2 (2010/11) is entirely dependent on the evidence from the demonstration sites.</p> <p>We have assumed that the upper limit for future costs would be <b>£4m a year from Year 3 onwards</b>, assuming that these elements of information campaigns will be delivered locally as services are configured, matching supply with demand.</p>	<p>Developing and delivering a general public information campaign.</p> <p>Inclusion of a strong prevention message that <b><i>'what's good for your heart is good for your head'</i></b>.</p> <p>Specific complementary local campaigns.</p> <p>Targeted campaigns for other specific groups (eg utilities, public-facing service employees, schools, and cultural and religious Orgs).</p>

Objective	Resource	Action
<p><b>Objective 2: Good-quality early diagnosis and intervention for all.</b> 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.</p>		<p>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. Their sole focus would be on early diagnosis of and intervention for people with dementia. This would include:</p> <ul style="list-style-type: none"> <li>• making the diagnosis well;</li> <li>• breaking the diagnosis well to the person with dementia and their family; and</li> <li>• providing directly appropriate treatment, information, care and support after diagnosis.</li> </ul>

Objective	Resource	Action
<p><b>Objective 3: Good-quality information for those with diagnosed dementia and their carers.</b> 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>A review of existing relevant information sets.</p> <p>The development and distribution of good-quality information sets on dementia and services available, of relevance at diagnosis and throughout the course of care.</p> <p>Local tailoring of the service information to make clear local service provision.</p>
<p><b>Objective 4: Enabling easy access to care, support and advice following diagnosis.</b> A dementia adviser to facilitate easy access to appropriate care, support and advice for those diagnosed with dementia and their carers.</p>		<p>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.</p> <p>Commission 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.</p> <p>Contact with a dementia adviser to be made following diagnosis. The dementia adviser not to duplicate existing 'hands-on' case management or care.</p>

Objective	Resource	Action
<p><b>Objective 6: Improved community personal support services.</b> Provide 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.</p>		<p>Implement <i>Putting People First</i> 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. 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; respite care/breaks that provide valued and enjoyable experiences for people with dementia as well as their family carers; Access to peer support networks; access to expert patient and carer programmes; Responsive crisis services; flexible and responsive respite care/breaks that can be provided in a variety of settings including the home of the person with dementia; Access to supported housing that is inclusive of people with dementia; independent advocacy services; and assistive technologies such as telecare.</p>

Objective	Resource	Action
<p><b>Objective 7: Implementing the Carers' Strategy.</b> 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.</p>		<p>Ensuring that the needs of carers for people with dementia are included as the strategy is implemented.</p> <p>Ensure that carers have 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</p> <p>Develop good quality personalised break options</p> <p>Promoting the development of breaks that benefit people with dementia as well as their carers.</p> <p>Better emergency and crisis support</p>
<p><b>Objective 8: Improved quality of care for people with dementia in general hospitals.</b> 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.</p>	<p><b>Psychiatric consultation-liaison intervention:</b> we estimate that this project could be commissioned for approximately <b>£0.7 million</b> and completed in one year.</p> <p>Leadership in Acute Hospital The total cost of this time is estimated at around <b>£3 million a year.</b></p>	<p>Identification of a senior clinician within the general hospital to take the lead for quality improvement in dementia in the hospital.</p> <p>Development of an explicit care pathway for the management and care of people with dementia in hospital, led by that senior clinician.</p> <p>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.</p> <p>Thereafter, the commissioning of specialist liaison older people's mental health teams to work in general hospitals.</p>

Objective	Resource	Action
<p><b>Objective 9: Improved intermediate care for people with dementia.</b> Intermediate care which is accessible to people with dementia and which meets their needs.</p>	<p>Total cost is around <b>£38 million a year</b>. This does not include any offsetting savings from reduced use of acute services.</p>	<p>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.</p> <p>Revised Guidance due for publication March 2009</p>
<p><b>Objective 10: Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers.</b> 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.</p>		<p>Monitoring the development of models of housing, including extra care housing, to meet the needs of people with dementia and their carers.</p> <p>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.</p> <p>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.</p>

Objective	Resource	Action
<p><b>Objective 11: Living well with dementia in care homes.</b> 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.</p>	<p>We have therefore profiled into the implementation a one-year project to assess implementation and to develop leadership and quality care aids for care homes costing at <b>£1.5 million over two years</b></p> <p>Overall, the long run annual cost of improving specialist in-reach services for all care homes on this basis is therefore around <b>£35 million per year.</b></p>	<p>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.</p> <p>Development of a local strategy for the management and care of people with dementia in the care home, led by that senior staff member.</p> <p>Only appropriate use of anti-psychotic medication for people with dementia.</p> <p>The commissioning of specialist in-reach services from older people's community mental health teams to work in care homes.</p> <p>The specification and commissioning of other in-reach services such as primary care, pharmacy, dentistry, etc.</p> <p>Readily available guidance for care home staff on best practice in dementia care.</p>

Objective	Resource	Action
<p><b>Objective 12: Improved end of life care for people with dementia.</b>            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.</p>		<p>Initiating demonstration projects, piloting and evaluation of models of service provision prior to implementation, given the current lack of definitive data in this area.</p> <p>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.</p> <p>Developing local end of life care pathways for dementia consistent with the Gold Standard framework as identified by the End of Life Care Strategy.</p> <p>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.</p> <p>Developing better pain relief and nursing support for people with dementia at the end of life.</p>

Objective	Resource	Action
<p><b>Objective 13: An informed and effective workforce for people with dementia.</b> 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.</p>	<p>We have costed this work on analysis and training development at <b>£1 million per annum for two years.</b></p>	<p>Department of Health workforce strategies to take on board the implications of the dementia strategy.</p> <p>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.</p> <p>These bodies to consider how to adapt their curricula and requirements to include these core competencies in pre- and post-qualification and occupational training.</p> <p>Such changes also to inform any review of national health and social care standards.</p> <p>Commissioners to specify necessary dementia training for service providers.</p> <p>Improving continuing staff education in dementia</p>

Objective	Resource	Action
<p><b>Objective 14: A joint commissioning strategy for dementia.</b> 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.</p>		<p>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</p> <p>Community focused, linking into Local Area Agreements and the development of sustainable communities; and</p> <p>Individually focus, drawing on the use of personal budgets and the commissioning of self-directed support.</p>
<p><b>Objective 15: Improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers.</b> Inspection regimes for care homes and other services that better assure the quality of dementia care provided.</p>		<p>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.</p>

Objective	Resource	Action
<p><b>Objective 16: A clear picture of research evidence and needs.</b></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>Budgeted for <b>£4.5m</b> over the first two years, beyond which evidence from the research will be considered before full roll out.</p> <p>We estimate that this project could be commissioned for approximately <b>£0.5m</b> and completed in 1 year</p>	<p>The Medical Research Council (MRC) with DH to convene a summit of parties interested in dementia research.</p>
<p><b>Objective 17: Effective national and regional support for implementation of the Strategy.</b></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, including information from evaluations and demonstrator sites.</p>	<p>This has been costed at <b>£2 million per year</b></p>	<p>The Department of Health will provide support implementing the strategy locally to ensure its delivery, particularly for those areas where services are less developed. Regional support teams will be convened to support local implementation.</p> <p>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.</p> <p>A national baseline measurement of services will be established.</p> <p>Specifically commissioned research, evaluations and data from demonstrator sites will support the implementation of the Strategy.</p>