Item No. 5

Report to Adult Social Care Partnership Board

3 March 2009

Living well with Dementia: A National Dementia Strategy

Report of the Director of Health, Housing and Adult Services

1. Purpose of the Report

The purpose of the report is to summarise the recently published ‘Living well with Dementia: A National Dementia Strategy’ (DH, January 2009).

2. Summary

There are approximately 570,000 people with dementia in England, with at least 15,000 people aged under 65 and approximately 15,000 people from minority ethnic groups have some form of dementia. It is projected that the number of people with dementia will double to 1.4 million in the next 30 years. The cost of dementia for the UK is about £17 billion per year. This is expected to rise to over £50 billion per year in the next 30 years.

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, local authorities, acute hospital and 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 expectation of those affected by dementia and their family carers

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 higher quality of care.

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 in three parts:

- To encourage help seeking and help offering by changing public and professional attitudes, understanding and behaviour

- Make early diagnosis 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 make the diagnoses well, break those diagnoses sensitively and well to those affected, and provide individuals with immediate treatment, care and peer and professional support as needed.

- 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

The Strategy outlines 17 objectives and how they will be delivered. Under each objective is the case for change including key objectives for commissioners to meet.

3. Key points of the document

Chapter 3 – Raising Awareness and Understanding

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

This will be delivered by:

- 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:

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. There is generally a low level of public and non specialist professional understanding of dementia. There is also a wide spread mistaken attribution of symptoms to old age resulting in an unwillingness to seek or offer help and there is a false view that there is little or nothing that can be done to assist people with dementia and their carers. These factors lead to delay in diagnosis and access to good quality care. As well as helping the large and growing number of people who already have dementia, ways of preventing new cases of dementia, if possible, need to be looked into.

Chapter 4 – Early diagnosis and support

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.

This will be delivered by:

- 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:

Currently, only about one third of people with dementia receive a formal diagnosis at any time in their illness. When diagnoses are made, it is often too late for those suffering from the illness to make choices. Furthermore, diagnoses are often made at a time of crisis – a crisis that potentially could have been avoided if diagnosis had been made earlier. A core aim of this strategy is to ensure that effective services for early diagnosis and intervention are available for all on a nationwide basis. Early diagnosis and intervention can improve quality of life and delays or prevents unnecessary admissions into care homes.

Diagnosis of dementia, particularly mild dementia, is complex and should be carried out by a clinician with specialist skills. There is a reluctance on the part of primary care to be directly involved in the diagnosis of dementia, therefore new specialist services need to be commissioned to deliver good quality early diagnosis and intervention. This service would need to provide a single focus for referrals from primary care and would work locally to stimulate understanding of dementia and referrals to the service.

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

This will be delivered by:

- Piloting the role of Dementia Adviser and evaluating the models of service provision

- 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

- Contact with a dementia adviser to be made following diagnosis

- The dementia adviser not to duplicate existing ‘hands on’ case management of care

The case for change:

Consistently, people with dementia and their carers express the desire for there to be someone who they can approach for help and advice at any stage of the illness. 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.

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

This will be delivered by:

- 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 third sector services commissioned by health and social care

The case for change:

People with dementia and their carers benefit significantly 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, however they often cater for only a small proportion of those who might benefit from them. 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.

Chapter 5 – Living well with dementia

Objective 6: Improved community personal support. 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 interventions 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.

This will be delivered by:

- 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:

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. 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. Continuity, reliability and flexibility of home care services are important in ensuring that people with dementia and their carers have choice and control over the services they receive. 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.

People with dementia are known to be an ‘at risk’ group in terms of abuse, particularly through financial exploitation, fraud and theft. Feedback from the consultation exercises highlighted concerns from carers and professionals about inadequate safeguards for people with dementia, therefore services should make sure there is clear information available on how to complain about poor standards of care, or report concerns about possible abuse.

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.

This will be delivered by:

- 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:

Most people want to remain in their own homes for as long as possible. Most family carers want to be able to provide support to help the person with dementia stay at home, but they sometimes need more assistance than is currently routinely available. All too often people with dementia find themselves being admitted to long term residential care because it appears that there are no alternatives available. 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, however 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 competencies to provide appropriate care.

Equally there is a clear need for breaks and day services to support families in their caring role in the community. These services need to provide valued and enjoyable experiences for the person with dementia and their family carer. The arrangements for the breaks need to be flexible and responsive to the individual needs of each person with dementia and their carer and they need to be available on emergency, urgent and planned bases.

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.

This will be delivered by:

- 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:

Up to 70% of acute hospital beds are currently occupied by older people and up to half of these may be people with cognitive impairment, including those with dementia and delirium. The majority of these patients are not known to specialist mental health services and are undiagnosed. General hospital wards are particularly challenging for people with memory and communication problems and people with dementia have worse outcomes in terms of length of stay, mortality and institutionalisation. This impact is not widely appreciated by clinicians, managers and commissioners.

There is a lack of leadership and ownership of dementia in most general hospitals and there are marked deficits in the knowledge and skills of general hospital staff who care for people with dementia. Person centred care is not delivered and this can lead to under recognition of delirium and dementia. There is often a lack of co-ordination between hospitals and care providers at the point of discharge, with a delay in access to care packages that might enable successful discharge.

Specialist liaison older people's mental health teams 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 can cover the whole range of mental health problems in older adults, not just dementia.

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

This will be delivered by:

- 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

The case for change:

Pathways out of hospital and to avoid hospitalisation, such as intermediate care, often exclude people with dementia, meaning they cannot access rehabilitation services that could enable them to return home or prevent their admission to hospital. 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. There is also a false assumption that people with dementia cannot benefit from rehabilitation, however there is good clinical evidence that people with mild to moderate dementia with physical rehabilitation needs do well if given the opportunity.

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.

This will be delivered by:

- 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:

People with dementia can benefit from the support offered in sheltered and extra care housing, however they are not always offered the opportunity. Flexible care packages are important in meeting the needs of people with dementia in extra care housing, this includes responsive care packages through floating support services. Many residents with dementia in sheltered or extra care housing have complex health needs, however these needs can be met where health, social care and housing work together to provide a whole system strategy.

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.

This will be delivered by:

- 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:

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.

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.

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 and the prevalence rises to between 90 and 95% in homes for the elderly mentally infirm. It is estimated that 50% of all care home residents have depressive disorders that would warrant intervention. Current input from mental health services is generally on an ad hoc basis or reactive with referrals at times of crisis.

An issue of concern is the use of anti-psychotic medication in care homes for the management of behavioural and psychological symptoms in those residents with dementia. There are particular risks that are serious and negative in the use of anti-psychotic medication for people with dementia, including mortality and stroke. There is accumulating evidence that in care homes they are initiated too freely, not reviewed appropriately and not withdrawn as quickly as they could be.

It has been suggested that one way to address these problems would be to have a system of regular specialist mental health assessment following admission to the care home and regular specialist review. Commissioners can achieve this by commissioning an extension to the existing role of older people's community mental health teams and also joint commissioning in reach services of other professionals.

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.

This will be delivered by:

- Initiating demonstrator 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 care

The case for change:

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. 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 care be made real, including the effective use of specialist liaison teams with palliative care providers and skilled training in pain detection, pain relief and end of life nursing care. 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, with few people with dementia having access to hospice care.

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’, yet people with dementia receive less analgesia that other older people for a given illness.

Chapter 6 – Delivering the National Dementia Strategy

PCTs and local authorities will be expected to demonstrate continued progress towards meeting the 17 objectives outlined in the strategy. Priorities for improvement will be for local determination and will need to take into account 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.

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.

This will be delivered by:

- 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 bodes 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:

People with dementia and their carers feedback that professionals who should have been there to help them get a diagnosis did not seem to have the skills and knowledge needed to do so and that professionals often seemed unable to understand that what works for people without dementia may not work for people with dementia. Professionals are often unable or unwilling to adapt their practice to make it work for people with dementia.

People with dementia access all services and so need informed understanding and support from all the services they come into contact with. Awareness and skills are needed in all sections of the workforce and society. A lack of understanding in dementia in the workforce can lead to care practices that can make the situation worse for both the person with dementia and their carers.

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. Action can be taken in the short term, by PCTs and local authorities commissioning a trained and competent workforce using regional and local workforce development resources. In the medium and longer term, curricula for undergraduate professional qualifications and continuing professional development should contain modules on dementia care. The best arrangements will be where health and social care systems work together to develop their workforce.

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.

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 care services will change. It is important for PCTs and local authorities to consider the need for the commissioning of coherent joint services. A joint commissioning strategy will need to be based on the Joint Strategic Needs Assessment and 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 have an individual focus, drawing on the use of personal budgets and the commissioning of self directed support. As a local priority, local authority, PCTs and practice based commissioners should lead the development of an integrated care pathway, specifying the elements of the pathway against which services will be procured and performance managed.

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.

The Care Quality Commission (CQC) will be operational from April 2009 and will have a crucial role in driving up standards, particularly for people with dementia who require support across health and social care. The CQC will contribute to a better understanding about the experience of people living with dementia and their carers across care pathways. Assessing the real life experiences of people with dementia is an important part of the inspection process and is crucial to understanding the quality of outcomes that people experience. Inspections should also include observing care, support and interactions between staff and people who use services. Inspectorates of care homes need to ensure that their inspections include an assessment of the quality of care that people with dementia experience.

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.

This will be delivered by:

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

The case for change:

There is the need to build the research base in 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. The MRC will convene a summit to focus on how research funders, charities and industry could work more effectively together to begin to deliver the research needed on prevention, cause, cure and care.

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.

This will be delivered by:

- 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 of Health 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 commissioner research, evaluations and data from demonstrator sites will support the implementation of the Strategy

The case for change:

The Department of Health will provide regionally based diagnostic advice and improvement support to local health and social care economies to implement the Strategy. 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 conferences and workshops. It is important to ascertain the nature of current dementia services and to track these over time to monitor the progress of the Strategy, therefore a national baseline measurement of service content, finance and local service audits will be required.

The nature of risk and need in older people with mental disorders means that in order to provide services that are 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. Specialist mental health services are needed that can deliver good quality care that is attuned to the specific needs of older people with both functional and organic disorders.

4. How Sunderland are responding to the National Dementia Strategy

The Older People Mental Health Group is a multi agency group, currently led by Health, Housing and Adult Services. The remit of the group is to inform the commissioning of mental health services for older people. The Group is currently undertaking an audit of Sunderland's position against the recommendations outlined in the Strategy. Once the audit is complete, the group will develop a plan to implement the National Dementia Strategy in Sunderland.

5. Recommendations

The Board are requested to receive this report for information.