

Living well with dementia –  
the **National Dementia Strategy**  
Joint commissioning framework for dementia

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# Foreword

Currently 570,000 people live with dementia, a disease that carries a massive personal, family, social and economic cost. Society and public services must work immediately to address the challenges presented by dementia.

The National Dementia Strategy, *Living well with dementia*<sup>1</sup>, was published in February 2009 and set a clear vision that people with dementia and their carers should be helped to live well with dementia, no matter what the stage of their condition or where they are in the health and care system.

Throughout a person's life with dementia, health and care needs are often inseparable. That is why *Living well with dementia* clearly set out the expectation that local health and care organisations would jointly plan and commission services on behalf of the local population.

The challenges are significant but they can be met. Combining the rigour of World Class Commissioning<sup>2</sup> and the vision of *Putting People First*<sup>3</sup> creates a potent force for transforming services for people with dementia and their carers.

Commissioners should be leading this transformation. With the responsibility to plan and commission services on behalf of the local population, commissioners can orchestrate the delivery of the full spectrum of services that people need. *Living well with dementia* describes the outcomes and range of services that people with dementia and their carers should be able to access to improve their experience of dementia.

The DH committed to provide implementation support to frontline health and care services. This Joint Commissioning Framework is one of the ways in which we are encouraging health and care services to work together productively to deliver high quality outcomes for people with dementia and their carers. It provides a framework of best practice guidance on commissioning each of the service objectives set out in *Living well with dementia*. This documents sets out the levers for commissioning in the NHS and in local

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1 *Living well with dementia: a National Dementia Strategy* Department of Health 2009  
<http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Olderpeople/NationalDementiaStrategy/index.htm>

2 World Class Commissioning Department of Health  
<http://www.dh.gov.uk/en/Managingyourorganisation/Commissioning/Worldclasscommissioning/index.htm>

3 *Putting People First: A shared vision and commitment to the transformation of adult social care* Department of Health 2007  
[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_081118](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081118)

authorities so that commissioners can work more effectively with their commissioning partners.

During the implementation phase of the National Dementia Strategy we look forward to seeing the transformation of services for people with dementia and their carers.



David Behan  
Director-General, Social Care,  
Local Government and Care Partnerships



Mark Britnell  
Director-General  
Commissioning and System Management

# Executive summary

*Living well with dementia*, the National Dementia Strategy (NDS) sets a very clear vision for the future of support and services to people with dementia and their carers.

The NDS has three themes – improved public and professional awareness, early diagnosis and support, and living well with dementia. There are 17 objectives that describe the range of services that people with dementia and their carers should be able to access locally, and ways in which such services can be delivered.

Annex 1 of *Living well with dementia* provides World Class Commissioning (WCC) guidance for dementia, outlining the policy context for the NDS and government support to commissioners. It lists who should be involved in commissioning and outlines the WCC competencies for primary care trusts (PCTs) alongside the objectives set out in the strategy.

Objective 14 of *Living well with dementia* outlines the recommendation for a joint commissioning strategy:

- 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. Those commissioning plans should be informed by World Class Commissioning guidance for dementia developed to support this strategy.

When *Living well with dementia* was published the Department of Health committed to a number of measures to support commissioners including:

- Provide specific guidance on key services, such as memory services for early intervention, community personal support, liaising services in general hospitals, dementia advisors and in-reach into care homes etc (p 79)

This joint commissioning framework is part of the Strategy's implementation support programme<sup>4</sup> and provides supplementary information about the levers available to commissioners to deliver the recommended and universal services covered in *Living well with dementia*.

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<sup>4</sup> National Dementia Strategy implementation plan Department of Health 2009  
[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_094058](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094058)

This paper outlines the NHS and local authority framework in which local commissioning strategies will develop. Resources within this framework include:

- a template for joint strategic needs assessments for dementia
- a summary of levers available to commissioners
- an outline of how the threads of policy wrap around the needs of people with dementia and their carers.

This joint commissioning framework provides more detailed ‘how to’ and best practice guidance on joint commissioning, drawing together World Class Commissioning<sup>5</sup> and *Putting People First*<sup>6</sup>, the key driver for social care commissioning. It addresses the responsibilities of PCTs and local authorities to jointly commission services for people with dementia.

This joint commissioning framework should complement regional and local development programmes that focus on improving commissioning capability within PCTs and local authorities.

## Funding the National Dementia Strategy

At the time of the publication of *Living well with dementia*, the Department of Health (DH) also announced £150 million funding over two years to support implementation, with £60 million available in 2009/10 and £90 million in 2010/11 in PCT baseline allocations. These are increasing by 5.5 percent in both 2009/10 and 2010/11 – a total increase of £8.6 billion over the two years. The growth in allocations is new money going into the NHS and the £150 million is the national estimate of the proportion that is required to implement the National Dementia Strategy.

Individual PCT allocations are deliberately not ring-fenced and broken down into funding for individual policy streams. It is for PCTs to decide locally how best to deliver the national requirements and local priorities set out in the Operating Framework for the NHS in England 2009/10<sup>7</sup>, includes dementia.

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5 World Class Commissioning Department of Health

<http://www.dh.gov.uk/en/Managingyourorganisation/Commissioning/Worldclasscommissioning/index.htm>

6 *Putting People First: A shared vision and commitment to the transformation of adult social care* Department of Health 2007

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_081118](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081118)

7 *The NHS in England: The Operating Framework for 2009/10* Department of Health 2008

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_091445](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_091445)



The impact assessment for the National Dementia Strategy<sup>8</sup> sets out the national estimates of the cost of delivering the strategy. The £150 million made available actually exceeds the impact assessment, giving PCTs the scope to go further, faster. But actual costs and expenditure by PCTs will depend on local circumstances and priorities as well as the extent of services that are already in place.

The NDS emphasises the need for joint planning across social services, and PCTs will wish to consider the case for using pooled budget arrangements with local authorities, as appropriate, in delivering the best possible care for people with dementia and their carers. Such a joint approach is endorsed in the NHS Operating Framework 2009/10, which states:

- PCTs will want to work with local authorities to consider how they could improve dementia services.

All information in this document is accurate at the time of going to press. This is a fast moving agenda and up to date information is available at [www.dh.gov.uk/dementia](http://www.dh.gov.uk/dementia)

## Services to be commissioned

The size of the challenge for commissioners is considerable. There are currently 570,000 people in England with dementia. Dementia is thought to cost the economy £17 billion a year. These costs are spread across health and care services, as well as individual costs borne by people with dementia and their carers through loss of earnings and payment for personal support. The number of people with dementia is set to double to 1.4 million in the next 30 years and the cost will treble.

The NDS sets out a wide range of services that should be available to every person with dementia and their carers. The recommended services are based on:

- evidence-based interventions (see NICE/SCIE guidance template at Annex 1)
- services that people with dementia and their carers told the NDS consultation *Transforming the quality of dementia care*<sup>9</sup> would be useful support through their journey of managing dementia.



8 *National Dementia Strategy impact assessment* Department of Health 2009 [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_094058](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094058)

9 *Transforming the quality of dementia care: Consultation on a National Dementia Strategy* Department of Health 2008 [http://www.dh.gov.uk/en/Consultations/Closedconsultations/DH\\_085570](http://www.dh.gov.uk/en/Consultations/Closedconsultations/DH_085570)

The NDS recommends that the following services should be available locally to all people with dementia.

- Objective 1: Improved public and professional awareness and understanding of dementia
- Objective 2: Good quality early diagnosis and intervention for all
- Objective 3: Good quality information for those diagnosed with dementia and their carers
- Objective 4: Easy access to care, support and advice following diagnosis, facilitated by a dementia advisor
- Objective 5: Structured peer support and learning networks
- Objective 6: Community personal support services
- Objective 7: Services within the Carers' Strategy<sup>10</sup>
- Objective 8: Good quality care within general hospitals
- Objective 9: Intermediate care for people with dementia
- Objective 10: Good housing, housing-related and telecare support
- Objective 11: High quality services within care homes
- Objective 12: Good end of life care
- Objective 13: An informed and effective workforce across all services
- Objective 14: Joint commissioning strategy

Further information is available in section 3 for commissioning each Objective.

The Strategy has three further objectives to secure improved services and support for people with dementia.

- Objective 15: Better regulation and assessment
- Objective 16: Review of research
- Objective 17: National and regional implementation support

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<sup>10</sup> *Carers at the heart of 21st families and communities* Department of Health 2008  
<http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Carers/NewDealforCarers/index.htm>

# Section 1: The commissioning task

The vision in the National Dementia Strategy is that services and society should transform their approach and attitudes to enable people with dementia and their carers to live well with dementia. This is in contrast to the current situation, where in many services people with dementia are simply ‘managed’.

This means that commissioners are responsible for ensuring a full range of services and support is delivered to achieve positive outcomes for people with dementia and their carers.

The task is considerable. Not only are commissioners responsible for securing delivery of high-quality specialist services, their reach must spread to universal services to ensure that a person with dementia receives high-quality care whenever they need to access care and support in primary, community and secondary health, social care and housing services. This is why it is essential that local health and care services develop a joint commissioning strategy.

Proportionality is necessary; there might be some instances where a universal service does not need to be accessible to people with dementia because there is a specialist service that provides a better alternative.

## **Dementia: The commissioner’s role**

The vision for World Class Commissioning places a clear emphasis on commissioning for improvement in health outcomes. It focuses on three areas - technical commissioning competence, governance, and improvement in outcomes. Together with the person-centred outcome focus of Putting People First, it provides a strong framework for local commissioning communities to create a commissioning structure through which a range of high-quality services can be delivered.

The commissioner should function as the local driver for implementing the National Dementia Strategy. To achieve this, the commissioner can:

- commission to secure local delivery of the full range of services set out in the Strategy
- influence commissioners of other services, such as acute hospital care, to help them understand the requirements of people with dementia who will access the services they commission

- co-ordinate inclusion of a number of policy themes around dementia, including Dignity in Care<sup>11</sup> and the Carers' Strategy.

## **Overarching principles for commissioning dementia services**

There are a number of key principles that should be integrated into all commissioning activity.

### ***Keep the person with dementia and their carers at the centre of all commissioning activity***

- Keep people with dementia and their carers at the centre of all developments through consistent engagement with them about the support and services they require.
- Empower people with dementia and their carers through the commissioning process, and put systems and services in place to ensure they retain control and choice over their lives and the focus is on the individual's abilities.

### ***Work across the commissioning community***

- Commissioners leading on dementia should work in partnership with commissioning colleagues, notably commissioners of acute general healthcare, mental healthcare, PCT primary and community services, practice-based commissioning, learning disabilities services, end of life care, public health and health promotion services, social care and housing services.
- Working collaboratively should result in services that are connected and provide a joined-up pathway for people with dementia and their carers.

### ***Build quality and dignity into every service***

- The vision of the Strategy is that people are helped to live well with dementia, which means they must have a full range of services and support available that is delivered to high-quality standards. Therefore, commissioners should build quality and dignity into every contracted service.
- The NHS Operating Framework 2009/10 repeatedly states that every PCT should have 'quality as its organising principle'.
- The Dignity in Care campaign sets out 10 challenges to be met by all services.

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<sup>11</sup> Dignity in Care campaign  
<http://www.dhcarenetworks.org.uk/dignityincare>

## **Equality**

- Commissioners should particularly consider certain groups of people with dementia to ensure their specific needs are met. These groups include:
  - younger people with dementia
  - people with learning disabilities
  - people with alcohol-related dementia
  - people with other mental health problems (eg depression).
  - people on low incomes and in poverty
  - minority ethnic groups
  - lesbian, gay and transsexual people
  - people living in isolated rural areas
  - disabled people
  - people who live alone
  - asylum seekers
  - people with basic skills needs (eg literacy and numeracy)
  - travellers
  - prisoners.

## **Ensure people's legal rights are maintained**

- Commissioners should ensure all relevant legislation is adhered to when commissioning services for people with dementia, in particular:
  - the Single Equalities Act 2008 – this can be used as a lever to ensure that older people are not marginalised from accessing services
  - the Mental Health Act 2007 – this can be used as a safeguard to protect the interests of people with dementia
  - the Mental Capacity Act 2005 – this can be used as a safeguard to protect the interests of people with dementia
  - the Human Rights Act 1998 – this can be used to uphold a person with dementia's right to have their private and family life and personal beliefs respected.

### **Commission services that maintain and enhance an individual's abilities**

- All services for people with dementia should aim to promote and maintain independent functioning.

### **Including all groups of people affected by dementia**

Commissioners are responsible for ensuring that services are provided to all individuals affected by dementia in the local population. Section 2a of the NHS Constitution<sup>12</sup> states that patients:

*“...have the right to expect your local NHS to assess the health requirements of the local community and to commission and put in place the services to meet those needs as considered necessary.”*

### **Younger people with dementia**

The needs of younger people with dementia may be different because they may be in work at the time of diagnosis, have dependent children or family, be more physically fit and active and have heavy financial commitments, such as a mortgage. Existing dementia services may be restricted to those over 65 or not set up to meet the needs of younger people, such as respite services provided by residential homes for older people.

Service models should be user-led and will vary depending on the population distribution and other local circumstances. A dedicated service may be required or it may be possible to meet local needs through the innovative use of existing resources.

Services should be flexible and span organisational boundaries through partnership working. Dedicated support workers can help maintain independence and avoid inappropriate placement with older and more physically frail people.

Young onset dementia is more likely to be caused by genetic factors and access to genetic counselling should be available for families.

More information on services for younger people with dementia is available from the Alzheimer's Society information sheet<sup>13</sup> on this topic.

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12 *The NHS Constitution*

<http://www.dh.gov.uk/em/Healthcare/NHSConstitution/index.htm>

13 *Younger people with dementia* Alzheimer's Society factsheet

<http://www.alzheimers.org.uk/factsheet/440>

### ***People with learning disabilities and dementia***

People with Down's Syndrome are at high risk of developing dementia at a younger age. At least 55 percent of people with Down's Syndrome aged 60-69 are affected by dementia, compared with five percent of the general population aged over 65. With the increased life expectancy of people with Down's Syndrome, this is a growing area of need.

The Quality and Outcomes Framework (QOF) indicator LD1 refers to production, by a practice, of a register of patients with learning disabilities. The register can be segmented by age. Such segmentation will give an indication of the current and future numbers of people who have – or may be at risk of developing – learning disabilities and dementia.

Commissioners can work with local primary care and learning disabilities services to put in place appropriate functioning assessment services to enable faster diagnosis of dementia.

The NHS has introduced a directed enhanced service for annual health checks for people with learning disabilities who are known to local authorities, and the NHS Vital Signs indicator reflects the take-up of these health checks.

Commissioners should also ensure that people with learning disabilities and their carers have access to information and signposting about such services, and support to enable them to access assessment and services to support needs that arise from dementia.

Commissioners should ensure there are effective arrangements for communication and partnership working between primary care and other healthcare providers to improve the overall quality of healthcare for people with a learning disability. This includes specific services for people with learning disabilities who develop dementia.

A joined-up approach is necessary so that people with dementia and learning disabilities do not fall between generic dementia services, specialist mental health services and learning disability services, none of which can meet their complex needs alone. Joint protocols between agencies should be in place, covering care pathways, roles and responsibilities, and access and support arrangements, including staff training.

More information on services for people with learning disabilities and dementia is available from the Alzheimer's Society information sheet<sup>14</sup> on this topic.

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<sup>14</sup> *Learning disabilities and dementia* Alzheimer's Society factsheet  
<http://www.alzheimers.org.uk/factsheet/430>

### **Alcohol-related dementia**

It is estimated that up to 10 percent of dementias are related to alcohol<sup>15</sup>. Services to support people with alcohol-related dementia frequently fall between standard dementia services and alcohol services. Traditional dementia services are unlikely to meet the needs of an individual with problems with alcohol misuse, particularly if the individual is still in an acute phase of drinking.

The National Alcohol Strategy<sup>16</sup> does not make reference to alcohol-related brain damage or dementia.

Alcohol-related dementia remains an area for further development for research as well as service development. At this stage, commissioners are encouraged to work with their colleagues working on alcohol misuse commissioning to assess local needs and develop appropriate services to meet those needs.

### **Advocacy**

People with dementia and carers sometimes want an advocate to help them to obtain services or to get their views across. Advocacy may be most appropriately provided by an organisation independent of mainstream health and social care services. Joint working between local statutory and voluntary sector organisations is important to ensure that dementia advocacy and its development are embedded as a core component of wider service provision.

Dementia advocacy services should:

- have a clear philosophy and model of service that distinguishes advocacy from other forms of advice and support
- be equipped to address the needs of the diverse social, ethnic and cultural backgrounds of people with dementia locally
- train both paid and voluntary advocates to ensure they have the specialist skills to work with people with dementia
- demonstrate a robust value and ethical basis for practice, underpinned by a framework of supporting policies and procedures.

More information about dementia advocacy is available through the Dementia Advocacy Network<sup>17</sup>.

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15 Lishman W A, 1990, *Alcohol and the brain*, British Journal of Psychiatry 15, 6, 635-644

16 *Safe. Sensible. Social. The next steps in the National Alcohol Strategy* Department of Health 2007 [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_075218](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_075218)

17 Dementia Advocacy Network  
<http://www.wassr.org/dementia.htm>



# Section 2: Commissioning levers

This section outlines the commissioning levers that are available to commissioners across health and care. These levers include funding, contracting and service redesign.

The levers are set out within the three broad headings used in World Class Commissioning and the commissioning cycle:

- strategic planning
- outcomes and procurement
- demand and performance.

## Strategic planning

Services for people with dementia and their carers should be commissioned within a wider strategic framework. The NHS Next Stage Review<sup>18</sup> and *Putting People First* set the high-level strategic vision for health and care services respectively. Subsequent publications and plans provide more detailed direction for NHS and social care organisations.

## Quality of services

The NHS Operating Framework 2009/10 sets out a framework for NHS commissioners to focus on quality of services. It identifies three key domains.

- Safety – Commissioners leading on implementation of the National Dementia Strategy should assess every service that people with dementia access to ensure that their mental and physical health is maintained during contact with that service.
- Effectiveness – Commissioners should monitor the effectiveness of services from the patient's perspective, eg using patient reported outcome measures (PROMs), as well as clinical outcomes such as mortality and survival rates. For people with dementia and their carers, effectiveness might be measured by maintenance – and even enhancement – of an individual's skills and abilities during contact with a service.
- Patient experience – For people with dementia this could include maintenance of their dignity.

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18 *High quality care for all: NHS Next Stage Review* Department of Health 2008  
[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_085825](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825)

The NHS Operating Framework 2009/10 identifies enablers to help staff contribute to quality by:

- empowering patients to improve quality
- ensuring that commissioning focuses on quality
- providing leadership for quality and a high-quality workforce
- developing high-quality providers
- using informatics to support quality improvement.

### ***Strategic commissioning and co-production***

A key component of effective commissioning is to ensure that key stakeholders are involved throughout the commissioning cycle. Co-production is about working with people who use services, the wider public, providers and other stakeholders throughout the entire commissioning process. It means that commissioners should engage with stakeholders when planning and shaping services. Co-production requires commissioners to involve people in more than the formal consultation period at the end of a piece of work and where, typically, commissioners offer the public a choice of one or two options of care.

Annex 1 of *Living well with dementia* outlines World Class Commissioning guidance for dementia and includes a section on who is involved in commissioning for health outcomes for people with dementia and their carers.

Co-production is the focus of three World Class Commissioning competencies:

- WCC 2 – work with local partners
- WCC 3 – engage with public and patients
- WCC 4 – collaborate with clinicians
- WCC 5 – manage knowledge and assess needs
- WCC 8 – promote improvement and innovation

### ***Involving people with dementia and their carers***

Involving people with dementia and their carers is an essential ingredient for effective implementation of the National Dementia Strategy. People with dementia are able to articulate their needs and wants. If they are unable to do so verbally, particularly in later stages of dementia, expression can take non-verbal behavioural forms.

It is an intention of the Strategy to see more evidence that people with dementia and their carers have a role in shaping and designing the services they use. Tools such as *Strengthening*

*the Involvement of People with Dementia*<sup>19</sup> provide a valuable resource for developing commissioner capabilities in working with people with dementia and their carers.

### **Involving providers**

Good commissioning will achieve engagement throughout the cycle. Commissioners should be mindful that clinicians from NHS provider trusts carry both clinical expertise and commercial responsibilities. That is, provision of clinical services must be open to market opportunities and therefore, open to competition.

We asked social care provider organisations how they would define good commissioning.

*“Good commissioning focuses on outcomes, not processes, respects the professionalism of providers and uses independent costs of care models to ensure that there are the resources available to deliver quality care. Good commissioners commission the outcomes of government strategies and ensure that services reflect the priorities and outcomes of strategies around dementia, end of life, carers and other important initiatives.”*

Martin Green, chief executive, English Community Care Association

*“It is becoming increasingly possible for people with dementia to be cared for at home by appropriately vetted, well-trained and motivated staff where the familiarity of their surroundings is of positive benefit. Commissioners need to use an outcomes-based approach and pay a fair price to ensure that providers have the flexibility to deal with needs that may differ over time, and which enables them to respond in creative ways, with dignity and to support family carers. Supporting and disseminating the use of telecare approaches is also vital as growing numbers of people with dementia require care.”*

Mike Padgham, chair, UK Home Care Association (UKHCA)

### **Needs assessment**

All commissioning should be based upon robust assessment of local need. Local commissioning communities have a duty to undertake a joint strategic needs assessment (JSNA) that identifies the current and future health and well-being needs of the local population.

The Care Quality Commission expects localities to have robust integrated commissioning strategies and implementation plans that reflect the needs identified in joint strategic needs assessments.

A good quality needs assessment also reflects the voice of local people. Commissioners should find ways of engaging people with dementia, their carers and the wider public in

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<sup>19</sup> *Strengthening the Involvement of People with Dementia* Department of Health <http://www.olderpeoplesmentalhealth.csp.org.uk/service-user-and-carer-engagement-tool.html>

determining the type of services that they need to support them through the journey of dementia (see Involving people with dementia and their carers above).

Attached at **Annex 2** is a template for assessing local dementia needs. The template includes the following domains.

- Prevention – ‘what’s good for the heart is good for the head’
- Population prevalence taken to local level

The template also includes key domains for service mapping so that commissioners can begin to assess whether they have the right capacity and balance of services to meet the needs of their local population. All local services should be mapped, including those not funded through the local authority or PCT.

### **Co-ordinating and influencing budgets**

People with dementia often have complex needs that require far-reaching responses from services across health and local authorities. Commissioners should work with commissioning colleagues to ensure that the needs of people with dementia are fully met.

Commissioners should work with:

- services for people with learning disabilities, to ensure services and funding are in place if and when an individual’s primary needs make the transition from learning disabilities to those more closely associated with dementia
- funding opportunities made available through the Carers’ Strategy
- acute care budgets, particularly where there might be opportunities to raise standards of care in medical settings using the commissioning for quality and innovation (CQUIN) payment framework<sup>20</sup>
- mental health services, particularly where there are co-morbidities or where there are opportunities for people with dementia to benefit from other mental health services.



<sup>20</sup> *Using the Commissioning for Quality and Innovation (CQUIN) payment framework* Department of Health 2008 [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_091443](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_091443)

## Outcomes and procurement

### *Commissioning for outcomes*

The effectiveness of services for people with dementia and their carers can be measured by health, social and economic outcomes, and the impact on wider society.

More information on outcomes-based commissioning can be found at the Department of Health Better Commissioning website<sup>21</sup>.

### *Decommissioning services*

Commissioners might want to decommission services for a number of reasons including changing priorities, emerging evidence of efficacy of interventions and performance of providers.

Commissioners are responsible for ensuring that providers are meeting performance targets and delivering good outcomes for people with dementia and their carers. Where outcomes are not achieved, commissioners should work closely with providers to address weaknesses and give very clear timescales for remedial action to result in improved performance. Where a service has failed to deliver outcomes and standards of care, the commissioner has a responsibility to give notice to the provider and to identify a suitable alternative provider.

Before decommissioning a service a commissioner should work with providers and people who use services to:

- agree the performance standards and outcomes the provider is expected to deliver
- agree remedial steps to agree performance within a reasonable timescale
- involve people who use services in activity around poorly performing services
- agree planned exit strategies
- put in place alternative services.

Decommissioning can be challenging, particularly where large providers are involved and when decommissioning one service might compromise the viability of other services. The introduction of diversity in the market, particularly for health services, means that new providers can be introduced to local markets.

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<sup>21</sup> Better Commissioning website <http://www.dhcarenetworks.org.uk/BetterCommissioning/Outcomes-basedcommissioning/index.cfm>

The Care Services Efficiency Programme has developed a decommissioning toolkit<sup>22</sup> that includes guidance and a checklist for decommissioning social care services. Many of the principles are transferable to health and other support services.

## **Demand and performance**

### ***Primary and community services***

Commissioners are responsible for commissioning general practice (GP) provider services as well as working with practice-based commissioning (PBC) consortia to redesign services.

### ***Commissioning primary care***

There are two Quality and Outcomes Framework (QOF)<sup>23</sup> indicators directly relating to dementia:

- DEM 1 – A register of patients diagnosed with dementia, produced by the practice
- DEM 2 – The percentage of patients diagnosed with dementia whose care has been reviewed within the previous 15 months

Dementia registers can be an indicator of a number of issues within the local healthcare community, including:

- the awareness that GPs have of dementia
- reliability of coding
- availability of local memory assessment services.

Where availability of memory services is highlighted as an issue, GPs can use practice-based commissioning systems to design and commission memory assessment services as well as other therapeutic interventions.

### ***Practice-based commissioning***

Practice-based commissioning is the vehicle through which PCTs can engage clinicians in commissioning by identifying local needs and delivering services differently to result in better outcomes for people.

PBC encourages clinical ownership and leadership by supporting local clinicians to take a more active role in commissioning services for their patients. PBC provides a framework

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22 Care Services Efficiency Programme decommissioning toolkit <http://www.dhcarenetworks.org.uk/Solutions/betterBuying/commissioningToolkit/>

23 Quality and Outcomes Framework <http://www.dh.gov.uk/en/Healthcare/Primarycare/Primarycarecontracting/QOF/index.htm>

that local clinicians can use to develop a wider range of integrated community-based services designed around the needs of individuals, secure greater investment in early interventions that keep people healthy for longer, and drive continuous quality improvement and innovation, securing better value for money in the process

More information about the Department of Health vision for practice-based commissioning<sup>24</sup> can be found at the DH website.

### **Contracting for quality**

Commissioners of dementia services should work with other commissioners to co-ordinate budgets to maximise the impact of services for people with dementia and their carers. For example, working with acute care commissioning colleagues will provide opportunities to improve the quality of care for people with dementia in medical settings.

Commissioners may be able to use the commissioning for quality and innovation (CQUIN) payment framework, which aims to embed quality improvement and innovation within the commissioner-provider discussion.

The framework is intended to ensure contracts with providers include clear and agreed plans for achieving higher levels of quality by allowing PCTs to link a specific modest proportion of providers' contract income to the achievement of locally agreed goals.

All providers should be able to earn this money, but will not have an automatic right to be given it. The CQUIN element of the contract sets aside up to 0.5 percent of a contract for quality. Providers must demonstrate that they have delivered quality services before they can receive payment of the quality element of the contract.

The locally agreed goals, which should be stretching and realistic, should be discussed between co-ordinating commissioners and providers, with support from the strategic health authority, and included as part of contracts. Use of agreed metrics provides a robust basis for developing and improving services. South East Coastal SHA (see Annex 3) has worked extensively with primary and secondary care to develop a set of dementia metrics that are being used to continually improve services.



<sup>24</sup> *Clinical commissioning: our vision for practice-based commissioning* Department of Health 2009  
[http://www.dh.gov.uk/en/Managingyourorganisation/Commissioning/Practice-basedcommissioning/DH\\_095694](http://www.dh.gov.uk/en/Managingyourorganisation/Commissioning/Practice-basedcommissioning/DH_095694)

# Section 3: Commissioning NDS recommended services

This section looks at the commissioning implications and levers for each of the recommended services set out in *Living well with dementia*. It focuses on Objectives 1 to 13, all of which are concerned with provision of local health and care support services.

## Objective 1: Improved public and professional awareness and understanding of dementia

The national programme supporting the implementation of the Strategy will be delivering public awareness campaigns.

Regional and local commissioners should support the national campaign through social marketing and awareness-raising campaigns targeted at local priority groups, including:

- people aged 50+ – this will include population segments who might be finding symptoms in themselves or a close relative or friend
- carers of people with dementia
- minority groups including black and minority ethnic (BME) and people with learning disabilities.

Professionals will also benefit from public information campaigns. Better awareness for professionals is covered under Objective 13 of this joint commissioning framework.

Campaigns might include information on:

- the neurological process of dementia
- symptoms and behaviours associated with dementia
- the benefits of creating a person-centred built and social environment
- knowledge of how to access diagnosis and support services.

The Department of Health has established a social marketing programme<sup>25</sup> in partnership with the National Social Marketing Centre<sup>26</sup>. Every strategic health authority has a social

<sup>25</sup> Department of Health social marketing programme [http://www.dh.gov.uk/en/Publichealth/Choosinghealth/DH\\_066342](http://www.dh.gov.uk/en/Publichealth/Choosinghealth/DH_066342)

<sup>26</sup> National Social Marketing Centre  
<http://www.nsms.org.uk/public/default.aspx>



marketing expert who should be available to support local awareness-raising and advise on which methods of communication are likely to successfully reach target groups.

The Department of Health dementia implementation team will publish details of its awareness-raising campaign on the DH web pages on dementia<sup>27</sup>.

### **Case example**

Norfolk and Waveney Mental Health NHS Foundation Trust provides specialist dementia care learning through its older people's training, education and development (OPTED) team and mental health liaison specialist nurse, offering structured support for clinical and social care staff at Norfolk and Norwich University Hospital, which sees a high proportion of people with dementia in the older people's medical unit. Workshops covering dementia care mapping, communication and care planning have a focus on the social psychological needs of people with dementia and their carers when faced with the stress of hospital admission.

For more information, email [opted@nwmhp.nhs.uk](mailto:opted@nwmhp.nhs.uk)

## **Objective 2: Good quality early diagnosis and intervention for all**

Commissioners should work with their PCT primary care commissioning colleagues and practice-based commissioning consortia to improve the quality of diagnosis and increase the numbers of formal diagnoses.

### **Memory assessment**

Commissioners should maximise the opportunities for screening for risk factors such as coronary heart disease, stroke and diabetes, during a patients' annual review.

For associated risk factors commissioners can use QOF indicators:

- CHD 1 – the practice can produce a register of patients with coronary heart disease
- STROKE 1 – the practice can produce a register of patients with stroke or TIA
- BP1 – the practice can produce a register of patients with established hypertension

There are challenges in co-ordinating data between specialist memory assessment and primary care databases. However, GPs should record all diagnoses of dementia on dementia registers.

<sup>27</sup> Department of Health web pages on dementia [http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Olderpeople/NationalDementiaStrategy/DH\\_083358](http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Olderpeople/NationalDementiaStrategy/DH_083358)

There are two relevant QOF indicators:

- DEM 1 – the practice can produce a register of patients diagnosed with dementia
- DEM 2 – the percentage of patients diagnosed with dementia whose care has been reviewed in the previous 15 months

Commissioners can use GP dementia registers to measure performance of primary care activity in referral and registration of people with dementia.

See **Annex 3** for South East Coastal SHA work on dementia metrics using QOF and other reliable data.

Commissioners should model the impact of early diagnosis on other services. People diagnosed early are likely to receive pharmaceutical and therapeutic interventions that will help them live active lives for longer. Commissioning services should therefore be set within the context of whole pathways of services and support.

### **Case example: Memory assessment**

Croydon Memory Service (CMS) is an integrated service offering a comprehensive assessment, diagnosis and management service, a wide range of medical, psychological and social interventions, support groups, specific initiatives focused on people from BME groups and outreach work with local groups. The service has been evaluated by King's College London.

For more information, email [CroydonMemoryServiceCroydon@slam.nhs.uk](mailto:CroydonMemoryServiceCroydon@slam.nhs.uk)

### **Investing in early intervention**

The 2007 National Audit Office report *Improving services and support for people with dementia*<sup>28</sup> estimated that re-engineering systems for dementia could yield £6.5 million of acute trust savings per year.

The NDS consultation document *Transforming the quality of dementia care* includes an appendix on the clinical and health economic case for early diagnosis and intervention services for people with dementia. The economic case demonstrates how, over 10 years, reductions can be made in admissions to long-term institutional care thus releasing revenue to invest in prevention and early intervention.

<sup>28</sup> *Improving services and support for people with dementia* National Audit Office 2007 [http://www.nao.org.uk/publications/0607/support\\_for\\_people\\_with\\_dement.aspx](http://www.nao.org.uk/publications/0607/support_for_people_with_dement.aspx)

The Partnership for Older People Pilots (POPPs) programme<sup>29</sup> was established by the Department of Health to develop the evidence base for early intervention. Of the 29 POPPs sites across England, a number focus on dementia and older people's mental health. Evidence is emerging of significant improvements in outcomes for people using POPPs services. Users report that their health-related quality of life has improved in five key domains – mobility, washing/dressing, usual activities, pain and anxiety.

Financial evidence is also encouraging. For every £1 spent on POPPs, 73 pence will be saved on the cost per month of emergency bed days, assuming the cost of bed days to be £120.



Other early intervention programmes are also finding improved outcomes for people who use prevention services. The *Putting People First* programme's publication *Making a strategic shift to prevention and early intervention*<sup>30</sup> provides a comprehensive guide for health and care communities to build early intervention services.

### Case example: Early intervention

Thurrock Council and South West Essex PCT jointly commission two members of the local Alzheimer's Society to offer early intervention, memory assessment, continence management assessment, advisory and support services to people with dementia and their carers, funded from the adult social care budget and kick-started by an access and systems grant. The Alzheimer's Society workers have a service level agreement to carry out specific activities and report to the joint commissioning manager based at the local authority. Regular evaluation is built into intervention activities so people with dementia and their carers have an opportunity to say whether or not the service is meeting their needs. Other third sector groups are part of a network providing linked services.

For more information, contact NHS South West Essex commissioner for mental health Irene Lewsey at [irene.lewsey@swessex.nhs.uk](mailto:irene.lewsey@swessex.nhs.uk) and Thurrock Council commissioner Sarah Carter at [sacarter@thurrock.gov.uk](mailto:sacarter@thurrock.gov.uk)

29 Partnership for Older People Pilots <http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Olderpeople/PartnershipsforOlderPeopleProjects/index.htm>

30 *Guide to making a strategic shift to prevention and early intervention* Department of Health 2008 <http://www.dhcarenetworks.org.uk/Prevention/type/Resource/?cid=4421>

### **Case Example: Dementia Counselling**

Camden Council talking therapies service has recruited volunteer therapists from BME groups and given them dementia training so that they can offer same-language, culturally sensitive counselling to older people from BME communities. It is generally considered difficult to provide therapeutic services that rely on an interpreter. An ongoing commitment to invest in prevention services encouraged the local authority to fund the service from savings made elsewhere. The service relies on volunteers, so the majority of funding is for a full-time co-ordinator post.

For more information, contact Robert Holman at [Robert.Holman@camden.gov.uk](mailto:Robert.Holman@camden.gov.uk)

## **Objective 3: Good quality information for those diagnosed with dementia and their carers**

People with dementia and their carers say that they want high-quality information when they need it. Different people need different information and at different times. It can be overwhelming to receive too much information when a person is trying to absorb news of a diagnosis.

As local leads for implementation of the National Dementia Strategy, commissioners should co-ordinate information regarding:

- dementia as a clinical condition and treatments available
- symptoms and behaviours related to dementia
- creating a positive environment for a person with dementia and their carer
- services and support available locally.

Alongside memory assessment services should sit information and signposting to early intervention to address such issues as:

- legal and financial information, including mental capacity and benefits entitlement
- local adult protection procedures
- home environment and driving assessments
- assistive technology to maintain independent living.

It is likely that a number of local organisations funded by PCTs and local authorities already produce information on dementia and services. A commissioner should audit the information to cut out any duplication and ensure consistency in information provided.

### **Case Example: Information Prescriptions**

The Isle of Wight DH information prescription pilot site has targeted people with dementia, especially pre-diagnosis, and their carers. A web-based directory of local and national services, a self-help booklet and other material is available to people with dementia and their carers to select information to meet individual needs. Liaison with mental health services ensures all advice is in line with current clinical guidance. Local call centre and library staff have been trained to support people in accessing information and the service has been promoted through community and voluntary service partners.

Useful websites: Isle of Wight information prescriptions [www.iwight.com/onelink](http://www.iwight.com/onelink)

Information prescription project (including online resource, templates, reading lists) [www.informationprescription.info](http://www.informationprescription.info)

## **Objective 4: Easy access to care, support and advice following diagnosis facilitated by a dementia advisor**

People with dementia, their carers and families need guidance on clinical and social support throughout the disease process. Dementias are complex both clinically and behaviourally. It is not always clear to people with dementia and their carers what the most appropriate interventions are to problems that arise. The dementia advisor role should help people with dementia and their carers find easy access to the right support to anticipate or resolve each problem they encounter.

The success of the dementia care advisor role will be dependent on:

- commissioners taking a joint approach to commissioning the role and to commissioning information that is available to the advisor to signpost and support people with dementia and their carers
- a single point of access to the advisor eg at the point of diagnosis
- the advisor complementing, not duplicating, specialist services.

The Department of Health NDS Implementation Programme is leading a series of demonstration sites<sup>31</sup> to evaluate the role of dementia advisor and to gather the outcome and economic evidence for these new roles.

### Case example: Support officer

Bristol PCT is using its PBC innovation fund for a dementia support officer to provide and co-ordinate ongoing support and information on dementia services to people with dementia and their carers. The support officer will also provide workforce training and education across the whole system. This role is intended to improve the quality of care provided, promote independence and reduce admissions from crisis and promote early discharge. The role will be based at Bristol Alzheimer's Society, with referrals coming from local GPs, patients and carers.

For more information, contact Emma Bird at [emma.bird@bristolpct.nhs.uk](mailto:emma.bird@bristolpct.nhs.uk)

## Objective 5: Structured peer support and learning networks

Structured peer support and learning networks are to be piloted nationally. Currently peer support is mainly provided through the voluntary sector, and information is being gathered nationally to evaluate its effectiveness. Emerging evidence of outcomes and cost effectiveness will be published on the DH dementia web pages.

The success of structured peer support and learning networks will be dependent on commissioners ensuring:

- integration into mainstream services, possibly running a peer support group alongside memory assessment services
- accessibility to all people with dementia and their carers, including those in rural areas, from different cultural backgrounds and with specialist needs eg people with learning disabilities and younger people
- information and evidence gathered from the national pilots and existing services are used to inform service models
- people who attend peer groups or learning networks are listened to and are able to contribute to the local commissioning debate on what services they require. This may require commissioners to visit local groups rather than expecting people to come to commissioning meetings/forums
- a joint approach to commissioning structured peer support

<sup>31</sup> Demonstrator sites programme and up to date information  
[www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_097629](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_097629)

- alignment with information services and dementia care advisors to ensure consistency.

The Department of Health NDS Implementation Programme demonstration sites will evaluate managed peer support networks and gather the outcome and economic evidence for these new roles.

### **Case example: Well-being cafés**

Bradford Partnership for Older People Pilots (POPP) programme has set up a series of 'well-being cafés' for people with dementia. The cafés provide a social environment where people with dementia – and their carers – can meet weekly to socialise in a friendly and supportive environment. There is a rolling programme of between six and nine sessions. Each session includes an information slot with a presentation and discussion on some aspect of health and care and a structured group activity. Leaflets and written information about services, support and relevant information are always available to participants to take away with them. The emerging findings from the pilots demonstrate an increase in peer support, self-reported improvements in feelings of 'wellness' of participants.

For more information, go to [www.bradfordhealthinmind.nhs.uk](http://www.bradfordhealthinmind.nhs.uk)

## **Objective 6: Community personal support services**

Two-thirds of people with dementia live in their own homes. There is enormous potential to commission services to support people to maintain their skills and abilities, to maintain their social networks and to remain living in their own homes.

### **Personalisation**

Personalised budgets (and eventually personalised health budgets) enable the development of innovative and flexible services and support to meet individual needs. Commissioners should use the Strategy as a catalyst to increase the focus on dementia and personal budgets because the evidence<sup>32</sup> so far shows that older people are least likely to make use of the opportunities afforded by personal budgets.

Commissioners should:

- adopt a whole systems approach to locally benchmarking and mapping availability and effectiveness of local services

<sup>32</sup> *Evaluation of the Individual Budgets pilot programme* Personal Social Services Research Unit 2008  
<http://www.pssru.ac.uk/pdf/IBSEN.pdf>

- use information available nationally on the effectiveness of commissioning different service models eg DH domiciliary care commissioning toolkit<sup>33</sup>
- implement *Putting People First* personalisation changes
- ensure robust protocols and procedures for adult safeguarding are in place, in accordance with national guidance<sup>34</sup>
- give consideration to flexibly combining specialist day services and day hospital models to:
  - provide intensive treatment and support that enables the person with dementia to return home in the evening
  - provide person-centred activities that maximise the service user’s skills
  - work closely with specialist integrated teams to provide a comprehensive assessment of an individual’s future care needs eg need for respite, residential or social care
  - provide short-break opportunities for carers.



### Case example: Community groups

The Mount specialist centre in Luton offers enhanced day care services for people with dementia, including culturally appropriate information, advice and support from 10 different community groups, including befriending services and life story work appropriate to individuals from various local BME communities. As well as offering these groups the training to deliver services, the local authority has simplified its tendering process to encourage bids. Clearer templates have been developed for service level agreements and other paperwork, and project workers help the community groups collect data required for monitoring services.

For more information, email [pops@luton.gov.uk](mailto:pops@luton.gov.uk)

Supporting material: The Mount centre brochure

<http://www.dhcarenetworks.org.uk/Dementia/Topics/Browse/CareAtHome/?parent=3780&child=5670>

<sup>33</sup> Domiciliary care commissioning toolkit  
[www.dhcarenetworks.org.uk/Dementia](http://www.dhcarenetworks.org.uk/Dementia)

<sup>34</sup> Guidance on protocols and procedures for adult safeguarding  
<http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Vulnerableadults/index.htm>



### ***Avoidance of unnecessary admission/discharge planning through better community support***

People with dementia may be repeatedly admitted to hospital because they are not otherwise in touch with any statutory services, and their dementia means they are neither aware of their disability nor able to ask for assistance.

Many admissions happen when people with dementia are unwell – but not acutely ill enough to need the specialist care provided in acute hospitals – simply because it is difficult to diagnose and manage their care within A&E target times without any prior knowledge of the person.

Commissioners should establish a liaison service to work with discharge co-ordinators and intermediate care teams to assist in early discharge planning and prevention of delayed discharges. This liaison role may be expanded to include responsibility for hospital staff dementia training and education, to improve the quality of experience of a hospital stay for people with dementia. Links with community services are also very important to prevent further unnecessary admissions.

#### **Case example: Dementia discharge team**

Sheffield PCT funds an Accelerated Discharge Dementia (ADD) team, employed by Sheffield Health and Social Care NHS Foundation Trust, to work at the city's Northern General Hospital, where previously general nursing staff were reluctant to risk discharging people with dementia. ADD registered mental health nurses have particular experience of dementia, so can assess to support a patient's discharge to their own home. Dementia-trained support workers deal with any problems in the fortnight post-discharge, checking on medication, home care, and follow-up by social services, for example. The team works with a specialist psychiatrist and occupational therapist.

For more information, contact ADD team leader Ann Powell at [Ann.Powell2@shsc.nhs.uk](mailto:Ann.Powell2@shsc.nhs.uk)

### ***Crisis prevention and response***

Crisis resolution and home treatment (CRHT) services that are directly accessible to people with dementia and their carers, as well as professionals, can help reduce unnecessary admissions to hospital.

Commissioners should assess current CRHT capacity in the context of local need, and re-engineer sufficient resources to make fully staffed 24/7 CRHT teams an integral part of local mental healthcare services, including social care provider services that operate crisis services out of hours and at weekends.

It is important local mental healthcare providers, acute trusts, adult social services, out-of-hours services, GP practices and local implementation teams jointly develop, negotiate and agree comprehensive local protocols for dementia referrals.

### **Case example: Home support**

Mental health charity Rethink has been commissioned to provide a housing-related support service across four authorities in the south west to help younger people with dementia and older people with memory problems or dementia continue to live independently. The £770,000 cross-authority overall cost of the service per annum is funded from the Supporting People budgets and is expected to generate wider health and social care savings from reduced admissions to hospital and residential care.

The service offers individuals around five to 10 hours of support per week, including guidance on maintaining a safe and secure home, finances and paying bills, and staying healthy. The service specification also requires Rethink to deliver services in a manner that maintains the individual's rights to dignity, privacy and confidentiality. A total of 10 outcomes such as minimising intervention by other agencies and increasing the service user's capability and self-esteem are measured by each authority quarterly in accordance with the Communities and Local Government framework. Rethink has also been set service targets to achieve quarterly, including working in partnership with other providers and avoiding duplication of services.

For further information, contact Viv Streeter at [vstreeter@somerset.gov.uk](mailto:vstreeter@somerset.gov.uk)  
Supporting material: Somerset home support service specification and leaflet  
<http://www.dhcarenetworks.org.uk/Dementia/Topics/Browse/CareAtHome/?parent=3780&child=5669>

## **Objective 7: Services within the Carers' Strategy**

The National Audit Office report, *Improving services and support to people with dementia and their carers*, estimates there are 460,000 unpaid carers and that they are the mainstay support for people with dementia who live in the community. However, carers also have higher than average levels of psychological co-morbidities such as depression. Co-residence of a carer is also a strong predictor of a person with dementia remaining living in the community and avoiding entry to institutional care<sup>35</sup>.

<sup>35</sup> Banerjee et al 2003, *Predictors of institutionalisation in people with dementia*, Journal of Neurology, Neurosurgery and Psychiatry 74, 9 1315-1316

For commissioners, the success of implementing the Carers' Strategy is reliant upon consulting with carers to commission flexible and responsive services, such as short breaks, in a variety of settings, on a planned or emergency basis.



There are different ways in which short breaks can be commissioned, including:

- home care services
- day services
- peer support groups
- voluntary sector support services
- expanding direct payments to carers
- expanding individual budgets for people with dementia.

The NHS Operating Framework 2009/10 includes the Vital Sign indicator:

- proportion of carers receiving a 'carer's break' or a specific service for carers as a percentage of clients receiving community-based services.

### **Case example: Carer short breaks**

Torbay Care Trust has commissioned a voluntary sector provider to develop a scheme that offers people with dementia short breaks in a family environment. The initial two-year contract is for a development worker to recruit and train 18-20 local families and individuals who can take people for short stays on a regular basis, providing consistency of care in familiar surroundings. The service is for people at different stages of dementia, with spot payments for stays banded according to complexity of need, including personal care requirements. The new service complements the trust's existing Days Out host carer scheme, agreed under a three-year block contract, which offers structured day care – but not personal care – for up to four people with dementia at a time in a host's own home.

For more information, contact James Drummond, lead officer, integrated carers services, Torbay Care Trust at [jamesdrummond@nhs.net](mailto:jamesdrummond@nhs.net)

Supporting material: Torbay Care Trust carer strategy 2008-10  
<http://www.dhcarenetworks.org.uk/Dementia/Topics/Browse/Objective7/>

### Case example: Carer support

West Essex PCT has used its partnership fund for community initiatives to commission an online skills course to prevent people with dementia and their carers becoming isolated. Practice-based commissioning leads and GPs on the professional executive committee flagged up a need to give carers access to information and support while they are caring for someone. For example, they will be able to shop online and get in touch with other carers through internet forums. Mental health charity Mind will deliver the training and local libraries will participate in the scheme.

For more information, contact Cathi Emery at [cathi.emery@westessexpct.nhs.uk](mailto:cathi.emery@westessexpct.nhs.uk)

## Objective 8: Good quality care within general hospitals

The Royal College of Psychiatrists report *Who care wins*<sup>36</sup> on improving outcomes for older people with mental health needs in acute general hospital estimates that up to a quarter of people in general acute care at any one time have dementia. This indicates that commissioners of acute hospital services are also responsible for securing high-quality care for people with dementia.

*Living well with dementia* suggests improving care for people with dementia in general hospital by providing leadership through a nominated senior clinician, and developing a care pathway for people with dementia that is supported by a specialist liaison service.

Commissioners can enable this to happen by:

- including existing mental health liaison services in the benchmarking process (see **Objective 6**)
- using available national and local evidence on service models to inform commissioning eg *Between two stools* (University of Leeds 2002) and *Managing Urgent Mental Health Needs in the Acute Trust* (Academy of Medical Royal Colleges 2008)
- ensuring the acute trust is represented on locality commissioning boards for dementia
- ensuring general hospital staff are included in workforce development plans
- ensuring the needs of people with dementia and their carers are included in all commissioning contracts with acute trusts by using existing levers eg the Dignity in Care campaign and Essence of care standards<sup>37</sup>

<sup>36</sup> *Who cares wins* Royal College of Psychiatrists 2005  
<http://www.rcpsych.ac.uk/PDF/WhoCaresWins.pdf>

<sup>37</sup> Essence of Care benchmarking process  
[http://www.dh.gov.uk/en/PublicHealth/Patientsafety/Clinicalgovernance/DH\\_082929](http://www.dh.gov.uk/en/PublicHealth/Patientsafety/Clinicalgovernance/DH_082929)

- making it explicit within contracts that liaison services are integrated with other services within the general hospital, eg discharge planning teams and A&E services, as well as linked to community services eg CRHT and intermediate care teams.

Being an inpatient in a general hospital unit is often detrimental to the well-being of a person with dementia. It is often the case that the presence of a dementia prolongs the length of stay. This may be because treatment and therapeutic interventions can take longer, partially due to lack of staff expertise in caring for the person with dementia.

The NHS Operating Framework 2009/10 includes the Vital Sign indicator:

- number of delayed transfers of care per 100,000 population (aged 18 and over).

Investigating delayed transfers of care is therefore likely to give commissioners an understanding of the gaps in services and, as a result, commissioning priorities.

### **Case example: Acute care team**

Bristol and South Gloucestershire older people's acute hospital mental health liaison team works in wards where there is a high proportion of people with dementia. The team offers rapid specialist mental health assessment and follow-on reviews alongside treatment of the primary condition leading to admission, resulting in increased accuracy of assessment, diagnosis and timely and appropriate treatment. Collaboration with hospital social work and discharge nurse teams helps maintain the independence of patients with dementia, increasing return home rates, reducing lengths of stay where appropriate and resulting in fewer unnecessary delays and readmissions.

Ward teams, hospital social workers and other staff are trained to better identify and manage dementia, making it easier to treat primary medical conditions.

For more information, contact Neil Mason at [neil.mason@awp.nhs.uk](mailto:neil.mason@awp.nhs.uk)

### **Case example: Acute care dementia team**

Mid-Essex Hospitals Trust has secured SWIFT funding for a dedicated dementia team within the hospital, comprising a nurse, speech and language therapist and weekly sessions from a consultant psychiatrist and psychologist. As part of the elderly care team it will help ensure appropriate treatment and timely discharge for patients with dementia admitted with acute medical and surgical problems.

For more information, contact Vicki Leah at [Vicki.leah@meht.nhs.uk](mailto:Vicki.leah@meht.nhs.uk)

## Objective 9: Intermediate care for people with dementia

Intermediate care should be available to people with dementia to maximise their potential for recovery and rehabilitation following injury or illness.

Department of Health intermediate care guidance is being reviewed and a revised version is due to be published. It is anticipated that commissioners will be expected to satisfy themselves that people with dementia will have full access to intermediate care services. The guidance is expected to offer advice to commissioners on how this may be achieved.

Commissioners could commission intermediate care for people with dementia in various ways, including the following.

- Expand existing services eg those offered by community hospitals, to expressly include people with dementia. This may require some specialist input from mental health teams
- Commission a specialist mental health intermediate care service that would cover all mental health needs, rather than just dementia
- Commission specialist residential intermediate care beds

One of the challenges for commissioners is to ensure that staff who work in intermediate care services have the required understanding of dementia (see **Objective 13**).

## Objective 10: Good housing, housing-related and telecare support

Housing, telecare and assistive technologies are an integral part of services for people with dementia if improving quality of care and maximising choice, independence and control are to be achieved.

Housing should be based on need and not the environment in which it is provided. Commissioners can enable this through the following.

- Involving housing and telecare professionals in developing joint strategic needs assessments and commissioning strategies for dementia
- Commissioning extra care housing options with flexible day care support options (see **Objective 6**)
- Commissioning assistive technology advice and support options for those who wish to remain at home, again with additional day care options
- Working with housing partners, eg housing associations and independent care homes, to offer flexible day care support for people with dementia, maximising the options for short breaks for carers

- Ensuring housing staff are integrated into workforce development plans (see **Objective 13**)
- Facilitating the flexible use of individual budgets to support the housing choices of people with dementia
- Closely monitoring the evidence base that is emerging on the existing range of housing and telecare options

### Case example: Extra care

Duddon Mews in Cumbria offers people with dementia extra care housing, incorporating assistive technology, 24-hour domiciliary care and a specialist day centre. It is run by a partnership of Cumbria County Council, Supporting People, the community mental health team, Home Group, Age Concern and Croftlands Trust. A protocol sets out different roles and responsibilities. The capital cost of the build came from a Housing Corporation grant and Home Group funding. Ongoing funding is from Supporting People for support provision and social services for the care package. There are separate contracts for the different elements of social care. The service is measured against the Supporting People quality assessment framework and adult social care performance audits. Staff undergo dementia training provided by the various partners.

For more information, contact Brenda Lindsay at [Brenda.lindsay@cumbriacc.gov.uk](mailto:Brenda.lindsay@cumbriacc.gov.uk)

## Objective 11: High quality services within care homes

Up to two-thirds of people living in care homes have dementia although few of these are likely to have a formal diagnosis and care plan to meet the needs presented by their dementia. The Commission for Social Care Inspection 2008 report *See me, not just the dementia*<sup>38</sup> looks at the state of dementia services within care homes.

The requirement to improve the quality of care in care homes is laid out explicitly in *Living well with dementia*. Commissioners can enable this through the following actions.

- Closely monitoring capacity and demand for services from care homes, possibly utilising the range of capacity planning tools available on the open market
- Ensuring care home staff are integrated into workforce development plans (see **Objective 13**)

<sup>38</sup> *See me, not just the dementia* Commission for Social Care Inspection 2008  
[http://www.cqc.org.uk/\\_db/\\_documents/Dementia%20Report-web.pdf](http://www.cqc.org.uk/_db/_documents/Dementia%20Report-web.pdf)

- Working with regulators to jointly analyse outcome data to identify where priorities for improvements should lie
- Jointly commissioning in-reach services to care homes, eg specialist mental health support from community teams, dentistry and pharmacy services. This does not have to be an additional service – a redesign of service delivery might be sufficient to improve in-reach services
- Working with GPs and PCT pharmacy leads to monitor prescribing rates of anti-psychotic drugs against expected drug usage. This is an extension of existing services, rather than a separate service
- Engaging care home managers, possibly through a commissioning forum, to identify dementia champions/leaders in care homes who will take responsibility for improving quality and ensuring that people within care homes have access to a range of activities and social opportunities, which may include their families
- Use available evidence and existing toolkits to inform commissioning

Help the Aged has led the My Home Life collaborative programme<sup>39</sup>, aimed at improving the quality of life of those who are living, dying, visiting and working in care homes for older people.

The programme uses eight themes – managing transitions, maintaining identity, creating community, sharing decision-making, improving health and healthcare, supporting good end of life care, keeping workforce fit for purpose, and promoting a positive culture.

### **Case example: Specialist care home support**

Somerset PCT has topped up normal local authority funding for residential care to provide specialist care development nurses to manage independent care home admissions, ensure specialist support for people with dementia is available, train care home staff and help them develop and implement individual care plans for every patient. Somerset County Council and the PCT have jointly commissioned 250 specialist residential care places on an extended contract, providing care to an enhanced service specification, geared to providing an appropriate level of stimulation for each individual. Service requirements include promoting independence and a positive view of life with dementia in a care setting.

For more information contact Fred Parkyn at [feparkyn@somerset.gov.uk](mailto:feparkyn@somerset.gov.uk)

<sup>39</sup> My Home Life Help the Aged <http://www.myhomelife.org.uk/WhatIsMyHomeLife.htm>



## Objective 12: End of life care for people with dementia

End of life care is concerned with ensuring everyone has a ‘good death’ that manages pain and distress and meets a person’s cultural, religious and spiritual needs. About half a million people die each year, a third of them from frailty or dementia. Most people with dementia die in residential care or hospital.

Commissioners have two areas of responsibility to ensure people with dementia receive good end of life care.

- Putting services in place that support individuals in planning their preferred care pathways, through advanced care planning or advanced directives
- Ensuring that services are available to provide high-quality end of life care

The NHS Operating Framework 2009/10 states:

*“To deliver the End of Life Care Strategy, Promoting high quality care for all adults at the end of life<sup>40</sup>, and the local SHA visions, PCTs will want to consider delivering extended and improved service provision with their partners.”*

Commissioners leading on the dementia strategy should work with commissioning leads for the End of Life Care programme<sup>41</sup> and the NHS Next Stage review<sup>42</sup> to ensure good quality end of life care for people with dementia is in place. The End of Life Care programme published *Information for commissioning end of life care*<sup>43</sup> in 2008. <http://www.endoflifecare.nhs.uk/eolc/eolcpub.htm>

Primary care QOF indicators relating to dementia and palliative care are:

- PC 3 – the practice has a complete register available of all patients in need of palliative care and support, irrespective of age
- PC 2 – ongoing management – the practice has regular (at least three-monthly) multi-disciplinary case review meetings where all patients on the palliative care register are discussed.

### **Advanced care planning**

Commissioners can ensure that local people with dementia have good quality information available about advanced care planning and services to support individuals to develop

<sup>40</sup> *End of Life Care Strategy* Promoting high quality care for all adults at the end of life Department of Health 2008 [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH\\_086277](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH_086277)

<sup>41</sup> End of life care programme <http://www.endoflifecare.nhs.uk/eolc>

<sup>42</sup> <http://www.ournhs.nhs.uk/>

<sup>43</sup> *Information for commissioning end of life care* <http://www.endoflifecare.nhs.uk/eolc/eolcpub.htm>

advanced directives within a legal and good practice framework. The Alzheimer's Society has produced a factsheet<sup>44</sup> that will help commissioners – as well as the public – understand the legal framework and issues relating to advanced directives.

### **Commissioning services**

Assessing the level of end of life care needs is complex. Commissioners can assess the level of end of life care needs for people with dementia by using local data on population prevalence of dementia against population characteristics such as age profile and mortality figures. Approximately two-thirds of people with dementia in the last year of life require palliative care.

Commissioners can ensure that people with dementia have access to good quality end of life care whether the cause of death is dementia or a co-morbidity.

Where co-morbidity exists, commissioners should ensure that the person with dementia has access to appropriate treatment, including pain control. A person with dementia might express pain and discomfort in behavioural as well as verbal ways. Commissioners can expect that providers, such as mental health trusts and nursing homes, can identify when an individual requires additional expert care for a co-morbidity. A person in a nursing home receiving care and support for their dementia should also expect access to expert cancer care and pain control where such a co-morbidity occurs.

Commissioners and providers can agree appropriate models of care. Outcome-based commissioning will be concerned with ensuring that providers have protocols and services in place to ensure good end of life care services. Providers can develop the protocols and systems that are most appropriate.

## **Objective 13: An informed and effective workforce across all services**

People with dementia and their carers should be able to expect services and support from staff who are knowledgeable about dementia and who have skills to work effectively with individuals.

As members of the workforce, commissioners are included in this expectation and therefore need to understand dementia, to know what high-quality services look like and what outcomes they can reasonably expect from services.

An informed and effective workforce should be present in specialist as well as universal services. The level of skill and expertise should be proportionate to the level of contact staff have with people with dementia.

<sup>44</sup> *Advance decision* Alzheimer's Society factsheet <http://www.alzheimers.org.uk/factsheet/463>

It is the provider's responsibility to train and educate their staff, but the commissioner can work with providers – particularly small providers – to help them commission and co-ordinate training and education services. Commissioners might negotiate funding or top-slicing payments with providers to fund education and training.

Commissioners should work with county workforce groups within SHAs, and at PCT and local authority level develop a coherent and cohesive whole-system strategy for workforce development, education and training.

The role of the commissioner in developing the workforce includes the following.

- Audit the status of the workforce across health and care to understand capacity and capability
- Work with the local workforce to understand the most effective methods for delivering training and education
- Take a role in recruitment to under-resourced sectors, particularly where co-ordination across organisations or sectors will be of benefit
- Integrate volunteers into training and education opportunities where appropriate
- Maximise the potential for joint commissioning of training and education programmes and develop a local commissioning strategy for workforce development
- Identify county priorities for workforce development and commission according to those priorities
- Use county workforce groups as a lever for developing the workforce
- Look imaginatively at how workforce can be developed in terms of dual functionality and integration of roles
- Use individual budgets as a lever to flexibly commission workforce
- Identify tools that commissioners themselves can use to be more informed about the needs of people with dementia
- Commission sustained specialist vocational courses on dementia for staff who work directly with people with dementia

Training and education around dementia, raising awareness, skills, attitudes and dignity, should be an integral part of foundation training of health, social care and third sector staff and commissioners may work with foundation training organisations to ensure this is implemented.

Skills for Care has developed a knowledge set for dementia<sup>45</sup>.

Commissioners should link with local dementia forums and clinical networks. These are both a source of clinical and practice expertise and a useful route to engaging local workforce on development and training issues.

### **Case example: Dementia forum**

The Haringey Dementia Forum has the key aims:

- to advance dementia care locally
- to provide a forum for all health, social care and voluntary staff who work with people with dementia and their carers
- to provide education and training on any aspects of dementia care
- to provide a discussion forum on any relevant policy or practice issues.

The forum meets on a quarterly basis and has presented on a wide range of issues, including cognitive stimulation therapy, the Mental Capacity Act, a carers panel, dementia and learning disabilities and end of life care.

Members come from mental health services, primary care, specialist palliative care, social care, acute care and the voluntary and private sectors, and include local commissioners, carers and representatives from learning disabilities groups.

A dementia interest group has also been formed with the further aims of:

- steering the dementia forum and its programme
- taking an active role in promoting and lobbying to improve dementia care and services locally
- providing expert advice on any issues related to dementia care locally.

For further information contact Karen Harrison Dening, Consultant Admiral Nurse, at [karen.harrison@beh-mht.nhs.uk](mailto:karen.harrison@beh-mht.nhs.uk)

<sup>45</sup> Skills for Care Knowledge set for dementia

[http://www.skillsforcare.org.uk/developing\\_skills/knowledge\\_sets/dementia.aspx](http://www.skillsforcare.org.uk/developing_skills/knowledge_sets/dementia.aspx)

# Section 4: Next steps

Implementation of the National Dementia Strategy is a five-year programme. The Department of Health (DH) has committed funding support to the programme for the next five years, within the current Comprehensive Spending Review (CSR). Funding for the remaining three years of the strategy will be part of the next CSR negotiations.

Implementation activity is taking place at national, regional and local level. We aim to deliver a co-ordinated programme of commissioning development over the next two years. The national programme will lead developments with national stakeholders such as DH World Class Commissioning and *Putting People First* teams, the Mental Health Development Unit (formerly NIMHE) and social care provider organisations.

Ongoing support for NDS Objective 14: Joint commissioning strategy has the following three themes.

1. Create a community of practice

An electronic community of practice is being established via the dementia pages on the DH care networks website. Terms of reference and programme activity are available on these pages.

The purpose of the community of practice is to:

- facilitate peer learning and development
- exchange best practice
- create a dialogue between the policy implementation team and commissioners in health and care.

2. Work with health and care commissioning communities to develop best practice models of commissioning, to develop an evidence base on:

- effectiveness of joint, integrated and lead commissioning models
- commissioning practice that delivers transformational changes
- outcome-based commissioning for dementia services.

3. Work with providers of health and care services, including NHS mental health trust providers and providers of community and residential social care, to develop models to:
  - stimulate the market to ensure local availability of the full range of high-quality dementia services
  - support innovation in commissioning and provision of services.

For up-to-date information on implementation support, visit the DH care networks dementia web pages<sup>46</sup> where you will find:

- Contact details for DH Regional Dementia Implementation Leads
- Links to DH Regional Dementia websites (where available)
- Best practice information for commissioners and providers



<sup>46</sup> DH Care Networks Dementia web pages <http://www.dhcarenetworks.org.uk/Dementia>

# Annex 1: NICE/SCIE guidance

## **Objective 1: Improved public and professional awareness and understanding of dementia**

SCIE guide 3 *Assessing the mental health needs of older people*

**<http://www.scie.org.uk/publications/guides/guide03/framework/index.asp>**

This guide draws from research to describe mental health problems commonly experienced by older people, including dementia. It looks at good practice in assessing such problems, awareness of the needs of carers and the importance of communication skills.

Idea from practice: Displays about mental health in later life, located in public venues to raise awareness, challenge myths and stereotypes and provide acceptable and accessible information on mental health for older people and their carers.

SCIE e-learning resource *An introduction to mental health of older people. Understanding the early stages of dementia* (2007)

**<http://www.scie.org.uk/publications/elearning/mentalhealth/mh05/index.asp>**

This learning module looks at recognising and diagnosing dementia, the symptoms and causes, and prevalence of different kinds of dementia. It addresses the emotional impact of dementia on the individual and their family, and values and attitudes relevant to meeting the needs of someone with dementia and their carers.

NICE public health guidance 6 *Behaviour change at population, community and individual levels* (2007)

**<http://www.nice.org.uk/Guidance/PH6>**

This guidance provides a set of generic principles that can be used as the basis for planning, delivering and evaluating public health activities aimed at changing health-related behaviours.

SCIE research briefing 26 *Mental health and social work* (2008)

**<http://www.scie.org.uk/publications/briefings/briefing26/index.asp>**

This highlights the need for professional awareness and understanding of mental health problems, with a focus on the role of social care in community mental health provision. It addresses issues of discrimination and ignorance, and the unmet needs of older people with mental health problems and highlights the value of traditional social care skills like actively listening and helping older people to accept support and access personalised services.

Social Care Online

**<http://www.scie-socialcareonline.org.uk/default.asp>**

This website is an extensive database of social care information, useful for keeping up to date with new dementia publications and a wide range of resources including training material. Specific topics include older people and mental health problems.

## **Objective 2: Good quality early diagnosis and intervention for all**

NICE online guide *Memory assessment service for the early identification and care of people with dementia* <http://www.nice.org.uk/usingguidance/commissioningguides/memoryassessmentservice/memoryassessmenthome.jsp>

This guide makes the case for commissioning a memory assessment service, specifies service requirements, and helps to determine local service levels and ensure corporate and quality assurance. NICE advises that it should be used in conjunction with the clinical guidelines in the joint NICE/SCIE guide *Dementia: supporting people with dementia and their carers*, which covers clinical and cost effectiveness in detail, and the NICE technical appraisal TA111.

NICE/SCIE national clinical practice guideline 42 *Dementia: supporting people with dementia and their carers* (2006)

**<http://www.scie.org.uk/publications/misc/dementia/dementia-fullguideline.pdf>**

This guide looks in detail at specialist assessment services, diagnosis of dementia, and options for treatment available. It all addresses issues of inclusion and diversity.

NICE technical appraisal 111 *Donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease* (2007)



This clarifies the steps healthcare professionals should take when assessing the severity of Alzheimer's disease, and the need to offer equal access to treatment to people with communication difficulties for whom the mini mental state exam (MMSE) is a less reliable indicator.

<http://www.nice.org.uk/guidance/index.jsp?action=byID&o=11600>

### **Objective 3: Good quality information for those diagnosed with dementia and their carers**

SCIE accessibility guidelines *How to produce information in an accessible way* (2005)

<http://www.scie.org.uk/publications/misc/accessguidelinespublications.pdf>

This guide explains how to make sure information is written in a way that is easily understood, both generally and by specific groups, such as older people with visual impairment, and people with learning difficulties.

*Understanding the NICE-SCIE guidance Dementia: supporting people with dementia and their carers* (2006)

<http://www.scie.org.uk/publications/misc/dementia/dementia-understanding.pdf>

This booklet aims to help people who have been diagnosed with dementia and their carers understand the support and treatment options that should be available.

SCIE research briefing 3 *Aiding communication with people with dementia* (2004)

<http://www.scie.org.uk/publications/briefings/briefing03/index.asp>

This looks at barriers to communication caused by dementia and the impact on quality of life. A lot of research has been done in this area including involving people with dementia in discussions about services and developing ways to help people with dementia express themselves like memory aids and music therapy. Examples of innovative practice include communication training for carers and storyboard projects.

SCIE guide 15 *Dignity in care* (updated 2009)

<http://www.scie.org.uk/publications/guides/guide15/index.asp>

This highlights the need to provide information in a way that enables a person to reach agreement in care planning and exercise their rights to consent to care and treatment, with adequate support and advocacy supplied when people have communication difficulties or cognitive impairment.

SCIE knowledge management report 15 *Using digital media to access information and good practice for paid carers of older people: A feasibility study* (2006)

**<http://www.scie.org.uk/publications/reports/report15.pdf>**

This study looks at designing information systems for paid carers of older people. It includes a literature review (p3) on information needs and information seeking behaviours in residential care and related fields that states: ‘In addition to the practical aspects of caring, a study of informal carers and professionals (nurses and social workers) working with people with dementia found that all respondents wanted information relating to the emotional side of caring, that is coping with emotions and stress management (Turner and Street 199, p.175)’.

SCIE knowledge review 13 *Outcomes-focused services for older people* (2007)

**<http://www.scie.org.uk/publications/knowledgereviews/kr13.pdf>**

This research review looks at outcomes that older people value, and what organisational arrangements can impede or facilitate outcome-focused services

Individualised approaches to communication and consultation can help people with dementia to articulate their views and preferences. Maximising their control over opportunities for communication, using pictures, using the older person’s own vocabulary and phrasing and interpreting non-verbal communication can be effective, although they require time and confidence on the part of staff. Specialist services and staff with skills in communicating with people with little language are vital to maintain quality of life of people with dementia in residential settings. (p23)

SCIE’s e-learning resources *An introduction to mental health of older people: Understanding later stage dementia*

**<http://www.scie.org.uk/publications/elearning/mentalhealth/mh06/index.asp>**

This looks at the treatments and interventions, including psychological and behavioural approaches, communication and changes to the person’s environment that are important in not taking away someone’s dignity or independence. It also looks at the needs of carers.

#### **Objective 4: Easy access to care, support and advice following diagnosis facilitated by a dementia advisor**

*Understanding the NICE-SCIE guidance Dementia: supporting people with dementia and their carers* (2006) <http://www.scie.org.uk/publications/misc/dementia/dementia-understanding.pdf>

The booklet for people with dementia and their carers outlines the support and treatment options that should be available within the NHS and social care.

SCIE guide 15 *Dignity in care* (updated 2009)

**<http://www.scie.org.uk/publications/guides/guide15/index.asp>**

Idea from practice: Staff at Birmingham and Solihull Mental Health Trust use a person-centred care position statement to value people with dementia as individuals and provide a positive social environment. Focus groups for carers, patients and staff identify areas for improvement, resulting in evidence-based interventions.

SCIE guide 3 *Assessing the mental health needs of older people*

**<http://www.scie.org.uk/publications/guides/guide03/needs/info.asp>**

This highlights the importance of giving people accurate and timely information to help them understand the diagnosis and make plans with their families, for instance, knowing what mainstream, specialist and alternative services are available.

**<http://www.scie.org.uk/publications/guides/guide03/minority/index.asp>**

This looks at needs and barriers in different black and ethnic minority communities, such as language, religious beliefs and levels of awareness. Case studies include research into service-related needs of older people with dementia and their carers in an Asian community.

**<http://www.scie.org.uk/publications/guides/guide03/abuse/index.asp>**

This points out that people with cognitive impairment or behavioural problems are particularly vulnerable to abuse. It looks at possible indicators of abuse and what to do about it.

SCIE knowledge review 13 *Outcomes-focused services for older people* (2007)

**<http://www.scie.org.uk/publications/knowledgereviews/kr13.pdf>**

This research review looks at what organisational arrangements can impede or facilitate outcome-focused services, including the experiences of minority ethnic older people (p17). Barriers to receiving good quality care include lack of knowledge about services, language and communication barriers, and scepticism about the appropriateness and cultural sensitivity of services. In some localities there may be few specialised services, particularly in residential settings, although day centres and lunch clubs are more common. Research with professionals into provision for minority ethnic older people with dementia has also identified culturally inappropriate services, as well as lack of resources and poor co-ordination between services.

SCIE guide 3 *Assessing the mental health needs of older people*

<http://www.scie.org.uk/publications/guides/guide03/needs/main.asp>

Idea from practice: Housing 21, a housing association providing extra care sheltered housing, appointed a dementia services advisor in 2004 to provide professional advice and support to their scheme managers in identifying and supporting tenants with dementia and promoting good practice in dementia care.

## **Objective 5: Structured peer support and learning networks**

SCIE position paper 10 *Seldom heard - developing inclusive participation in social care* (2008)

<http://www.scie.org.uk/publications/positionpapers/pp10.asp>

This offers practice examples of working with groups of people less likely to be heard by practitioners, managers and decision makers because of the way services and organisations operate, including people with dementia. The guide

Includes examples in which people with dementia felt heard and supported in activities (p9), a case study of a day opportunity centre for people with dementia (p16) and a model for everyday participation.

SCIE guide 17 *The participation of adult service users, including older people, in developing social care* (2006)

<http://www.scie.org.uk/publications/guides/guide17/files/guide17.pdf>

This guide highlights that people with dementia are seriously under-represented in the majority of systems for participation, although research identifies a number of methods for including people with dementia (p45).

NICE/SCIE national clinical practice guideline 42 *Dementia: Supporting people with dementia and their carers in health and social care* (2006)

<http://www.scie.org.uk/publications/misc/dementia/dementia-fullguideline.pdf>

The guidance looks at educational interventions versus standard care.

Idea from practice (p269): An evaluation of the effects of telephone contact with care consultants employed through the Alzheimer's Association in the USA. The approach involved empowering people with dementia and their carers, developing an individualised care plan, based on strengths and resources, and made use of other services, including education and training programmes, support groups and respite care.

SCIE guide 15 *Dignity in care* (updated 2009)

**<http://www.scie.org.uk/publications/guides/guide15/index.asp>**

Idea from practice: To alter the image of a ‘minding’ service, the trust redeveloped their day care service for older people with dementia. They used ‘Drama as a powerful clinical tool: fun with a purpose’ as a teaching tool for staff, who have since developed activities for people with dementia and expanded community links.

## **Objective 6: Community personal support services**

SCIE resource guide 5 *Direct payments: Answering frequently asked questions* (2005)

**<http://www.scie.org.uk/publications/guides/guide10/files/guide10.pdf>**

Idea from practice: Example of how a person with early onset dementia makes use of direct payments to take part in sports and social activities, supported by a personal assistant.

SCIE research briefing 20 *The implementation of individual budget schemes in adult social care* (2009)

**<http://www.scie.org.uk/publications/briefings/files/briefing20.pdf>**

This updated research briefing looks at factors that aid implementation of various types of scheme, the risks involved and support required to access them.

SCIE knowledge review 13 *Outcomes-focused services for older people* (2007)

**<http://www.scie.org.uk/publications/knowledgereviews/kr13.pdf>**

This research review looks at outcomes that older people value, and what organisational arrangements can impede or facilitate outcome-focused services. It identifies outcomes particularly important to older people with dementia, including personal safety, social contact, opportunities to be active, having control over everyday life and feeling valued and respected.

SCIE report 20 *Personalisation: A rough guide* (2008)

**<http://www.scie.org.uk/publications/reports/report20.asp>**

This outlines what the introduction of direct payments, individual budgets and personal budgets means for services, including implications for staff, different sorts of provider and commissioners.

SCIE position paper 10 *Seldom heard - developing inclusive participation in social care* (2008)

<http://www.scie.org.uk/publications/positionpapers/pp10.asp>

This offers practice examples of working with groups of people less likely to be heard by practitioners, managers and decision makers because of the way services and organisations operate, including people with dementia. The guide

Includes examples in which people with dementia felt heard and supported in activities (p9), a case study of a day opportunity centre for people with dementia (p16) and a model for everyday participation.

### **Objective 7: Services within the carers strategy**

SCIE guide 3 *Assessing the mental health needs of older people*

<http://www.sie.org.uk/publications/guides/guide03/index.asp>

Section 5 of this guide looks at assessing the needs of carers and what information carers require.

NICE/SCIE national clinical practice guideline 42 *Dementia: Supporting people with dementia and their carers in health and social care* (2006)

<http://www.scie.org.uk/publications/misc/dementia/dementia-fullguideline.pdf>

The guidance looks at social care assessment of carers' needs, and carers' views of how the needs of people with dementia are assessed (p83). It covers psychological interventions for carers of people with dementia, recognising that many carers are the spouses of people with dementia, and this is vital because the proportion of people with dementia will rise in line with the aging population.

SCIE knowledge management report 15 *Using digital media to access information and good practice for paid carers: A feasibility study* (2006)

<http://www.scie/publications/reports/report15.pdf>

This report looks at technology available to provide carers with information, such as the internet and digital TV.

### **Objective 8: Good quality care within general hospitals**

Helping you through a hospital stay: advice from older people

<http://www.scie.org.uk/publications/misc/hospitaldischarge/index.asp>

This booklet, produced with the help of an advisory group of older people, explains what to expect before, during and after a hospital stay.

NICE clinical guidelines *Nutrition support in adults* (2006) <http://www.nice.org.uk/Guidance/CG32>

This guidance provides best practice advice on the care of adults who are malnourished or at risk of malnutrition in a hospital, home or community setting.

## **Objective 9: Intermediate care for people with dementia**

SCIE research briefing 12 *Involving individual older patients and their carers in the discharge process from acute to community care: implications for intermediate care* (2005)

<http://www.scie.org.uk/publications/briefings/briefing12/index.asp>

This focuses on the means, benefits and difficulties of participation by individual patients and carers in planning discharge to intermediate care, especially when a person's ability to communicate preferences is affected by dementia. Includes a template for providing intermediate care to people with dementia that includes user involvement issues concerning assessment and consent.

SCIE guide 3 *Assessing the mental health needs of older people*

<http://www.scie.org.uk/publications/guides/guide03/needs/main.asp>

Health and social services are required to ensure intermediate care is available to people with dementia, but there is a risk that changes in environment and routine can exacerbate their difficulties, so transfers of care should be kept to a minimum, and handled carefully within hospital and from hospital.

## **Objective 10: Good housing, housing-related and telecare support**

SCIE research briefing 28 *Assistive technology and older people*

<http://www.scie.org.uk/publications/briefings/briefing28/index.asp>

This guide looks at benefits of assistive technology, such as promoting independence and feelings of security, for people with dementia, their family and carers, and the impact on wider health and social care organisations.

SCIE guide 3 *Assessing the mental health needs of older people*

<http://www.scie.org.uk/publications/guides/guide03/needs/main.asp>

The role of housing and housing-related services in meeting older people's mental health and social care needs has been neglected, but many services like sheltered and extra care housing are now more likely to accept people with a wide range of needs, including dementia.

SCIE knowledge management report 15 *Using digital media to access information and good practice for paid carers: A feasibility study* (2006)

**<http://www.scie.org.uk/publications/reports/report15.pdf>**

This report points out that much of the focus on telecare has been on its use in supporting people with dementia and their carers through systems tackling behaviour and monitoring cognitive decline.

SCIE guide 15 *Dignity in care* (updated 2009)

**<http://www.scie.org.uk/publications/guides/guide15/index.asp>**

Idea from practice: At Portland House extra care scheme for people with dementia, a combination of the physical environment, philosophy and person-centred practice has enabled the eight tenants to maintain their skills, build confidence in their own abilities and has boosted their self-respect.

## **Objective 11: High quality services within care homes**

SCIE guide 15 *Dignity in care* (updated 2009)

**<http://www.scie.org.uk/publications/guides/guide15/index.asp>**

This guide identifies particular risks and barriers facing people with dementia in care homes, such as mealtimes and nutritional care and making complaints.

NICE *Nutrition support in adults clinical guidelines* (2006) <http://www.nice.org.uk/Guidance/CG32>

This guidance provides best practice advice on the care of adults who are malnourished or at risk of malnutrition in a hospital, home or community setting.

SCIE research briefing 1 *Preventing falls in care homes* (updated 2005)

**<http://www.scie.org.uk/publications/briefings/briefing01/index.asp>**

This briefing looks at how falls in care homes can be actively prevented, for instance through individual risk assessment, outlining ethical and other issues and offering practice guidelines and examples.



## Objective 12: Good end of life care

NICE/SCIE national clinical practice guideline 42 *Dementia: Supporting people with dementia and their carers in health and social care* (2006)

<http://www.scie.org.uk/publications/misc/dementia/dementia-fullguideline.pdf>

The NICE guidance identifies ethical issues around end of life care and dementia. Studies suggest there is inadequate palliative care for people with dementia. (p100)

## Objective 13: An informed and effective workforce across all services

SCIE knowledge management report 15 *Using digital media to access information and good practice for paid carers: A feasibility study* (2006)

<http://www.scie.org.uk/publications/reports/report15.pdf>

This study looks at providing information for health and care professionals through technology, including digital e-learning applications in care-related NVQ programmes.

SCIE knowledge review 13 *Outcomes-focused services for older people* (2007)

<http://www.scie.org.uk/publications/knowledgereviews/kr13.pdf>

Individualised approaches to communication and consultation can help people with dementia to articulate their views and preferences. (p23)

SCIE guide 3 *Assessing the mental health needs of older people*

This guide summarises findings about skills required by practitioners such as communication, information gathering and risk assessment.

<http://www.scie.org.uk/publications/guides/guide03/process/understanding.asp>

Idea from practice: **Developing empathy** – an extract from Cambridgeshire social services toolkit for training residential care staff. It aims to help practitioners understand the older person's experience from their point of view.

<http://www.scie.org.uk/publications/guides/guide03/framework/index.asp>

Idea from practice: In Warwickshire, one locality used joint finance to put on a programme of dementia awareness training available free of charge to staff from any home care agency, care home or housing provider in the locality.

NICE/SCIE quick reference guide *Dementia: Supporting people with dementia and their carers in health and social care* (2006)

**<http://www.scie.org.uk/publications/misc/dementia/dementia-qrg.pdf>**

This summarises the NICE guidelines, including checklists of what might be covered in dementia awareness and managing challenging behaviour training.

NICE/SCIE national clinical practice guideline 42 *Dementia: Supporting people with dementia and their carers in health and social care* (2006)

**<http://www.scie.org.uk/publications/misc/dementia/dementia-fullguideline.pdf>**

The guidance looks at models of staff training and identifies barriers that may prevent learning being put into practice. It looks particularly at training to manage challenging behaviours and emotion-oriented care programmes. (p275)

Mental Capacity Act training materials

**<http://www.scie.org.uk/publications/misc/mca.asp>**

These training materials support implementation of the Mental Capacity Act in a range of care settings.

SCIE People Management website

**<http://www.scie-peoplemanagement.org.uk/>**

This website aims to support organisations in improving their people management policies and practice by encouraging the sharing of ideas, problems and good practice.

SCIE guide 3 *Assessing the mental health needs of older people*

**<http://www.scie.org.uk/publications/guides/guide03/needs/main.asp>**

Idea from practice: One locality used joint finance to put on a programme of dementia awareness training available free of charge to staff from any home care agency, care home or housing provider in the locality.

## **Objective 14 A joint commissioning strategy**

NICE/SCIE national clinical practice guideline 42 *Dementia: Supporting people with dementia and their carers in health and social care* (2006)

**<http://www.scie.org.uk/publications/misc/dementia/dementia-fullguideline.pdf>**

This guidance states that greater co-ordination and integration between health and social services are important steps to take in improving support for people with dementia. It

adopts *Everybody's Business* as the preferred source for guidance on service development and as the template for the planning, implementation and delivery of health and social care services for all people with dementia. There is a specific section on integrated health and social care services. (p115)

## **Objective 15 Improved assessment and regulation of health and social services**

No evidence available

## **Objective 16 Research evidence**

SCIE guide 3 *Assessing the mental health needs of older people*

**<http://www.scie.org.uk/publications/guides/guide03/needs/index.asp#dem>**

Summary of research findings, such as what older people with mental health needs want from services and what services are most effective.

SCIE guide 15 *Dignity in care* (updated 2009)

**<http://www.scie.org.uk/publications/guides/guide15/index.asp>**

This guide highlights gaps in the research. Many of the studies that involve interviewing samples of older care users have commented that people were selected by virtue of their capacity to take part in interviews and or complete questionnaires. By definition, people with dementia, other cognitive impairments or communication difficulties have been excluded, contributing to their relative absence from 'involvement' activity in health and social care.

SCIE research briefing 3 *Aiding communication with people with dementia* (2004)

**<http://www.scie.org.uk/publications/briefings/briefing03/index.asp>**

This briefing identifies key themes of research in this area, including developing therapeutic ways for people with dementia to express themselves, ethical considerations and contributing factors to communication barriers.

NICE/SCIE national clinical practice guideline 42 *Dementia: Supporting people with dementia and their carers in health and social care* (2006)

**<http://www.scie.org.uk/publications/misc/dementia/dementia-fullguideline.pdf>**

The guidance gives examples of research and provides research recommendations throughout. It outlines the methodology used to locate and present evidence on which to base recommendations. (p49)

Research Register for Social Care

**<http://www.researchregister.org.uk/default.asp>**

This is a general database of current and completed research projects that have been subject to independent ethical and scientific review. Currently source data is primarily provided by local authorities and bodies that carry out research for the Department of Health.

Social Care Online

**<http://www.scie-socialcareonline.org.uk/default.asp>**

This website is an extensive database of social care information – useful for finding out what research has been published on dementia

## **Objective 17 National and regional implementation**

NICE/SCIE joint implementation support tools for national clinical practice guideline 42 *Dementia: Supporting people with dementia and their carers in health and social care* (2006)

**<http://www.nice.org.uk/Guidance/CG42#implementation>**

This set of tools to support local implementation of the NICE guidance includes implementation advice for health and social care service providers, an audit checklist to assess compliance with guidelines, costing report on resource implications of implementation and costing template to assist with financial planning.

SCIE knowledge review 16 *Improving social and health care services* (2007)

**<http://www.scie.org.uk/publications/knowledgereviews/kr16.pdf>**

This knowledge review explores the processes and actions that have proven most effective in bringing about and sustaining improvement in social and health care services. One case study is Age Concern Sheffield, highlighting its role in providing choice to older people.

NICE *How to change practice* (2007) and *How to put NICE guidance into practice to improve the health and well-being of communities* (2008)

**[http://www.nice.org.uk/using\\_guidance/implementation\\_tools/howtoguide/145how\\_to\\_guide.jsp](http://www.nice.org.uk/using_guidance/implementation_tools/howtoguide/145how_to_guide.jsp)**

Practical advice on how to identify and overcome barriers to changing practice in line with the latest guidance and to support the implementation of NICE guidance generally.

# Annex 2: Template for assessing local dementia needs

**Completion of any or all of the domains in this template is entirely discretionary.**

**This template includes a range of population and service measures that commissioners will find useful for population based assessment of need and mapping available services to meet that need.**

<b>Aspect</b>	<b>Issues to consider</b>	<b>Questions to ask</b>	<b>Data source</b>
What's good for the heart is good for the head	<p>The data items in this section are the same as those data items as the stroke JSNA template in the DH's <i>Improving stroke services: a guide for commissioners</i> (page 18) <a href="http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PolicyAndGuidance/DH_063260">http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PolicyAndGuidance/DH_063260</a></p> <p>Incidence of TIA and stroke and pulmonary vascular disease</p>	How many? Age profile? Ethnicity?	<p>ASSET, LDP Cardiovascular line, Health Survey England, <a href="http://www.dh.gov.uk/en/Publicationsandstatistics/PublishedSurvey/HealthSurveyForEngland/DH_632">http://www.dh.gov.uk/en/Publicationsandstatistics/PublishedSurvey/HealthSurveyForEngland/DH_632</a></p> <p>Quality and Outcomes Framework <a href="http://www.ic.nhs.uk/statistics-and-data-collections/supporting-information/audits-and-performance/the-quality-and-outcomes-framework/qof-2007/08/data-tables">http://www.ic.nhs.uk/statistics-and-data-collections/supporting-information/audits-and-performance/the-quality-and-outcomes-framework/qof-2007/08/data-tables</a></p> <p>Contact: <a href="mailto:Kate.Croft@ic.nhs.uk">Kate.Croft@ic.nhs.uk</a></p>
	Circulatory disease mortality target		<p>Progress on 4 week quitters</p> <p>Contact: <a href="mailto:Alyson.Whitmarsh@ic.nhs.uk">Alyson.Whitmarsh@ic.nhs.uk</a> (Lifestyles)</p>
	<i>Smoking prevalence</i>		QOF obesity register <a href="http://www.ic.nhs.uk/statistics-and-data-collections/supporting-information/audits-and-performance/the-quality-and-outcomes-framework/qof-2007/08/data-tables">http://www.ic.nhs.uk/statistics-and-data-collections/supporting-information/audits-and-performance/the-quality-and-outcomes-framework/qof-2007/08/data-tables</a>
	<i>Diet and physical activity issues</i>		QOF hypertension data, prescribing rates, disease prevalence models also available via the Association of Public Health Observatories <a href="http://www.ic.nhs.uk/statistics-and-data-collections/supporting-information/audits-and-performance/the-quality-and-outcomes-framework/qof-2007/08/data-tables">http://www.ic.nhs.uk/statistics-and-data-collections/supporting-information/audits-and-performance/the-quality-and-outcomes-framework/qof-2007/08/data-tables</a>
	<i>Hypertension treatment</i>		QOF hypertension data, prescribing rates, disease prevalence models also available via the Association of Public Health Observatories <a href="http://www.ic.nhs.uk/statistics-and-data-collections/supporting-information/audits-and-performance/the-quality-and-outcomes-framework/qof-2007/08/data-tables">http://www.ic.nhs.uk/statistics-and-data-collections/supporting-information/audits-and-performance/the-quality-and-outcomes-framework/qof-2007/08/data-tables</a>
	<i>Cholesterol management</i>		
	<i>Atrial fibrillation management</i>		<p><a href="http://www.ic.nhs.uk/webfiles/QOF/2007-08/NewFilesGS/QOF0708_Pracs_AtrialFibrillation.xls">http://www.ic.nhs.uk/webfiles/QOF/2007-08/NewFilesGS/QOF0708_Pracs_AtrialFibrillation.xls</a></p>

Aspect	Issues to consider	Questions to ask	Data source
Population data	<p>Predicted population of people with dementia in local community now and future modelling including;</p> <ul style="list-style-type: none"> <li>• People with learning disabilities aged 50+</li> <li>• People from BME populations at higher risk of dementia</li> </ul>	<p>Plot trajectories over 5, 10, 15 and 20 years. Include trajectories for BME and LD populations.</p> <p>Is there a planned increase in local extra care housing or residential/nursing home facilities that will increase the trajectory?</p>	<p>Dementia UK prevalence figures: <a href="http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=4">http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=4</a></p> <p>POPPI - <a href="http://www.poppi.org.uk/">http://www.poppi.org.uk/</a></p> <p>PANSI - <a href="http://www.pansi.org.uk/">http://www.pansi.org.uk/</a></p> <p>DWP data on learning disability - <a href="http://83.244.183.180/100pc/tabtool.html">http://83.244.183.180/100pc/tabtool.html</a></p> <p>QOF – 2 indicators DEM01 and DEM02 <a href="http://www.ic.nhs.uk/statistics-and-data-collections/supporting-information/audits-and-performance/the-quality-and-outcomes-framework/qof-2007/08/data-tables">http://www.ic.nhs.uk/statistics-and-data-collections/supporting-information/audits-and-performance/the-quality-and-outcomes-framework/qof-2007/08/data-tables</a></p>
Number of carers of people with dementia living locally	Number of carers of people with dementia living locally	Carers might live in a different locality to the person receiving care	<p>QOF Management 9 - Carer register</p> <p><a href="http://www.ic.nhs.uk/statistics-and-data-collections/supporting-information/audits-and-performance/the-quality-and-outcomes-framework/qof-2007/08/data-tables">http://www.ic.nhs.uk/statistics-and-data-collections/supporting-information/audits-and-performance/the-quality-and-outcomes-framework/qof-2007/08/data-tables</a></p>

Aspect	Issues to consider	Questions to ask	Data source
Diagnosis	<p>Number of people diagnosed with dementia;</p> <ul style="list-style-type: none"> <li>• by type of diagnosis ie AD, vascular, mixed etc</li> <li>• by level of need: low, moderate, high</li> </ul>	Do these numbers equate with predicted prevalence?	<p>GP dementia register – QOF Dem 1 (See link above)                      Alzheimer’s Society  <a href="http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=4">http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=4</a>                      Memory Assessment Clinics                      IC Prescribing have announced that they shall be making PCT level data available down to BNF section level from the 28th of April. - David.Lloyd@ic.nhs.uk  <a href="http://www.ic.nhs.uk/statistics-and-data-collections/primary-care/prescriptions">http://www.ic.nhs.uk/statistics-and-data-collections/primary-care/prescriptions</a>                      18 weeks dataset</p>
Healthcare	<p>Number of people admitted to hospital with diagnosis of dementia (primary, secondary or tertiary reason for admission)</p> <p>Memory assessment services</p>	<p>Consider issues including:</p> <ul style="list-style-type: none"> <li>• Repeat admissions</li> <li>• Unplanned admissions</li> <li>• Length of stay</li> </ul> <p>Number of local memory services per 1000 population.                      Does the capacity of local memory assessment services meet local demand?                      Are services located in areas accessible to population in need?</p>	<p>HES – list relevant ICD10 codes (F000, F001, F002, F009, F010, F011, F012, F013, F018, F019, F020, F021, F022, F023, F024, F028, F03, F03X, F050, F051)                      Split acute and mental health trusts  <a href="http://www.nhs.uk/ServiceDirectories/Pages/AcuteTrustListing.aspx">http://www.nhs.uk/ServiceDirectories/Pages/AcuteTrustListing.aspx</a></p> <p>Local data</p>



Aspect	Issues to consider	Questions to ask	Data source
	<p>Prescribing activity; Anti-dementia drugs donepezil, rivastigmine, galantamine Memantine Antipsychotic drugs</p>	<p>Doe prescribing activity match prevalence and new diagnosis data?</p>	<p>Available locally from PCT Prescribing Advisory team</p>
	<p>Number of people with dementia admitted to A&amp;E</p>	<p>Investigate reasons for admission to A&amp;E. Should more appropriate services be commissioned?</p>	<p>Local data</p>
	<p>Number of people on GP dementia registers</p>	<p>Are numbers on registers what you would expect based on prevalence data? What interventions can be commissioned to improve numbers on dementia registers?</p>	<p>QOF Dem 1 number of people on GP dementia register QOF Dem 2 shows percentage of patients on dementia register whose care has been reviewed in last 15 months: <a href="http://www.ic.nhs.uk/webfiles/QOF/2007-08/NewFilesGS/QOF0708_Pracs_Dementia.xls">http://www.ic.nhs.uk/webfiles/QOF/2007-08/NewFilesGS/QOF0708_Pracs_Dementia.xls</a></p>
	<p>Number of carers of people with dementia</p>	<p>How do numbers of carers match with numbers of people with dementia? Are there strong links between commissioning dementia services and commissioning carers services?</p>	<p>RAP C1 (MH), <a href="http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/community-care-statistics-2007-2008:-referrals-assessments-and-packages-of-care-for-adults-england-provisional-council-data">http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/community-care-statistics-2007-2008:-referrals-assessments-and-packages-of-care-for-adults-england-provisional-council-data</a> 2001 Census, Alzheimers' Society</p>

Aspect	Issues to consider	Questions to ask	Data source
	Day hospitals	Are day hospital services for people with dementia embedded within local dementia strategy services?	Contact: Kathryn.Knight@ic.nhs.uk
Voice	Local people's views on dementia services	What services and support do people want?  How are people rating existing services?	Patient surveys from HCC – inpatient, outpatient, MH, A&E  <a href="http://www.healthcarecommission.org.uk/yourviews/patientsurveys/mentalhealthservices.cfm">http://www.healthcarecommission.org.uk/yourviews/patientsurveys/mentalhealthservices.cfm</a>  CSCI surveys in care homes <a href="http://www.csci.org.uk/default.aspx?page=901&amp;key=">http://www.csci.org.uk/default.aspx?page=901&amp;key=</a>  Local Surveys
Social care and housing	Number of people receiving the following services		

Aspect	Issues to consider	Questions to ask	Data source
	Domiciliary care	Include data by subsets of funding sources including: <ul style="list-style-type: none"> <li>• Local authority</li> <li>• Continuing NHS Care</li> <li>• Self-funding</li> <li>• Charitable funding</li> </ul>	RAP P2f/P2s – for MH, LD  <a href="http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/community-care-statistics-2007-2008:-referrals-assessments-and-packages-of-care-for-adults-england-provisional-council-data">http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/community-care-statistics-2007-2008:-referrals-assessments-and-packages-of-care-for-adults-england-provisional-council-data</a>
	Day services		RAP P2f/P2s – for MH, LD  <a href="http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/community-care-statistics-2007-2008:-referrals-assessments-and-packages-of-care-for-adults-england-provisional-council-data">http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/community-care-statistics-2007-2008:-referrals-assessments-and-packages-of-care-for-adults-england-provisional-council-data</a>
	Residential care		RAP P1 – for MH, LD,  <a href="http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/community-care-statistics-2007-2008:-referrals-assessments-and-packages-of-care-for-adults-england-provisional-council-data">http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/community-care-statistics-2007-2008:-referrals-assessments-and-packages-of-care-for-adults-england-provisional-council-data</a>  CSCI – beds <a href="http://www.csci.org.uk">http://www.csci.org.uk</a> (nothing under publications)
	Nursing care  (also look at Continuing NHS Care data)		RAP P1 – for MH, LD,  <a href="http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/community-care-statistics-2007-2008:-referrals-assessments-and-packages-of-care-for-adults-england-provisional-council-data">http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/community-care-statistics-2007-2008:-referrals-assessments-and-packages-of-care-for-adults-england-provisional-council-data</a>  CSCI – beds <a href="http://www.csci.org.uk">http://www.csci.org.uk</a> (nothing under publications)
	Extra care housing		Local Delivery Plan?

Aspect	Issues to consider	Questions to ask	Data source
	<p>Number of people with dementia receiving :</p> <p>Direct payment</p> <p>Individual/personal budgets</p>	<p>Direct payments-</p> <p>Individual/Personal budgets-</p>	<p>RAP P2f/P2s – for MH, LD  <a href="http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/community-care-statistics-2007-2008:-referrals-assessments-and-packages-of-care-for-adults-england-provisional-council-data">http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/community-care-statistics-2007-2008:-referrals-assessments-and-packages-of-care-for-adults-england-provisional-council-data</a>                      RAP P2s from 2008/09                      (not yet available online)</p>
	<p>Number of people using assistive technology</p>		<p>Self Assessment Survey (SAS)  <a href="http://www.csci.org.uk/pdf/SAS_report_Nov_2007.pdf">http://www.csci.org.uk/pdf/SAS_report_Nov_2007.pdf</a></p>
<p>Joint health and care services</p>	<p>Intermediate care</p> <p>Expenditure data</p>	<p>Do services meet with the forthcoming Intermediate care refresh guidance?</p> <p>Examine expenditure against outcome as well as activity.                      Does expenditure on services represent value for money?</p>	<p>New collection for 08/09 on the number of people still at home 3 months after discharge into joint rehabilitation.                      Local data</p> <p>Programme budgeting data - DH</p> <p>PSSEX1 from 2009/10 but may be available locally in the meantime</p>
	<p>End of life care</p>	<p>Are the needs of people with dementia met in local EoLC strategies and services?</p>	<p>Local data</p>

# Annex 3: South East Coastal SHA dementia metrics

## The Development of Dementia Metrics in NHS South East Coast

### Background

In the autumn of 2007, South East Coast SHA embarked on a Clinical Metrics Development Programme which had the aim of developing more sophisticated metrics than were currently used locally to describe a number of conditions, one of which was dementia. This work was undertaken jointly with the Information Centre for Health and Social Care.

For each pathway, the Clinical Metrics Development Programme aimed to develop intelligent measures which were constructed from existing (credible) data sources, which were relevant to clinicians across the pathway and which incorporated a range of outcome measures to demonstrate quality of care along with cost effectiveness. It was intended that once a set of measures had been agreed, comparative information would be provided for organisations within South East Coast and this information would be updated on a regular basis.

A group of clinicians and managers from across South East Coast met on a number of occasions to:

- Identify data sets available to describe the pathway;
- Define metrics which are useful;
- Review analysis which has subsequently been undertaken and debate why variation appears to exist in different areas of South East Coast;
- Further refine measures already defined and agree new metrics.

### DATA SETS RELEVANT TO DEMENTIA

As expected, only a limited number of data sets relevant to dementia were identified. It has, however, been possible to provide analysis for a number of indicators which clinicians have told us are useful in prompting discussion. The work so far has focussed on utilising health data sets. It is likely that a number of social care indicators could supplement the health indicators already developed.

A summary of the relevant data sets identified appears below: -

#### 1. Quality and Outcomes Framework (QOF)

The QOF was introduced as part of the new General Medical Services (GMS) contract on 1 April 2004. QOF is measured by QMAS, a national IT system developed by NHS Connecting for Health (CfH). QMAS ensures consistency in the calculation of quality achievement and disease prevalence, and is linked to payment systems. There are two indicators which relate to dementia services.

- The practice can produce a register of patients diagnosed with dementia;
- The percentage of patients diagnosed with dementia whose care has been reviewed within the previous 15 months;

#### 2. Programme Budget data

In 2002, the Secretary of State for Health requested the collection of financial information that identifies all Primary Care Trust (PCT) expenditure, including primary care services, to programmes of care based on medical condition. This information is referred to as Programme Budgeting. One of the programme budget spend areas is organic mental health disorders which includes dementia.

#### 3. Acute Trust inpatient data

The inpatient data set enables us to know how many patients were admitted to hospital with a primary or subsequent diagnosis of dementia, what the primary diagnosis was if dementia was not the primary diagnosis, how long each patient stayed in hospital, whether they were male or female, how old they were, the PCT of residence, postcode of where each patient resides and where the patient was discharged to.

#### 4. Mental Health Trust inpatient data

The same data set as described for acute Trusts is available for inpatient stays in mental health Trusts.

#### 5. Prescribing data

Data for the prescription of anti-dementia drugs in both primary and secondary care is available, however local analysis in this area has not yet been provided due to data not being available for all commissioners and providers.

## 6. PCT population data and predicted prevalence information

Information is available which describes PCT populations and organisations such as the Alzheimer's Society and National Audit Office provide models for predicted prevalence.

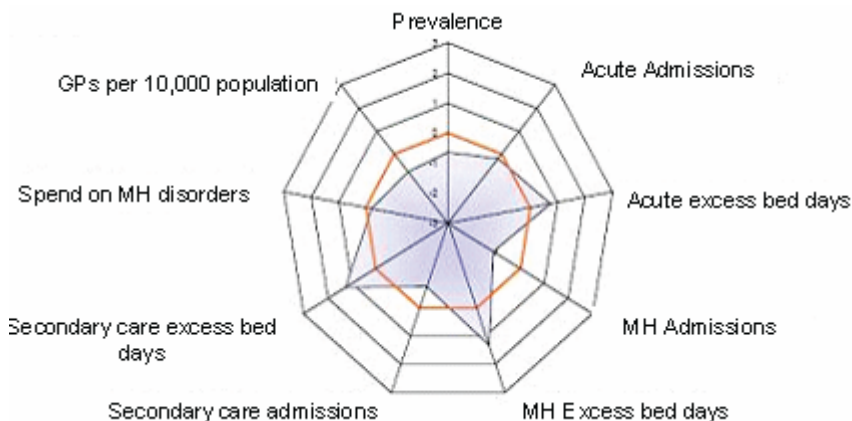
The MHMDS (Mental Health Minimum Data Set) was not used as a data source. Historically, clinical coding of this data set has been limited making it hard to obtain accurate figures for the numbers of dementia cases. Local providers have worked hard over the past year to improve the level of coding which will make it a very powerful data source for use in future as it contains information on the entire patient journey through mental health services (including outpatient attendances, contacts with occupational therapists, community nurses and other Allied Health professionals). Unfortunately it was not possible to access up to date data for this exercise.

### ANALYSIS UNDERTAKEN

It has been possible to provide comparative information on the following indicators: -

- Programme Budget Spend on organic mental health disorders (which includes dementia) over time;
- % practices that can produce a dementia register;
- % patients diagnosed with dementia whose care has been reviewed in the previous 15 months;
- Information on admissions to secondary care (mental health and acute providers) where dementia is the primary diagnosis or within the first three positions. This includes the number of admissions, number of bed days utilised, financial cost of these stays and length of stay;
- By GP practice, a comparison of the predicted number of patients diagnosed with dementia compared to the number on dementia registers.

As part of the work undertaken jointly with CHKS, different elements of information were triangulated to test out whether there were relationships between different variables. On the next page, you can see a radar plot for one PCT which combines information on spend acute and mental health admissions, excess bed days, prevalence and numbers of GPs. We do not currently know what a 'good shape' looks like, however we do know that the shape of the radar plot for PCTs within South East Coast are very different and this has prompted lots of discussion within local health communities.



The two areas of analysis that have prompted the most discussion are the practice based prevalence information and the information on admissions to provider units. Both of these have significant implications for Commissioners and will be covered in the next section.

### KEY FINDINGS

#### Inpatient admissions to Acute Hospitals

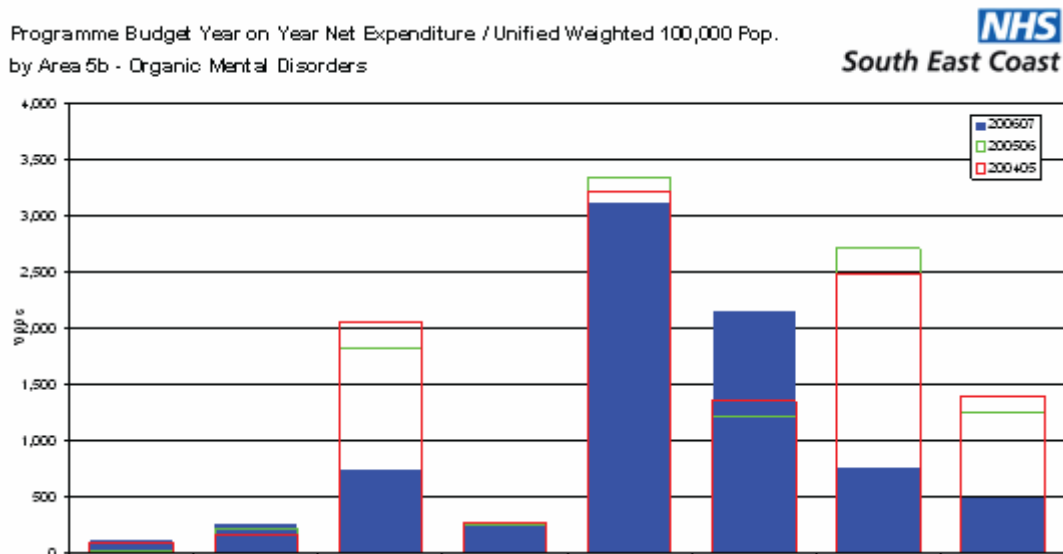
A considerable number of patients are admitted to Acute Trusts within South East Coast with a diagnosis of dementia.

For 2007/8, there were nearly 500 admissions with a primary diagnosis of dementia. These admissions utilised 8,631 bed days. Based on a bed day cost of £300, this equates to over £2.5 million.

Expanding the analysis to the first three diagnostic positions, there were nearly 5,500 admissions which utilised 57,280 bed days. Based on a bed day cost of £300, this equates to over £17 million. With the correct model of diagnosis and treatment, it should be possible to reduce the number of costly admissions to acute Trusts thereby freeing up resources to be used more cost effectively.

**Reported spend on dementia services**

There is a significant variation in the amount that PCTs reportedly spend on organic mental health disorders (which includes dementia). According to Programme Budget data, some PCTs have significantly reduced their spend on this clinical group over the past three years. This may be based on differences in categorising spend, however it has again provided a useful discussion point for local health communities, particularly when considered alongside the prevalence modelling.



**Prevalence**

The one measure that the dementia group agreed from the start that was absolutely critical, is a comparison of the predicted number of patients in a given geography expected to have dementia compared to the numbers diagnosed with dementia. The QOF data provides numbers of patients on dementia registers and using practice population information (provided by PCTs), it has been possible to model expected numbers using the National Audit Office prevalence profile. It has been possible to provide this comparison for each GP practice within South East Coast. Results reinforce national estimates that PCTs are currently identifying less than 41% of the predicted population (between 31% and 40% for PCTs within South east Coast and much more variable when looked at by practice).

There are no doubt a number of factors which may impact upon this low level of diagnosis. It can be difficult to make a diagnosis in someone with mild cognitive impairment. GPs may suspect dementia but there may not be sufficient evidence to warrant a formal diagnosis. Alternatively the GP may not be aware of the process to obtain a formal diagnosis or services may be difficult to access/not available locally.

**Products available to enable PCTs and Trusts to monitor progress**

Secondary care dementia dashboard

A dashboard has been developed (which is updated on a quarterly basis) which shows the impact upon secondary care of patients admitted with a diagnosis of Dementia (ICD10 F00-F03) in one of the first three diagnostic positions. A sample of the dashboard can be seen below – it is possible to select any secondary care organisation within South East Coast. The data has been taken from SUS and covers inpatient care in the acute and mental health sectors, and is based on admissions. There are 8 metrics in this Dashboard.

**1. LoS Distribution**

This shows the length of stay grouped up for all patients in the time period, and is split into patients with a primary diagnosis of dementia and those with dementia in any of the first three diagnostic positions



## 2. Discharge Destination

Where dementia patients were discharged to - again covering the whole time period and split into Primary and Any of the first three diagnostic positions

## 3. Top Ten Diagnoses

Where the primary diagnosis is not dementia this shows the ten most common primary diagnoses for each Trust

## 4. Numbers of Diagnoses

Numbers of diagnoses of dementia per quarter split into primary & secondary diagnosis

## 5. Average length of stay

By quarter the mean length of stay for patients with a diagnosis of dementia - split by primary diagnosis and first three diagnostic positions

## 6. Total Bed days

By quarter the mean total number of bed days consumed by patients with a diagnosis of dementia - split by primary diagnosis and first three diagnostic positions

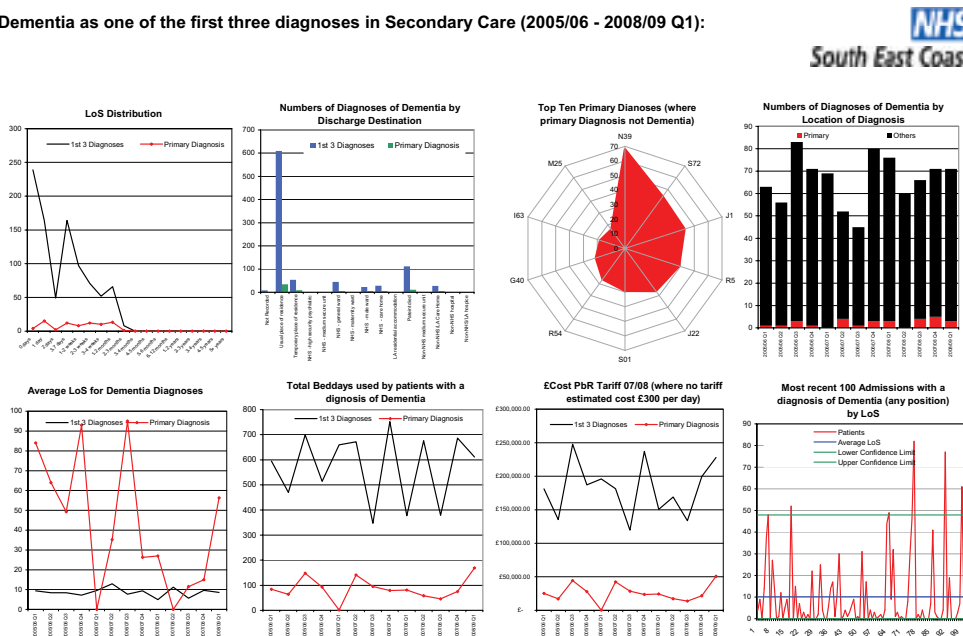
## 7. Cost

By quarter the cost to the Trust of patients with a diagnosis of dementia - split by primary diagnosis and first three diagnostic positions. Where a valid HRG exists the 07/08 PbR tariff cost is assigned. Where there was no valid HRG an average cost per case of £300 is assigned.

## 8. Length of stay SPC Chart

Shows the actual length of stay for the 100 most recent cases of dementia (any diagnostic position) in the Trust.

Dementia as one of the first three diagnoses in Secondary Care (2005/06 - 2008/09 Q1):



### Commissioner dementia dashboard

A comparable commissioner based dashboard is currently in development. We hope that this will be available by the end of April 2009.

Both of these dashboards should provide local organisations with a mechanism to monitor how planned changes in service provision are impacting a number of variables.

### FURTHER INFORMATION

Further detail regarding the dementia metrics work and associated monitoring tools can be obtained from Adam Cook, Specialist Information Analyst, NHS South East Coast ([adam.cook@southeastcoast.nhs.uk](mailto:adam.cook@southeastcoast.nhs.uk) or 01293 778846)

Further information is also available from the Knowledge Management website (N3 connection only). Users need to register as a user and then log on to access relevant files. Once this has been done, please go to the 'Clinical Information' section of 'Downloads'.

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# Annex 5: Acknowledgements

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