5. Services for people with dementia

5.1 WHAT DEFINES HIGH-QUALITY DEMENTIA SERVICES?

Based on the strategic documents, the overall vision of high-quality dementia care is as follows:

**Information**
- Public awareness of the disease and a positive attitude to it, with access to good-quality information on the illness and services available.

**Early diagnosis**
- High awareness among care staff of early signs of dementia.
- Good-quality local services to diagnose dementia and coordinate early interventions.

**Coordinated care**
- A dementia adviser to facilitate access to services.
- Multi-agency coordinated team to support people with dementia.
- An adequate and flexible range of services, support and technology that are personalised for people with dementia who are living at home, and their carers, including adequate housing support and services.
- Intermediate care, such as community hospitals and rehabilitation, for people with dementia, to help avoid the need for hospital admission and a pathway out of hospital, including appropriate use of telecare and other technology.

**Treatment of symptoms and challenging behaviour**
- Recognition of signs of distress and appropriate responses to diffuse anxiety and support the person’s understanding of what they are experiencing.
- Minimal use of inappropriate medication such as antipsychotic drugs to sedate people.
Carer support

- Social networks offering peer support for people with dementia and their carers and input into designing services.
- Support to encourage independence and continued involvement in social and community activity.
- Support and good-quality planned breaks for carers of people with dementia, and strengthened support for carers who are children.

Hospital care

- Specialist liaison older people’s mental health teams and clinical leadership for dementia care in hospitals, with defined care pathways.

End-of-life care

- Care homes that have planned care for residents with dementia including defined care pathways and specialist in-reach services from community mental health teams, primary care and dentistry.
- End-of-life care planning that begins early after diagnosis and based on the Gold Standard framework for palliative care, with good pain relief and nursing support for people with dementia at the end of their life.

Staff training

- All staff involved in the care of the patient has appropriate training, awareness of the disease and a positive attitude to it.

Funding and commissioning

- Services that are jointly commissioned by health and local authorities, which are planned to cater for the needs of the local population.
- Support at national and regional levels to ensure appropriate services are implemented.
- Improved assessment and inspection of healthcare, social care and residential services by the Care Quality Commission.

Sections 5.2–5.13 provide data on what support and services are being provided for people with dementia and their carers in England.
5.2 INFORMATION AND SUPPORT

Most people with dementia go to their GP for help within a year of noticing their symptoms, but some wait longer. There are several reasons for this delay, including people not recognising that their problems could be because of dementia, or thinking that nothing can be done to help or concerns about the stigma associated with a diagnosis of dementia.31, 32

Carers often struggle to get enough support, including accessing the information they need to help them care for a person with dementia. Members of community mental health teams report that policies on giving information to people with dementia and their carers are often not in place or not followed.

The National Dementia Strategy Impact Assessment calculated that the cost of providing information about dementia for patients and carers, relevant for different subgroups of people, would cost £1.5m in the first two years.20 The cost of producing one leaflet was £15,000 to £30,000, and designing and pre-testing the content cost between £12,000 and £67,000.

Figure 14: Variability in information provision for patients and carers16
5.3 TRAINING OF HEALTH AND SOCIAL CARE STAFF

The NICE/SCIE (2006) clinical guideline for dementia\(^1\) states that all health and social care managers should ensure all staff working with older people in the health, social care and voluntary sectors have access to dementia care training and skill development. This has been reinforced by the publication of ‘the common core principles for supporting people with dementia.’\(^5\) The aim is for the principles to provide a common framework as the basis for training programmes for the care workforce.

A survey of UK GPs in 2006 asked them about their attitudes to early diagnosis of dementia and how well equipped they felt they were to contribute to the diagnostic process. The survey found that two-thirds agreed that making an early diagnosis was important, but less than one-third felt they were adequately trained in diagnosing and managing dementia.\(^6\) These findings are summarised in figure 15.

Figure 15: Attitudes of GPs to caring for patients with dementia, 2006\(^33\)
A key recommendation of the national policy and guidance, summarised in section 3 of this report, is that staff in acute hospitals need training in how to recognise dementia and how to care for people with dementia when they are admitted to hospital for other conditions. The preliminary findings from the National Audit of Dementia state that very few hospitals reported that training in awareness of dementia was mandatory for all staff. In addition, in the majority of hospitals, the training and knowledge framework or strategy (or both) did not identify necessary skill development in caring for people with dementia.

The quality of educational material on dementia is often poor. One study in Florida found that over 90% of training programmes for all health and social care staff who looked after people with dementia were poorly designed and often contained inaccurate information, language that was not person-centred, and were missing required training components. Linking training to the national occupation standards, as set out in the core competencies, should ensure that training covers the eight principles identified, with particular emphasis on meaningful communication for people with dementia and respect and support for carers.
5.4 SERVICES FOR PEOPLE WITH DEMENTIA IN ENGLAND

People with dementia have complex needs that require coordination between health and social care services. A particularly vulnerable group are those under the age of 65 years with complex needs who may not be eligible for elderly care services.

Figure 16: Type of social care services received, 2008-09

![Pie chart showing 58% community-based services, 28% residential care, 14% nursing care.]

Of the 570,000 people living with dementia in England, just over 70,000 receive relevant social care services. Improved early diagnosis of dementia should increase the number of people who receive these services, but then the costs for care of people with dementia are likely to increase substantially.

Of those people receiving social care services in 2008-09, more than half were community-based, with 28% in residential care and 14% receiving nursing care.
People with memory problems and dementia usually follow a complex care pathway and have difficulty accessing the limited available services. Not every elderly person with memory problems has dementia or is suitable for dementia services. Diagnosis can be made by a range of experts including the GP, community mental health team, psychiatrist or elderly medicine physician, but liaison between service providers can be challenging. Investigations such as CT scans can be used to exclude treatable problems, but the main needs are for social care services, because relatively little can be offered to treat dementia.

The care pathway for a person who has been diagnosed with dementia needs to be an iterative one, with repeated assessment and prescribing reviews as the patient’s condition changes over time.

Care pathways should involve health and social care professionals from the initial diagnosis to end-of-life care. For most patients, the GP is the central healthcare provider who coordinates care for their health and social problems.
Figure 18: Typical dementia care pathway\textsuperscript{37}
A more detailed pathway is available from the Map of Medicine.\textsuperscript{38}
5.6 DIAGNOSIS

The diagnosis of dementia is essentially clinical, based on low or deteriorating scores on tests such as the mini mental state examination (MMSE).

Diagnosis may involve two types of assessment – a comprehensive geriatric assessment to identify all physical and mental health and social problems, and specific screening for dementia.

As with many long-term problems, dementia can be difficult to diagnose early, when the person's symptoms may be very similar to the increased forgetfulness of getting older. Data suggest that dementia is under-diagnosed in the UK population, even in more severe cases.

There is likely to be an ideal clinical ‘window’ for diagnosing dementia, when the symptoms are sufficiently advanced to make the diagnosis reasonably certain, but still mild enough that the person and their family can benefit from treatments and support. Effective care early in dementia includes the identification and treatment of associated health problems, such as poor sight or hearing, that could be contributing to the person's confusion or worsening their quality of life. Support from a multidisciplinary team of social services, primary care and specialist psychiatry or psychogeriatric services at an early stage might prevent crises when the person becomes unable to cope, and can help maintain the person's independence for as long as possible. In this way, it might be possible to reduce the need for emergency admission to hospital or to delay a move into long-term residential care.

Equitable access to dementia services is an issue particularly for ethnic minority groups, who may find it difficult to access information in a language they can understand, and for younger age groups, as many services are targeted at people aged over 65 years. The Alzheimer’s Society report on dementia in the UK in 2007 estimated there were more than 11,000 people from black and minority ethnic groups with dementia, 6% of whom have early onset dementia, compared with 2% of the rest of the UK population. Early onset dementia affects more men than women, and is often caused by frontotemporal dementia. The Alzheimer’s Society report estimated that there were at least 15,000 people under 65 years known to have dementia in the UK, although the true figure could be three times as high, compared with almost 669,000 aged over 65.

One measure widely used to assess the severity of dementia is MMSE:

- mild dementia: MMSE 21-26
- moderate dementia: MMSE 10-20
- moderately severe dementia: MMSE 10-14
- severe dementia: MMSE less than 10.
5.6.1 Failed diagnoses

A major problem is the continuing failure to correctly diagnose people with dementia.⁶

Between a half and two-thirds of the number of people estimated to have dementia in each PCT area will not be on a dementia register, and therefore will not be identified as being in need of support.

Figure 19: Proportion of people who are estimated to have dementia who are actually on their GP's dementia register (broken down by PCT area)²,³⁹
5.6.2 Potential cost savings from early diagnosis

Failure to diagnose dementia early leads to patients and carers missing out on important care and support. Not only does this impact negatively on their quality of life, it also means that interventions that might prevent or delay the need for residential care are not available in time for them to make a difference.

Banerjee and Wittenberg (2009) evaluated one particular approach to early intervention: the Croydon Memory Service Model. This model uses a multidisciplinary and multiagency team to provide early diagnosis, followed by information and medical, social and psychological help to people diagnosed with dementia and their carers. Banerjee and Wittenberg modelled the impact of such a service on dementia care throughout England, and concluded that it would be:

(a) cost-effective after 10 years if it led to a 10% or more reduction in residential care admissions
(b) cost saving if it led to a 20% or more reduction in residential care.

These estimates for reduction in the number of residential places required for people with dementia are likely to be achievable. One UK study found that 18% fewer people needed residential care if they had access to a care manager to coordinate their health and social care needs, with 33% of patients receiving current types of care still able to live at home after two years, compared with 51% of the case management group.

A Healthcare for London report used these calculations to determine the effect of establishing such a memory service for the 862,000 people aged 65 and over in London, as well as implementing the NICE/SCIE guideline recommendation of psychological therapy for carers of people with dementia, reduced use of electroencephalograms and increased use of structural imaging of the brain. This evaluation concluded that the set-up and running costs of the new service would be likely to delay entry to residential care and reduce emergency admissions to secondary care by improving management of the condition and preventing crises that would normally lead to an acute admission. The enhanced service would be cost saving in London if the need for residential care fell by 10% and emergency admissions fell by 13%, or if residential care fell by 20% and emergency admissions by 4.5% (figure 20).
Figure 20: Balancing the costs of a memory clinic service in London: two scenarios

Costs of memory clinic (£27.4m)

AND

Costs of psychological therapy and imaging (£6.3m)

AND

Reduction in residential care of 10% (£14.8m)

AND

Reduction in acute admissions of 13%
5.7 PRIMARY CARE

As noted in the previous section, most people with suspected dementia are diagnosed by their GP and most of the care they receive is coordinated by primary care teams. The primary care team, led by the GP, therefore plays a crucial role in the care of people with dementia from diagnosis to the end of life.

A report by the King's Fund, based on a literature review, guidelines and expert opinion, concluded that GPs could deliver high-quality care for people with dementia and their carers in the following ways:

- Being aware of the risk factors and symptoms of dementia and knowing what action to take when a patient presents with symptoms that could be caused by dementia.
- Being proactive in finding patients with suspected dementia.
- Carrying out baseline assessment of patients with suspected dementia.
- Referring patients promptly and appropriately to specialist units such as memory clinics.
- Participating in shared care with specialist services and providing continuity of care so that patients can be cared for in the community for as long as they wish.
- Providing information for patients and carers to support self-care.
- Devising care plans for patients and their carers that are tailored to the on-going needs of the individual.
- Providing holistic ongoing care for the patient and their carer, referring to other services as appropriate, and with thorough reviews of the patient every six to 12 months.

All staff in the primary care team should have appropriate training and knowledge to be able to provide appropriate holistic care for people with dementia and their carers. Where specialist services are not available in an area, the report recommends that GPs should be proactive in making sure that they are commissioned.

The report found evidence that in some cases, GPs failed to recognise early signs of dementia, were unwilling to take action when dementia was diagnosed, and tended not to want to take ownership of dementia care by undertaking case management or shared care. However, it also found examples where general practices had been proactive in reducing late diagnoses and providing multidisciplinary care.
5.8 COMMUNITY CARE

5.8.1 Recommended composition of community mental health team

The previous sections showed that a team of health and social care professionals could improve the quality of care for people with dementia.

The Royal College of Psychiatry, London (2004)\textsuperscript{43} recommended the composition of the community mental health team (CMHT), for an average PCT population (figure 21).

A survey of CMHTs conducted in 2006 found fewer than half had the recommended number of staff, and at least one-quarter had no social worker or clinical psychologist.\textsuperscript{16}

Figure 21: Recommended composition of community mental health team\textsuperscript{43}
5.8.2 Availability of community care services

A survey of CMHTs in 2006 found significant variations in the availability of community services for patients with dementia.

Almost one in five CMHTs reported that either meals on wheels or occupational therapy were not available to their community. One-third could not provide respite care and one-quarter had no day care.16

Figure 22: Proportion of community care services available for CMHTs, 200616
5.8.3 Inconsistent coordination of health and social care services

High-quality care for people with dementia depends greatly on how well health and social care services work together, along with their partners in the private and voluntary sectors.

Collaboration depends on several factors, such as communication and streamlined access to resources. Despite this, only 29% of community mental health teams, in one survey, had any joint health and social care funding arrangements in place (figure 23).

Figure 23: Opinion of CMHTs on coordination of services in their area: Percentage of respondents agreeing with the statement

- Local authority social services
- Voluntary sector organisations
- Ambulance services
- Primary care
- Elderly care medicine
- Younger adult psychiatry services

Excellent coordination
Good coordination
Little or no coordination

%
5.8.4 Variability in person-centred care

Person-centred care, recognised as an important component of high-quality care for people with dementia, encompasses four major elements:44

- A value base that asserts the absolute value of human life regardless of age or cognitive ability.
- An individualised approach that recognises uniqueness.
- Understanding the world from the perspective of the service user.
- Providing a social environment that supports psychological needs.

The proportion of people aged 65 years and over receiving person-centred care, varies across local authorities, ranging from none in the Isles of Scilly and Southend-on-Sea, to over 10%, in Richmond-upon-Thames, Suffolk, and Westminster.

5.8.5 Support for carers to enable home care

A 2011 survey of people with Alzheimer’s and those caring for them in their own home found that 83% responded that being able to continue to live in their own home was very important for the person with dementia.45 The same survey found that a majority of people with dementia would want to be active in the community for as long as possible and that maintaining their independence was one of the key ways they look to primary and community health services helping them. The expansion of personal health budgets is one way in which this may be achieved.
5.9 HOSPITAL CARE

5.9.1 Adverse impact of hospital admission on people with dementia

As dementia is primarily a condition that affects older people, many people with the disease also suffer from other conditions common to old age that may require hospital admission. When a person with dementia is admitted to hospital they risk developing delirium (acute confusion) arising from infection, post-anaesthetic effects and side effects of some medications. The key policy documents and guidelines for good practice, summarised earlier in this report, all highlight the need for improved care for people with dementia when they are admitted to a general hospital for another condition. This has also been highlighted in guidance from the NHS Confederation and in guidance produced by the RCN.46, 47

To ensure appropriate care is given, it is essential that an older person's mental state is assessed when they are admitted to hospital. The preliminary findings reported in December 2010 from the National Audit of Dementia (Care in General Hospitals) found that the majority of hospitals say it is their policy that an assessment of people with dementia includes a mental state assessment. However, an audit of case notes showed that fewer than half the sample of patients had received a standard mental state test and very few had been assessed for delirium, or been formally tested for the presence of depression.34

People with dementia may have difficulty communicating with hospital staff and a carer or relative can provide vital information to help hospital staff detect signs of deterioration in the person's mental state. The same audit found that a minority of hospitals have a formal system for gathering information pertinent to caring for a person with dementia and a minority of case notes had a section dedicated to collecting information from the carer, next of kin, or person who knows the patient well.
Overall the audit found that hospitals are failing to recognise the needs of people with dementia and they are not safeguarding people with the disease from longer hospital stays. Few hospitals said they had a system to ensure that staff on the ward are made aware if a patient has dementia and therefore the staff lack information on how the disease may affect the patients and how to adequately care for them. Only a minority of hospital boards review delayed discharge or readmissions of people with dementia. Carers often report that being in hospital had a negative effect on the person’s dementia and the symptoms of dementia, especially for those with greater lengths of stay. Figure 24 shows how carers responded to the question: ‘Do you think that being in hospital had a negative effect on the person’s dementia and the symptoms of dementia?’ The longer the patient is in hospital, the more they deteriorate.

Figure 24: Response of carers to the question: ‘Do you think that being in hospital had a negative effect on the person’s dementia and symptoms of dementia?’

![Figure 24: Response of carers to the question: ‘Do you think that being in hospital had a negative effect on the person’s dementia and symptoms of dementia?’](image-url)
5.9.2 Clinical leadership

A survey of 218 psychiatrists for elderly people, working in England in 2009 found that one quarter were not sure what changes had been implemented locally as a result of the National Dementia Strategy.7

More than half of district general hospitals had mental health liaison teams, but dementia care pathways, intermediate care or rehabilitation services were available in no more than one-quarter of hospitals.

The National Dementia Strategy Impact Assessment reported that providing 2.4 hours of a psychiatrist’s time per patient could reduce the duration of their admission by over two days. The cost of appointing a clinical leader for one session per week per acute trust to develop and oversee the implementation of care pathways for dementia would cost £3m a year in total across England.

Figure 25: Dementia services available in hospitals, England, 20097
5.10 DRUG THERAPY

5.10.1 Use of antipsychotic drugs

People with dementia often become more confused and agitated when they are in unfamiliar surroundings, such as when they are admitted to hospital or residential care. Confusion and distress could be reduced through better staff training and more patient-centred care (see sections 6.6 and 6.8).

Antipsychotic drugs, such as risperidone, olanzapine, quetiapine, aripiprazole, and haloperidol, are used to treat people with disturbed thinking and behaviour because of problems such as schizophrenia. Some patients with dementia may need antipsychotic drug treatment, but there is a concern that they are prescribed to people who don't need them, for ‘behavioural control’ as the drugs can also sedate a distressed patient.

The level of prescribing which is inappropriate is such that four-fifths of those prescribed antipsychotic medication receive no benefit from it but are instead exposed to increased risk of a cerebrovascular adverse event. Research has shown that inappropriate prescribing is more likely with longer hospital admissions, and may therefore be a contributory factor in the worsening of dementia symptoms in people who have longer admissions.19

Figure 26: Proportion of people with dementia on antipsychotics according to length of stay28
The Department of Health is committed to reducing the use of antipsychotics prescribed to people with dementia by two-thirds by November 2011. Preliminary findings from the National Audit of Dementia (Care in General Hospitals)\textsuperscript{34} suggest there is some way to go to achieve this because the majority of hospitals in the survey did not have policy to govern interventions for patients displaying challenging behaviour, aggression and extreme agitation, suitable for people with dementia. However, those hospitals that did have a protocol reported that restraint and sedation were only used as final options and for the best interests of the person with dementia.

The analysis of case notes undertaken as part of the national dementia audit of care in general hospitals showed a minority of people with dementia (20 - 44\%) were prescribed an antipsychotic drug. For less than a third of these patients, the drug was newly prescribed during their admission to hospital (most of these prescriptions had therefore been made in the community).\textsuperscript{34}

In response to these reports, the Dementia Action Alliance, together with the NHS Institute for Innovation and Improvement initiated a campaign for ‘The Right Prescription’ – a call to action on the use of antipsychotic drugs for people with dementia, in June 2011. The campaign commits to involving and working with pharmacists, psychiatrists, nurses, GPs, people with dementia and their family members to ensure that every person with dementia on antipsychotic medication receives a clinical review to ensure an evidence-based, personalised care plan, by March 2012.
5.10.2 Use of anti-dementia drugs

Several drugs have been licensed for use in people with dementia in the UK. Guidance from NICE on four of these drugs, donepezil, galantamine, rivastigmine and memantine, in their 2009 review, is as follows:48

- Donepezil, galantamine and rivastigmine are recommended as options for people with moderate severity of Alzheimer’s disease only, that is, a MMSE score of between 10 and 20 points. Only specialists should initiate treatment, and treatment should be stopped if and when the MMSE score falls to below 10 points at a six-monthly review.

- Memantine is not recommended for patients with Alzheimer’s disease, other than as part of clinical trials.

The effects of the four drugs on different types of symptoms of dementia are summarised in table 7.

The table shows the outcomes for which the drugs have been shown to have a statistically significant benefit. However, the clinical significance of the benefits, especially in the long term, is less certain.
Table 7: Estimates of clinical effectiveness of anti-dementia drugs

<table>
<thead>
<tr>
<th>Symptom type</th>
<th>Donepezil</th>
<th>Galantamine (higher doses, 16 mg/day or more)</th>
<th>Rivastigmine (higher doses, 6-12 mg/day)</th>
<th>Memantine</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive (thinking)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>?</td>
</tr>
<tr>
<td>Functioning</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>?</td>
</tr>
<tr>
<td>Behaviour</td>
<td>X</td>
<td>?</td>
<td>?</td>
<td>X</td>
</tr>
<tr>
<td>Overall (global) scores</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>

✓ = significant benefit  X = no significant benefit  ? = mixed results, benefit uncertain

A cost-effectiveness analysis by NICE concluded that the use of these drugs could reduce the length of time spent in full-time residential care by 1.41 to 1.54 months. The cost per quality-adjusted life year gained was as follows:

- Donepezil 10 mg daily: £97,000
- Galantamine 24 mg daily: £82,000
- Rivastigmine 6-12 mg daily: £70,000.
5.11 INTERMEDIATE CARE

The National Service Framework for older people set out the requirements for the NHS and local authorities to provide enhanced intermediate care services at home or in designated care settings. These services aim to prevent unnecessary admission to hospital and long-term residential care, and to provide effective rehabilitation to facilitate early discharge from hospital.

One study of hospitals in the UK in 2006-07 found that 1.6% of all 50m bed-days were caused by delayed discharges.\(^5^0\) In contrast, a survey of 158 elderly patients in one UK district general hospital in 2007, with median age of 82 years, found that 58 experienced a delayed discharge of almost five days on average. Of the delayed discharges, 26% were people awaiting residential or nursing home places, 29% were waiting for assessment of needs, and 28% were waiting for domiciliary care to be implemented. During the delay, seven out of the 58 people developed new medical problems including hospital-acquired chest and Clostridium difficile infections, and three deaths occurred as a result of pulmonary embolism, bronchopneumonia and C. difficile infection.

Although the study did not state how many patients had dementia, delayed discharge was more likely in older patients and those with confusion at the time of admission.\(^5^1\)

Intermediate care services should be multidisciplinary, involve short-term interventions lasting one to six weeks, and be designed to maximise independence and facilitate the elderly person being able to live safely at home.

Figure 27 demonstrates regional variability in the proportion of older people who are still living at home three months after being discharged from hospital, from 67% of people aged 85 and over in the South East to 82% in Yorkshire and the Humber.
5.12 Residential Care

Up to 75% of residents in general care homes have dementia. The Alzheimer’s Society (2008) reported that more than half of carers think people with dementia don’t have enough to do in care homes, and studies have shown that residents interact with others for only two minutes in every six hours. Patients and staff enjoy having more activities to do, and this can improve quality of life, reduce mortality and improve mental and physical function.

The National Dementia Strategy Impact Assessment recommended that community psychiatric nurses (CPN) should be used to improve the quality of care for patients in residential homes, by assessing them for mental health problems such as depression, which is found in at least 40% of residents with dementia. The level of input required was estimated to be four CPNs per PCT area, and the annual cost nationally would be £35m a year.
5.13 RESEARCH INTO DEMENTIA

Figure 28 shows that, although dementia accounts for over 50% of the combined health and social care costs of cancer, stroke and heart disease, dementia only receives 6% of the combined research funding that is available for these conditions. In contrast, cancer accounts for just over 20% of health and social care costs but receives nearly three-quarters of the total medical research funding for these four diseases.

Funding for research on dementia in the UK has been estimated as follows:\textsuperscript{21}

- £14m from charitable sources.
- £36m per year from government sources.

Figure 28: Proportion of total health and social care costs and research funding spent on dementia, cancer, stroke and heart disease\textsuperscript{21}
This report has identified that the evidence base on how to make the most cost-effective use of resources for dementia care is weak. Although a number of strategies are suggested for delivering high-quality care which are able in theory to lead to savings, these are based largely on extrapolated data and assumptions on effectiveness from small pilot studies. Future research into dementia should be focused on testing these assumptions and prioritising strategies that will have the greatest impact on overall quality of care in the most cost-effective way.