Guidance for commissioners of dementia services

Volume Two: Practical mental health commissioning
Other resources

This document was co-written by Ruth Eley and the JCP-MH editorial team and is based partly on the more detailed Dementia Commissioning Pack produced by the Department of Health in 2011 (http://dementia.dh.gov.uk/category/dementia-commissioning-pack). For a more detailed introduction to commissioning mental health, mental wellbeing and learning disability services, Practical Mental Health Commissioning can be downloaded at www.jcpmh.info
Executive summary

A comprehensive dementia commissioning programme includes:

- a strong public health component that focuses on prevention, early identification of people with dementia and targets high-risk groups such as people who fall, those who have a strong family history of dementia, and those with vascular risk factors.

- assessment and early diagnosis services for people with memory problems. This includes advice and support during the assessment phase and after diagnosis to assist with action planning for the future. It should include a treatment service that uses anti-Alzheimer’s medication (acetylcholinesterase inhibitors) in accordance with NICE recommendations. The service should identify those with mild cognitive impairment and arrange follow-up, given the risk of progression to dementia.

- ongoing dementia support services based in the community. These will incorporate evidence-based interventions for patients and carers. They will also coordinate care for individuals either by a member of the primary mental health care team or an identified person in a voluntary sector organisation (linking with the primary mental health care team). This could include a dementia advisor or a designated member of the health or social care team to act as the care manager if the person has more complex needs. A range of community supports will be required, including telecare, housing adaptations, carer support and day opportunities.

- specialist mental health care services for patients with dementia who present with behaviours that challenge, patients whose dementia is complicated by comorbid functional mental health problems, and those with complex diagnoses. These services will include a specialist service to manage patients with extremely challenging behaviours who need intensive support (including assessment and interventions to manage behaviours that place the individual or others at risk). This service will have a strong community focus, but will have access to a limited number of inpatient beds. Its patients will include those detained under the Mental Health Act or the Deprivation of Liberty Safeguards. Special attention should be given to people living in care homes.

- mental health liaison services based in acute general hospitals with specialist expertise in dementia and delirium. These services will have links with physical health services for the elderly, and with older people’s community mental health teams.
Introduction

The Joint Commissioning Panel for Mental Health (JCP-MH) (www.jcpmh.info) is a new collaboration co-chaired by the Royal College of General Practitioners and the Royal College of Psychiatrists, which brings together other organisations and individuals with an interest in commissioning for mental health and learning disabilities. These include:

- Service users and carers
- Department of Health
- Association of Directors of Adult Social Services
- NHS Confederation
- Mind
- Rethink Mental Illness
- National Survivor User Network
- National Involvement Partnership
- Royal College of Nursing
- Afiya Trust
- British Psychological Society
- Representatives of the English Strategic Health Authorities
- Mental Health Providers Forum
- New Savoy Partnership
- Representation from Specialised Commissioning

The JCP-MH is part of the implementation arm of the government mental health strategy No Health without Mental Health.1

The JCP-MH has two primary aims:
- to bring together service users, carers, clinicians, commissioners, managers and others to work towards values-based commissioning
- to integrate scientific evidence, patient and carer experience and viewpoints and innovative service evaluations in order to produce the best possible advice on commissioning the design and delivery of high quality mental health, learning disabilities and public mental health and wellbeing services.

The JCP-MH:
- has published Practical Mental Health Commissioning,2 a briefing on the key values and principles for effective mental health commissioning
- provides practical guidance and a developing framework for mental health commissioning
- will support commissioners of public mental health to deliver the best possible outcomes for community health and wellbeing
- has published a series of short guides describing ‘what good looks like’ in various mental health service settings.

WHO IS THIS GUIDE FOR?
The guide has primarily been written for Clinical Commissioning Groups, local authorities, and Health and Wellbeing Boards. It will also be of interest to patients, carers and voluntary sector and provider organisations.

HOW WILL THIS GUIDE HELP YOU?
This guide has been written by a group of dementia care experts, in consultation with patients and carers.

The content is primarily evidence-based but ideas deemed to be best practice by expert consensus have also been included. By the end of this guide, readers should be more familiar with the concept of dementia services and better equipped to understand what a good quality, modern dementia service looks like.

This guide does not cover mental health services for working age adults, functional mental health services for older people, access to psychological therapies or liaison psychiatry.

Companion guides and information on these issues are available at www.jcpmh.info.
What are dementia services?

Dementia services describe a wide range of generic and specialist mental health services that meet the needs of people with dementia and their carers in many settings:

- in their own home
- in acute general hospitals
- in intermediate care
- in sheltered and extra care housing
- in residential care homes and nursing homes
- in hospices.

Dementia services aim to cover the whole spectrum of needs (see Figure 1, taken from the 2009 National Dementia Strategy, which describes the range of different components of dementia commissioning and care).

Spanning mild to severe symptoms, these services start with the identification of possible memory or cognitive problems, include diagnosis, and continue through to end of life care.

Specialist dementia services support people during particular phases of their illness, including at diagnosis, during a stay in an acute general hospital, or when they are experiencing behavioural or psychosocial problems that require expertise beyond that normally provided by the primary care team.

Figure 1: Joint commissioning of services to enable people to live well with dementia

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Why are dementia services important to commissioners?

DEMENTIA: An Overview

Dementia is a syndrome caused by a number of illnesses in which there is a progressive functional decline in memory, reasoning, communication skills and the ability to carry out daily activities.

Alongside this decline, individuals may also develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering. These cause problems in themselves, complicate care, and can occur at any stage of the illness. Although the risks of developing dementia increase with age, it is not an inevitable part of ageing.

There are several different types of dementia:

- Alzheimer’s disease (which accounts for 60% of all cases in people aged over 65)
- vascular dementia (15–20% of all cases of people aged over 65)
- dementia with Lewy bodies (15–20% of all cases of people aged over 65)
- frontotemporal dementia (more common among younger people).

Between 30% and 70% of people with Parkinson’s disease develop dementia, depending on duration of the condition and age.

HOW COMMON IS DEMENTIA?

There are approximately 750,000 people known to be living with dementia in the UK, and this number is expected to almost double within 30 years.4

Only about 40% of cases of dementia are diagnosed. In the UK, dementia affects:

- 1 in 6 people aged over 80
- 1 in 25 people aged 70–79
- 1 in 100 people aged 65–69
- 1 in 1400 people aged 40–64.

In the UK around 15,000 people aged under 65 have dementia. This is probably an under-estimate as it is based on referrals to services, and not all people will seek help early in the course of the disease.5

An estimated 15,000 people from black and minority ethnic groups have dementia, and six per cent will have young onset dementia, compared with two per cent in the wider UK population.3

People with learning disabilities are at higher risk of dementia. People with Down’s syndrome have an increased genetic risk. Higher risk of dementia is also associated with stroke and some other neurological conditions.3

Two thirds of people with dementia live in the community. The remaining third live in care homes and are usually at a more advanced stage of the illness.4

WHAT IS THE IMPACT OF DEMENTIA?

Dementia is a long-term condition. Some people live with it for 10–12 years. On average people live seven years after developing symptoms, and two years after diagnosis. This is because many people are not diagnosed until late in their illness.

The average annual cost of caring for a person with late-onset dementia was £25,500 in 2007.4 The average annual cost per person with dementia cared for in the community was £16,689 (mild dementia), £25,877 (moderate dementia) and £37,473 (severe dementia), and £31,296 for those in care homes.4

Identification and diagnosis of dementia often comes late in the illness, when the person needs more expensive care services. Earlier interventions that would be more cost-effective and could improve quality of life are not widely available.6
What do we know about current dementia services?

There is no uniform model

There is currently no uniform model for dementia services across England. The vast majority of people with dementia are looked after in primary care, and less than a quarter have contact with old age psychiatry services at any time in their illness. This is because most people with dementia live in their own home, supported by neighbours, families and mainstream services.

Specialist services can help

GPs and primary care teams may need help and support to respond to challenging behaviours, such as agitation or aggression, that affect some people with dementia. These behavioural challenges can affect anyone with dementia, whether they live at home or in residential or nursing care.

Early interventions are more cost-effective

A National Audit Office report has found that the stigma attached to older people with mental health problems, combined with poor quality data and lack of effective joint working across health and social care, means that services are not delivering value for money to the taxpayer or to people with dementia and their families.

In particular, the report found that spending came too late, with too few people receiving a diagnosis or being diagnosed early enough. Early interventions that were known to be cost-effective and that would have improved quality of life were not being made widely available. This resulted in higher spending at a later stage on necessarily more expensive, because they were more intensive, services.

Although there are examples of good and excellent services, people with dementia and their carers generally report poor experience of mainstream acute hospitals, home care and residential care.

Dementia in care homes

A Commission for Social Care Inspection report found that people with dementia may be admitted to hospital when caring at home breaks down. They are more likely to experience delays in discharge from hospital, and in many cases are discharged straight from hospital to a care home. A third of people with dementia live in care homes and, according to Dementia UK, two thirds of people living in care homes have dementia.

The Alzheimer’s Society has suggested that the primary task of the care home sector is to provide good quality care to this group. This report found that many homes were still not providing the one-to-one, person-centred care that people with dementia need, and that access to support from external specialist services was unacceptably variable.

Care in the person’s home needs to improve

A 2011 Alzheimer’s Society survey found that 50% of carers and people with dementia living at home said that the person with dementia was not getting enough support and care to meet their needs. This was said to have serious repercussions, including avoidable admissions to hospital and early entry to long-term care. The majority (80%) of care workers surveyed said that being able to care for the same person over a long period of time would help in supporting the person to stay in their own home.
What would a good dementia service look like?

KEY PRINCIPLES

The key principles underpinning dementia commissioning can be summarised as follows.

1 People want seamless services between health, social care, housing and other providers.

2 Services should be commissioned and provided on the basis of need, not chronological age. However, a service for an 80-year-old should not be assumed to be appropriate to meet the needs of a 40-year-old. Services should be age-sensitive and, in particular, ensure that people with dementia, who may have complex needs including physical co-morbidities, receive the highest level of expert treatment, as would any other patient group.

3 Different services are needed at different times – from diagnosis, as the disease progresses, through to end of life care. These services include:

   • information and support – people should have the information they need to understand the signs and symptoms of dementia, and know where to go for help. They should receive a diagnosis as early as possible and know what treatments are best for them, what the implications of the diagnosis are, and how they will be supported to make good decisions.

   • help when needed – people living with dementia, and their carers/families, should feel confident that they have the practical, emotional and financial support they need to lead as normal a life as possible throughout the course of the illness. They should be supported to get help when they need it.

   • living well – people with dementia and their carers should be supported in all aspects of the illness, so they can lead as full and active a life as possible.

   • end of life care – well before people enter the final stages of their life, they need to be supported to make decisions that allow them and their families/carers to prepare for their death. Their care should be well co-ordinated and planned well in advance so that they are able to die where and in the way that they have chosen.

4 Dementia should be seen as everybody’s business. Most people with dementia live at home, supported by neighbours, communities and mainstream services. Mainstream health and social care services should be ‘dementia friendly’ and all staff should have a basic awareness of dementia and what it means.

5 Care should be delivered in partnership – organisations and individuals should work together to ensure that people with dementia and their carers/families are fully involved in their health care, receive high quality care and achieve the best outcomes. Care should make best use of skills, assets and resources in communities to enable people with dementia and their carers/families to live well.

6 Care should be personalised – services and support should be tailored to the needs of the individual with dementia; people should have choice and control about their health care and support.

Putting principles into practice

To achieve this, commissioners will want to consider commissioning a range of services to meet needs across the course of the disease, including:

• preventive public health interventions
• dementia assessment, diagnosis and intervention services
• home care and care home support
• specialist mental health care
• acute hospital liaison services
• support for carers.
Guidance for commissioners of dementia services

PUBLIC HEALTH COMMISSIONING TO PREVENT DEMENTIA

Preventing onset of dementia is important, given there is currently no cure. Consequently, commissioners should understand the potential risk factors for dementia (these include hypertension, heavy alcohol use and smoking), ensure primary care services are involved in preventative work, and recognise the role of public health in improving the early identification of people with dementia in the community.

Interventions

Preventative interventions that commissioners may wish to support include:

- cerebrovascular health promotion. Improved diet, lifestyle interventions and take-up of health checks are likely to reduce dementia rates, given the current evidence that up to 50% of dementia cases may have a vascular component (i.e. vascular or mixed dementia)
- identification of people with dementia in the community. Although general population screening for dementia is not recommended, GPs should take the opportunity to review patients that they see regularly for other conditions, such as heart disease, diabetes, asthma and hypertension. Early identification of mild cognitive impairment, and other symptoms that may indicate onset of dementia, will enable the patient to receive an early diagnosis and appropriate advice and support.

Outcomes

Taking these steps can help achieve improved outcomes, including:

- reduced dementia risk as a consequence of reduction in vascular disease
- earlier access to support, advice and information, as a consequence of earlier identification of dementia.

ASSESSMENT, DIAGNOSIS AND INTERVENTION SERVICES

Improving diagnosis – including early diagnosis – is a gateway to more effective dementia care and support. High quality assessment, diagnosis and intervention services for people with mild and moderate dementia should have the following characteristics. They should:

- make the diagnosis well
- communicate the diagnosis well
- provide appropriate treatment (medication, psychological and behavioural), information, care and support following diagnosis.

The objectives of a dementia assessment, diagnosis and intervention service are to:

- promote and facilitate early identification and referral and encourage eligible patients to attend for assessment
- provide a high quality, accurate diagnosis of dementia that is communicated in a person-centred way to the person with dementia and to their carers and meets their individual needs
- ensure that people with dementia and their carers are given information so they can manage their care more effectively along the pathway, understand how to access other help and make practical arrangements for the future (such as arranging a Lasting Power of Attorney)
- involve people with dementia and their carers in decisions about the care options available to them, including the development of individual care plans.

Expected outcomes from such a service are:

- an increase in the proportion of people with dementia receiving a formal diagnosis compared with the local predicted prevalence (NICE quality standard 2 – see page 13 in this guide)
- an increase in the proportion of people with dementia receiving a diagnosis when they are in the mild stages of the illness (NICE quality standards 1, 3, 4)
- an increase in the number of patients and carers who have a positive experience of health care services
- reduced risk of crises later in the course of the illness.

Early identification and treatment can also extend the period of time that the person with dementia can live and be cared for at home, if this is what they want.

The cost savings of early diagnosis are estimated to be around £2,685 per person diagnosed. These savings derive mainly from extending the time that someone can be cared for in the community, before they need to be admitted to a nursing home.

Referral criteria

Assessment, identification and diagnosis services are designed to meet the needs of adults of all ages with symptoms of mild to moderate dementia who have not already received a diagnosis.

GPs should refer patients with suspected symptoms of dementia that they believe are beginning to have an impact on their day-to-day living.
The service provider should accept referrals from GPs. The commissioner should consider whether direct referrals from other sources – for example, hospital clinicians or adult social care services – or self-referrals may also be accepted. These services are not appropriate for:

- patients with an existing diagnosis of dementia made by an appropriate clinician – they should continue to receive care and treatment from that team
- patients who present with more advanced symptoms of dementia – they may be diagnosed and managed in primary care with or without the help of the community mental health team
- patients with severe or more complex behavioural and psychological problems or risk (including suicidal ideation) – they are likely to require direct referral to a community mental health team for older people for more intensive support and casework
- patients with learning difficulties – they should have access to professionals with an understanding of dementia in that client group (the level of service provided should be equivalent to that provided to other patients with dementia)
- patients with cognitive and other impairments arising from traumatic brain injury.

**Prescribing medication**

The service needs to be commissioned to deliver the current national guidance on treatment with anti-dementia drugs. The capacity of the service should be sufficient to initiate, monitor and maintain the expected number of people with Alzheimer’s disease on appropriate anti-dementia medication.

Expertise is required in the appropriate prescription of medication to older people, in particular because of the changes in physiology in older adults, physical health co-morbidities and the consequent increased risk of adverse drug interactions when the person is receiving treatment for multiple disorders.

People with dementia may lack capacity to consent to treatment. Prescribers need a sound knowledge of the Mental Capacity Act and the legal requirements for treating people who lack capacity.

**Prescribing anti-dementia medication**

Access to anti-dementia medications has historically been limited in the UK. However, more recent NICE guidance has reinstated the recommended use of donepezil, galantamine and rivastigmine for managing mild as well as moderate Alzheimer’s disease, and memantine is now recommended for managing people with moderate and severe Alzheimer’s disease.

Ensuring appropriate access to the recommended medications for treating dementia is one of the key benefits of assessment and early diagnosis. These medications may improve cognitive functioning, reduce behaviours that carers find challenging and, alongside other early interventions, improve independent living and delay entry to long-term nursing home care.  

Rates of use of such medications in the UK are among the lowest in Europe.

Commissioners should aim to achieve an increase in prescription rates to the level of the European average. They may also wish to ask providers to monitor and report patient response at six and 12 months, and duration of treatment.

**Inappropriate use of antipsychotic medication**

A key national dementia policy goal is a reduction in the inappropriate use of antipsychotic medication to treat older people with dementia. Of particular concern has been the high level of inappropriate antipsychotic use in care homes. Antipsychotic medications are helpful to treat psychosis and some cases of aggression and severe agitation. However, antipsychotic medications have been commonly prescribed for behaviours such as restlessness, agitation and loss of inhibition, where the evidence for their benefits is weak.

A government commitment to reduce by two thirds by November 2011 the overprescribing of antipsychotic drugs to people with dementia has been supported by a ‘call to action’ from the Dementia Action Alliance, and accompanying guidance on managing behavioural and psychological symptoms of dementia.

Anti-depressants, benzodiazepines and night sedation may also be used inappropriately for people with dementia.

**Follow-up**

Commissioners need to specify whether patients with mild cognitive impairment should be offered follow-up to monitor possible cognitive decline and other signs of dementia so care can be planned, if needed, at an early stage. Follow-up could be undertaken in primary care or through a specialist dementia assessment, diagnosis and intervention service, which can also provide in-reach and education services.
Commissioners should determine at what point responsibility for a patient’s care should be returned to primary care. Memory assessment services should be commissioned to give the diagnosis, provide information on sources of help and advice, and arrange a follow-up meeting with the patient and carer to draw up an agreed action plan for the future.

Further information on commissioning a comprehensive memory assessment service can be found in the Department of Health commissioning pack at http://dementia.dh.gov.uk/category/dementia-commissioning-pack

COMMISSIONING SUPPORT AT HOME, OR IN A CARE HOME

The aim of supporting patients with dementia (and their carers) at home, or in a care home, is to ensure they maintain independence and a high quality of life where they have chosen to live.

Patients and their carers should have rapid access to information and support when needed. The objective of home care and support is to work with primary care services to prevent crises and reduce the need for specialist referrals, unplanned hospital admissions and residential care placements.

What needs to be commissioned?

To maintain independence and a high quality of life in the community, patients and their carers need access to mainstream health and social care provision. This may include the following:

- information and advice
- carer support
- peer support
- personalisation support
- intermediate care
- rehabilitation
- home care
- housing adaptations
- assistive technology
- extra care housing
- respite care and short breaks
- end of life care
- dementia cafes.

Commissioners will need to ensure these services meet the needs of people with dementia. Staff should receive basic awareness training on dementia and how to support people with dementia and their carers.

Easy access to information and advice is of crucial importance to people with dementia and their carers. Commissioners should consider establishing the dementia adviser role, as outlined in the National Dementia Strategy, to meet this need, particularly for people in the early stages of the illness who do not meet the eligibility criteria for social care support.

For people with more complex needs, a lead individual should be identified to facilitate rapid access to appropriate services across the range of health and social care and to act as care co-ordinator. Good care may require access to specialist advice from mental health services.

Outcomes

The following outcomes should be achieved from high quality support at home and in care homes.

I get the treatment and support that are best for my dementia and my life.

Links to NICE quality standards 1, 4, 5, 7, 8; National Dementia Strategy objectives 2, 6, 8, 9, 10, 11, 13, 18.

I am treated with dignity and respect.

Links to NICE quality standard 1; National Dementia Strategy objectives 1, 13.

I know what I can do to help myself and who else can help me.

Links to NICE quality standards 1, 3, 4, 5; National Dementia Strategy objectives 3, 4, 5, 6, 13.

Those around me and looking after me are well supported.

Links to NICE quality standards 3, 4, 6, 10; National Dementia Strategy objectives 3, 4, 5, 7.

I can enjoy life.

Links to NICE quality standards 3, 4; National Dementia Strategy objectives 1, 5, 16.

I feel part of a community and I’m inspired to give something back.

Links to National Dementia Strategy objectives 1, 5, 16.

I am confident my end of life wishes will be respected. I can expect a good death.

Links to NICE quality standards 5, 9; National Dementia Strategy objectives 12, 13.

Further information on commissioning better care at home and in care homes, including a case for change, a self assessment tool, dementia specific ‘inserts’ for generic service contracts and a service specification for a specialist service to support primary care, can be found in the Department of Health’s commissioning pack at http://dementia.dh.gov.uk/category/dementia-commissioning-pack
What would a good dementia service look like? (continued)

**COMMISSIONING SPECIALIST MENTAL HEALTH CARE**

The primary care team managing patients with dementia will need access to advice from specialist mental health care services in the following areas:

- making complex diagnoses
- managing patients with co-morbid functional mental health problems
- managing patients with behaviours that challenge
- managing patients with extremely challenging behaviours who are putting themselves and others at risk
- using appropriate medications other than anti-dementia drugs to help manage a patient with dementia.

This specialist care service needs to be multi-professional, with input from appropriate mental health trained practitioners, including community psychiatric nurses or Admiral Nurses, psychiatrists, psychologists, occupational therapists and social workers.

**Service aims and objectives**

The aim of this service is to support people in their own homes, other domestic settings, or in care homes. To achieve this, it works alongside primary care and other community services to maintain people in the community, and manage symptoms and behaviours that might otherwise make independent living unviable.

**What needs to be commissioned?**

What is needed is a multi-professional community mental health service, integrated within a broader community mental health team for old age psychiatry. The service will provide expert advice and treatment in the management of patients in their own homes or appropriate care settings, and offer specialist advice on the prescription of antipsychotics and other medication for people with dementia.

The service will include care home liaison on a pro-active, in-reach basis to prevent inappropriate admissions to hospital. As well as interventions for individual referrals, the service will provide education, training and coaching to care home staff to enable them to recognise, prevent and manage challenging behaviours more effectively. The team should also work closely with the hospital liaison service to facilitate rapid and smooth discharge from hospital in-patient beds. There is a clear evidence base for such services.

The service will ensure that carers are appropriately assessed and have access to the treatment and support they need. The team will provide specialist support to primary care.

Further information about commissioning a specialist community mental health service to support primary care, including a case for change, costing tool and service specification, can be found in the Department of Health’s commissioning pack at [http://dementia.dh.gov.uk/category/dementia-commissioning-pack](http://dementia.dh.gov.uk/category/dementia-commissioning-pack)

**COMMISSIONING MENTAL HEALTH LIASON SERVICES FOR DEMENTIA IN ACUTE HOSPITALS**

Good dementia care requires the commissioning of an acute hospital mental health liaison service. This is because:

- up to 70% of hospital beds are occupied by older people
- up to half of these may be people with cognitive impairment, including dementia and delirium
- when people with dementia are admitted for treatment of other conditions, they stay in hospital longer than people with the same condition but without dementia.

Acute mental health liaison services provide:

- support and advice on assessment and diagnosis
- support and advice on care planning and behaviour management
- access to other available specialist supports
- support to staff training and organisational development.

Hospital liaison services cannot be expected to deal with all the challenges associated with managing people with dementia appropriately in the acute general hospital setting. Commissioners should satisfy themselves that specifications for acute hospital care take account of the needs of people with dementia.

The Department of Health commissioning pack (see opposite) includes a template for commissioners to invite acute trusts to submit an action plan to improve dementia care in their hospitals in three areas. One of these must be workforce development and training but the others could be nutrition, signage and the physical environment, for example. This approach lends itself to incentive payments through Commissioning for Quality and Innovation (CQUIN) schemes to reward successful implementation of service improvements.

**Outcomes**

Outcomes from commissioning effective mental health liaison services include:

- reductions in unplanned admissions and re-admissions to acute and psychiatric hospitals from home/care homes
• reduction in antipsychotic medication use for people with dementia in care homes/other residential settings
• increase in the number of patients and carers who have a positive experience of hospital care, and fewer complaints
• reduction in the number of patients discharged directly from hospital to care homes as a new place of residence.

Further information on commissioning a mental health liaison service, including a case for change, a costing tool and a service specification, can be found in the Department of Health commissioning pack, available at http://dementia.dh.gov.uk/category/dementia-commissioning-pack.

SUPPORTING CARERS

All commissioned services need specific guidance on the support to be provided for carers.

Psycho-educational interventions for family caregivers can result in significant reductions in caregiver burden and improvements in depression, subjective mental wellbeing and perceived caregiver satisfaction. However, not all interventions achieve the same outcomes: respite and day care have been found to reduce caregiver depression; support groups increase caregiver coping capacity, but have no effect on depression. Early intervention for caregivers can improve wellbeing and reduce mental health problems, with associated benefits for capacity to care. The dementia adviser role (as recommended in the National Dementia Strategy) could ensure easy access to information and advice for carers of people with dementia. The Department of Health has commissioned an evaluation of 22 pilot projects testing out the role, which will report in autumn 2012.

KEY STANDARDS AND OUTCOMES

There are a number of ways to describe the standards and outcomes of good quality dementia interventions and services. Some are listed below.

NICE quality standards for dementia

Quality standards are specific statements defining what high quality care ‘looks like’. NICE published ten quality standards for dementia in June 2010.

1. People with dementia receive care from staff appropriately trained in dementia care.
2. People with suspected dementia are referred to a memory assessment service specialising in the diagnosis and initial management of dementia.
3. People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and the support options in their local area.
4. People with dementia have an assessment and an ongoing personalised care plan across health and social care that identifies a named coordinator and addresses need.
5. People with dementia, while they have capacity, have the opportunity to discuss and make decisions, with their carer/s, about the use of advance statements, advance decisions to refuse treatment, Lasting Power of Attorney and preferred care priorities.
6. Carers of people with dementia are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan.

7. People with dementia who develop non-cognitive symptoms causing significant distress, or who develop behaviour that challenges, are offered an assessment at an early opportunity to establish generating/aggravating factors. Interventions to improve behaviour or distress should be recorded in their care plan.

8. People with suspected or known dementia using acute and general hospital inpatient services or emergency departments have access to a liaison service that specialises in the diagnosis and management of dementia and older people’s mental health.

9. People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs.

10. Carers of people with dementia have access to a comprehensive range of respite/short-break services that meet the needs of both the carer and the person with dementia.

www.nice.org.uk/guidance/qualitystandards/dementia/dementiaqualitystandard.jsp
What would a good dementia service look like? (continued)

National Dementia Strategy quality outcomes
Building on the 2009 National Dementia Strategy for England, nine quality outcome measures were published in 2010. These are linked to the NICE quality standards and cover four areas:
- improved awareness
- earlier diagnosis
- higher quality of care
- reduced use of anti-psychotic medication.

I was diagnosed early.
Links to NICE quality standards 2, 3; Dementia Strategy objectives 1, 2.

I understand, so I make good decisions and provide for future decision making.
Links to NICE quality standards 3, 5; Dementia Strategy objectives 3, 4, 5.

I get the treatment and support which are best for my dementia, and my life.
Links to NICE quality standards 1, 4, 5, 7, 8; Dementia Strategy objectives 2, 6, 8, 9, 10, 11, 13, 18.

I am treated with dignity and respect.
Links to NICE quality standard 1; Dementia Strategy objectives 1, 13.

I know what I can do to help myself and who else can help me.
Links to NICE quality standards 1, 3, 4, 5; Dementia Strategy objectives 3, 4, 5, 6, 13.

Those around me and looking after me are well supported.
Links to NICE quality standards 3, 4, 6, 10; Dementia Strategy objectives 3, 4, 5, 7.

I can enjoy life.
Links to NICE quality standards 3, 4; Dementia Strategy objectives 1, 4, 5, 6.

I feel part of a community and I’m inspired to give something back.
Links to Dementia Strategy objectives 1, 5, 16.

I am confident my end of life wishes will be respected.
I can expect a good death.
Links to NICE quality standards 5, 9; Dementia Strategy objectives 12, 13.

The Quality Outcomes Framework (QOF)
Introduced in 2004, the QOF is a voluntary incentive scheme for GP practices in the UK that rewards them for how well they care for patients. The QOF comprises groups of indicators against which practices score points according to their levels of achievement.

In simple terms, the higher the score, the higher the financial reward for the practice. Dementia has three QOF indicators:

1. the GP practice can produce a register of patients diagnosed with dementia
2. the percentage of patients diagnosed with dementia on the register whose care has been reviewed in the last 15 months
3. the percentage of patients with a new diagnosis of dementia (from April 2011) who have received specified physical tests in the six months before or after diagnosis.

Once patients are on the QOF dementia register, GPs and the wider primary health care team have an opportunity to help them live well by encouraging healthy and active lifestyles, providing advice and information, and offering regular health checks. As needs change, the primary health care team can plan with the person with dementia and their carers/family how their care will be co-ordinated.
Primary care teams should ensure all practice staff (including administrative staff) receive basic dementia awareness training. They should annually review the numbers of people receiving a dementia diagnosis and compare this with expected prevalence rates for their area, and consider how to identify patients at highest risk of developing dementia who may be attending clinics for treatment for other conditions (e.g. diabetes care or vascular health).


**Dementia care standards for acute general hospitals**

The Royal College of Psychiatrists College Centre for Quality Improvement (CCQI), through its National Audit of Dementia, has produced a set of standards for hospitals providing general acute inpatient services to measure aspects of care delivery known to impact on people with dementia admitted to hospital. These are as follows.

- all people with dementia receive a comprehensive assessment that includes assessment of their mental health needs.
- people with dementia in hospital can access assessment and treatment from a specialist psychiatric liaison service with expertise in responding to their needs
- people with dementia receive care that is tailored to their needs and takes account of the impact of the condition
- the hospital plans, provides and reviews services to meet the needs of people with dementia and their carers
- people with dementia are supported by a discharge planning process that takes account of individual needs and the impact of the condition
- resources are in place to support the needs of people with dementia in hospital
- people with dementia are cared for by staff who are supported to identify and respond to individual needs
- people with dementia are cared for in an environment that is adaptable to their needs and preferences
- people with dementia and their carers are listened to and treated with respect, and provided with the information they need about care, support and discharge.

www.rcpsych.ac.uk/quality/nationalclinicalaudits/dementia/nationalauditofdementia.aspx

**Dementia care standards for memory services**

The CCQI, through its Memory Services National Accreditation Programme, publishes standards to assure/improve the quality of memory services for people with memory problems/dementia and their carers. The standards are as follows:

- any clinic run by the memory service is accommodated in an environment that is appropriate to the needs of people with memory problems/dementia
- the memory service provides timely access to assessment and diagnosis
- the memory service ensures that a diagnosis of dementia is made only after a comprehensive and holistic assessment of the person’s needs by appropriate professionals, either within the service or elsewhere
- assessment outcomes are communicated to all relevant parties in a timely manner
- additional tests/investigations are in accordance with individual and clinical need
- the service is able to offer appropriate support, advice and information to people with memory problems/dementia and their carers at the time of assessment and diagnosis
- the memory service ensures each person with memory problems/dementia has a care plan
- professionals in the memory service ensure that the person (and their carer) is able to access a range of post-diagnostic supports and interventions
- the service ensures each person with memory problems/dementia is followed up.

www.rcpsych.ac.uk/quality/qualityandaccreditation/memoryservices/memoryservicesaccreditation.aspx

**Dementia care CQUIN**

A nationally mandated CQUIN was published in 2012 which aimed to improve awareness and diagnosis of dementia, using risk assessment, in an acute hospital setting. These indicators covered dementia screening, dementia risk assessment, and referral for specialist diagnosis.
Supporting the delivery of the mental health strategy\textsuperscript{1} and National Dementia Strategy\textsuperscript{3}

The JCP-MH believes that good dementia commissioning, as described in this guide, will support the delivery of the shared objectives set out in the mental health strategy for England.\textsuperscript{1}

Shared objective 1: More people will have good mental health.

Prevention, early identification, diagnosis and treatment of people with dementia will increase the number of people receiving appropriate care and support and delay the development of more severe symptoms in more people.

Shared objective 2: More people with mental health problems will recover.

A specialist dementia programme can enable patients to retain as much functioning as possible will help them to continue to live as independently as possible for as long as possible through improved memory, communication and other daily living skills.

Shared objective 3: More people with mental health problems will have good physical health.

Commissioning can ensure patients’ physical health needs are taken into account in mental health settings, and their mental health needs are addressed in physical health care settings.

Shared objective 4: More people will have a positive experience of care and support.

Addressing both physical and mental health needs together will ensure patients receive a more holistic and positive experience of care.

Shared objective 5: Fewer people will suffer avoidable harm.

Good dementia commissioning will address the safety of patients with dementia, who are at high risk of harm from, for example, falls.

Shared objective 6: Fewer people will experience stigma and discrimination.

Everyone with dementia – not just the minority – should be treated with dignity and respect. People with dementia has a right to a quick diagnosis and a high level of care, support and treatment from health professionals.

The JCP-MH also strongly believes that good dementia commissioning as described in this guide will support the delivery of the National Dementia Strategy.\textsuperscript{2}
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**Development process**

This guide has been written by a group of dementia care experts, in consultation with patients and carers. Each member of the Joint Commissioning Panel for Mental Health received drafts of the guide for review and revision, and advice was sought from external partner organisations and individual experts. Final revisions to the guide were made by the Chair of the Expert Reference Group in collaboration with the JCP’s Editorial Board (comprised of the two co-chairs of the JCP-MH, one user representative, one carer representative, and technical and project management support staff).
References


4 Dementia UK (2007). Dementia UK: a report into the prevalence and cost of dementia prepared by the Personal Social Services Research Unit (PSSRU) at the London School of Economics and the Institute of Psychiatry at King's College London, for the Alzheimer's Society. London: Alzheimer's Society.


