1 Guideline title

Dementia: the management of dementia, including the use of antipsychotic medication in older people

1.1 Short title

Dementia

2 Background

(a) The National Institute for Clinical Excellence (‘NICE’ or ‘the Institute’) has commissioned the National Collaborating Centre for Mental Health to develop guidance on dementia for use in the NHS in England and Wales. This follows referral of the topic by the Department of Health and Welsh Assembly Government (see Appendix). The guidance will provide recommendations for good practice that are based on the best available evidence of clinical and cost effectiveness. Cross reference will be made to these and other documents as appropriate. The guideline will also include relevant recommendations from two Technology Appraisals currently being carried out by the Institute, which are due for publication in May 2005. These are “New pharmaceutical treatments for non-Alzheimer’s dementias” and “Drugs for the treatment of Alzheimer’s disease (which will incorporate a review of NICE’s donepezil, rivastigmine and galantamine appraisal guidance from 2001).

(b) The Institute’s clinical guidelines will support the implementation of National Service Frameworks (NSFs) in those aspects of care where a Framework has been published. The statements in each NSF reflect the evidence that was used at the time the Framework was prepared. The clinical guidelines and technology appraisals published by the Institute after an NSF has been issued will have
the effect of updating the Framework. The guidance will support national initiatives outlined in the NSF for the elderly and the NHS plan.

This guideline is being developed jointly by the National Institute for Clinical Excellence and the Social Care Institute for Excellence (SCIE), to reflect the fact that most people with dementia receive care from both the health and social care sectors.

3 Clinical need for the guideline

a) Dementia is a clinical syndrome characterised by a widespread loss of mental function, with some or all of the following features: memory loss, language impairment, disorientation, change in personality, self neglect, and behaviour which is out of character (for example, sexual disinhibition or aggression).

b) Dementia has a number of causes; the most common causes include the following:

i. Alzheimer’s disease – this causes up to 60% of cases of dementia. It is characterized by memory loss and difficulties with language in its early stages, and gradually becomes more severe over several years.

ii. Vascular dementia – this is the consequence of strokes and/or insufficient blood flow to the brain and causes up to 20% of cases of dementia. It has a varied clinical picture depending on which parts of the brain are most affected. In any individual, Alzheimer’s disease and vascular dementia can co-exist.

iii. Dementia with Lewy bodies – this causes up to 15% of dementia cases and is characterized by symptoms similar to Parkinson’s Disease as well as hallucinations and a tendency to fall.
c) Dementia is a very common condition although there is substantial variation in estimates of prevalence, probably because of difficulties of establishing ‘caseness’ in marginal and mild cases. It is estimated that about 700,000 people in the UK suffer from dementia, with the incidence and prevalence increasing with age. This represents 5% of the total population aged 65 and over, and 20% of the population aged 80 and over.

d) Dementia is associated with complex needs and, especially in the later stages, high levels of dependency and morbidity, often leading to very substantial burdens upon carers and services. Of the people with dementia, about 154,000 live alone. Those living with carers (a further 250,000) present serious challenges to their carers and wider social networks. About 200,000 patients live in nursing homes, of whom about a third receive antipsychotic medication, not necessarily appropriately or safely. Recent evidence suggests that some types of antipsychotic may also increase the risk of stroke amongst people with some types of dementia. The annual direct costs in England of caring for people with Alzheimer’s disease alone were estimated in 2001 at £7–15 million. Indirect costs are likely to be very much higher than this.

e) In the later stages of the condition, people with dementia can present carers and social care staff with complex and challenging management and support problems including aggressive behaviour, restlessness and ‘wandering’, eating problems, incontinence, delusions and hallucinations, and mobility difficulties.

f) People from minority ethnic groups have special considerations. Higher rates of blood pressure and diabetes among African, Caribbean and Asian people increase the risk of developing vascular dementia in older age. Also, impairment of memory can lead to additional communication problems if English is not the person’s first language.

g) Current treatment options include the use of the acetylcholinesterase inhibitor family of drugs (donepezil, rivastigmine, galantamine) to
improve cognitive functioning, and psychosocial and drug interventions for behavioural problems. The use of antipsychotic drugs for symptomatic and behavioural control has already been referred to. A variety of service level interventions are in use, including community dementia support teams, day hospitals, in-patient admission and long-term institutional care both inside and outside the NHS, and those provided by social services. The families and carers of people with dementia often need support and help, provided both formally and informally through the NHS and through social services.

h) A number of guidelines, consensus statements and local protocols exist, including a practice guide for assessing the mental health needs of older people developed by SCIE in 2002. This guideline will review evidence of clinically effective and cost-effective practice, together with current guidelines, and will offer guidance on best practice.

4 The guideline

a) The guideline development process is described in detail in two publications which are available from the NICE website (see ‘Further information’). *The Guideline Development Process – An overview for Stakeholders, the public and the NHS* describes how organisations can become involved in the development of a guideline. The *Guideline Development Methods – Information for National Collaborating Centres and Guideline Developers* provides advice on the technical aspects of guideline development. The process for developing a SCIE practice guide is described in SCIE’s work plan 2003–2004, which is available on the SCIE website or in hard copy. It is intended that this guideline will be developed in accordance with NICE development processes, whilst incorporating important and relevant elements SCIE methodology. The SCIE version of this guideline will be available as an electronic, interactive SCIE practice guideline with a summary print version.
b) This document is the scope. It defines exactly what this guideline will (and will not) examine, and what the guideline developers will consider. The scope is based on the referral from the Department of Health and Welsh Assembly Government (see Appendix).

c) The areas that will be addressed by the guideline are described in the following sections.

4.1 Population

4.1.1 Groups that will be covered

a) Both sexes of all ages. There is no lower age limit.

b) All the major forms of dementia, including Alzheimer's disease, vascular dementia, Lewy body type of dementia, multi-infarct dementia, subcortical dementia, and mixed cortical and subcortical dementia. The guidelines will, where appropriate, address the differences in treatment and care for people with mild, moderate and severe dementia, whether of Alzheimer, vascular, or Lewy body type. Dementia encountered in the course of Parkinson's Disease will also be addressed.

c) The guideline will be sensitive to the diverse approaches of different ethnic and cultural groups, and will be aware of the issues of both internal (to the NHS and social services) and external social exclusion.

d) Dementia usually affects the whole family or household and the guideline will recognise the role of carers in the care and support of people living with dementia.

4.2 Healthcare setting

a) Primary and secondary care services in the NHS.

b) Social services.
c) Housing associations and other private organisations contracted by either the NHS or social services to provide care for people with dementia.

4.3 Clinical management

4.3.1 Areas that will be covered

The guideline will cover the following areas of clinical practice and will do so in a way that is sensitive to the cultural, ethnic and religious backgrounds of people with dementia and their carers.

a) The full range of care routinely made available by the NHS with regard to people with dementia.

b) Early diagnosis and identification of dementia: clarification and confirmation of diagnostic criteria currently in use, and therefore the diagnostic factors that trigger the use of this guideline and the assessment methods that might be used in diagnosis.

c) The guideline will include appropriate use of psychosocial and social interventions, which may include:

- behavioural and psychosocial interventions for dementia
- care management
- social support
- cognitive behavioural treatments
- skills training for carers
- reality orientation and reminiscence therapy
- memory training
- validation therapy
- multisensory therapy.

d) Pharmacological treatment for people with dementia, (including the use of antipsychotics), including type, dose and duration. When referring to pharmacological treatments, normally guidelines will recommend use only within the licensed indications. However, where the evidence
clearly supports it, recommendations for use outside the licensed indications may be made in exceptional circumstances. It is the responsibility of prescribers to be aware of circumstances where medication is contraindicated. The guideline will assume that prescribers are familiar with the side-effect profile and contraindications of medication they prescribe for patients with dementia.

e) Appropriate use of self-management strategies, for example, self-help methods and interventions to promote medication adherence.

f) Appropriate service level interventions, for example types of teams and service models provided for service users and their carers.

g) The role of the family and other carers in the treatment and support of people with dementia and the provision of relevant information to them.

4.3.2 Areas that will not be covered

The following areas will not be addressed by this guideline:

a) The treatment and management of dementia encountered in the context of other diseases, such as Creutzfeldt-Jakob Disease (CJD), Huntington's Chorea and Human Immunodeficiency Virus (HIV).

b) The physical treatments of organic disease sometimes associated with different forms of dementia, such as the treatment of convulsions or motor disorders.

c) The treatment of physical ill-health that is commonly encountered amongst elderly people, especially those with dementia, such as cardiovascular and neurological disease/disorders, except where the treatment of such conditions may alter the progress of dementia.

d) Medical treatments that are not normally available within the NHS.
4.4 Social care setting

a) The guideline will cover the care provided by social care staff who have direct contact with dementia sufferers in home-based, group care and residential settings.

b) This is a joint NICE and SCIE guideline. Consequently, it will have application for social care staff operating in integrated health and social care services, statutory social services, and the voluntary and independent sectors.

c) The guideline will include the role of:

- domiciliary support
- assisted housing
- care management
- day centres/day activities
- residential care
- the interface of health and social care services.

4.5 Social care management

a) The guideline development will cover the full range of care routinely made available by councils with social services responsibilities and independent and voluntary sector providers of social care services.

b) It will provide guidance to service users and carers on pathways to care.

c) There will be guidance in relation to supporting service users to exercise choice.

d) The guideline will cover risk assessment.

4.5.1 Notes for implementers

a) This guideline will be of relevance for both NHS and social services staff who are involved in the care of people who develop dementia and their carers, including GPs, psychiatrists, other mental healthcare
professionals, social workers, care home managers, care staff and community pharmacists.

b) It will also be of relevance to professionals working in the private sector who provide housing, support and care for people with dementia, where they are contracted or commissioned to do so by either the NHS or local social services.

4.6 Audit support within the guidance

The guideline will include review criteria for the audit of key recommendations, which will enable objective measurements to be made of the extent and nature of local implementation of this guidance, and particularly of its impact upon practice and outcomes for people with dementia.

4.7 Status

4.7.1 Scope

This is the consultation draft scope, which is subject to a six week period of consultation with stakeholders. After the consultation, the scope will be re-drafted and submitted to the Guidelines Review Panel and then to the Institute’s Guidance Executive for approval. Once approved, it will be posted on the Institute’s website.

4.7.2 Guideline

The development of the guideline recommendations will begin in September 2004.

5 Further information

Information on the guideline development process is provided in:

- *The Guideline Development Process – An overview for Stakeholders, the public and the NHS*

- *Guideline Development Methods – Information for National Collaborating Centres and Guideline Developers*
These booklets are available as PDF files from the NICE website (www.nice.org.uk). Information on the progress of the guideline will also be available from the website.

Appendix – Referral from the Department of Health and Welsh Assembly Government

The Department of Health and Welsh Assembly Government asked the Institute:

“To prepare a clinical guideline for the NHS in England and Wales for the assessment and management of dementia. This will form part of the National Service Framework for Older People giving guidance on the treatments aimed at improving cognitive (memory) impairment and the behavioural and psychological symptoms of dementia. The guideline will cover:

a) all forms of dementia

b) patients of all ages

c) early identification and diagnosis of patients with dementia

d) psychological, social, drug based and non-drug approaches to treatment and management; and specifically

e) the prescribing of antipsychotic medication for older people with dementia for General Practitioners and other prescribers, including care home managers, care staff and community pharmacists as means of ensuring good practice.

Guidance will also be given on the support to be offered to those caring for persons with dementia.”