1 Guideline title

Parkinson’s disease: diagnosis, management and treatment of adults with Parkinson’s disease in primary and secondary care

1.1 Short title

Parkinson’s disease

2 Background

a) The National Institute for Clinical Excellence (‘NICE’ or ‘the Institute’) has commissioned the National Collaborating Centre for Chronic Conditions to develop a clinical guideline on Parkinson’s disease 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 guideline will provide recommendations for good practice that are based on the best available evidence of clinical and cost effectiveness.

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.

3 Clinical need for the guideline

a) Parkinson’s disease is a progressive neurodegenerative condition leading to death of the dopamine-containing cells of the substantia
The ‘cardinal signs’ of the disease are rest tremor, rigidity and bradykinesia. Postural instability and falls occur later during the course of the condition. Additional common findings are asymmetric onset of symptoms and symptomatic response to L-Dopa (levodopa). Although Parkinson’s disease is predominantly a movement disorder, cognitive impairments including dementia do occur. All of these problems lead to significant disability and handicap with impaired quality of life for both patients and their carers and increased healthcare costs.

b) Parkinson’s disease is one of the commonest neurological conditions. It is estimated to affect up to 160 people per 100,000, with an annual incidence of 15–20 per 100,000. Many population studies have shown the rising prevalence with age (up to 2% of the population aged 80 and over). Around 1 in 7 cases are diagnosed below the age of 60 years.

c) The costs of treatment have been estimated at between £560,000 and £1.6 million per 100,000 people. Significant cost drivers include the onset of motor fluctuations, psychiatric symptoms, and institutional care. Parkinson’s disease is a frequent cause of falls, fractures, and hospital admission, and is therefore a costly disease, especially in the later stages.

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. Guideline Development Methods – Information for National Collaborating Centres and Guideline Developers provides advice on the technical aspects of guideline development.
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) Men and women older than 20 years

b) Diagnoses of Parkinson’s disease and parkinsonism

c) Treatment of idiopathic Parkinson’s disease only

4.1.2 Groups that will not be covered

a) Juvenile onset Parkinson’s disease (in people younger than 20 years of age)

b) Pregnant women

c) Treatment of parkinsonism (a neurological disorder that manifests with bradykinesia, tremor or muscular rigidity) and other tremulous disorders (for example, essential tremor) will not be covered, except for accurate differential diagnosis.

4.2 Healthcare setting

The guideline will be relevant to primary, secondary and tertiary NHS care settings.

4.3 Clinical management

a) Diagnosis and monitoring

- Clinical expert diagnosis (using UK brain bank criteria)
  - versus non-expert diagnosis
• versus post-mortem gold standard.

• Other diagnostic tests (for example, acute levodopa and apomorphine tests, radionuclide imaging [PET and SPECT], magnetic resonance imaging, magnetic resonance volumetry, magnetic resonance spectroscopy, growth hormone stimulation test).

b) Patient engagement and self-help

• Communication of the diagnosis to enable patient understanding
• Patient engagement and self-help.

c) Pharmacotherapy

• Prevention of progression – the use of neuro-protective therapy (for example, dopamine agonists, monoamine oxidase B inhibitors, amantadine, co-enzyme Q10, vitamins).

• Functional disability – treatment of early disease with:
  – immediate-release levodopa
  – modified-release levodopa
  – dopamine agonists
  – monoamine oxidase B inhibitors
  – amantadine
  – anticholinergics
  – beta-blockers.

• Adjuvant pharmacotherapy
  – dopamine agonists
  – catecholamine-O-methyl-transferase (COMT) inhibitors
  – monoamine oxidase B inhibitors

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− amantadine
− intermittent apomorphine injections and continuous infusion.

- Treatment of non-motor symptoms (for example, sleep disturbance).

Note that for pharmacological interventions, guideline recommendations will normally fall within licensed indications. Exceptionally and only where clearly supported by evidence, use outside a licensed indication may be recommended. The guideline will assume that prescribers will use the Summary of Product Characteristics to inform their decisions for individual patients.

d) Non-pharmacological management

- Current surgical options (for example, deep brain stimulation)
- Physiotherapy
- Speech and language therapy
- Occupational therapy
- Parkinson’s disease specialist nursing.

e) Neuropsychiatric conditions

- Psychosis management specific to Parkinson’s disease
- Depression management specific to Parkinson’s disease
- Dementia management specific to Parkinson’s disease.

f) Palliative care

- End-of-life issues specific to Parkinson’s disease.

g) Interventions/management that will not be included

- Radical therapies that do not form common clinical management will not be addressed: fetal cell transplantation; stem cells; genes that code protein responsible for producing dopamine; drugs that
block the action of glutamate; giant cell line-derived neutrophilic factor (GDNF); viral transfection.

- Co-morbidities in Parkinson’s disease (except where treatment will differ from treatment of these co-morbidities in patients without Parkinson’s disease).
- Generic health problems where the care for people with Parkinson’s disease does not differ from that of the general population (for example, constipation)

4.4 Status

4.4.1 Scope

This is the final draft of the Scope.

4.4.2 Guideline

The development of the guideline recommendations will begin in the last quarter of 2003/4.

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 the Welsh Assembly Government asked the Institute:

(May 2002)

“To prepare clinical guidelines for the NHS in England and Wales for the diagnosis, management and treatment of Parkinson’s disease in both primary and secondary care settings, including examination of the evidence for the effectiveness of management of the condition by physiotherapy, speech, language and occupational therapies, self-help, drug therapies and surgery.”