



*National Institute for
Health and Clinical Excellence*

Quick reference guide

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Parkinson's disease

Diagnosis and management in primary and
secondary care

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This guidance is written in the following context

This guidance represents the view of the Institute, which was arrived at after careful consideration of the evidence available. Healthcare professionals are expected to take it fully into account when exercising their clinical judgement. The guidance does not, however, override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer.

Introduction

Parkinson's disease (PD) is a progressive neurodegenerative condition resulting from the death of the dopamine-containing cells of the substantia nigra. There is no consistently reliable test that can distinguish PD from other conditions that have similar clinical presentations. The diagnosis is primarily clinical, based on a history and examination.

People with PD classically present with the symptoms and signs associated with parkinsonism, namely bradykinesia, rigidity and rest tremor.

Parkinsonism can also be caused by drugs, and conditions that are less common than PD. These include multiple cerebral infarction and degenerative conditions such as progressive supra-nuclear palsy (PSP) and multiple system atrophy (MSA).

Although PD is predominantly a movement disorder, other impairments frequently develop including psychiatric problems such as depression and dementia. Autonomic disturbances and pain (which is rarely a presenting feature of PD) may later ensue, and the condition progresses to cause significant disability and handicap with impaired quality of life for the affected person. Family and carers may also be affected indirectly.

Patient-centred care

Treatment and care should take into account patients' individual needs and preferences. Good communication is essential, supported by evidence-based information, to allow patients to reach informed decisions about their care. Carers and relatives should have the chance to be involved in discussions unless the patient thinks it inappropriate.

Key priorities for implementation

The following recommendations have been identified as priorities for implementation.

Referral to expert for accurate diagnosis

- People with suspected PD should be referred quickly¹ and untreated to a specialist with expertise in the differential diagnosis of this condition.

Diagnosis and expert review

- The diagnosis of PD should be reviewed regularly² and reconsidered if atypical clinical features develop.
- Acute levodopa and apomorphine challenge tests should not be used in the differential diagnosis of parkinsonian syndromes.

Regular access to specialist nursing care

- People with PD should have regular access to the following:
 - clinical monitoring and medication adjustment
 - a continuing point of contact for support, including home visits, when appropriate
 - a reliable source of information about clinical and social matters of concern to people with PD and their carerswhich may be provided by a Parkinson's disease nurse specialist.

Access to physiotherapy

- Physiotherapy should be available for people with PD. Particular consideration should be given to:
 - gait re-education, improvement of balance and flexibility
 - enhancement of aerobic capacity
 - improvement of movement initiation
 - improvement of functional independence, including mobility and activities of daily living
 - provision of advice regarding safety in the home environment.

¹ The Guideline Development Group considered that people with suspected mild PD should be seen within 6 weeks but new referrals in later disease with more complex problems require an appointment within 2 weeks.

² The Guideline Development Group considered that people diagnosed with PD should be seen at regular intervals of 6–12 months to review their diagnosis.

Key priorities for implementation *continued*

Access to occupational therapy

- Occupational therapy should be available for people with PD. Particular consideration should be given to:
 - maintenance of work and family roles, employment, home care and leisure activities
 - improvement and maintenance of transfers and mobility
 - improvement of personal self-care activities, such as eating, drinking, washing and dressing
 - environmental issues to improve safety and motor function
 - cognitive assessment and appropriate intervention.

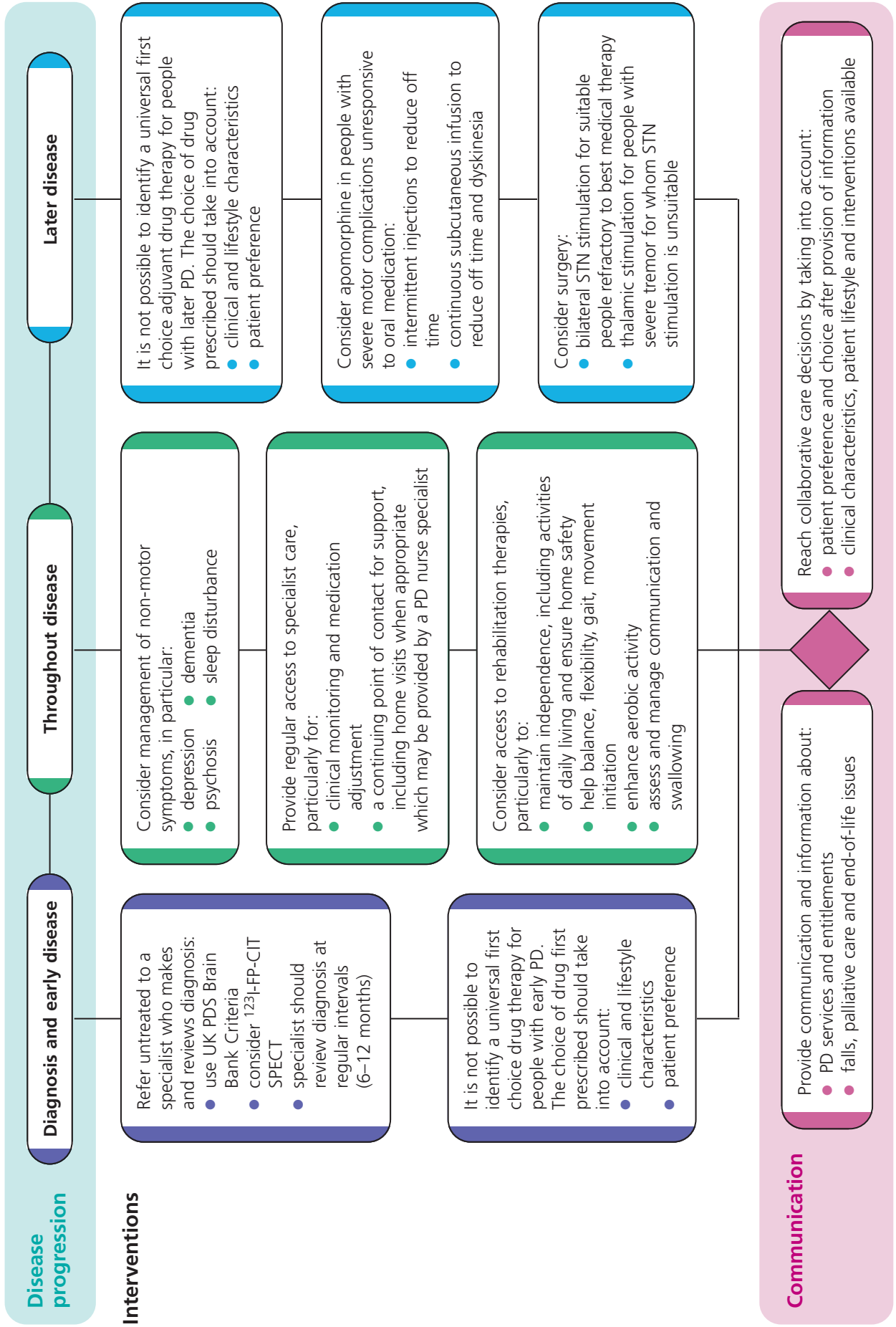
Access to speech and language therapy

- Speech and language therapy should be available for people with PD. Particular consideration should be given to:
 - improvement of vocal loudness and pitch range, including speech therapy programmes such as Lee Silverman Voice Treatment (LSVT)
 - teaching strategies to optimise speech intelligibility
 - ensuring an effective means of communication is maintained throughout the course of the disease, including use of assistive technologies
 - review and management to support the safety and efficiency of swallowing and to minimise the risk of aspiration.

Palliative care

- Palliative care requirements of people with PD should be considered throughout all phases of the disease.
- People with PD and their carers should be given the opportunity to discuss end-of-life issues with appropriate healthcare professionals.

Interventions for people with PD



Communicating with people with PD and their carers

- Aim to empower people with PD to participate in judgements and choices about their own care.
- Aim to achieve a balance between provision of honest, realistic information about the condition and promoting optimism.
- Because people with PD may develop impaired cognitive ability, a communication deficit and/or depression, provide:
 - individually tailored oral and written communication throughout the course of the disease, reinforced as necessary
 - consistent communication from the professionals involved.
- Give families/carers information about the condition, their entitlements to care assessment and the support services available.
- Agree a comprehensive care plan with the person with PD, their family/carers and specialist and secondary healthcare providers.
- Offer an accessible point of contact with specialist services. This could be provided by a Parkinson's disease nurse specialist.
- Advise all people with PD who drive that they should inform the DVLA and their car insurer of their condition at the time of diagnosis.

Diagnosing PD

- PD should be suspected in people presenting with tremor, stiffness, slowness, balance problems and/or gait disorders.
- Refer people with suspected PD quickly³ and untreated to a specialist in the differential diagnosis of PD.

Diagnosis and regular review

- Diagnose PD clinically and based on the UK Parkinson's Disease Society Brain Bank Criteria.
- Consider discussing with patients the possibility of tissue donation to a brain bank for diagnostic confirmation and research.
- Regularly review⁴ the diagnosis of PD and reconsider if atypical clinical features develop.

Differential diagnosis of parkinsonian syndromes

- Consider ¹²³I-FP-CIT SPECT for people with tremor where essential tremor cannot be clinically differentiated from parkinsonism.
 - ¹²³I-FP-CIT SPECT should be made available to specialists with expertise in its use and interpretation.
- Structural MRI should not be used in the differential diagnosis of PD but may be considered in the differential diagnosis of parkinsonian syndromes.

Tests that should not be used

- PET (positron emission tomography), except in clinical trials.
- Magnetic resonance volumetry, except in clinical trials.
- Objective smell testing, except in clinical trials.
- Magnetic resonance spectroscopy.
- Acute levodopa and apomorphine challenge tests.

³ The Guideline Development Group considered that people with suspected mild PD should be seen within 6 weeks, but new referrals in later disease with more complex problems require an appointment within 2 weeks.

⁴ The Guideline Development Group considered that people diagnosed with PD should be seen at regular intervals of 6–12 months to review their diagnosis.

Neuroprotection

- Do not use vitamin E as a neuroprotective therapy in PD.
- Do not use the following as neuroprotective therapies in PD, except in clinical trials:
 - co-enzyme Q₁₀
 - dopamine agonists
 - MAO-B inhibitors.

Pharmacological interventions

Treatment options for early and later PD

It is not possible to identify a universal first-choice drug therapy for either early PD or for adjuvant drug therapy for later PD. (Most people with PD will develop, with time, motor complications and will eventually require levodopa therapy.)

Table 1 indicates drug options that may be used for symptomatic treatment in early PD. **Table 2** indicates options that may be used adjuvant to levodopa to reduce motor complications in later PD. When choosing treatment, take account of:

- clinical and lifestyle preferences
- patient preference, after informing the patient of the short- and long-term benefits and drawbacks of drug classes.

Further drug administration considerations

- To avoid the potential for acute akinesia or neuroleptic malignant syndrome, do not:
 - withdraw antiparkinsonian medication abruptly
 - allow medication to fail suddenly due to poor absorption (for example, gastroenteritis, abdominal surgery).
- The practice of 'drug holidays' should not be undertaken because of the risk of neuroleptic malignant syndrome.
- People with PD admitted to hospital or care homes should have their medication:
 - given at appropriate times, which in some cases may mean allowing self-medication
 - adjusted by, or adjusted only after discussion with, a specialist in managing PD.
- Clinicians should be aware of dopamine dysregulation syndrome (an uncommon disorder in which misuse of dopaminergic medication is associated with behaviours such as hypersexuality, pathological gambling and stereotypic motor acts). This syndrome may be difficult to manage.

Table 1 Options for initial pharmacotherapy in early PD

Initial therapy for early PD	First-choice option	Symptom control	Risk of side effects		Notes
			Motor complications	Other adverse events	
Levodopa	✓	+++	↑	↑	<ul style="list-style-type: none"> Use lowest dose possible to maintain good function in order to reduce development of motor complications.
Dopamine agonists	✓	++	↓	↑	<ul style="list-style-type: none"> If side effects prevent titration to clinically efficacious dose, replace with another dopamine agonist or another drug class. If using an ergot-derived agonist, ensure a minimum of renal function tests, ESR and chest radiograph performed before starting treatment, and annually thereafter. (Full details of the restriction on pergolide use and monitoring are available in the 'Summary of product characteristics'.) Non-ergot-derived agonists should be preferred in most cases.
MAO-B inhibitors	✓	++	↓	↑	
β-Adrenergic antagonists	✗	Lack of evidence	Lack of evidence	Lack of evidence	<ul style="list-style-type: none"> For selected patients with postural tremor.
Amantadine	✗	Lack of evidence	Lack of evidence	Lack of evidence	
Anticholinergics	✗	Lack of evidence	Lack of evidence	Lack of evidence	<ul style="list-style-type: none"> Typically for young people with early PD and severe tremor. Limited efficacy and propensity for causing neuropsychiatric side effects.
Modified-release levodopa	✗	+++	↑	↑	<ul style="list-style-type: none"> Do not use modified-release levodopa to delay onset of motor complications.

+++ Good degree symptom control; ++ moderate degree symptom control; + limited degree symptom control; ↑ evidence of increased motor complications/other adverse events; ↓ evidence of reduced motor complications/other adverse events.

Table 2 Adjuvant pharmacotherapy options in later PD

Adjuvant therapy for later PD	First-choice option	Symptom control	Risk of side effects		Notes
			Motor complications	Other adverse events	
Dopamine agonists	✓	++	↓	↑	<ul style="list-style-type: none"> If side effects prevent titration to clinically efficacious dose, replace with another dopamine agonist or another drug class. If using an ergot-derived agonist, ensure a minimum of renal function tests, ESR and chest radiograph performed before starting treatment, and annually thereafter. (Full details of the restriction on pergolide use and monitoring are available in the 'Summary of product characteristics'.) Non-ergot-derived agonists should be preferred in most cases.
MAO-B inhibitors	✓	++	↓	↑	
COMT inhibitors	✓	++	↓	↑	<ul style="list-style-type: none"> Entacapone: due to poor concordance, if using entacapone, offer triple combination preparation (levodopa, carbidopa and entacapone⁵). Tolcapone: only use if entacapone fails due to lack of efficacy or side effects. Perform liver function tests every 2 weeks during first year of therapy, and according to the 'Summary of product characteristics' thereafter.
Amantadine	✗	NS	↓	↑	<ul style="list-style-type: none"> May be used for reducing dyskinesia.
Apomorphine	✗	+	↓	↑	<ul style="list-style-type: none"> Intermittent injections may be used to reduce off time in patients with severe motor complications. Continuous subcutaneous infusions may be used to reduce off time and dyskinesia in patients with severe motor complications. Initiation should be restricted to expert units with appropriate monitoring facilities.
Modified-release levodopa	✗	++	↓	↑	
+++ Good degree symptom control; ++ moderate degree symptom control; + limited degree symptom control; ↑ evidence of increased motor complications/other adverse events; ↓ evidence of reduced motor complications/other adverse events; NS non-significant result.					

⁵ Trade name Stalevo (Orion)

Surgery

NICE has published interventional procedure guidance on 'Deep brain stimulation for Parkinson's disease', which is available from www.nice.org.uk/IPG019

- Bilateral subthalamic nucleus (STN) or globus pallidus interna (GPi)⁶ stimulation may be used for people with PD who:
 - have motor complications that are refractory to best medical treatment,
 - are biologically fit with no clinically significant active comorbidity,
 - are levodopa responsive and
 - have no clinically significant active mental health problems, for example, depression or dementia.
- With current evidence, it is not possible to decide if STN or GPi is the preferred target for deep brain stimulation, or if one form of surgery is more effective or safer than the other. When considering the type of surgery, take account of:
 - the patient's clinical and lifestyle characteristics
 - patient preference, after he or she has been informed of the potential benefits and drawbacks of the different procedures.

Non-motor features of PD

Mental health problems

Depression

- Clinicians should have a low threshold for diagnosing depression in PD.
- Be aware of the difficulties of diagnosing mild depression, because clinical features of depression and motor features of PD overlap.
- Tailor the management of depression to the individual, in particular to their co-existing therapy.

Psychotic symptoms

- Give all people with PD and psychosis a general medical evaluation and treat any precipitating condition.
- Consider gradually withdrawing antiparkinsonian medication that might have triggered psychosis.
- Mild psychotic symptoms may not need active treatment if the patient and carer tolerate them well.
- Do not use typical antipsychotic drugs (such as phenothiazines and butyrophenones) because they exacerbate motor features of PD.

⁶ GPi deep brain stimulation is rarely performed for PD in the UK at present, although it is sometimes undertaken when STN stimulation is not possible.

- Atypical antipsychotics may be considered, although the evidence base for their efficacy and safety is limited.
- Clozapine may be used for treating psychotic symptoms. NB: requires registration with a mandatory monitoring scheme. It is recognised that few specialists caring for people with PD have experience with clozapine.

Dementia

- Although cholinesterase inhibitors have been used successfully in individual people with PD dementia, the NICE guideline recommends further research to identify those patients who will benefit from this treatment.

Sleep disturbance

- Take a full sleep history from people with PD who report sleep disturbance.
- Advise good sleep hygiene in people with any sleep disturbance⁷.
- Take care to identify and manage restless legs syndrome and REM sleep behaviour disorder.
- Advise people with sudden onset of sleep not to drive and to consider any occupational hazards.
 - Attempt to adjust medication to reduce its occurrence.

Daytime hypersomnolence

- Modafinil may be considered for daytime hypersomnolence.

Nocturnal akinesia

- Modified-release levodopa preparations may be used for nocturnal akinesia.

Falls in people with PD

- For all people with PD at risk of falling, refer to the NICE guideline 'Falls: the assessment and prevention of falls in older people.' *NICE clinical guideline* no. 21. (Available from www.nice.org.uk/CG021).

Autonomic disturbances

- Treat the following autonomic disturbances appropriately⁸:
 - urinary dysfunction
 - weight loss
 - dysphagia
 - constipation
 - erectile dysfunction
 - orthostatic hypotension
 - excessive sweating
 - sialorrhea.

^{7,8} Please refer to the full guideline for additional information.

Other key interventions

Specialist nurse interventions

- There should be regular access to the following:
 - clinical monitoring and medication adjustment
 - a continuing point of contact for support, including home visits, when appropriate
 - a reliable source of information about clinical and social matters of concern for people with PD and their carerswhich may be provided by a Parkinson's disease nurse specialist.

Physiotherapy

- Physiotherapy should be available for people with PD. Give particular consideration to:
 - gait re-education, improving balance and flexibility
 - enhancement of aerobic capacity
 - improvement of movement initiation
 - improvement of functional independence, including mobility and activities of daily living
 - provision of advice regarding safety in the home environment.
- The Alexander Technique may be offered to benefit people with PD by helping them to make lifestyle adjustments that affect both the physical nature of the condition and the person's attitudes to having PD.

Occupational therapy

- Occupational therapy should be available for people with PD. Give particular consideration to:
 - maintenance of work and family roles, home care and leisure activities
 - improvement and maintenance of transfers and mobility
 - improvement of personal self-care activities, such as eating, drinking, washing and dressing
 - environmental issues to improve safety and motor function
 - cognitive assessment and appropriate intervention.

Speech and language therapy

- Speech and language therapy should be available for people with PD. Give particular consideration to:
 - improvement of vocal loudness and pitch range, including speech therapy programmes such as Lee Silverman Voice Treatment (LSVT)
 - teaching strategies to optimise speech intelligibility
 - ensuring an effective means of communication is maintained throughout the course of the disease, including use of assistive technologies
 - review and management of the safety and efficiency of swallowing and minimising the risk of aspiration.

Palliative care

- Consider palliative care requirements of people with PD throughout all phases of the disease.
- Give people with PD and their carers the opportunity to discuss end-of-life issues with appropriate healthcare professionals.

Implementation

NICE has developed tools to help organisations implement this guidance (listed below). These are available on our website (www.nice.org.uk/CG035).

- Slides highlighting key messages for local discussion.
- Costing tools:
 - costing report to estimate the national savings and costs associated with implementation
 - costing template to estimate the local costs and savings involved.

- Implementation advice on how to put the guidance into practice and national initiatives which support this locally.

Further information

Quick reference guide

This quick reference guide to the Institute's guideline on Parkinson's disease contains the key priorities for implementation, summaries of the guidance, and notes on implementation. It has been distributed to health professionals in England (see www.nice.org.uk/CG035distributionlist).

It is also available from www.nice.org.uk/CG035quickrefguide

For printed copies, phone the NHS Response Line on 0870 1555 455 and quote reference number N1052.

NICE guideline

The NICE guideline, 'Parkinson's disease: diagnosis and management in primary and secondary care', is available from www.nice.org.uk/CG035NICEguideline

The NICE guideline contains the following sections: Key priorities for implementation; 1 Guidance; 2 Notes on the scope of the guidance; 3 Implementation in the NHS;

4 Research recommendations; 5 Other versions of this guideline; 6 Related NICE guidance; 7 Review date. It also gives details of the grading scheme for the evidence and recommendations, the Guideline Development Group and the Guideline Review Panel and technical detail on the criteria for audit.

Full guideline

The full guideline includes the evidence on which the recommendations are based, in addition to the information in the NICE guideline. It is published by National Collaborating Centre for Chronic Conditions. It is available from www.rcplondon.ac.uk/pubs/books/PD, the website of the National Library for Health (www.nlh.nhs.uk), and from www.nice.org.uk/CG035fullguideline

Information for patients and carers

NICE has produced a version of this guidance for people with Parkinson's disease and their carers ('Understanding NICE guidance'), which is available from www.nice.org.uk/CG035publicinfo

For printed copies, phone the NHS Response Line on 0870 1555 455 and quote reference number N1053.

Related guidance

For information about NICE guidance that has been issued or is in development, see the website (www.nice.org.uk).

NICE has issued clinical guidelines on 'Depression: management of depression in primary and secondary care' (available from www.nice.org.uk/CG023); 'Falls: the assessment and prevention of falls in older people' (available from www.nice.org.uk/CG021); and 'Nutrition support in adults: oral nutrition support, enteral tube feeding and parenteral nutrition' (available from www.nice.org.uk/CG032). NICE is developing a clinical guideline on 'Dementia: management of dementia, including use of antipsychotic medication in older people' (publication expected February 2007).

NICE has issued technology appraisal guidance on 'Alzheimer's disease – donepezil, rivastigmine and galantamine' (available from www.nice.org.uk/TA019). It is developing guidance on 'Donepezil, rivastigmine, galantamine and memantine for the treatment of Alzheimer's disease' (including a review of existing guidance no. 19). (Publication expected late 2006.)

NICE has issued interventional procedure guidance on 'Deep brain stimulation for Parkinson's disease' (available from www.nice.org.uk/IPG019).

Review date

The process of reviewing the evidence is expected to begin 4 years after the date of issue of this guideline. Reviewing may begin before this if significant evidence that affects the guideline recommendations is identified. The updated guideline will be available within 2 years of the start of the review process.

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