

# Parkinson's disease in adults

NICE guideline

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# Your responsibility

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

All problems (adverse events) related to a medicine or medical device used for treatment or in a procedure should be reported to the Medicines and Healthcare products Regulatory Agency using the [Yellow Card Scheme](#).

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should [assess and reduce the environmental impact of implementing NICE recommendations](#) wherever possible.

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This guideline replaces ESUOM48, ESUOM15, ES6 and ES9.

This guideline is the basis of QS164.

## Overview

This guideline covers diagnosing and managing Parkinson's disease in people aged 18 and over. It aims to improve care from the time of diagnosis, including monitoring and managing symptoms, providing information and support, and palliative care.

## Who is it for?

- Healthcare professionals
- Commissioners and providers
- Adults with Parkinson's disease and their families and carers

# Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in [making decisions about your care](#).

[Making decisions using NICE guidelines](#) explains how we use words to show the strength (or certainty) of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

## 1.1 Communication with people with Parkinson's disease and their carers

- 1.1.1 Communication with people with Parkinson's disease should aim towards empowering them to participate in judgements and choices about their own care. **[2006]**
- 1.1.2 In discussions, aim to achieve a balance between providing honest, realistic information about the condition and promoting a feeling of optimism. **[2006]**
- 1.1.3 Because people with Parkinson's disease may develop impaired cognitive ability, communication problems and/or depression, provide them with:
- both oral and written communication throughout the course of the disease, which should be individually tailored and reinforced as necessary
  - consistent communication from the professionals involved. **[2006]**
- 1.1.4 Advise family members and carers about their right to carer assessment, and assessment for respite care and other support.

See the [NICE guideline on supporting adult carers](#) for recommendations on identifying, assessing and meeting the caring, physical and mental health needs of families and carers. **[2006]**

- 1.1.5 People with Parkinson's disease should have a comprehensive care plan agreed between the person, their family members and carers (as appropriate), and specialist and secondary healthcare providers. **[2006]**
- 1.1.6 Offer people with Parkinson's disease an accessible point of contact with specialist services. This could be provided by a Parkinson's disease nurse specialist. **[2006]**
- 1.1.7 Advise people with Parkinson's disease who drive that they should inform the Driver and Vehicle Licensing Agency (DVLA) and their car insurer of their condition when Parkinson's disease is diagnosed. **[2006]**

## 1.2 Diagnosing Parkinson's disease

### Definition and differential diagnosis

- 1.2.1 Suspect Parkinson's disease in people presenting with tremor, stiffness, slowness, balance problems and/or gait disorders. **[2006]**
- 1.2.2 If Parkinson's disease is suspected, refer people quickly and untreated to a specialist with expertise in the differential diagnosis of this condition. **[2006, amended 2017]**

### Clinical and post-mortem diagnosis

- 1.2.3 Diagnose Parkinson's disease clinically, based on the UK Parkinson's Disease Society Brain Bank Clinical Diagnostic Criteria. **[2006]**
- 1.2.4 Encourage healthcare professionals to discuss with people with Parkinson's disease the possibility of donating tissue to a brain bank for diagnostic confirmation and research. **[2006]**

## Review of diagnosis

- 1.2.5 Review the diagnosis of Parkinson's disease regularly, and reconsider it if atypical clinical features develop. (People diagnosed with Parkinson's disease should be seen at regular intervals of 6 to 12 months to review their diagnosis.) **[2006]**

## Single photon emission computed tomography

- 1.2.6 Consider  $^{123}\text{I}$ -FP-CIT single photon emission computed tomography (SPECT) for people with tremor if essential tremor cannot be clinically differentiated from parkinsonism. **[2006, amended 2017]**
- 1.2.7  $^{123}\text{I}$ -FP-CIT SPECT should be available to specialists with expertise in its use and interpretation. **[2006]**

## Positron emission tomography

- 1.2.8 Do not use positron emission tomography (PET) in the differential diagnosis of parkinsonian syndromes, except in the context of clinical trials. **[2006, amended 2017]**

## Structural MRI

- 1.2.9 Do not use structural MRI to diagnose Parkinson's disease. **[2006, amended 2017]**
- 1.2.10 Structural MRI may be considered in the differential diagnosis of other parkinsonian syndromes. **[2006]**

## Magnetic resonance volumetry

- 1.2.11 Do not use magnetic resonance volumetry in the differential diagnosis of parkinsonian syndromes, except in the context of clinical trials. **[2006, amended 2017]**

2017]

## Magnetic resonance spectroscopy

- 1.2.12 Do not use magnetic resonance spectroscopy in the differential diagnosis of parkinsonian syndromes. **[2006, amended 2017]**

## Acute levodopa and apomorphine challenge tests

- 1.2.13 Do not use acute levodopa and apomorphine challenge tests in the differential diagnosis of parkinsonian syndromes. **[2006, amended 2017]**

## Objective smell testing

- 1.2.14 Do not use objective smell testing in the differential diagnosis of parkinsonian syndromes, except in the context of clinical trials. **[2006, amended 2017]**

# 1.3 Pharmacological management of motor symptoms

- 1.3.1 Before starting treatment for people with Parkinson's disease, discuss:
- the person's individual clinical circumstances, for example, their symptoms, comorbidities and risks from polypharmacy
  - the person's individual lifestyle circumstances, preferences, needs and goals
  - the potential benefits and harms of the different drug classes (see table 1). **[2017]**



**Table 1 Potential benefits and harms of dopamine agonists, levodopa and MAO-B inhibitors**

-	Levodopa	Dopamine agonists	Monoamine oxidase-B (MAO-B) inhibitors
<b>Motor symptoms</b>	More improvement in motor symptoms	Less improvement in motor symptoms	Less improvement in motor symptoms
<b>Activities of daily living</b>	More improvement in activities of daily living	Less improvement in activities of daily living	Less improvement in activities of daily living
<b>Motor complications</b>	More motor complications	Fewer motor complications	Fewer motor complications
<b>Adverse events</b>	Fewer specified adverse events	More specified adverse events	Fewer specified adverse events

- 1.3.2 Antiparkinsonian medicines should not be withdrawn abruptly or allowed to fail suddenly due to poor absorption (for example, gastroenteritis, abdominal surgery) to avoid the potential for acute akinesia or neuroleptic malignant syndrome. **[2006]**
- 1.3.3 The practice of withdrawing people from their antiparkinsonian drugs (so called 'drug holidays') to reduce motor complications should not be undertaken because of the risk of neuroleptic malignant syndrome. **[2006]**
- 1.3.4 In view of the risks of sudden changes in antiparkinsonian medicines, people with Parkinson's disease who are admitted to hospital or care homes should have their medicines:
- given at the appropriate times, which in some cases may mean allowing self-medication
  - adjusted by, or adjusted only after discussion with, a specialist in the management of Parkinson's disease. **[2006]**

## First-line treatment

- 1.3.5 Offer levodopa to people in the early stages of Parkinson's disease whose motor symptoms impact on their quality of life. **[2017]**

- 1.3.6 Consider a choice of dopamine agonists, levodopa or monoamine oxidase B (MAO-B) inhibitors for people in the early stages of Parkinson's disease whose motor symptoms do not impact on their quality of life. **[2017]**
- 1.3.7 Do not offer ergot-derived dopamine agonists as first-line treatment for Parkinson's disease. **[2017]**

Follow the [Medicines and Healthcare products Regulatory Agency guidance on the warnings and contraindications for ergot-derived dopamine agonists](#).

## Information and support

- 1.3.8 When starting treatment for people with Parkinson's disease, give people and their family members and carers (as appropriate) oral and written information about the following risks, and record that the discussion has taken place:
- Impulse control disorders with all dopaminergic therapy (and the increased risk with dopamine agonists). Also see [recommendations in the section on managing and monitoring impulse control disorders as an adverse effect of dopaminergic therapy](#)
  - Excessive sleepiness and sudden onset of sleep with dopamine agonists. Also see [recommendations on daytime sleepiness in the section on pharmacological management of non-motor symptoms](#)
  - Psychotic symptoms (hallucinations and delusions) with all Parkinson's disease treatments (and the higher risk with dopamine agonists). Also see the [recommendations on psychotic symptoms \(hallucinations and delusions\) in the section on pharmacological management of non-motor symptoms](#). **[2017]**

## Adjuvant treatment of motor symptoms

- 1.3.9 If a person with Parkinson's disease has developed dyskinesia and/or motor fluctuations, including medicines 'wearing off', seek advice from a healthcare professional with specialist expertise in Parkinson's disease before modifying

therapy. [2017]

- 1.3.10 Offer a choice of dopamine agonists, MAO-B inhibitors or catechol-O-methyl transferase (COMT) inhibitors as an adjunct to levodopa for people with Parkinson's disease who have developed dyskinesia or motor fluctuations despite optimal levodopa therapy, after discussing:
- the person's individual clinical circumstances, for example, their Parkinson's disease symptoms, comorbidities and risks from polypharmacy
  - the person's individual lifestyle circumstances, preferences, needs and goals
  - the potential benefits and harms of the different drug classes (see table 2).
- [2017]

Table 2 Potential benefits and harms of dopamine agonists, MAO-B inhibitors, COMT inhibitors and amantadine

-	Dopamine agonists	Monoamine oxidase-B (MAO-B) inhibitors	Catechol-O-methyl transferase (COMT) inhibitors	Amantadine
Motor symptoms	Improvement in motor symptoms	Improvement in motor symptoms	Improvement in motor symptoms	No evidence of improvement in motor symptoms
Activities of daily living	Improvement in activities of daily living	Improvement in activities of daily living	Improvement in activities of daily living	No evidence of improvement in activities of daily living
Off time	More off-time reduction	Off-time reduction	Off-time reduction	No studies reporting this outcome
Adverse events	Intermediate risk of adverse events	Fewer adverse events	More adverse events	No studies reporting this outcome
Hallucinations	More risk of hallucinations	Lower risk of hallucinations	Lower risk of hallucinations	No studies reporting this outcome

- 1.3.11 Choose a non-ergot-derived dopamine agonist in most cases, because of the monitoring that is needed with ergot-derived dopamine agonists. [2017]

Follow the [Medicines and Healthcare products Regulatory Agency guidance on the warnings and contraindications for ergot-derived dopamine agonists](#).

1.3.12 Only consider an ergot-derived dopamine agonist as an adjunct to levodopa for people with Parkinson's disease:

- who have developed dyskinesia or motor fluctuations despite optimal levodopa therapy **and**
- whose symptoms are not adequately controlled with a non-ergot-derived dopamine agonist. **[2017]**

Follow the [Medicines and Healthcare products Regulatory Agency guidance on the warnings and contraindications for ergot-derived dopamine agonists](#).

1.3.13 If dyskinesia is not adequately managed by modifying existing therapy, consider amantadine. **[2017]**

1.3.14 Do not offer anticholinergics to people with Parkinson's disease who have developed dyskinesia and/or motor fluctuations. **[2017]**

## 1.4 Managing and monitoring impulse control disorders as an adverse effect of dopaminergic therapy

### Predictors for the development of impulse control disorders

1.4.1 Recognise that impulse control disorders can develop in a person with Parkinson's disease who is on any dopaminergic therapy at any stage in the disease course. **[2017]**

1.4.2 Recognise that the following are associated with an increased risk of developing impulse control disorders:

- Dopamine agonist therapy.

- A history of previous impulsive behaviours.
- A history of alcohol consumption and/or smoking. **[2017]**

## Information and support

- 1.4.3 When starting dopamine agonist therapy, give people and their family members and carers (as appropriate) oral and written information about the following, and record that the discussion has taken place:
- The increased risk of developing impulse control disorders when taking dopamine agonist therapy, and that these may be concealed by the person affected.
  - The different types of impulse control disorders (for example, compulsive gambling, hypersexuality, binge eating and obsessive shopping).
  - Who to contact if impulse control disorders develop.
  - The possibility that if problematic impulse control disorders develop, dopamine agonist therapy will be reviewed and may be reduced or stopped. **[2017]**
- 1.4.4 Discuss potential impulse control disorders at review appointments, particularly when modifying therapy, and record that the discussion has taken place. **[2017]**
- 1.4.5 Be aware that impulse control disorders can also develop while taking dopaminergic therapies other than dopamine agonists. **[2017]**

## Managing dopaminergic therapy in people who have developed an impulse control disorder

- 1.4.6 If a person with Parkinson's disease has developed a problematic impulse control disorder, seek advice from a healthcare professional with specialist expertise in Parkinson's disease before modifying dopaminergic therapy. **[2017]**

- 1.4.7 Discuss the following with the person and their family members and carers (as appropriate):
- How the impulse control disorder is affecting their life.
  - Possible treatments, such as reducing or stopping dopaminergic therapy.
  - The benefits and disadvantages of reducing or stopping dopaminergic therapy. **[2017]**
- 1.4.8 When managing impulse control disorders, modify dopaminergic therapy by first gradually reducing any dopamine agonist. Monitor whether the impulse control disorder improves and whether the person has any symptoms of dopamine agonist withdrawal. **[2017]**
- 1.4.9 Offer specialist cognitive behavioural therapy targeted at impulse control disorders if modifying dopaminergic therapy is not effective. **[2017]**

## 1.5 Pharmacological management of non-motor symptoms

### Daytime sleepiness

- 1.5.1 Advise people with Parkinson's disease who have daytime sleepiness and/or sudden onset of sleep not to drive (and to inform the DVLA of their symptoms) and to think about any occupation hazards. Adjust their medicines to reduce its occurrence, having first sought advice from a healthcare professional with specialist expertise in Parkinson's disease. **[2017]**
- 1.5.2 Consider modafinil to treat excessive daytime sleepiness in people with Parkinson's disease, only if a detailed sleep history has excluded reversible pharmacological and physical causes. **[2017]**

Women who are pregnant or who are planning a pregnancy should not take modafinil, in line with the [MHRA safety advice on modafinil](#).

- 1.5.3 At least every 12 months, a healthcare professional with specialist expertise in Parkinson's disease should review people with Parkinson's disease who are taking modafinil. **[2017]**

Women who are pregnant or who are planning a pregnancy should not take modafinil, in line with the [MHRA safety advice on modafinil](#).

## Restless leg syndrome and rapid eye movement sleep behaviour disorder

- 1.5.4 Take care to identify and manage restless leg syndrome and rapid eye movement sleep behaviour disorder in people with Parkinson's disease and sleep disturbance. **[2017]**

- 1.5.5 Consider clonazepam or melatonin to treat rapid eye movement sleep behaviour disorder if a medicines review has addressed possible pharmacological causes. **[2017]**

For guidance on safe prescribing of benzodiazapines (such as clonazepam) and managing withdrawal, see [NICE's guideline on medicines associated with dependence or withdrawal symptoms](#).

In July 2017, this was an off-label use of clonazepam and melatonin. See [NICE's information on prescribing medicines](#).

## Nocturnal akinesia

- 1.5.6 Consider levodopa or oral dopamine agonists to treat nocturnal akinesia in people with Parkinson's disease. If the selected option is not effective or not tolerated, offer the other instead. **[2017]**
- 1.5.7 Consider rotigotine if levodopa and/or oral dopamine agonists are not effective in treating nocturnal akinesia. **[2017]**

## Orthostatic hypotension

- 1.5.8 If a person with Parkinson's disease has developed orthostatic hypotension, review the person's existing medicines to address possible pharmacological causes, including:
- antihypertensives (including diuretics)
  - dopaminergics
  - anticholinergics
  - antidepressants. **[2017]**
- 1.5.9 Consider midodrine for people with Parkinson's disease and orthostatic hypotension, taking into account the contraindications and monitoring requirements (including monitoring for supine hypertension). **[2017]**
- 1.5.10 If midodrine is contraindicated, not tolerated or not effective, consider fludrocortisone (taking into account its safety profile, in particular its cardiac risk and potential interactions with other medicines). **[2017]**

In July 2017, this was an off-label use of fludrocortisone. See [NICE's information on prescribing medicines](#).

## Depression

- 1.5.11 For guidance on identifying, treating and managing depression in people with Parkinson's disease, see the [NICE guideline on depression in adults with a chronic physical health problem](#). **[2017]**

## Psychotic symptoms (hallucinations and delusions)

In July 2017, the use of quetiapine in recommendations 1.5.16 and 1.5.18 was off-label. See [NICE's information on prescribing medicines](#).



- 1.5.12 At review appointments and following medicines changes, ask people with Parkinson's disease and their family members and carers (as appropriate) if the person is experiencing hallucinations (particularly visual) or delusions. **[2017]**
- 1.5.13 Perform a general medical evaluation for people with hallucinations or delusions, and offer treatment for any conditions that might have triggered them. **[2017]**
- 1.5.14 Do not treat hallucinations and delusions if they are well tolerated by the person with Parkinson's disease and their family members and carers (as appropriate). **[2017]**
- 1.5.15 Reduce the dosage of any Parkinson's disease medicines that might have triggered hallucinations or delusions, taking into account the severity of symptoms and possible withdrawal effects. Seek advice from a healthcare professional with specialist expertise in Parkinson's disease before modifying therapy. **[2017]**
- 1.5.16 Consider quetiapine to treat hallucinations and delusions in people with Parkinson's disease who have no cognitive impairment. **[2017]**
- 1.5.17 If standard treatment is not effective, offer clozapine to treat hallucinations and delusions in people with Parkinson's disease. Be aware that registration with a patient monitoring service is needed. **[2017]**
- 1.5.18 Be aware that lower doses of quetiapine and clozapine are needed for people with Parkinson's disease than in other indications. **[2017]**
- 1.5.19 Do not offer olanzapine to treat hallucinations and delusions in people with Parkinson's disease. **[2017]**
- 1.5.20 Recognise that other antipsychotic medicines (such as phenothiazines and butyrophenones) can worsen the motor features of Parkinson's disease. **[2017]**
- 1.5.21 For guidance on hallucinations and delusions in people with dementia, see the section on managing non-cognitive symptoms in the NICE guideline on dementia. **[2017]**

## Parkinson's disease dementia

- 1.5.22 Offer a cholinesterase inhibitor for people with mild or moderate Parkinson's disease dementia. **[2017]**

In July 2017, rivastigmine capsules are the only treatment with a UK marketing authorisation for this indication. Use of donepezil, galantamine and rivastigmine patches was off-label. See [NICE's information on prescribing medicines](#).

- 1.5.23 Consider a cholinesterase inhibitor for people with severe Parkinson's disease dementia. **[2017]**

In July 2017, this was an off-label use of cholinesterase inhibitors. See [NICE's information on prescribing medicines](#).

- 1.5.24 Consider memantine for people with Parkinson's disease dementia, only if cholinesterase inhibitors are not tolerated or are contraindicated. **[2017]**

In July 2017, this was an off-label use of memantine. See [NICE's information on prescribing medicines](#).

- 1.5.25 For guidance on assessing and managing dementia, and supporting people living with dementia, see the [NICE guideline on dementia](#). **[2017]**

## Drooling of saliva

In July 2017, use of glycopyrronium bromide in recommendations 1.5.27, 1.5.28 and 1.5.29 was off-label.

In September 2019, Xeomin was the only preparation of botulinum toxin A (recommendation 1.5.28) licensed in the UK for treating chronic sialorrhoea caused by neurological conditions in adults. Use of other preparation of botulinum toxin type A was off-label.

See [NICE's information on prescribing medicines](#).

- 1.5.26 Only consider pharmacological management for drooling of saliva in people with Parkinson's disease if non-pharmacological management (for example, speech and language therapy; see recommendation 1.7.8) is not available or has not been effective. **[2017]**
- 1.5.27 Consider glycopyrronium bromide to manage drooling of saliva in people with Parkinson's disease. **[2017]**
- 1.5.28 If treatment for drooling of saliva with glycopyrronium bromide is not effective, not tolerated or contraindicated (for example, in people with cognitive impairment, hallucinations or delusions, or a history of adverse effects following anticholinergic treatment), consider referral to a specialist service for botulinum toxin A. **[2017]**
- 1.5.29 Only consider anticholinergic medicines other than glycopyrronium bromide to manage drooling of saliva in people with Parkinson's disease if their risk of cognitive adverse effects is thought to be minimal. Use topical preparations if possible (for example, atropine) to reduce the risk of adverse events. **[2017]**

## 1.6 Pharmacological neuroprotective therapy

- 1.6.1 Do not use vitamin E as a neuroprotective therapy for people with Parkinson's disease. **[2006, amended 2017]**
- 1.6.2 Do not use co-enzyme Q10 as a neuroprotective therapy for people with Parkinson's disease, except in the context of clinical trials. **[2006, amended 2017]**
- 1.6.3 Do not use dopamine agonists as neuroprotective therapies for people with Parkinson's disease, except in the context of clinical trials. **[2006, amended 2017]**
- 1.6.4 Do not use MAO-B inhibitors as neuroprotective therapies for people with Parkinson's disease, except in the context of clinical trials. **[2006, amended 2017]**

## 1.7 Non-pharmacological management of motor and non-motor symptoms

### Parkinson's disease nurse specialist interventions

1.7.1 People with Parkinson's disease should have regular access to:

- clinical monitoring and medicines 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 Parkinson's disease and their family members and their carers (as appropriate),

which may be provided by a Parkinson's disease nurse specialist. **[2006]**

### Physiotherapy and physical activity

1.7.2 Consider referring people who are in the early stages of Parkinson's disease to a physiotherapist with experience of Parkinson's disease for assessment, education and advice, including information about physical activity. **[2017]**

1.7.3 Offer Parkinson's disease-specific physiotherapy for people who are experiencing balance or motor function problems. **[2017]**

1.7.4 Consider the Alexander Technique for people with Parkinson's disease who are experiencing balance or motor function problems. **[2017]**

### Occupational therapy

1.7.5 Consider referring people who are in the early stages of Parkinson's disease to an occupational therapist with experience of Parkinson's disease for assessment, education and advice on motor and non-motor symptoms. **[2017]**

- 1.7.6 Offer Parkinson's disease-specific occupational therapy for people who are having difficulties with activities of daily living. **[2017]**

## Speech and language therapy

- 1.7.7 Consider referring people who are in the early stages of Parkinson's disease to a speech and language therapist with experience of Parkinson's disease for assessment, education and advice. **[2017]**
- 1.7.8 Offer speech and language therapy for people with Parkinson's disease who are experiencing problems with communication, swallowing or saliva. This should include:
- strategies to improve the safety and efficiency of swallowing to minimise the risk of aspiration, such as expiratory muscle strength training (EMST)
  - strategies to improve speech and communication, such as attention to effort therapies. **[2017]**
- 1.7.9 Consider referring people for alternative and augmentative communication equipment that meets their communication needs as Parkinson's disease progresses and their needs change. **[2017]**

## Nutrition

- 1.7.10 Consider referring people with Parkinson's disease to a dietitian for specialist advice. **[2017]**
- 1.7.11 Discuss a diet in which most of the protein is eaten in the final main meal of the day (a protein redistribution diet) for people with Parkinson's disease on levodopa who experience motor fluctuations. **[2017]**
- 1.7.12 Advise people with Parkinson's disease to avoid a reduction in their total daily protein consumption. **[2017]**
- 1.7.13 Advise people with Parkinson's disease to take a vitamin D supplement. See the

NICE guideline on vitamin D for recommendations on vitamin D testing, and the NICE guidelines on falls in older people and osteoporosis. **[2017]**

- 1.7.14 Do not offer creatine supplements to people with Parkinson's disease. **[2017]**
- 1.7.15 Advise people with Parkinson's disease not to take over-the-counter dietary supplements without first consulting their pharmacist or other healthcare professional. **[2017]**

## 1.8 Deep brain stimulation and levodopa–carbidopa intestinal gel

### Deep brain stimulation

- 1.8.1 Offer people with advanced Parkinson's disease best medical therapy, which may include intermittent apomorphine injection and/or continuous subcutaneous apomorphine infusion. **[2017]**
- 1.8.2 Do not offer deep brain stimulation to people with Parkinson's disease whose symptoms are adequately controlled by best medical therapy. **[2017]**
- 1.8.3 Consider deep brain stimulation for people with advanced Parkinson's disease whose symptoms are not adequately controlled by best medical therapy. **[2017]**

### Levodopa–carbidopa intestinal gel

- 1.8.4 Levodopa–carbidopa intestinal gel is currently available through an NHS England clinical commissioning policy. It is recommended that this policy is reviewed in light of this guidance. **[2017]**

## 1.9 Palliative care

### Information and support

- 1.9.1 Offer people with Parkinson's disease and their family members and carers (as appropriate) opportunities to discuss the prognosis of their condition. These discussions should promote people's priorities, shared decision-making and patient-centred care. **[2017]**
- 1.9.2 Offer people with Parkinson's disease and their family members and carers (as appropriate) oral and written information about the following, and record that the discussion has taken place:
- Progression of Parkinson's disease.
  - Possible future adverse effects of Parkinson's disease medicines in advanced Parkinson's disease.
  - Advance care planning, including Advance Decisions to Refuse Treatment (ADRT) and Do Not Attempt Resuscitation (DNACPR) orders, and Lasting Power of Attorney for finance and/or health and social care.
  - Options for future management.
  - What could happen at the end of life.
  - Available support services, for example, personal care, equipment and practical support, financial support and advice, care at home and respite care. **[2017]**
- 1.9.3 When discussing palliative care, recognise that family members and carers may have different information needs from the person with Parkinson's disease. **[2017]**

### Referral

- 1.9.4 Consider referring people at any stage of Parkinson's disease to the palliative

care team to give them and their family members or carers (as appropriate) the opportunity to discuss palliative care and care at the end of life. **[2017]**



## Context

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

Parkinson's disease is one of the most common neurological conditions. It is estimated to affect up to 160 people per 100,000, with an annual incidence in the UK of 15 to 20 per 100,000.

People with Parkinson's disease classically present with the symptoms and signs described as 'parkinsonism': these include bradykinesia (slow movements), rigidity, rest tremor (shaking) and postural instability (loss of balance).

The symptoms of parkinsonism are not always a result of Parkinson's disease. Other causes include side effects of medicines, vascular disease, and less common degenerative conditions such as progressive supranuclear palsy and multiple system atrophy.

Parkinson's disease has historically been recognised as a primary movement disorder; however, other symptoms may be prominent, such as depression, cognitive impairment and dementia. In the later stages of the disease, people may develop pain and autonomic disturbances (such as dizziness and fainting, and problems with sweating, heart rate, digestion, vision and sexual function). These other symptoms are sometimes described as the 'non-motor' manifestations of Parkinson's disease. The condition may progress to cause significant impairments, adversely affecting quality of life and, indirectly, the quality of life of family and carers.

# Recommendations for research

The guideline committee has made the following recommendations for research. The committee's full set of research recommendations is detailed in the [full guideline](#).

## 1 Combination treatment for Parkinson's disease dementia

What is the effectiveness of combination treatment with a cholinesterase inhibitor and memantine for people with Parkinson's disease dementia if treatment with a cholinesterase inhibitor alone is not effective or no longer effective?

### Why this is important

The guideline committee felt that cholinesterase inhibitors, memantine and combination therapy with both treatments are all reasonable clinical options, but noted that some people do not tolerate cholinesterase inhibitors well due to side effects. The evidence base for memantine was considerably weaker than for cholinesterase inhibitors, and therefore there would be value in either additional trials of memantine compared with placebo (in people for whom cholinesterase inhibitors are not an option), or non-inferiority studies compared with cholinesterase inhibitors.

In clinical practice, memantine is often added to a cholinesterase inhibitor when it is no longer proving effective, but there is no evidence base for this and randomised trials to establish whether there is additional benefit would be valuable. Both of these questions could potentially be answered in a single study with 3 arms of memantine monotherapy, cholinesterase inhibitor monotherapy and combination treatment.

## 2 Orthostatic hypotension treatment

For people with Parkinson's disease, what is the most effective pharmacological treatment for orthostatic hypotension?

Particular interventions and comparisons of interest are:

- midodrine compared with fludrocortisone (primary comparison)
- pyridostigmine
- ephedrine
- pseudoephedrine.

## Why this is important

The guideline committee felt that orthostatic hypotension was an important practical problem, common in people with Parkinson's disease and a contributor to falls and injuries. The current best pharmacological treatment is not yet established and research in this area would help to determine this. The randomised controlled trials that have previously been undertaken have only provided low-quality evidence (because of both small sample sizes and weaknesses in the trial designs) and cover only a subset of the comparisons of interest, making future research in this area of value.

## 3 Psychotic symptoms (hallucinations and delusions)

What is the effectiveness of rivastigmine compared with atypical antipsychotic drugs for treating psychotic symptoms (particularly hallucinations and delusions) associated with Parkinson's disease?

## Why this is important

Rivastigmine is commonly used to treat Parkinson's disease psychosis because it has shown some effectiveness in improving behavioural symptoms in people with Parkinson's disease dementia. At present, no evidence exists to support the efficacy of rivastigmine in treating people with Parkinson's disease whose symptoms are predominantly psychotic. It would be beneficial to undertake primary research in this area to determine the most effective treatment options for managing Parkinson's disease psychosis.

## 4 Rapid eye movement sleep behaviour disorder treatment

What is the best first-line treatment for rapid eye movement sleep behaviour disorder (RBD) in people with Parkinson's disease?

### Why this is important

The guideline committee highlighted the importance of minimising RBD, for both people with Parkinson's disease and their carers, particularly because of potential safety concerns. Only 1 paper was found to address optimal management, and this involved people in whom first-line treatment had failed. With multiple possible treatment options and no current evidence on what the most effective first-line treatment is, research (in the form of randomised controlled trials) in this area would be beneficial.

## 5 Physiotherapy

Does physiotherapy started early in the course of Parkinson's disease, as opposed to after motor symptom onset, confer benefits in terms of delaying symptom onset and/or reducing severity?

### Why this is important

The guideline committee felt that physiotherapy was beneficial for those earlier in the course of the disease as it may delay or lessen problems associated with symptoms, as well as for those who have developed symptoms and problems. At present, no substantial evidence exists to support the efficacy of physiotherapy as an early intervention to prevent the onset or reduce severity of motor symptoms, because most of the trials have been conducted in people who have already developed motor symptoms.

If physiotherapy were shown to have a beneficial effect in either delaying the onset or decreasing the severity of symptoms, this would have a substantial beneficial impact on the quality of life of people with Parkinson's disease and their family and carers. Relevant trials would not compare physiotherapy with no physiotherapy, but rather early physiotherapy (at the time of diagnosis) with physiotherapy offered at the current standard times in the UK.

# Finding more information and committee details

To find NICE guidance on related topics, including guidance in development, see the [NICE topic page on neurological conditions](#).

For full details of the guideline committee's discussion and the evidence reviews, see the [full guideline](#). You can also find information about [how the guideline was developed](#), including [details of the committee](#).

NICE has produced [tools and resources to help you put this guideline into practice](#). For general help and advice on putting our guidelines into practice, see [resources to help you put NICE guidance into practice](#).

# Update information

**July 2017:** We have reviewed the evidence and made new recommendations on treating Parkinson's disease symptoms, deep brain stimulation, monitoring and managing impulse control disorders, and palliative care. These recommendations are marked **[2017]**.

We have also made some changes without an evidence review:

- changes made to clarify the action of a recommendation
- the timeframe for referral was removed because it was not evidence based.

These recommendations are marked **[2006, amended 2017]**.

Recommendations marked **[2006]** last had an evidence review in 2006. In some cases minor changes have been made to the wording to bring the language and style up to date, without changing the meaning.

## Minor changes since publication

**May 2022:** We added a link to NICE's guideline on medicines associated with dependence or withdrawal symptoms in section 1.5.

**March 2022:** The heading above recommendations 1.5.4 and 1.5.5 was amended to clarify that this section covers both restless leg syndrome and rapid eye movement sleep behaviour disorder, and the abbreviation RBD was written out in full for clarity.

**December 2020:** We added advice for women who are pregnant or who are planning a pregnancy to recommendations 1.5.2 and 1.5.3, in line with the [MHRA safety advice on modafinil](#).

**September 2020:** We linked to the NICE guideline on supporting adult carers in recommendation 1.1.4 and incorporated footnotes into the recommendations in line with accessibility requirements.

**October 2019:** Information was added to reflect a change in marketing authorisation status for botulinum neurotoxin type A preparations.

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