

Parkinson's disease in adults

Information for the public

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Parkinson's disease: the care you should expect

This information explains the care that NICE has said works best for adults with Parkinson's disease. It will help you, your family and carers know what to expect from health and care services.

In December 2020 we updated our advice in our guideline on Parkinson's disease with a warning about modafinil – a medicine offered to some people with sleep problems. Modafinil should not be used during pregnancy or if a pregnancy is being planned. This is because of the risk of malformations in the baby.

Why is this important for you?

NICE aims to help people get the best care no matter who they are or where they live. This NICE advice aims to:

- explain which medicines and therapies can help with Parkinson's disease symptoms

- help you manage common side effects of treatments
- make sure you and your family get the support and information you need as your condition progresses.

For more information, see [where can I find out more?](#)

Your healthcare team should know what NICE has said. Talk to a member of your team if you don't think you are getting the care NICE has said you should have.

What is Parkinson's disease?

Parkinson's disease is a neurological condition, which means it affects the brain.

People with Parkinson's disease don't make enough of a chemical called dopamine – this helps to control muscles.

Parkinson's disease gets worse over time, but how quickly it progresses varies a lot from person to person.

Finding out if you have Parkinson's disease

The main symptoms of Parkinson's disease are changes in your movement and balance. Symptoms may include:

- shaking (tremor)
- stiffness
- slowness
- balance problems
- changes in how you walk (your gait).

If you have problems with some or all of these things, and your GP suspects Parkinson's disease, they should refer you to a specialist – either a neurologist or a geriatrician.

A neurologist is a healthcare professional who specialises in disorders of the brain, spinal

cord and nerves, and a geriatrician is a healthcare professional who specialises in disorders that affect older people.

You should not be given any treatment before you see a specialist.

Seeing a specialist

When you see the specialist, he or she will examine you and talk with you in detail about your symptoms and your past health. Often, no tests are needed to diagnose Parkinson's disease.

What medicines might help?

There is no cure for Parkinson's disease but there are treatments to help you cope with your symptoms.

Before you start treatment, you should be given information about the risks and benefits of the different medicines.

If you find that a medicine you are taking becomes less helpful or you are having troublesome side effects, your healthcare professional should discuss treatment changes or lifestyle changes that might help.

Movement and balance: medicines to try first

The medicine that you will be offered for movement and balance problems will depend on your symptoms and how severe they are.

If your symptoms affect your day-to-day life, you should be offered a medicine called levodopa. This is usually prescribed as a medicine called co-beneldopa or co-careldopa.

If your symptoms are mild and don't affect your quality of life, there is more than one medicine that could help. The choice will depend partly on what is most important to you, and partly on your symptoms, other health problems you have and if you are taking any other medicines.

Your healthcare professional should discuss the treatment options with you, and the

possible effects and side effects of the different medicines, for example, the risk of having uncontrolled (involuntary) movements (called dyskinesia), sleep problems, impulse control disorder, and psychotic symptoms (hallucinations and delusions). Table 1 shows the different medicines.

Table 1 Comparing medicine choices for early Parkinson's disease

Effects and side effects	Names of medicines		
	Levodopa	Dopamine agonists	MAO-B (monoamine oxidase B) inhibitors
Can it help me with movement problems such as slowness and tremor?	☺☺☺ More improvement	☺ Less improvement	☺ Less improvement
Can it help me with day-to-day activities?	☺☺☺ More improvement	☺ Less improvement	☺ Less improvement
Might it cause dyskinesia (uncontrolled movements)?	☹☹☹ More likely	☹ Less likely	☹ Less likely
Might I get other side effects such as sleep problems, impulse control disorder or psychotic symptoms?	☹ Fewer side effects	☹☹☹ More side effects	☹ Fewer side effects

More help with movement and balance

If levodopa does not help your symptoms enough, your healthcare professional should offer you another medicine to take as well as levodopa. Table 2 shows the different types of medicine that you can try.

Table 2 Medicine choices for greater symptom control

Effects and side effects	Names of medicines		
	Dopamine agonists	MAO-B (monoamine oxidase B) inhibitors	COMT (catechol-O-methyl transferase) inhibitors
Can it improve movement problems such as slowness and tremor?	😊😊 Yes	😊😊 Yes	😊😊 Yes
Can it help me with day-to-day activities?	😊😊 Yes	😊😊 Yes	😊😊 Yes
I want my symptoms to improve for a longer time between doses. Can this medicine help?	😊😊😊 Yes, more than the others	😊😊 Yes	😊😊 Yes
Might I get side effects such as nausea or dizziness?	😞😞 Moderate side effects	😞 Fewer side effects	😞😞😞 More side effects
What is the risk of psychotic symptoms with this medicine?	😞😞😞 More risk	😞 Less risk	😞 Less risk

Sleep problems

If you feel abnormally sleepy during the day, your healthcare professional should try to find out the cause of the sleepiness, for example, if it is a side effect of a medicine. If there is no obvious cause, your healthcare professional might talk with you about trying a medicine called modafinil. But you shouldn't take this medicine if you are pregnant or planning to get pregnant. If you feel abnormally sleepy during the day, you should not drive or operate heavy machinery, and let the Driver and Vehicle Licensing Agency (DVLA) know.

You may experience other sleep problems such as:

- shouting in your sleep or acting out dreams, for example, kicking and punching (called rapid eye movement sleep behaviour disorder)

- problems turning over in bed (called nocturnal akinesia).

There are medicines that can help to treat these symptoms. Some sleep problems can be caused by medicines you are taking, or the time of day you take them. If you experience sleep problems, talk to a healthcare professional.

Impulse control disorder

One of the important possible side effects of Parkinson's disease treatment is impulse control disorder. This is where your behaviour changes and you can't stop yourself from doing something. This may harm you or those around you.

Symptoms may include compulsive gambling, binge eating, obsessive shopping or becoming preoccupied with sex, including pornography.

Impulse control disorders are more common in people who are taking a type of medicine known as a dopamine agonist (ask your healthcare professional if you are unsure whether you take this type of medicine). Also see the section [movement and balance: medicines to try first](#).

You are also more likely to develop impulse control disorder if you:

- have had problems with impulse control in the past
- drink alcohol or smoke.

Your healthcare professional should give you, your family and carers information about impulse control disorder if you start taking dopamine agonist therapy. They should explain the symptoms, the risks, who to contact if you develop the symptoms, and that certain medicines will be reviewed and might be reduced or stopped if you develop an impulse control problem. People who have impulse control might keep it hidden from their family and carers.

You should be able to discuss any concerns at your review appointments. If you have symptoms, this is a chance for you and your family or carers to talk about:

- how the impulse control disorder is affecting your life or the lives of those around you
- possible treatments

- the benefits and risks of stopping certain medicines.

If you develop impulse control disorder, and changing your medicine doesn't help, you should be offered specialist cognitive behavioural therapy, which is a type of talking therapy.

Psychotic symptoms (hallucinations and delusions)

Psychosis is a mental health condition that causes a person to see or hear things (called hallucinations), or stops a person from understanding what's real and what's not (called delusions). You should be asked if you are experiencing any psychotic symptoms at follow-up appointments and if your medicine changes. If you have psychotic symptoms, you should have a thorough health check to try to understand what may be causing the problem.

If it's possible that one of your medicines for Parkinson's disease is causing psychotic symptoms, your healthcare professional might suggest gradually reducing the dose to see if that helps. They should explain that this might mean that your Parkinson's disease symptoms get worse. Your healthcare professional can help you to decide whether to change your medicine or not. If the problem is not severe or not upsetting for you or your family and carers, you might prefer not to have any treatment.

If you decide that you should take a medicine to treat psychotic symptoms, medicines called quetiapine or clozapine may help. Quetiapine is recommended 'off-label'; see [where can I find out more?](#) If you take clozapine, you need to be registered with a monitoring scheme and have regular blood tests.

Healthcare professionals should not offer some medicines that would normally be used to help psychotic symptoms (called 'antipsychotics') because they can make Parkinson's disease symptoms worse.

Dementia

Parkinson's disease can sometimes cause symptoms of dementia, including memory loss and confusion. This is known as 'Parkinson's disease dementia'.

Speak to your healthcare professional if you are worried; help is available, and there are medicines you can try, depending on your symptoms. Your healthcare professional can tell

you about medicines that can help, such as cholinesterase inhibitors or memantine. These treatments are recommended 'off-label'; see [where can I find out more?](#) You may also want to read our [information for the public on dementia](#).

Depression

Depression is common in adults with Parkinson's disease. Speak to your healthcare professional if you are struggling with feelings of hopelessness, guilt, worthlessness or pessimism: help is available. You may also want to read our [information for the public on depression in adults with a chronic physical health problem](#).

Low blood pressure when standing

Feeling light-headed, faint or dizzy when you stand up quickly can be caused by a drop in your blood pressure – known as orthostatic hypotension. If you have these symptoms, talk to your healthcare professional.

Orthostatic hypotension can be caused by medicines you are taking for Parkinson's disease symptoms and/or other conditions. Your healthcare professional should review your medicines to see if that can help your symptoms.

There are also medicines that you could try for orthostatic hypotension, for example, midodrine or fludrocortisone. Fludrocortisone is recommended 'off-label'; see [where can I find out more?](#) Your healthcare professional should talk with you about the risks of those medicines and the monitoring that you need during treatment with them.

Drooling

Excessive drooling can be eased with treatments such as speech and language therapy.

If speech and language therapy does not help, your healthcare professional may discuss treatment with anticholinergic medicines (for example, medicines called glycopyrronium bromide or atropine), or refer you to have treatment with botulinum toxin A.

Glycopyrronium bromide and botulinum toxin A are recommended 'off-label'; see [where can I find out more?](#)

What else might help?

Your healthcare team

If you have Parkinson's disease, you should be given ongoing help and support from your healthcare professionals, which may include a nurse specialising in caring for people with Parkinson's disease. The support should include:

- monitoring your symptoms and adjusting your medicines if needed
- being a main point of contact for you and your family or carers
- visiting you at home if needed
- giving you information about care and support that might help you, your family and carers.

Physiotherapy and physical activity

If you have problems with movement and balance, you should be referred to a physiotherapist for specialist treatment.

You may be referred to a physiotherapist if you are in the early stages of Parkinson's disease.

Physiotherapy can help with muscle strengthening or stretching exercises (or both); and offer activities to help with posture. You may be referred for a therapy called the Alexander Technique if you have problems with movement and balance.

Occupational therapy

If you have problems with everyday activities, such as dressing, cooking and working, you should be referred to an occupational therapist.

You may be referred to an occupational therapist if you are in the early stages of Parkinson's disease.

Occupational therapists help by finding out what aspects of a person's condition and surroundings cause them difficulties, and find practical changes and activities that can help.

Speech and language therapy

If you have speech or communication problems or problems with swallowing or drooling, you should be referred to a speech and language therapist.

You may be referred to a speech and language therapist if you are in the early stages of Parkinson's disease.

If you find it difficult to speak clearly, devices called augmentative and alternative communication equipment can help. You may be referred for augmentative and alternative communication equipment that meets your needs as Parkinson's disease progresses and your needs change. This could be an alphabet, word or picture board and/or speech software on a computer or tablet device.

Diet and nutrition

You may be referred to a dietitian for specialist advice.

If you are taking levodopa but are having problems controlling your movements, your healthcare professional should also talk with you about changes you can make to your diet, such as eating most of your daily protein (for example, meat, fish, cheese and pulses) later in the day. However, you should not reduce the total amount of protein you eat.

Your healthcare professional should suggest that you take a vitamin D supplement, but you should not start to take any over-the-counter supplements without first talking to your healthcare professional or pharmacist.

Can surgery help?

Most people with Parkinson's disease use medicines and other therapies to control their symptoms. A type of surgery called deep brain stimulation is sometimes offered to people in the later stages of the disease, but only if other treatments have not helped. Surgery is not right for everyone. Ask your healthcare professional if you would like to find out more.

Follow-up checks

If you are diagnosed with Parkinson's disease, your healthcare professional should see you every 6 to 12 months.

Your healthcare professional should use these appointments to discuss the risk of developing unwanted side effects, especially after starting a new medicine or changing the dose of one you have been taking for some time.

Your healthcare professional should also ask you if you are experiencing hallucinations or delusions.

Support with decisions about end of life care

Making decisions about the future can be difficult but your healthcare professional can help by discussing all the different options with you and answering your questions. They should ask if you would like to talk about how Parkinson's disease may progress and the future. It is completely up to you whether you want to talk about these things, and if you do want to talk, when you want to do so.

Your healthcare professional can answer your questions about the disease getting worse and give you more information about the choices for your care and treatment towards the end of your life.

Your family or carers can be involved in the discussions if you would like them to be.

These are some of the areas that you might want to talk about:

- what to expect in the future as your Parkinson's disease progresses
- medicines you can take and how they can affect you
- what might happen at the end of your life

- things that you might want to plan for, such as:
 - whether you would like to be cared for at home or somewhere else, such as a hospice
 - who will look after your money and legal issues when you are too ill to do this
 - making a will so that your money and belongings go where you want them to
- what support is available for you and your family and carers, such as respite care and the loan of equipment.

Your healthcare professional might talk with you about referring you to a palliative care team. Palliative care aims to improve a person's quality of life throughout the course of their illness if they have a life-limiting illness.

Information and support

Your healthcare professional should give you written information and talk with you in a way that suits your needs at every stage of your care. If your needs change because your symptoms change or get worse, the way that you're given information should also reflect this. The information you are given should help you to be involved with decisions about your care.

Healthcare professionals should be honest and realistic about the future. They should also explain that although there is no treatment to cure Parkinson's disease, the symptoms can be treated, and there is a lot of research going on to find new treatments and a cure.

A plan for your care should be discussed and agreed with you, your family or carers and your healthcare professionals. You should also be given the name of someone in specialist services who you can contact if you have any questions or concerns, for example, your Parkinson's disease nurse specialist.

Your family members or carers should also be given information about Parkinson's disease and the support that's available to them, for example, their entitlement to a Carer's Assessment.

People with Parkinson's disease who drive should tell the Driver and Vehicle Licensing Agency (DVLA) and their insurer when they are diagnosed. Ask your healthcare

professional if you're not sure how to do this.

You should be part of all decisions about your care so you can agree which treatments and care are likely to suit you best. Your healthcare professional should involve you by:

- talking and listening with you so that they understand what matters to you
- giving you all the information you need so that you can make your mind up
- explaining if they think something that is mentioned here won't work for you and why, and discussing other options you could try instead.

There is more information about how you should be involved in [your care on the NICE website](#).

Questions you could ask

- What are the possible side effects of the medicines you are offering?
- Am I at a greater risk of some symptoms or side effects because of my other illnesses?
- Are there any lifestyle changes I could make to help my symptoms (for example, stopping smoking, drinking less alcohol)?
- Who can I contact if my symptoms are getting worse or if I am having side effects from my medicine?
- Can I continue to drive?
- Can I continue to do my job?

Where can I find out more?

- [Parkinson's UK](#), 0808 800 0303

You can go to the [NHS website](#) for more information on long-term conditions. You may also find useful information at [Healthtalk](#), where you can see and hear people's real-life experiences of living with Parkinson's.

You may also like to read [NICE's information for the public on patient experience in adult](#)

[NHS services](#). This sets out what adults should be able to expect when they use the NHS.

Off-label medicines

At the time of publication, some medicines may be recommended for 'off-label' use. Your doctor should tell you this and explain what it means for you. There is more information about when medicines are used off-label on the [NHS website](#).

What are NICE guidelines?

NICE gives advice to staff working in health and social care. Our guidelines help them to give the best care to people with different conditions and needs. We wrote this guideline with people who have been affected by Parkinson's disease and staff who support them. All the decisions are based on the best research available.

You can read the [guideline written for people who work in health and care services](#).

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Accreditation

