

## Understanding NICE guidance

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Information for people who use NHS services

### Parkinson's disease

*NICE 'clinical guidelines' advise the NHS on caring for people with specific conditions or diseases and the treatments they should receive.*

This booklet is about the care and treatment of people with Parkinson's disease in the NHS in England and Wales. It explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence). It is written for people with Parkinson's disease but it may also be useful for their families or carers or for anyone with an interest in the condition.

The booklet aims to help you understand the care and treatment options that should be available in the NHS. It does not describe Parkinson's disease or the tests or treatments for it in detail. A member of your healthcare team should discuss these with you. There are examples of questions you could ask throughout this booklet to help you with this. Some sources of further information and support are on page 16.



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### **The advice in the NICE guideline covers:**

- the diagnosis of Parkinson's disease and checking the diagnosis regularly
- the way people with Parkinson's disease should receive information
- the medicines that can be used
- other ways of helping with symptoms
- how to care for people whose mental health is affected
- the care people with Parkinson's disease should receive at the end of their life.

### **It does not specifically look at:**

- treatments that aren't common (for example, treatments that are in development or are not yet proven, such as fetal cell transplantation)
- other illnesses or health problems that can affect a person with Parkinson's disease (except where treatment needs to be different for a person with Parkinson's disease).

## Your care

Your treatment and care should take into account your personal needs and preferences, and you have the right to be fully informed and to make decisions in partnership with your healthcare team. To help with this, your healthcare team should give you information you can understand and that is relevant to your circumstances. All healthcare professionals should treat you with respect, sensitivity and understanding and explain Parkinson's disease and the treatments for it simply and clearly.

This information, and any discussions you have with your healthcare team, should include details of the possible benefits and risks of particular treatments. You can ask any questions you want to and can always change your mind as your treatment progresses or your condition or circumstances change. Your own preference for a particular treatment is important and your healthcare team should support your choice of treatment wherever possible.

Your treatment and care, and the information you are given about it, should take account of any religious, ethnic or cultural needs you may have. It should also take into account any additional factors, such as physical or learning disabilities, sight or hearing problems, or difficulties with reading or speaking English. Your healthcare team should be able to arrange an interpreter or an advocate (someone who supports you in asking for what you want) if needed.

If you agree, your carers and relatives should have the chance to be involved in decisions about your care. Carers and relatives also have the right to the information and support they need in their roles as carers.

If people are unable to understand a particular issue or are not able to make decisions for themselves, healthcare professionals should follow the advice that the Department of Health has produced about this. You can find this by going to the Department of Health website ([www.dh.gov.uk](http://www.dh.gov.uk)) and searching for information on 'consent'.

## Parkinson's disease

Parkinson's disease is a disease of the brain that progresses over time. It mainly affects older people, but it can also affect younger people. It happens because of an imbalance in 'messengers' in the brain. This is caused by the loss of cells that produce a messenger called dopamine, which is involved in controlling muscles. Levels of dopamine are closely linked with the levels of other chemicals in the brain, including one called acetylcholine. The low levels of dopamine, together with changes in other chemicals (including acetylcholine) lead to the symptoms of Parkinson's disease. At present, it is not known what causes the loss of the cells that produce dopamine.

The symptoms of Parkinson's disease typically include:

- slow movements – it becomes difficult to start to move or it takes longer to make movements (called bradykinesia)
- rigid or stiff muscles that can make some everyday tasks uncomfortable or difficult
- shaking, called tremor, in a part of the body when it's not being used – this usually happens in a hand or arm at first.

Parkinson's disease can also affect your balance and how you walk (gait). Although it mainly affects movement, people may have other symptoms. But it is important to remember that Parkinson's disease affects people differently and to different degrees and you may not experience all of the symptoms described.

The symptoms of Parkinson's disease can also occur in people who have other disorders. This is known as parkinsonism.

## Diagnosis

If your doctor thinks you may have Parkinson's disease, you should see a Parkinson's specialist (a neurologist or geriatrician) quickly for diagnosis. If it seems that you may be in the early stages of Parkinson's disease, you should see the specialist within 6 weeks. But if it is thought that you could be in the later stages, you should usually see the specialist within 2 weeks.

At present, there isn't a reliable test that tells whether a person has Parkinson's disease or not. The specialist makes a diagnosis by examining the person and their symptoms and from knowledge about the person's previous health.

You should not be given any treatment until you have seen the specialist.

If you have tremor and your specialist isn't sure whether it's happening because you may have Parkinson's disease, you may be offered a brain scan called a SPECT scan. The results can give more information about the causes of the tremor.

Sometimes a test called structural MRI may be used if your specialist suspects there could be another cause of your symptoms other than Parkinson's disease.

You should not be offered other tests, unless you are taking part in a research study (clinical trial).

## Once a diagnosis has been made

If you're diagnosed with Parkinson's disease, the diagnosis should be reviewed regularly (every 6–12 months) by your specialist. If you develop new symptoms that don't seem to be linked with Parkinson's disease, your specialist should consider other causes for your symptoms.

### Questions you might like to ask your healthcare team

- Please tell me more about Parkinson's disease.
- How might it affect my everyday activities, such as writing and driving?
- Are there any support organisations in the local area?
- Can you provide any information for my family/carer?

## Discussing your condition and getting information

Communication between you and your healthcare team and the information you are given should help you to take part in discussions about your condition, and make choices about the treatment you have.

Healthcare professionals should give you written information and talk to you in a way that suits your individual 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 change. It's also important that you're given consistent information from all the people you see.

When they're talking to you, your specialist and other healthcare professionals should be honest and realistic about the future. But they should also explain that although there is not a treatment for Parkinson's disease itself, the symptoms can be treated, and there is a lot of research going on to find an effective cure and new treatments.

A plan of your care should be 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, who may be a Parkinson's disease nurse specialist, if you have one in your area.

Your family members or carers should also be given information about Parkinson's disease and the support services that are available. The arrangements for assessing the support that you or your carers need should also be explained.

People with Parkinson's disease who drive should be advised to inform the Driver and Vehicle Licensing Agency (DVLA) and their car insurer about their condition when they are diagnosed. You might like to talk to your healthcare professional about this.

## General care

If you have Parkinson's disease, a healthcare professional should provide you with help in the areas listed below. You should have someone who:

- regularly checks how your medicines are making you feel, and makes changes if they are needed
- is a point of contact and support for you and your family or carers, and can come to see you at home, when appropriate
- gives you reliable information about Parkinson's disease and its symptoms and treatments, and the wider issues that can affect people with the disease and their family or carers.

A Parkinson's disease nurse specialist may do this. He or she is a nurse who specialises in caring for people with Parkinson's disease, and works closely with other specialists to provide care tailored to your needs.

## Supportive therapies

Physiotherapy, occupational therapy and speech and language therapy should be available to people with Parkinson's disease. These types of therapy aim to help you with your symptoms in your day-to-day life.

### *Physiotherapy*

Physiotherapy involves using exercises and other physical strategies to help improve:

- walking, balance and flexibility
- aerobic fitness (the sort of exercise that makes your heart and lungs stronger)
- movement
- how well you can do things for yourself (for example, how easily you get around, and how well you can carry out everyday tasks).

Physiotherapists can also give you advice on staying safe at home.

A technique called the Alexander technique may be helpful for improving your day-to-day movement. You can ask your healthcare professional for more information.

## **Occupational therapy**

Occupational therapy aims to help you to overcome the effects of your symptoms in your day-to-day life. It could help you to:

- carry on with your usual activities at work and in your home for as long as possible
- carry on with your hobbies and other leisure activities
- improve your mobility, or reduce the effect of mobility problems on your daily life
- be as independent as possible in looking after yourself, for example finding easier ways for you to eat, drink, wash and dress
- ensure your house or place of work is safe and suitable for you.

An occupational therapist can also help if you have specific needs because you sometimes become confused or distracted.

*Some treatments may not be suitable for you, depending on your exact circumstances. If you have questions about the specific treatments and options covered in this booklet, please talk to a member of your healthcare team.*

## **Speech and language therapy**

Speech and language therapy involves using vocal exercises and other exercises to help you communicate as clearly as possible. Therapists can also provide equipment if speaking unaided becomes too difficult. Speech and language therapy could help to:

- make your voice louder and sound more natural
- make sure that you can be understood (in the later stages you may need something to help, such as a voice amplifier, although there are different types of aid)
- check that you can swallow well enough and that you are doing it safely.

## **Medical treatments**

In this booklet, 'early disease' refers to Parkinson's disease in people who have started to have problems and need treatment for their symptoms. 'Later disease' refers to Parkinson's disease in people taking levodopa (see pages 9 and 10) who have developed involuntary movements (movements they cannot control) or 'wearing off' of the effects of levodopa (when symptoms come back before the next dose is taken).



## Early Parkinson's disease

There is no one particular medicine that is a suitable treatment for everyone in the early stages of Parkinson's disease.

Your specialist should explain the differences between the types of medicine, how each type might help you in the short and long term and describe the drawbacks of each treatment. When deciding which one to try, it's important to think about the things that are important to you in your daily life, and your current symptoms and health. All this should be covered in your discussions. Many people with Parkinson's disease find it helpful to make a short list of points they want to discuss. You may also find it helpful to take a friend or family member with you. Some questions you may want to ask are shown on page 11.

The box below shows the different types of medicine that can help with symptoms in the early stages of Parkinson's disease. Which one you are offered first will depend on your individual symptoms, circumstances and preferences.

### Options for early Parkinson's disease

One of the medicines in the top three boxes should be offered to you first.

Type of medicine	Notes
<b>Levodopa</b>	Levodopa may be used but a type called modified-release or long-acting levodopa should not be used to try to delay complications (such as movements you cannot control) from starting.
<b>Dopamine agonists</b>	Blood tests and a chest X-ray are needed before starting treatment if a particular type of dopamine agonist ('ergot-derived') is used. These tests should also be done on a yearly basis while taking the medicine.
<b>MAO-B inhibitors</b>	
<b>Beta-blockers</b>	These are suitable for certain people only, and should not be the first medicines tried.
<b>Amantadine</b>	This should not be the first medicine tried.
<b>Anticholinergic medicines</b>	These should not be the first medicines tried.

## Later stages of Parkinson's disease

All people in the later stages of Parkinson's disease will need to take levodopa, even if they start off on a different medicine. Other medicines may also be needed to help boost the effects of the levodopa. Which type of medicine is most helpful will depend on your symptoms and the stage of your disease, and also your lifestyle and wishes. Your specialist should explain the differences between the types of medicine, how each type might help you in the short and long term and describe the drawbacks of each type. The box below shows the different types of medicine that can help with symptoms in the later stages of Parkinson's disease.

### Options for later Parkinson's disease

One or more of the medicines below may be used as well as levodopa.

Type of medicine	Notes
<b>Dopamine agonists</b>	Blood tests and a chest X-ray are needed before starting treatment if a particular type of dopamine agonist ('ergot-derived') is used. These tests should also be done on a yearly basis while taking the medicine.
<b>MAO-B inhibitors</b>	
<b>COMT inhibitors</b>	If a COMT inhibitor called tolcapone is used, the person will need to have checks on their liver (every 2 weeks during the first year of treatment).
<b>Amantadine</b>	
<b>Apomorphine</b>	Apomorphine injections may be given from time to time to help cut down off time (when symptoms suddenly come back for a period of time). If symptoms are severe, apomorphine may be continuously delivered into the body through a tube under the skin. This should be set up in a specialist unit.
<b>Modified-release or long-acting levodopa</b>	This type of levodopa (which is designed to stay in the body longer than normal levodopa) should not be the first medicine tried.

Medicines for Parkinson's disease should not be stopped abruptly. For example, if you are admitted to hospital you should keep taking your medicines as you were (with support from hospital staff if necessary) unless they need to be changed. Any change should only be made after discussing it with you. Also, care should be taken to make sure that medicines don't stop working suddenly because of problems like stomach bugs that cause sickness and diarrhoea (gastroenteritis) or if a person has surgery on their abdomen. You should not be offered a 'drug holiday', where the medicine is withdrawn for a period of time.

Because sudden changes in medicines used for Parkinson's disease can cause problems (such as involuntary movements), people who have been admitted to hospital or a care home should have their medicine adjusted by a specialist, or by another healthcare professional after he or she has discussed it with a specialist. Your healthcare professional may suggest that you look after taking your medicine yourself so that you can do this at the most appropriate time.

### Questions you might like to ask about treatment

- Please tell me why you have decided to offer me this particular treatment.
- What are the pros and cons of this treatment?
- Please tell me what the treatment will involve.
- How will the treatment help me? What effect will it have on my symptoms and everyday life? What sort of improvements might I expect?
- How long will it take to have an effect?
- Are there any side effects associated with this treatment?
- What are my options for taking treatments other than the recommended treatment?
- Is there some written material (like a leaflet) about the treatment that I can have?

*If you think that your care does not match what is described in this booklet, please talk to a member of your healthcare team.*

## Trying to protect the brain cells

Because Parkinson's disease is caused by a reduction in the number of certain cells in the brain, there have been efforts to find medicines that protect the remaining brain cells. This is called neuroprotection or neuroprotective therapy. At the moment there is not enough evidence to justify taking medicines routinely for neuroprotection, and you should not be offered any unless you are taking part in a research study (clinical trial).

## Surgery

Most people with Parkinson's disease are treated with medicines alone. However, sometimes specialised surgery called deep brain stimulation may be used, in which electrical signals from a tiny implant in the brain help to reduce a person's symptoms. This should only be used for people who:

- still have a lot of off time (when symptoms suddenly come back for a period of time) or involuntary movements in spite of changes to their medicine,
- are generally fit and have no other major health conditions,
- have responded to levodopa all along, and
- have no current mental health problems, such as depression or dementia.

The surgery can be done in different areas of the brain, although usually it is done in a part called the subthalamic nucleus (the procedure is called subthalamic or STN stimulation). If you are considering surgery for Parkinson's disease, your specialist should explain the type of surgery you are being offered and discuss the possible benefits and risks with you. It is important for you and your specialist to think about the things that are important to you in your daily life, and your current symptoms and health.

## Treating other symptoms

People with Parkinson's disease can develop other problems besides the main symptoms affecting movement.

### Depression

If you have depression, it should be treated in a way that takes account of the other treatment you are receiving and it should suit your individual circumstances.

## Psychosis

Psychosis is the medical term for mental health problems that stop a person from understanding what's real and what's not (called hallucinations), thinking clearly and acting in a normal way. If you have psychosis, you should have a thorough evaluation of your health to try to understand what may be triggering the psychosis. You should also be offered treatment as appropriate.

If it's possible that one of your medicines for Parkinson's disease might be causing your psychosis, your specialist should think about gradually stopping the medicine.

But if the psychosis is mild and the symptoms aren't causing you or your carers too many problems, you and your specialist may decide that the benefits of your Parkinson's disease medicines outweigh the drawbacks of the psychotic symptoms. If this is the case, you and your specialist may decide not to change your medicines.

Medicines that would normally be used to help psychosis (called 'typical antipsychotics') shouldn't be prescribed because the side effects of these can make the symptoms of Parkinson's disease worse. Sometimes, medicines called 'atypical antipsychotics' may be offered.

A medicine called clozapine may be used to help with psychotic symptoms, but if you take this your specialist has to register you with a monitoring scheme. This is because a small number of people taking clozapine have a serious side effect which stops (or slows down) the bone marrow making white blood cells. This is called agranulocytosis. It's important that this is picked up early because the condition can be fatal. You need to have regular blood tests if you're taking clozapine.

## Dementia

Up to one in five people with Parkinson's disease have dementia, which can have symptoms such as memory loss, confusion and speech problems. A type of medicine called a cholinesterase inhibitor has worked for some people with this type of dementia. The NICE guideline recommends that more research is done to find out which patients would benefit from treatment with cholinesterase inhibitors.

## Sleep problems

People with Parkinson's disease sometimes have problems with their sleeping patterns. Some people may feel an overwhelming need to sleep during the daytime. It can also be difficult to move or turn in bed at night. This is called nocturnal akinesia.

If your sleeping patterns have changed, your healthcare professional should discuss this with you and take details of the problems you are having and how long it has been happening. They should also advise you on steps you can take to help you sleep better, such as avoiding caffeine at night and keeping to a regular sleep pattern. A bed lever or rails may be provided to help with moving and turning and medicines may be reviewed to avoid any drugs that may affect sleep or alertness.

If your Parkinson's disease makes you want to sleep in the daytime, you may be offered a medicine called modafinil, which works to make you feel more awake.

If you have nocturnal akinesia, switching to modified-release or long-acting levodopa may be an option. Long-acting levodopa is made in such a way that its effects should last for longer in the body than normal levodopa.

Healthcare professionals should look out for two other problems with sleep in people with Parkinson's disease. One is called 'restless legs syndrome', where the person has uncomfortable sensations in the legs and feels an uncontrollable need to move them. This often happens when the person is resting and so can be a problem at night. The second is called REM sleep behaviour disorder, where the person may 'act out' their dreams and move and jerk a lot in their sleep. If you have either of these problems you can ask for help from your healthcare professionals.

People who may fall asleep suddenly should be advised not to drive. They should also be aware of ways in which this may affect their job, such as their safety if operating machinery. Your medicine should be adjusted to stop this happening as much as possible.

*If it appears that a treatment described in this booklet is suitable for you, but it is not available, you should talk to your local Patient Advice and Liaison Service (PALS) in the first instance. If they are not able to help you, they should refer you to your local Independent Complaints Advocacy Service.*

## Falls

The symptoms of Parkinson's disease, such as stiffness in the muscles, can lead to problems with falls or the fear of falling.

NICE has issued some guidance on what to do when an older person falls and how to prevent falls<sup>1</sup>. Healthcare professionals should follow this guidance whenever the problem applies to a person with Parkinson's disease.

## Other problems

Parkinson's disease can also cause other problems because the messages to the nerves get disrupted. If you have any of the following, you should be offered treatment to help:

- problems passing urine
- weight loss
- difficulty swallowing
- constipation
- problems getting or maintaining an erection
- feeling faint when you stand up because of low blood pressure
- excessive sweating
- dribbling or drooling.

## Planning care for the advanced stage of Parkinson's disease

Your healthcare professionals should invite you to discuss the support and choices that are available and to plan together the care you want to receive when you are nearing the end of your life.

You should be put in touch with an appropriate person if you want to discuss the arrangements about your death or if you want to talk about how you feel about dying. Similarly, your family or carers should have access to this type of support.

<sup>1</sup> Falls: The assessment and prevention of falls in older people (2004). Available from [www.nice.org.uk/CG021](http://www.nice.org.uk/CG021)

## More information about Parkinson's disease

The organisation below can provide more information and support for people with Parkinson's disease. Please note that NICE is not responsible for the quality or accuracy of any information or advice provided by this organisation.

- Parkinson's Disease Society, freephone helpline 0808 800 0303, [www.parkinsons.org.uk](http://www.parkinsons.org.uk)

NHS Direct online ([www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)) may also be a good starting point for finding out more. Your local Patient Advice and Liaison Service (PALS) may also be able to give you further information and support.

### About NICE

NICE produces advice (guidance) for the NHS about preventing, diagnosing and treating different medical conditions. The guidance is written by independent experts including healthcare professionals and people representing patients and carers. They consider the best available evidence on the condition and treatments, the views of patients and carers and the experiences of doctors, nurses and other healthcare professionals working in the field. Staff working in the NHS are expected to follow this guidance.

*To find out more about NICE, its work and how it reaches decisions, see [www.nice.org.uk/aboutguidance](http://www.nice.org.uk/aboutguidance)*

*This booklet and other versions of this guideline aimed at healthcare professionals are available at [www.nice.org.uk/CG035](http://www.nice.org.uk/CG035)*

*You can order printed copies of this booklet from the NHS Response Line (phone 0870 1555 455 and quote reference N1053).*