

UK PARKINSON'S

Excellence
Network



Caring for your patient with Parkinson's

Information for ward staff



This booklet is for ward staff who need to understand the specific needs of people with Parkinson's.

You're likely to care for many patients with Parkinson's and it's important that their symptoms are managed appropriately – even if the reason for their admission is unrelated to their Parkinson's.

This booklet looks at the symptoms of Parkinson's, the treatments for the condition and the potential side effects of these treatments. It also suggests actions that will help

make sure that every patient with Parkinson's receives the highest quality of care.

Throughout the booklet, we will refer you to a range of free information resources produced by Parkinson's UK. Details of how to order these can be found at the end of the booklet.

Contents

Key messages.....	4
What is Parkinson’s?.....	6
How should I approach caring for a person with Parkinson’s?.....	8
How can I help people with Parkinson’s manage their symptoms?.....	9
What are the main drug treatments for Parkinson’s?.....	26
Why is it so important that people with Parkinson’s get their medication on time, everytime?	29
What other issues relate to Parkinson’s medication?.....	30
What are some of the potential side effects of Parkinson’s medication?.....	32
What else do I need to think about when I have a patient with Parkinson’s?.....	36
Advanced Parkinson’s and end of life.....	38
How can Parkinson’s UK support ward staff?.....	40
Glossary.....	40

Key messages

- Parkinson's is a progressive neurological condition. The main symptoms are tremor, rigidity and slowness of movement, but the condition doesn't only affect mobility.
- Remember that how the condition affects your patient can vary from hour to hour, or even minute to minute. The amount of help and support you give them will need to vary, too.
- If your hospital has a self-administration of medication policy and your patient is physically and mentally well enough to do so, you should encourage them to be responsible for taking their own medication.
- If your hospital doesn't have a self-administration of medication policy or your patient is too unwell to manage their own medication regime, make sure you give them their Parkinson's medication on time, every time. Taking medication at exactly the right time is crucial for people with Parkinson's and can make it easier for you to manage their care while in hospital.
- A Parkinson's nurse can advise you about the care and management of your patient with Parkinson's. You should check if there is one based at your hospital.
- It's vital that a person's Parkinson's medication is not stopped abruptly at any time.
- Certain drugs should be avoided in patients with the condition, unless they're recommended by a specialist, as they can make symptoms worse (see the 'Drugs to avoid' section for more details). Make sure you check the medication before you give it to someone.
- People with Parkinson's should have regular medical reviews by a specialist and access to any therapies they need.
- Parkinson's affects everyone in different ways. Listen to the person and their family about how the condition affects them – they know best how the symptoms impact them.
- It can be hard for someone with Parkinson's to move as quickly as they want to. This

can be frustrating for them. It's important to remember that people aren't being difficult when this happens.

- Some people with Parkinson's experience dyskinesia. These are involuntary muscle movements, such as jerking, twitches or spasms, which can affect any part of the body. This can be a side effect of some Parkinson's drugs, when they've been used for a long time. These random body movements can also make it hard to balance and walk, or sit on a chair without adequate anti-slip support.
- If your patient is confused, don't assume this means that there's a more serious problem, such as dementia. Other issues, including side effects from Parkinson's medication, the long-term use of medication and other medical problems, such as an infection, constipation and dehydration, can also cause cognitive problems. Be aware that many people with Parkinson's experience hallucinations alongside their confusion.
- Make sure your patient has access to a varied and balanced diet during their time in hospital. Also remember to take account of any swallowing or movement problems that could stop them from getting the nutrients they need. A dietitian and a speech and language therapist can help with this.
- Give your patient time to answer when you talk to them. It may take them time to respond, but this doesn't mean they're not listening or don't understand.

What is Parkinson's?

It's a neurological condition

People with Parkinson's don't have enough of the chemical dopamine because the nerve cells in the brain that make it have died. This loss of dopamine can cause problems with movement and mental processes.

The main motor symptoms of Parkinson's are tremor, rigidity and slowness of movement.

But the condition doesn't only affect mobility. People living with Parkinson's can experience a range of non-motor symptoms that can often have a greater impact on their lives than movement difficulties.

People with Parkinson's can experience over 40 non-motor symptoms, which can include depression, sleep problems, anxiety, excessive sweating, constipation and pain. These non-motor symptoms are present at all stages of the condition but they can dominate in the later stages of Parkinson's.

About one adult in every 37 in the UK is diagnosed with Parkinson's. That's around

145,000 people. Most people who get Parkinson's are aged 50 or over, but younger people can get it too.

It's progressive

Parkinson's gets worse over time and it can be difficult to predict how quickly the condition will progress. For most people, it can take years for the condition to progress to a point where it can cause major problems. For others, Parkinson's may advance more quickly.

Treatment and medication can help to manage the symptoms, but may become less effective in the later stages of the condition. There is currently no cure.

It's not known why people get Parkinson's, but research suggests that it's a combination of genetic and environmental factors that cause the dopamine-producing nerve cells to die. By the time Parkinson's symptoms are obvious, a person will have lost around 60–80% of their dopamine-producing nerve cells.

It fluctuates

Not everyone with Parkinson's experiences the same combination

of symptoms – they can vary from person to person and at a different speed. Because of this, no two people will follow exactly the same medication routine.

Also, how Parkinson's affects someone can change from hour to hour, and even from minute to minute – symptoms that may be noticeable one day may not be a problem the next.

This can either be caused by Parkinson's or the medication used to treat it. Symptoms will get worse when someone's Parkinson's drugs are wearing off, but will improve again once they take their medication.

For more information on this, see the 'What other issues relate to Parkinson's medication?' section.

Parkinsonism

Parkinsonism is an umbrella term used to describe symptoms or signs that are found in Parkinson's but which can also be found in other conditions that cause slowness of movement, stiffness and tremor.

Most people with a form of parkinsonism have idiopathic Parkinson's or Parkinson's.

'Idiopathic' means the cause is unknown.

People showing symptoms of parkinsonism who are not diagnosed with idiopathic Parkinson's may have another type of parkinsonism, such as multiple system atrophy (MSA), progressive supranuclear palsy (PSP) or corticobasal degeneration (CBD).

These symptoms can get worse when someone is stressed, or if their Parkinson's drugs are wearing off.

Find out more at
parkinsons.org.uk/what-parkinsons

How should I approach caring for a person with Parkinson's?

Because of the fluctuating nature of Parkinson's, it can be hard to assess the needs of someone with the condition. This supports the need for a person-centred approach to care. This means focusing on the needs of people with Parkinson's as individuals, and the fact their lives are not defined by the condition.

People with Parkinson's and their carers know best how the condition affects them. You should talk to them about what they think their needs are. Anyone involved in the care of a person with Parkinson's should focus on what they can do, not what they can't do.

Care plan actions:

- Remember that how the condition affects your patient can vary from hour to hour, or even minute to minute.
- Speak to your patient and their carer about their individual needs. They're the best authority on how the condition affects them.

Multidisciplinary working

Because of the nature of Parkinson's, it's important that people with the condition have access to a multidisciplinary team of healthcare professionals. This remains crucial as a person's condition progresses and their needs increase.

The multidisciplinary team can include their specialist, Parkinson's nurse, physiotherapist, psychologist, dietitian, occupational therapist and speech and language therapist. You're also a key part of this team, as someone who can monitor the condition on a regular basis, and raise any issues with the relevant healthcare professional.

Different members of this team should also be able to advise you on any relevant care points, such as swallowing techniques, and posture and different diet options if someone has problems eating. They can also advise on equipment that may help with mobility, and strategies to help someone who's experiencing hallucinations, delusions or anxiety.

The importance of Parkinson's nurses

Parkinson's nurses make sure that people with the condition have a range of care and support.

A Parkinson's nurse can inform and educate people with Parkinson's and people who care for them, including ward staff. They may work in a hospital or in the community, covering a wide geographical area.

Some Parkinson's nurses are hospital-based and are therefore more able to be closely involved with in-hospital care. For example, they will be able to make any recommended changes to Parkinson's medications and can support discharge planning.

Unfortunately, not all areas have a Parkinson's nurse. Ask your patient's GP or Parkinson's specialist if there is a Parkinson's nurse near you. You can find out more **at parkinsons.org.uk/nurses**

How can I help people with Parkinson's manage their symptoms?

Here's some guidance about how you can help people with

Parkinson's manage their symptoms. Remember that not everyone with the condition has the same symptoms and they will affect each person in a different way.

Stiff or rigid muscles

Simple movements, such as getting up from a chair, rolling over in bed or moving fingers to write or fasten a button, can be difficult or painful for someone with Parkinson's. Stiff and painful joints, especially in the shoulders, are also common.

Slow movements (bradykinesia)

It can be hard for someone with Parkinson's to move as quickly as they want to. This can be frustrating for them.

It's important to remember that people are not being difficult when this happens.

Difficulties moving may include getting up from a chair, getting dressed or finding it hard to turn over in bed. Their ability to move might change very quickly, so at times they can move well, but within minutes they might slow down or stop.

Care plan actions:

- Give your patient plenty of time, support and patience.
 - See if they need to be referred for physiotherapy.
 - Some people may find it helpful to use walking aids. Before using any equipment, a person with Parkinson's should get advice from a physiotherapist or occupational therapist, who can assess their needs and make appropriate suggestions.
- Remember that it might also take a person with the condition longer to answer questions because of speech and swallowing problems related to slow movements.

Tremor

A tremor is an uncontrollable, regular shaking movement that affects a part of the body, usually the hand. Many people think that everyone with Parkinson's has a tremor, but this isn't the case.



A tremor may be more obvious when your patient is resting, when their medication is wearing off, or when they get worried or excited.

Care plan actions:

- Try to help your patient avoid stress as it can make a tremor worse.
- Your patient's specialist, which can be their Parkinson's nurse, may be able to suggest changes to their drug treatment that will improve this symptom.
- Make sure your patient can take their medication on time.

Find out more at
parkinsons.org.uk/tremor

Freezing

This is when people with Parkinson's suddenly stop while moving or starting a movement.

This can't always be treated by changing medication, so some people with the condition use 'cueing' strategies to help them when they freeze. These are techniques your patient can use to restart or continue

a movement after freezing. They include counting steps and using trigger words to encourage movement.

People with Parkinson's can also experience frozen facial muscles, which can make it hard to smile or speak, and gives them a blank expression.

Freezing only affects certain movements. So a person may not be able to walk, but will still be able to reach out for support. Be aware that this may cause a person to overbalance and fall.

Care plan actions:

- Make sure the person is receiving their medication on time, every time. See the 'What other issues relate to Parkinson's medication?' section for more information on medication management.
- A physiotherapist can advise you on 'cues'. If your patient experiences freezing, try not to talk to them while they're walking because this can make it worse. If you need to discuss something with your patient, do it while they're sitting down.

- Encourage your patient to take regular exercise while they're in hospital, and when they leave, if this is appropriate. This can help to strengthen muscles, increase mobility in their joints, and build up their general fitness and health. They may need a referral to a physiotherapist.
- If you see your patient regularly freezing, speak to their specialist or Parkinson's nurse as their medication regime may need adjusting.
- For some people, it's the start of a movement that's hard, such as taking the first step to walk. A physiotherapist can give your patient tips to help with this.

Find out more at parkinsons.org.uk/freezing, and parkinsons.org.uk/exercise

Bladder problems

Incontinence is a common problem for people with Parkinson's. The most frequent problems associated with the condition are urge incontinence and nocturia (the urge to urinate during the night).

Someone with Parkinson's may have practical problems too when they use the bathroom. Many people have difficulty with fine finger movements, such as unbuttoning clothes, bloating or flatulence (wind).

Care plan actions:

- Help your patient fill out a fluid chart, if they have one. This will help to specify their needs and help healthcare professionals find out what the appropriate treatment should be.
- It's important that a person doesn't cut down on the amount of fluid they drink, as this can lead to dehydration. Dietitians recommend six to eight cups a day. Any fluid is suitable, including water, fruit juice, milk, tea, coffee and squash.

- Check if they need to be seen by a relevant member of the multidisciplinary team, such as a continence advisor.
- Medication may be an option for some bladder problems.
- Be aware that someone with Parkinson's might need to urinate often and may need to visit the toilet without much warning. They may benefit from using a hand-held urinal or a commode, especially at night.
- If your patient has problems moving around, you may need to help them visit the toilet.
- Allow plenty of time so they feel comfortable and unhurried.
- Some people with Parkinson's can't move around very well or exercise much, so their bowels aren't stimulated enough to work properly.
- Some people have difficulty chewing and swallowing food, so it's harder for them to have a diet with plenty of fibre, which helps to keep stools soft and easy to pass.
- Some people don't drink enough fluid, and this can cause the motions to be harder and more difficult to pass.
- Some Parkinson's medication can make constipation worse.

It's important that people with Parkinson's don't become constipated as this can result in poor absorption of their medication and therefore poor symptom control.

Constipation

Constipation can be a common problem for people with Parkinson's. This is because:

- Parkinson's symptoms, such as slowness of movement and rigidity, affect the muscles in the bowel wall. This can make it harder to push stools out of the body.
- Medication may be an option for constipation.
- If your patient has difficulty moving around, you may need to help them visit the toilet.

- Allow plenty of time so they feel comfortable and are unhurried.
- Help your patient to fill out a diet chart or stool chart. This will help to specify their needs and find out what the appropriate treatment should be.
- Check if they need to be seen by a relevant member of the multidisciplinary team, such as a dietitian.
- Make sure your patient drinks enough fluids. Dietitians recommend six to eight cups a day. Any fluid is suitable, including water, fruit juice, milk, tea, coffee and squash.
- Make sure your patient maintains a healthy, balanced diet that's high in fibre. This may include fruits – fresh, stewed, tinned or dried – and vegetables, especially peas, beans and lentils. A dietitian will be able to advise you on this.
- When increasing a person's intake of fibre, it's important to do so gradually to avoid bloating or flatulence (wind). Introduce one new fibre food every three days.



- If your patient has problems chewing and swallowing, there are soluble varieties of fibre available and even some high-fibre drinks. A dietitian or a speech and language therapist can give advice about this.

Find out more at
parkinsons.org.uk/diet, and
parkinsons.org.uk/bladder-and-bowel-problems

Eating, swallowing and saliva control

Many people with Parkinson's have trouble with swallowing at some point during the course of their condition.

Excess saliva or drooling can be a sign of a swallowing problem. This will happen because your patient can't close their lips properly, they find it hard to swallow regularly, or because they aren't sitting in a good position. These can cause saliva to collect in the mouth, causing a person to drool, which may be embarrassing for them.

People who have swallowing problems are also at risk of chest problems as food or liquid from

the mouth can go into the lungs, rather than the stomach.

In some cases, people with Parkinson's can have what's called 'silent aspiration'. This is when food enters the windpipe and goes down into the lungs without any of the usual signs of coughing or choking. This can lead to problems, such as aspiration pneumonia.

If your patient has experienced silent aspiration, this should be noted in their nutritional assessment, which will be completed when they're admitted to hospital. Your patient may also show signs of a swallowing problem if they:

- have an unclear voice
- can't clear food from their mouth or if food sticks in their throat
- have pain or discomfort in their chest or throat
- cough or choke on food, drink or saliva
- have trouble swallowing their medication
- have heartburn, acid reflux or lots of chest infections

In these circumstances, a referral to a speech and language therapist is vital. They can assess the patient and make appropriate suggestions for treatment. This may include tests to assess the problem, including a video examination (videofluoroscopy), a fibre-optic endoscopic examination of swallowing safety (FEES), or a laryngoscopy.

A speech and language therapist can help your patient to manage this symptom through exercises to strengthen the lip, tongue and throat muscles. They can also advise on ways to improve swallowing techniques.

A dietitian can provide advice on changes to a person's diet so that foods and liquids are easier and safer to swallow – such as avoiding hard, dry or crumbly foods.

Liquids may be thickened with powdered thickeners, milk powder, instant potato powder or plain yoghurt, as thicker liquids move more slowly and are easier to control. A dietitian may also recommend nutritional supplements.

Care plan actions:

- If it's appropriate, refer your patient to a speech and language therapist or a dietitian.
- Ask your patient if they have problems with chewing and swallowing, which could cause choking or breathing problems. It can also lead to weight loss if a person can't eat their food properly.
- Make sure that your patient can take their medication on time so they can swallow well at meal times.
- Your patient might need a lot of time to enjoy eating on their own, or they might need your help at every meal.
- Try making changes to the person's posture when they're eating or drinking – having their head tilted forwards will make it harder for food to go to the lungs.
- Your patient might use specially designed cutlery or cups. Ask their carer, family member or friend to bring them into the ward or an occupational therapist can advise you on the best ones to use.

- Make sure your patient drinks enough fluids.
- Check if your hospital uses the red tray system. If a patient needs assistance with eating or drinking in some way, the meal is served on a red tray so ward staff can easily identify patients that require help.
- Because it may take a long time for someone to eat, don't assume they aren't hungry if they don't finish their food within a certain time. If possible, you could give them half of the meal and keep the other half warm until they're ready to eat it.
- If your patient's dentures are loose and uncomfortable, you may suggest they visit their dentist when they leave hospital.

For some people, these solutions won't be enough and a different feeding method might be needed. The Royal College of Physicians has a publication, *Oral feeding difficulties and dilemmas*, that you might want to read. This is available to download at www.rcplondon.ac.uk

Find out more at parkinsons.org.uk/eating-swallowing-and-saliva-control, and parkinsons.org.uk/mouth-and-dental-issues

Falls

Problems with balance and posture are common in Parkinson's. A person with the condition may walk very slowly, and take small, unsteady steps and stoop forward, which makes them more likely to fall.



Some people with Parkinson's may experience dizziness when they stand up due to low blood pressure (postural hypotension). This means they're more likely to fall over. As blood pressure can be difficult to regulate for people with the condition, their balance may be affected and they may have a history of falls.

Sometimes, Parkinson's medication can make blood pressure problems worse.

If your patient experiences falls, this should be noted in their falls risk assessment, which will be completed when they are admitted to hospital.

Care plan actions:

- Your patient may benefit from seeing a physiotherapist or occupational therapist. They can suggest exercise techniques to help the patient avoid falls and provide advice on suitable walking aids.
- Many hospitals now have a falls team, or a falls prevention service. If your patient experiences falling, they

should be referred to this team (if available).

- Check their lying and standing blood pressure as a matter of routine. Make sure there's at least a one-minute gap between recording a person's lying and standing blood pressure.
- If your patient experiences balance problems, try not to talk to them while they're walking because this can make it worse. If you need to discuss something with them, do it while they're sitting down.

Find out more at parkinsons.org.uk/falls-and-dizziness

Pain

Many people with Parkinson's experience pain. This can include dystonia, which are involuntary muscle contractions most commonly experienced when a person's drugs are 'wearing off'. They may also experience these contractions if they're taking their medication less frequently.

Care plan actions:

- Your patient may take pain relief as part of their drugs regime. If they're not happy with what they take, or if pain relief needs to be added to their regime, talk to their specialist or Parkinson's nurse.
- If your hospital has a pain management team, your patient may benefit from a referral to them.

Find out more at [parkinsons.org.uk/pain](https://www.parkinsons.org.uk/pain)

Sleep problems and tiredness

Sleep and night-time problems, such as insomnia, pain and nocturia, are common in Parkinson's.

These difficulties can leave people feeling tired and sleepy during the day. Your patient's Parkinson's symptoms may get worse when they're tired.

Parkinson's, or the medication that treats it, can cause vivid dreams or trouble sleeping. It can make someone with Parkinson's confused or irritated and can make it more likely that the person

will experience hallucinations or delusions.

Turning over in bed can be difficult for people with Parkinson's because of rigidity. Because of this, you should see if they need any care for pressure ulcers. They may also need access to appropriate equipment.

Restless legs can cause pain or discomfort at night for people with Parkinson's. It can be caused by Parkinson's drugs 'wearing off' or by restless legs syndrome.

Care plan actions:

- Ensure your patient has a call bell within their reach, so they know help is at hand at night when it's harder to move.
- Check that they have a night light to hand, if possible.
- Reassure your patient if they're experiencing nightmares.
- Make sure people have adequate pain relief.
- Your patient might find it helpful to keep a sleep diary, so they can explain their



symptoms to a specialist or Parkinson's nurse.

- Make sure they take their medication on time so they can move as easily as possible.
- Check your patient's skin regularly for signs of pressure ulcers, especially if they're having issues with mobility or have been on prolonged bed rest.

Find out more at [parkinsons.org.uk/sleep-and-parkinsons](https://www.parkinsons.org.uk/sleep-and-parkinsons)

Communication problems

Someone with Parkinson's may have speech problems. Their voice may be slurred, hoarse or quieter than it used to be.

People may find it harder to control how quickly they speak – they may find it difficult to start talking or make their speech get faster. They can also find their voice can become more monotone.

People with the condition can also experience slowness of thought. When you ask a person with Parkinson's a question, it

can often take a while for them to listen to what you said, think about their response and then say what they want to. This can become even more difficult when people are stressed or anxious.

Some people with the condition can have impaired or altered facial expressions because they have difficulty controlling their facial muscles. A person may make an expression that they didn't plan to make. At other times, they may find it difficult to smile or frown.

Body language may also be affected by Parkinson's symptoms such as slowness of movement, stiffness and tremor.

Communication problems don't mean that your patient with Parkinson's isn't interested or doesn't understand you.

Care plan actions:

- Be patient and give the person time to talk. They may need extra time to talk and respond, so try not to interrupt them or walk away.
- Talk normally, listen carefully and don't shout.
- Use short sentences and stress key words. Try not to ask difficult questions or more than one question at a time.
- Make sure they can see and hear you.
- Be reassuring and help the person affected to relax if they're obviously stressed when trying to talk.
- Organise a referral to a speech and language therapist (if appropriate).

Find out more at [parkinsons.org.uk/speech-and-communication-problems](https://www.parkinsons.org.uk/speech-and-communication-problems)

Depression and anxiety

Depression affects many people with Parkinson's. Some of the features of depression, such as slowness of thinking, are like those of Parkinson's.

Depression can change how someone thinks, feels and functions. Someone who's depressed will typically have a low mood, lack of interest in their usual activities and difficulties concentrating.

There are several causes for depression in Parkinson's. It may be a side effect of your patient's Parkinson's medication. If this is the case, their drugs regime should be reviewed by their specialist. Treatment has to be tailored to each person with Parkinson's, as medication for depression can be difficult to combine with their other drug treatment.

Some people with Parkinson's get feelings of anxiety. These can be intense, especially if physical symptoms aren't under control. When their drugs are wearing off, your patient might feel anxious. After they've taken their medication, their mood may lift again.

Care plan actions:

- If your patient is anxious, regularly unhappy or negative, or you have any concerns about their mental health, report it to their specialist or Parkinson's nurse. They may need adjustments to their medication regime or a mental health referral.
- Be aware of changes in emotions and any link with communication problems.

Find out more at parkinsons.org.uk/depression, and parkinsons.org.uk/anxiety

Mild memory problems

It may not be immediately obvious if someone with Parkinson's has mild cognitive impairment. This is because they may appear to function very well on a day-to-day basis.

The main difficulties people with mild memory problems may have include issues with planning, multi-tasking, moving quickly from one activity to another, or doing tasks in a particular order.

They may also have a tendency to start a task and not complete it. People may also experience slow thought processes.

While many people can experience mild memory problems, this doesn't necessarily indicate a more serious problem, such as dementia.

It's vital that a person's condition is reviewed by a specialist because sometimes it may seem like they're experiencing dementia symptoms, but they may have

mild memory problems or other communication difficulties instead.

Certain factors, including side effects from Parkinson's medication, the long-term use of medication and other medical problems, such as infection, may be the cause of thinking and memory problems. They can also be made worse simply because a person has been taken away from their normal surroundings and routine. For example, if they've had a stay in hospital. It's important not to always assume that a person's condition is simply getting worse.

Be aware of sudden changes in cognition because any changes are usually slow and progressive in Parkinson's.

[Find out more at parkinsons.org.uk/mild-memory-and-thinking-problems](https://www.parkinsons.org.uk/mild-memory-and-thinking-problems)

Parkinson's dementia

Dementia is not uncommon in Parkinson's, particularly if people have had the condition for many years. Many of the problems are similar to mild memory problems, but are of a more severe nature.

Symptoms may include slow thought processes and difficulty concentrating. People also experience forgetfulness and tend to find it increasingly difficult to make decisions, plan activities and solve problems. This can make everyday activities, such as dressing, increasingly hard.

People can also experience changes in their appetite, energy levels and sleeping patterns, so they may find themselves sleeping more during the day.

They may become less engaged with what's going on around them and have a lack of motivation or interest in things they previously enjoyed.

Anxiety, depression or irritability may become an issue. Some people may also find it difficult to control their emotions and experience sudden outbursts of anger or distress, although these problems are not common.

Some people with Parkinson's dementia develop visual hallucinations and delusions.

Dementia with Lewy bodies

Dementia with Lewy bodies is diagnosed when someone has the symptoms of dementia first and then develops Parkinson's-like symptoms.

In some cases of dementia with Lewy bodies, no Parkinson's-like symptoms may develop at all.

Dementia with Lewy bodies affects a person's memory, language, concentration and attention. It also affects their ability to recognise faces, carry out simple actions and their ability to reason. People with this form of dementia commonly

experience visual hallucinations, which can be quite vivid. This can happen early on in the condition.

They might also experience difficulty in judging distances and movements, which can cause them to fall over for no apparent reason. The condition can also cause someone to experience episodes of confusion, which can change a lot from hour to hour, or over weeks or months.

Some people may also develop Parkinson's-type symptoms, such as slowness of movement, stiffness and tremor. In some cases, a person's heart rate



and blood pressure can also be affected.

Care plan actions:

- Although your patient is in an unfamiliar place, try to make them feel as comfortable as possible. walk away.
- Encourage someone with dementia to keep engaging and interacting with other people.
- Take care with communication. Use familiar phrases, speak clearly, listen well and give your patient time to respond to you.
- If a patient's confusion is caused by an infection, it should be treated with medication and fluids.
- Be aware that some patients with Parkinson's will be taking medications for dementia.
- Many people won't tell you when hallucinations or delusions happen, so ask your patient if you suspect they are experiencing these symptoms. Again, their specialist or Parkinson's nurse may be able to adjust their medication to ease these symptoms.

Find out more at parkinsons.org.uk/dementia

What are the main drug treatments for Parkinson's?

Medication is the main treatment used to control Parkinson's symptoms. Your patient may be taking one or more of the following type of drugs. Some of these are available in generic form, as well as the branded options mentioned.

Levodopa

This drug is a chemical building-block that the body converts into dopamine, the chemical that is lacking in the brains of people with Parkinson's.

Types include co-beneldopa (Madopar or generic form) and co-careldopa (Sinemet, Duodopa, Caramet, Lecado, Stalevo or unbranded form).

There are different forms of each drug. There is a dispersible form of Madopar that may be swallowed whole or dissolved in water. Note that Madopar capsules should NOT be broken.

Duodopa is an intestinal gel. The drug is pumped continuously through a tube that is surgically inserted in the intestine.

For a small number of people with Parkinson's, protein in food interferes with how well levodopa medication works, by stopping how well the drug is absorbed by the body.

If this affects one of your patients with Parkinson's, they might benefit from taking their medication at least 30 minutes before they eat. Talk to their specialist about this first.

Dopamine agonists

These work in a similar way to dopamine to improve movement symptoms. The most common examples include ropinirole (Requip, Requip XL, Eppinix XL or unbranded form), rotigotine (Neupro) and pramipexole (Mirapexin or Mirapexin PR).

The following dopamine agonists are not so widely used but you may still find the occasional patient still taking them:

- cabergoline (Cabaser or unbranded form).

- bromocriptine (Parlodel or unbranded form)

Apomorphine

Apomorphine is a dopamine agonist given by injection or infusion pump. A person with Parkinson's may be admitted who is already using an Apo-go infusion pump or Apo-go pen inject. They and their carer will know how to set this.

Apomorphine pumps are rarely initiated when a patient is in hospital for their Parkinson's. But if it is, it should be set up and monitored by the Parkinson's nurse or an apomorphine nurse. You'll need to be trained how to use it by a Parkinson's nurse.

Some people will need to have injections of apomorphine between doses of their usual tablets. Injections are taken in a similar way to insulin for diabetes.

This medication can cause short-term nausea and sickness, so an anti-sickness drug called domperidone (Motilium) will also be given for at least two days before treatment is started.

Other anti-sickness drugs can make Parkinson's symptoms worse. See the 'Drugs to avoid' for more details.

Impulsive and compulsive behaviour is a side effect that affects some people taking dopamine agonists. It can also affect some people taking other Parkinson's drugs, including levodopa. See the 'What are some of the potential side effects of Parkinson's medication?' section for more information.

Anticholinergics

These block acetylcholine (a chemical related to movement) in the brain. These drugs are not a standard or first-choice treatment for Parkinson's and are rarely used.

Examples include:

- trihexyphenidyl/benzhexol (Broflex or unbranded form)
- procyclidine (Kemadrin, Arpicolin or unbranded form) and orphenadrine (Biorphen or unbranded form)
- Benzhexol, orphenadrine and procyclidine, which are available in liquid form.

Glutamate antagonist

Amantadine controls tremor and stiff muscles. It's thought to increase dopamine in the brain. NICE guidelines say there's not enough evidence for it to be a first-choice drug for the condition, although some patients may be taking it to help control dyskinesia. It comes in capsule or syrup form.

COMT inhibitors

Examples include tolcapone (Tasmar), entacapone (Comtess) and opicapone (Ongentys). Tolcapone and entacapone have to be taken at the same time as levodopa, otherwise they will be ineffective.

Stalevo is a combination drug therapy in one tablet. In addition to carbidopa and levodopa, Stalevo contains entacapone, a substance that enhances the benefits of levodopa.

MAO-B inhibitors

These prevent the breakdown of dopamine in the brain by blocking the enzyme type MAO-B.



Examples include:

- selegiline (Eldepryl, Zelapar or generic form)
- Safinamide (Xadago)
- rasagiline (Azilect)

This drug is a stimulant, and should be taken in the morning so it doesn't disturb sleep.

Drugs to avoid

Some drugs can bring on Parkinson's-like symptoms and should be avoided,

unless they're recommended by a specialist. These are some (but not all) of the drugs to avoid:

- chlorpromazine (Largactil)
- perphenazine (Fentazin/Triptafen)
- trifluoperazine (Stelazine)
- flupenthixol (Fluanxol/Depixon)
- haloperidol (Serenace/Haldol)
- metoclopramide (Maxolon)
- prochlorperazine (Stemetil)

Anti-sickness drugs

Domperidone (Motilium) is the anti-sickness drug of choice to prevent and treat nausea and vomiting caused by levodopa. Domperidone can cause heart rhythm problems (arrhythmias) in some people over the age of 60.

If your patient is taking this medication, you should understand what the signs of irregular heart rhythms are. These can include feeling faint, breathless or dizzy. You should also make other ward staff aware. Other anti-sickness drugs that are generally considered useful include cyclizine (Valoid) and

5-HT3 receptor antagonists, like ondansetron.

Find out more at [parkinsons.org.uk/parkinsons-drugs](https://www.parkinsons.org.uk/parkinsons-drugs)

Why is it important that people get their medication on time, every time?

It's really important to make sure that people with Parkinson's take their drugs at the right time, every time. These times will vary from person to person and may be different to ward drug rounds.

If people with Parkinson's are unable to take their medication at the right time, the balance of chemicals in their body can be severely disrupted. This leads to their condition becoming uncontrolled – increasing their care needs considerably. This will mean that staff will need to do more for the person with Parkinson's than would otherwise be necessary. It can take someone with the condition a long time to get back normal after this.

Understandably, your patient may be very anxious about getting their drugs on time. Parkinson's UK runs a campaign called Get It On Time to highlight the

importance of people with Parkinson's getting their medication on time, every time. For more information, visit [parkinsons.org.uk/getitontime](https://www.parkinsons.org.uk/getitontime)

What other issues relate to Parkinson's medication?

When levodopa wears off

When a person takes levodopa, their Parkinson's symptoms will improve. But these symptoms can sometimes return before the next dose of medication is due, causing their condition to fluctuate. This can be called 'wearing off'.

In the early stages of Parkinson's, someone with the condition may not notice when a dose of levodopa begins to wear off. But as Parkinson's progresses, some people find that a dose doesn't last as long as it used to. These fluctuations can become even more unpredictable in the advanced stage of the condition.

Sometimes the effects of wearing off happen quickly – this is called 'on/off'. Being 'on' describes when a person's symptoms are controlled and they're feeling at

their most capable. Being 'off' is when Parkinson's symptoms recur and are at their most debilitating. Some people have described this as like a light switch being turned on and off, or going up and down like a yo-yo.

As well as having an effect on motor symptoms, people may also experience non-motor symptoms, including sleepiness or low mood as their medication wears off. 'On/off' is different from 'freezing'. There are different ways of managing freezing and 'on/off' swings, so they must be seen as separate problems.

During 'off' periods, a person will hardly be able to move at all, so walking, going up stairs or reaching for a cup will be impossible. But when a person freezes, it only affects certain movements. So they may not be able to walk, but they're still able to reach for a cup.

Care plan actions:

- A person with Parkinson's may have a medication diary, so check this regularly.
 - Make sure all staff are aware that your patient has Parkinson's and that drugs may have to be given outside of usual drug rounds.
 - Make sure everyone knows how important the timing of Parkinson's medication is.
 - If you have a self-administration policy in place and the person with Parkinson's meets the criteria, they should be allowed to manage their own medication. check this regularly.
 - If your patient can't swallow tablets, there are different preparations of Parkinson's drugs available. Speak to the person's specialist or your ward pharmacist about this.
 - If your patient is fed by a tube, their medication should also be in liquid form. Speak to their specialist about their drug routine before a feeding tube is fitted. Consult a pharmacist for other preparations of their drugs.
 - If your patient is struggling to swallow, make them aware
- A person with Parkinson's may have a medication diary, so check this regularly.

of alternative medication options – for example, a patch or liquid instead of hard tablets.

- It's dangerous to stop medication suddenly. If your patient is going to be nil-by-mouth, the timing of their medication needs to be carefully planned. Think about how to give their Parkinson's medication so their drug routine is kept to before, during and after surgery. This should be discussed with an anaesthetist.
- Set up a Parkinson's UK training session for staff.
- Order our Get It On Time resources to help with staff training and to remind them how important it is for people with Parkinson's to get their drugs on time.

What are some of the potential side effects of Parkinson's medication?

We can't list the side effects of all Parkinson's drugs, but some of the drugs used to treat Parkinson's can cause problems with movement, behaviour, thinking and memory. It may not

be obvious that these problems are the result of medication.

Dyskinesia

Dyskinesia are involuntary muscle movements, such as jerking, twitches or spasms, which can affect any part of the body. This is a side effect of some Parkinson's drugs, when they've been used for a long time. These random body movements can also make it hard to balance and walk. They shouldn't be mistaken for tremor.





The strength of dyskinesia can vary from mild to severe.

People with dyskinesia use up vast amounts of energy and calories because of their constant movement. It's very important to look carefully at their diet to ensure they're not at risk of becoming malnourished.

Care plan actions:

- If someone is experiencing increasing periods of dyskinesia, you should report it to their specialist or Parkinson's nurse. They may need a change in drug treatment.
- Some people may prefer to have involuntary movements, as opposed to taking medication that may leave them unable to move. Talk to your patient about their movement difficulties and how they want to manage their symptoms.
- If a person is dyskinetic, they may find it difficult to keep still and may have the urge to keep walking around the ward area. Their restlessness may be due to too much medication. A specialist or Parkinson's nurse can help.

Find out more at parkinsons.org.uk/dsykinesia-and-wearing

Neuroleptic malignant syndrome

If any of the drugs used for treating Parkinson's need to be stopped, it's important that this is done gradually. Rarely, abrupt withdrawal of certain drugs can result in neuroleptic malignant syndrome. This is a very serious condition that may cause death from complications of the respiratory, cardiovascular or renal system. This is rare, but it does emphasise the importance of the Get It On Time message.

Dopamine agonist withdrawal syndrome

This happens when a person's dopamine agonist treatment is stopped or reduced. This could be when a person is experiencing impulsive or compulsive behaviour as a side effect and needs to stop taking (or reduce the amount of) the medication causing the behaviour (see the following section).

Stopping or reducing treatment should always take place in

consultation with the person's specialist.

Symptoms of dopamine agonist withdrawal syndrome can include anxiety, panic attacks, depression, insomnia, irritability and drug cravings. To avoid this, people with Parkinson's must get help from their specialist and withdrawal must be done gradually.

Dopamine dysregulation syndrome

When people have the compulsion to take more medication than is needed to control their Parkinson's symptoms, this is known as dopamine dysregulation syndrome. This is a type of impulsive and compulsive behaviour (see the next section for a fuller explanation).

If someone is taking too much levodopa, this can lead to further side effects, such as severe involuntary movements (dyskinesia). If this is suspected, you should get help from the person's specialist or Parkinson's nurse.

Impulsive and compulsive behaviour

This is a side effect that affects some people taking dopamine agonists. However, it can affect people taking other Parkinson's drugs too, including levodopa.

Impulsive behaviour is when a person can't resist the temptation to carry out certain activities that could lead them to harm themselves or others. This includes a strong urge to gamble, shop or binge-eat. Some people with Parkinson's experience hypersexuality, where they become so preoccupied with sex that it can cause problems with their work or personal life.

Compulsive behaviour is when a person has an overwhelming drive or urge to act in a certain way, often repetitively, to reduce the worry or tension that they get from their drive or urge. This can include collecting, sorting and organising objects.

In a lot of cases, this behaviour is out of character. The person experiencing it may or may not experience distress, and may not realise the effects their behaviour will have. Impulsive and

compulsive behaviour can have a devastating impact on people with Parkinson's and those around them.

Care plan actions:

- Make sure that people with Parkinson's and their families know about this potential side effect of Parkinson's medication, and that these can be managed.
- Listen to family members, friends and carers when they say they're worried about someone with Parkinson's and make sure a person's specialist or Parkinson's nurse is aware of these conditions.
- You may encourage them to read our information on impulsive behaviour in Parkinson's.
- Ask the patient's specialist to review their medication if you think they're taking too much of their medicine on purpose – this could be a sign of drug-related compulsive behaviour.
- If you suspect a severe drug reaction, report it to the Medicines and Healthcare Products Regulatory Agency (MHRA) using their Yellow

Card reporting scheme
– call **020 3080 6000**
or visit **mhra.gov.uk**

You can find more information about impulsive and compulsive behaviour for professionals at **parkinsons.org.uk/icbresources**

Find out more at [parkinsons.org.uk/impulsive-and-compulsive-behaviours-parkinsons](https://www.parkinsons.org.uk/impulsive-and-compulsive-behaviours-parkinsons)

Hallucinations and delusions

Your patient may experience hallucinations, where they see, hear, feel or taste things that aren't there. They may also experience delusions, when they have thoughts or beliefs that aren't based on reality. These can include paranoia, jealousy or extravagance (the belief a person has special powers that they do not).

Hallucinations and delusions can be a side effect of medication, but there may be other causes. Simple blood or urine tests may help to make sure that another problem, such as a fever resulting from a chest or bladder infection, isn't causing the symptoms. Research shows that hallucinations

and delusions often happen when someone with Parkinson's also has problems with memory or thinking, dementia, depression, sleep problems, or very severe Parkinson's movement symptoms. Your patient may not report them as problems, as they seem very real to them.

It's important that you tell your patient's specialist or Parkinson's nurse if you suspect that they have these side effects.

Care plan actions:

- Don't rely on someone telling you they are experiencing hallucinations or delusions. They may not realise what they are, or they might not want to tell you. If they seem to be behaving or reacting in a strange way, gently ask them what the matter is.
- If you know or suspect that a person is experiencing these symptoms, report it to their specialist or Parkinson's nurse.
- If hallucinations or delusions are very severe, questioning them or doubting their existence (by telling the person experiencing them that they aren't real) may

not help. It could lead to conflict and further distress.

- Anxiety can make hallucinations and delusions worse. Try to find ways to help the person relax.

Find out more at parkinsons.org.uk/hallucinations-and-delusions-side-effect

What else do I need to think about when I have a patient with Parkinson's?

Surgery

Surgery doesn't cure or slow down the progress of the condition, but it can help some people control their symptoms.

Deep brain stimulation is the main type of surgery used to treat the physical symptoms of Parkinson's.

If a patient has had this type of surgery, it's important that all healthcare professionals involved in their care are informed. The healthcare team should assess the patient's care needs and work together to produce a care plan based around these needs.

Diathermy shouldn't be used if the person has had deep brain stimulation surgery. Diathermy is the use of a high-frequency electronic current to produce heat, which is often used for muscle relaxation.

MRI scans can only be used under very strict conditions, and antibiotics have to be prescribed when there's a risk of germs getting into the blood stream – for example, during surgery.

Find out more at parkinsons.org.uk/deep-brain-stimulation

Going home

Your patient's return home should be planned on their admission to hospital. They may need a referral to a hospital social worker about the arrangements. Your patients may also benefit from a referral to an occupational therapist, and a home visit may be required to see if there are any tasks that might be difficult on their return.

It can be stressful to stay in hospital, so it might take someone with Parkinson's longer to get over their treatment.

Advanced Parkinson's and end of life

Parkinson's progresses in stages. These stages are diagnosis, maintenance, complex (or 'advanced') and palliative. Although the condition progresses differently and at a different speed for each person, the advanced stage can potentially cover a long period of time.

Someone with advanced Parkinson's may experience the following:

- drug treatments that are no longer as effective
- complicated drugs regime
- less control of their Parkinson's symptoms, which become less predictable
- more 'off' periods and dyskinesia
- increased mobility problems and falls
- problems with swallowing
- mental health symptoms such as depression, anxiety, hallucinations and delusions and dementia

- many people with advanced Parkinson's will experience pain. Management of pain is crucial at this stage, particularly if the person has reduced mobility.

Care planning and end of life

Some of the more advanced symptoms of Parkinson's can lead to increased disability and poor health. This can make someone more open to infection.



People with Parkinson's most often die because of an infection or another condition.

If a person with Parkinson's has a care plan in place, it should include details of their wishes for end of life. This will include who they want to be with them, any spiritual or religious needs, and where they want to be when they're dying. This may or may not be where they currently live.

Care plans are often made in partnership with your patient's healthcare team, so you should talk to your patient's specialist, GP or Parkinson's nurse.

Care plan actions:

- It's important that you find out whether your patient has a care plan in place, listing their preferences for how their condition should be managed in its advanced stages. This care plan should also include information about care planning and end of life.
- Your patient may have a 'Do not resuscitate' (DNR/ DNACPR) order in place, which they will have discussed early on with their healthcare team. It's important to support the patient and their



family, and to follow the order if one is in place.

- If your patient doesn't have a care plan in place, their GP or Parkinson's nurse should help them gather this information at an early stage of their condition. This should be in discussion with the person themselves, their carer and family members (if relevant).
- We have information that gives people with Parkinson's more details about preparing for the practical and emotional aspects of death and dying.

Find out more at [parkinsons.org.uk/preparing-end-life](https://www.parkinsons.org.uk/preparing-end-life)

How can Parkinson's UK support ward staff?

Join the UK Parkinson's Excellence Network

The UK Parkinson's Excellence Network brings together health and social care professionals to transform care for people affected by Parkinson's.

The Network offers resources to support service improvement and engage people affected by Parkinson's, comprehensive information about education and training and collaboration opportunities. It also has the latest news, events and funding opportunities for professionals.

Through the Excellence Network, we run a range of online and facilitator-led learning programmes for health and social care professionals.

Details of these, and courses run by independent training companies across the UK, can be found in the education and training directory.

Visit parkinsons.org.uk/excellencenetwork

Access further information

Find information on all aspects of Parkinson's for everyone affected by the condition on our website and through our publications and other resources. Visit parkinsons.org.uk to find out more.

Glossary

Bradykinesia

Slowing of voluntary movements – one of the three main symptoms of Parkinson's.

Cognitive processes

Mental processes involving thinking and memory.

Compulsive behaviour

Behaviour resulting from an uncontrollable need to perform a particular action.

Cues

A way to help someone complete a task by offering prompts.

Deep brain stimulation

A form of surgery used to treat some of the symptoms of Parkinson's.

Delusions

When a person has thoughts and beliefs that aren't based on reality.

Dopamine

A neurotransmitter or chemical messenger. This chemical helps to control the messages the brain sends to the muscles to help people perform sequences of movement. Dopamine also

contributes to some thinking and memory processes.

Dopamine dysregulation syndrome

When a person takes more medication than they need to control their Parkinson's. A form of impulsive and compulsive behaviour.

Dyskinesia

Involuntary movements, and often a side effect of taking Parkinson's medication for a long period of time.

Dystonia

A sustained, involuntary muscle contraction that can affect different parts of the body.

Freezing

A symptom of Parkinson's where someone will stop suddenly while walking or when starting a movement.

Hallucinations

When a person sees, hears, feels, smells or even tastes something that doesn't exist.

Hypotension

Low blood pressure.

Impulsive behaviour

When a person can't resist the temptation to carry out certain activities.

Lewy bodies

Protein deposits that develop inside some nerve cells in the brain, causing the cells to die. This loss leads to dementia with Lewy bodies.

Levodopa

The most effective drug treatment for Parkinson's. A drug replaces dopamine, the chemical that is lost, causing the development of Parkinson's.

Multidisciplinary team

A group of healthcare professionals with different areas of expertise who can unite and treat complex medical conditions.

Motor symptoms

Symptoms related to movement.

Neuroleptic malignant syndrome

A rare syndrome caused by abrupt withdrawal of some Parkinson's drugs.

Non-motor symptoms

Parkinson's that aren't associated with movement difficulties.

'On/off'

A potential side effect of levodopa and some other Parkinson's medication. 'On' means the drugs are working and symptoms are well controlled and 'off' is when there's no response to medication and symptoms become much more of a problem.

Parkinsonism

An umbrella term that describes conditions which share some of the symptoms of Parkinson's (slowness of movement, stiffness and tremor).

Patient-centred care

A focus on the needs of a person with a long-term condition as an individual who is the best authority on their own needs.

Silent aspiration

When food enters the windpipe and goes into the lungs without a person coughing or choking. Caused by difficulties swallowing.

'Wearing off'

This is where a Parkinson's drug becomes less effective before it's time for a person's next dose. This may cause them to go 'off'.

More information and support for your patients

Our free confidential helpline can provide general support and information. Call **0808 800 0303** (calls are free from UK landlines and most mobile networks) or email hello@parkinsons.org.uk

Our helpline can put your patients in touch with one of our Parkinson's advisers, who can give information and support to anyone living with or caring for someone with Parkinson's. They can also provide links to local groups and services.

Our website parkinsons.org.uk has a lot of information about Parkinson's and everyday life with the condition. There are details of local support teams and local group meetings at localsupport.parkinsons.org.uk

Your patients can visit forum.parkinsons.org.uk to chat to other people with similar experiences on our online discussion forum.

Thank you

Thank you very much to everyone who contributed to or reviewed this information.

The UK Parkinson's Excellence Network is the driving force for improving Parkinson's care, connecting and equipping professionals to provide the services people affected by the condition want to see.

This is your Network. Get involved at parkinsons.org.uk/professionals/uk-parkinsons-excellence-network

Order code: INFOB0002
Last updated: April 2022

© Parkinson's UK. Parkinson's UK is the operating name of the Parkinson's Disease Society of the United Kingdom. A charity registered in England and Wales (258197) and in Scotland (SC037554).

