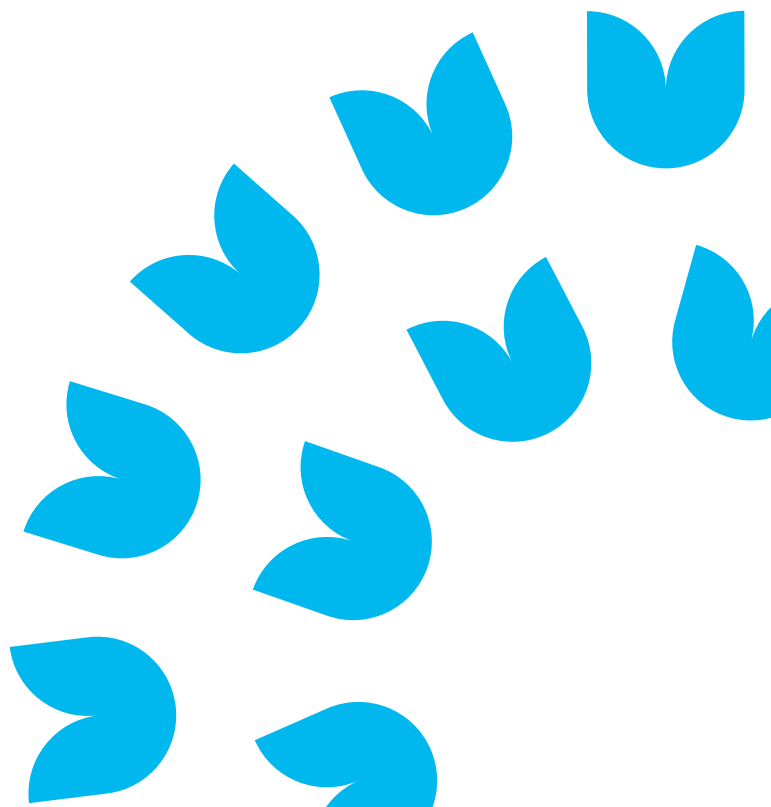


# **Parkinson's: a guide for home care workers**





**This booklet is for home care workers who need to understand the specific needs of people with Parkinson's.**

Parkinson's is a complex condition and it's vital that a person's symptoms are well-managed. This will help to maintain their quality of life and independence.

This booklet looks at the symptoms of Parkinson's, the treatments available and the potential side effects of these treatments.

It will help you make sure that every person with Parkinson's receives the best care possible. These are symptom-specific, but there is also a general care action plan on page 4 that may apply to any client with Parkinson's.

There is a glossary at the end of the booklet that explains terms you may not be familiar with. The first time a glossary term appears in the booklet, we have highlighted it in bold for you.

# Contents

General care plan actions	4
What is Parkinson's?	6
How should I approach caring for a person with Parkinson's?	7
How can I help people with Parkinson's manage their symptoms?	9
How do I monitor my client's general health?	30
What are the main treatments for Parkinson's?	32
When levodopa wears off	36
Why is it important that people with Parkinson's get their medication on time, every time?	37
What are some of the potential side effects of Parkinson's medication?	38
Advanced Parkinson's and end of life	43
How can Parkinson's UK support home care workers?	45
Glossary	46

## General care plan actions

Parkinson's affects everyone in different ways. Listen to the person with Parkinson's and their family (if they are involved in your client's care) as they have firsthand experience and understand how the condition affects them.

- How Parkinson's affects a person can vary from hour to hour and minute to minute. So if a person can carry out an activity once but isn't able to do it again – even on the same day – this doesn't mean they are being difficult, or that they aren't trying.
- The amount of help and support you give your clients will need to vary, according to what they're able to do each time you see them.
- If you have any concerns about your client's condition, report them to your manager or follow your company's procedure for doing this.
- Taking medication at exactly the right time is crucial for people with Parkinson's.
- Make sure your client is taking their Parkinson's medication on time, every time.
- It's vital that a person's Parkinson's medication is not stopped abruptly at any time.
- Some people may benefit from taking medication for symptoms that aren't related to movement problems. Speak to your manager about arranging a medication review for your client if you have any concerns.
- Give your client time to answer when you talk to them. It may take them time to respond, but this doesn't mean they aren't listening or don't understand.
- People with Parkinson's should have regular medical reviews by a specialist and access to the multidisciplinary care team. Make sure this happens and let your manager know if you have any concerns.



- Give your client time to answer when you talk to them. It may take them time to respond, but this doesn't mean they aren't listening or don't understand.
- People with Parkinson's should have regular medical reviews by a specialist and access to the multidisciplinary care team. Make sure this happens and let your manager know if you have any concerns.
- Make sure your client has access to a varied and balanced diet. If they have any swallowing or movement problems that could stop them from getting the nutrients they need, report it to your manager.
- Keeping active is important for people with Parkinson's. Find out if your client has been assessed by an exercise professional (such as a physiotherapist). They may have a tailored home exercise programme to complete and may need your support to encourage participation.

# What is Parkinson's?

## It's neurological

People get Parkinson's because some of the nerve cells in their brains that produce a chemical called **dopamine** have died. This loss of dopamine means that people can have great difficulty controlling movement. The main **motor symptoms** of Parkinson's are tremor, rigidity and slowness of movement.

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

Non-motor symptoms include depression, sleep problems, anxiety, excessive sweating, constipation and pain. They are present at all stages of the condition but they can dominate in the later stages of Parkinson's.

There are 'around 153,000 people are already living with Parkinson's. Every hour, two more people are diagnosed. That's the same as 18,000 people every year.

## It's progressive

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

Not everyone with Parkinson's experiences the same combination of symptoms – they can vary from person to person and progress 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 might not be a problem the next. This can either be caused by Parkinson's itself or the medication used to treat it.

Symptoms will get worse when someone's Parkinson's drugs are **wearing off** and improve again after the drugs are taken.

## Parkinsonism

The main symptoms of Parkinson's are also the main symptoms of a range of conditions that together are called 'parkinsonism'.

Idiopathic Parkinson's is the most common form of parkinsonism. Idiopathic means the cause is unknown.

Other types include multiple system atrophy (MSA), progressive supranuclear palsy (PSP) and corticobasal degeneration (CBD).

**Find out more:** at [parkinsons.org.uk/information-and-support/types-parkinsons](https://parkinsons.org.uk/information-and-support/types-parkinsons)

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

Because of the changing nature of Parkinson's, it can be hard to assess the needs of someone with the condition.

Keep in mind that people with Parkinson's will have good days and bad days. For example, a person may be able to move quite well on one visit then unable to the next. Their individual care plan should be reviewed regularly to take into account their changing needs.

People with Parkinson's may need early morning visits because movement difficulties may leave them unable to get out of bed. So if they don't get any help with getting up or taking their medication, they could spend the morning not being able to move.

## Person-centred care

It's important to take a **person-centred approach** to caring for a person with Parkinson's.

This means focusing on someone's needs as an individual and the fact their life is not defined by the condition. Remember that people with Parkinson's and their carers best know how the condition affects them – they should be asked about their needs and how they manage their symptoms. It's important that their daily routine includes tasks that they would like to complete on their own, allowing themselves extra time if required.

## Multidisciplinary team

You will not be the only person involved in the care of a person with Parkinson's. Collaborative health and social care is essential and people with the condition will often need the expert professional help of a **multidisciplinary team**.

The multidisciplinary team can include a doctor who is a Parkinson's specialist, Parkinson's nurse, physiotherapist, occupational therapist, and speech and language therapist. The person with Parkinson's is also an important part of this team.

Different members of this team should be able to advise you about different aspects of care, such as swallowing techniques if someone has problems eating, equipment that may help with mobility, and strategies to help someone who is experiencing **hallucinations**, **delusions** or anxiety.

This booklet will help you to recognise when a person with Parkinson's needs support and care from various health and social care professionals. As someone who can monitor a person's condition on a regular basis, you're a key part of this team.

If you think a person you're caring for needs extra support, it's vital that you tell your manager or supervisor so they can report the issue to the person's GP, specialist or Parkinson's nurse.

By reporting any issues or concerns, you can help to provide the standard of care needed to make a positive difference to the lives of people with Parkinson's.

## Parkinson's nurses

Parkinson's nurses make sure that people with Parkinson's have a range of care and support. A Parkinson's nurse can inform and educate people with the condition and people who care for them, including home care staff.

They may work in hospital or in the community, covering a wide geographical area. Unfortunately, not all areas have a Parkinson's nurse.

Ask your client's GP or specialist if there is a Parkinson's nurse near you. You can find out more about Parkinson's nurses at **[parkinsons.org.uk/nurses](https://parkinsons.org.uk/nurses)**

## Care plan actions:

- Speak to the person with Parkinson's and their carer about their individual needs. They are the best authority on how Parkinson's affects them.
- Make sure your client's care plan is Parkinson's-friendly and reflects the changing nature of the condition.
- Make contact with your local Parkinson's nurse (if you have one).
- Report any issues or concerns about your client's condition to your manager or supervisor.

## 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 and make their daily life a bit easier.

Remember that not everyone with Parkinson's has the same symptoms – 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.

It's important to check if the person you're caring for is taking, or needs, pain relief for these symptoms. If you think they do need relief, report this to your manager. Generally, the person's GP or Parkinson's nurse will be able to give them appropriate medication. If this doesn't help, they may need to see their specialist. See the 'Pain' section for more information.



## Slow movements (bradykinesia)

It might be hard for people with Parkinson's to move as quickly as they want to. This can be frustrating for them and it's important to remember that people are not being difficult when this happens.

Some people's ability to move might change very quickly, so at times they can move well, but within minutes they may slow down or stop. Difficulties moving may include getting out of a chair or turning over in bed. A person may also lack co-ordination in their hands.

### Care plan actions:

- Give people plenty of time, support and patience.
- Find out how well your client can move around. You may need to tell your manager about any mobility problems, so that they can contact a physiotherapist.
- Walking aids may be helpful – but always get advice from a physiotherapist before buying anything.
- Remember that it might also take some people longer to answer questions because of speech and swallowing problems (see the 'Eating, swallowing and saliva control' section).

## Tremor

A tremor is an uncontrollable, regular shaking movement that affects a part of the body, usually the hand. Many people think that all people with Parkinson's shake, but not everyone with the condition does.

Tremor will usually begin on one side of the body and then progress to both sides as Parkinson's progresses.

A tremor may be more obvious when a person with Parkinson's is resting or when they get worried or excited. Sometimes you'll hear it referred to as a 'resting tremor' because it usually lessens when a person is carrying out an activity, such as picking up a tea cup.

### Care plan actions:

- If you think a person's tremor is becoming unmanageable, report this to your manager, who will contact their GP, specialist or Parkinson's nurse.
- Remember stress can make a tremor worse, so try to help people with Parkinson's find ways to stay calm and relaxed, such as exercise or complementary therapies.
- Make sure your client takes their medication on time.

**Find out more:** at [parkinsons.org.uk/tremor](https://parkinsons.org.uk/tremor)

### Freezing

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

**Freezing** can sometimes be triggered by a change in flooring (for example, from hard surfaces to carpet) or often people have difficulties when approaching doorways. This can't always be treated by changing medication, so some people with Parkinson's use 'cueing' strategies to help them when they freeze. These are techniques or prompts that the person can use to restart or continue a movement after freezing, such as counting steps and using trigger words to encourage movement.

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 them to overbalance and fall. It's also important to note that stress can make freezing symptoms worse.

### Care plan actions:

- Find out if the person has any problems with freezing by observing them or asking them. If they do, report the problem to your manager. Their medication may need adjusting or they may benefit from seeing a physiotherapist.

- Often, it's the start of a movement that is hard, such as taking the first step to walk. A physiotherapist can give tips to help with this.
- A physiotherapist can also advise on 'cues'.
- Make sure the person is receiving their medication on time, every time.
- Encourage people to take regular exercise, if appropriate. This can help to strengthen muscles, increase mobility in their joints and build up their general fitness and health.
- If a person experiences freezing, try not to talk to them while they're walking because this can make it worse.
- Stress can also make freezing episodes worse, so giving yourself time to complete tasks and keeping calm when addressing a freezing episode is key.

**Find out more:** at [parkinsons.org.uk/freezing](https://parkinsons.org.uk/freezing)

### Bladder problems

Incontinence is a common problem for people with Parkinson's.

The most common problems associated with the condition are urge incontinence (an urgent need to pass urine before having time to visit the toilet) and nocturia (the need to get up during the night to urinate).

### Care plan actions:

- Be aware that someone with Parkinson's might need to urinate often and may need to visit the toilet without much notice. They may benefit from using a hand-held urinal or a commode, especially at night.

- If your client has problems moving around, you may need to help them visit the toilet. Keep in mind that people with Parkinson's may have practical problems using the toilet. For example, many people have difficulties with fine finger movements, such as unbuttoning clothes or using zips.
- Allow plenty of time so they feel comfortable and unhurried.
- It's important that a person doesn't cut down on the amount of fluid they drink, which may lead to dehydration. Six to eight glasses a day are recommended. Any fluid is suitable, including water, fruit juice, milk and squash.
- Report bladder problems to your manager as your client may need to be seen by the relevant member of the multidisciplinary team, such as a continence adviser. Medication may be an option for some bladder problems.
- Help your client fill out a fluid chart. This will help to specify their needs and help healthcare professionals find out what the appropriate treatment should be.

**Find out more:** at [parkinsons.org.uk/bladder-and-bowel-problems](https://parkinsons.org.uk/bladder-and-bowel-problems)

## Constipation

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

- 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.
- Some people with Parkinson's can't move around very well or exercise much, so their bowels aren't stimulated enough to work properly
- People with the condition may have difficulty chewing and swallowing food. This makes it harder for them to include fibre in their diet, which helps to keep stools soft and easy to pass.

- Some Parkinson's medication can make constipation worse.
- Some people do not drink enough fluid and this can cause bowel motions to become harder and more difficult to pass.

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.

## Care plan actions:

- Report the problem to your manager. Medication may be an option for constipation.
- See if your client needs to be seen by the relevant member of the multidisciplinary team, such as a dietitian.
- Make sure they drink enough fluids. Six to eight glasses a day are recommended.
- Make sure your client maintains a healthy balanced diet that's high in fibre. This may include fruits (fresh, stewed, tinned or dried), vegetables (especially peas, beans and lentils), wholegrain and wholemeal foods (such as wholegrain breakfast cereals, wholemeal bread and wholemeal pasta).
- If your client has difficulty moving around, you may need to help them visit the toilet. Allow plenty of time so they feel comfortable and unhurried.
- Help your client fill out a diet or stool chart. This will help to specify their needs and find out what the appropriate treatment should be when they are seen by their healthcare professional.
- Remember that some people with Parkinson's may have problems chewing and swallowing. This can make it difficult to eat a diet with plenty of fibre. There are some soluble varieties available and even some high-fibre drinks. A dietitian or a speech and language therapist can give advice about 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.



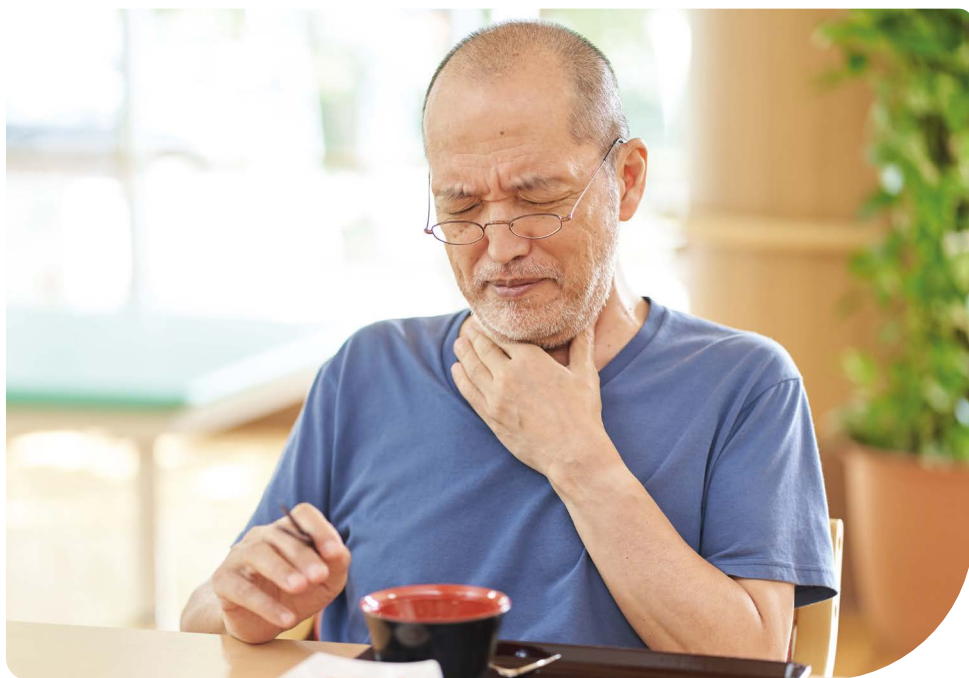
**Find out more:** at [parkinsons.org.uk/bladder-and-bowel-problems](https://parkinsons.org.uk/bladder-and-bowel-problems)

## Eating, swallowing and saliva control

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

People with Parkinson's may show signs of dysphagia if they:

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



Drooling is one of the first signs of a swallowing problem. This will happen because a person may find it hard to swallow regularly, or they forget to swallow because they're focusing on other things, such as watching TV or doing daily tasks.

Sometimes, the person can't close their lips properly or aren't sitting in a good position. Any of these things can cause saliva to collect in the mouth, which can lead to drooling.

These difficulties can cause problems with eating and drinking. Sometimes it may take a person a long time to eat and their food may become cold and unappetising. Because of this, people with Parkinson's may need a lot of time to enjoy eating on their own or they may need your help at every meal.

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.

If someone has silent aspiration, they won't cough or choke. This is what usually happens if food or drink goes down the 'wrong way', so you may not know it's happening. Over time, silent aspiration can lead to problems such as aspiration pneumonia.

If you're concerned that your client has swallowing problems, a referral to a speech and language therapist is vital. They can assess the person and make appropriate suggestions for treatment.

A speech and language therapist can help your client with exercises to strengthen the lip, tongue and throat muscles. They can also advise on ways to improve swallowing techniques.

A dietitian can advise your client on changes to their diet so that foods and liquids are easier and safer to swallow.

### Care plan actions:

- Report any chewing or swallowing problems to your manager.
- Your client may benefit from seeing a speech and language therapist, occupational therapist or dietitian.
- Make sure that medication is taken on time so the person can swallow well at meal times. If your client is having problems swallowing their medication, report it to your manager immediately.
- Changes to a person's medication regime may also help and there are drugs that may control saliva production.
- 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 into the lungs.
- If the person's dentures are loose and uncomfortable, they may need to see a dentist.
- If they want to eat on their own, allow them lots of time as they may be slow.
- Make sure they drink enough fluids. Six to eight glasses a day are recommended.
- Your client might find specially designed cutlery or cups useful. If they don't already have any, an occupational therapist can advise on the best ones to use.
- Hard, dry or crumbly foods should be avoided. Liquids may be thickened with powdered thickeners, milk powder, instant potato powder or plain yoghurt, as thicker liquids are often easier to control. A dietitian may also recommend nutritional supplements.

For some people, these solutions will not 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 may find useful. Visit [www.rcplondon.ac.uk](http://www.rcplondon.ac.uk)

### Dry mouth

Some people with Parkinson's may also experience problems with a dry mouth. Specialist products, such as artificial saliva, are available. A GP, specialist or Parkinson's nurse will be able to provide advice.

**Find out more:** at [parkinsons.org.uk/information-and-support/eating-swallowing-and-managing-saliva](http://parkinsons.org.uk/information-and-support/eating-swallowing-and-managing-saliva)

### Weight loss

If your client does leave their food because of difficulties eating, this can lead to weight loss.

**Dyskinesia** (involuntary movements) can also lead to weight loss. For more information, see the section on dyskinesia.

### Care plan actions:

- If you notice your client has lost weight, report it to your manager. They may need a referral to a dietitian.
- It may take a person a long time to eat, so don't assume your client isn't hungry if they don't finish their food within a certain time. If possible, you could give them half of a meal and keep the other half warm until they're ready to eat it.
- It could also be that their dentures are loose and uncomfortable, so they may need to see a dentist.
- Make sure your client is drinking enough fluids.
- If your client's weight is going up and down, or they lose weight on a regular basis, you should record their weight, food and fluid intake on a chart. This will help other members of the multidisciplinary team suggest ways to manage the situation.

**Find out more:** at [parkinsons.org.uk/information-and-support/eating-swallowing-and-managing-saliva](http://parkinsons.org.uk/information-and-support/eating-swallowing-and-managing-saliva), and [parkinsons.org.uk/diet](http://parkinsons.org.uk/diet)

## Falls

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

Some people with Parkinson's experience dizziness or fainting when they stand up due to low blood pressure (postural hypotension). This can cause people to fall. Sometimes the medication taken for Parkinson's can make blood pressure problems worse.

### Care plan actions:

- Report any falls to your manager. Your client may benefit from physiotherapy, so a referral may be necessary.
- If your client experiences balance problems, try not to talk to them while they are walking because this can make it worse. If you need to discuss something with your client, do it while they're sitting down.

There are many things that could make people more likely to fall, including slippery floors, loose carpets and general clutter. Here are some tips on how to help your client reduce hazards in their home:

- Try to clear away as much clutter as you can and arrange the furniture so that moving around is as easy as possible.
- Hand or grab rails may be useful in tight spaces, such as in toilets, bathrooms or by the stairs. Putting non-slip mats in the bathroom will also help.
- Always make sure a person's environment is well lit.
- If possible, apply strips of coloured tape to the edge of steps to reduce slipping and to make them more visible.
- Make sure they have commonly used items close to hand.

- Floor coverings can sometimes be a hazard. For example, carpet patterns can be visually confusing. Speak to an occupational therapist or physiotherapist about applying strips of tape or plastic footsteps on the carpet. These can guide people in places they may be more likely to fall, such as a tricky turn on stairs, or in doorways.

**Find out more:** at [parkinsons.org.uk/falls](https://parkinsons.org.uk/falls)

## Pain

Many people with Parkinson's experience pain. This can include **dystonia**. These are uncontrollable muscle contractions, which may be very painful, like bad cramp. They tend to occur most often when Parkinson's drugs are 'wearing off'.

### Care plan actions:

- People with Parkinson's might take pain relief as part of their drugs regime. Speak to your manager if your client is not happy with what they take, or if pain relief needs to be added to their regime. They may need a review of their medication with their specialist or Parkinson's nurse.

**Find out more:** at [parkinsons.org.uk/pain](https://parkinsons.org.uk/pain), and [parkinsons.org.uk/dystonia-and-muscle-cramps](https://parkinsons.org.uk/dystonia-and-muscle-cramps)

## 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 (lethargic) during the day.

Parkinson's, or the medication that treats it, can cause vivid dreams or trouble sleeping. Not getting enough sleep can cause problems similar to the symptoms of depression.

These difficulties can also make someone with Parkinson's confused or irritated and can make it more likely that they will experience hallucinations and delusions.

Turning over in bed can be difficult for people with Parkinson's because of rigidity and slowness of movement (**bradykinesia**), so you should see if they need any care for pressure ulcers (see the 'pressure ulcers' section for details). They may also need access to appropriate equipment to help their mobility in bed.

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



### Care plan actions:

- You may find that your client gets tired more quickly than someone without Parkinson's, so let them rest when they need to.
- They will need reassurance if they are experiencing nightmares. These can be very distressing.
- Keep a sleep chart. This can be taken to the person's next appointment with their specialist to assess their difficulties.
- Keep a call bell within their reach, so they know help is at hand at night when it's harder to move.
- Make sure people have adequate pain relief. Seek advice from an appropriate medical professional.
- There's no specific bed or mattress recommended for people with Parkinson's, but an occupational therapist can provide advice about aids to help people get in and out of bed.
- Some people with Parkinson's use satin pyjamas or satin sheets because the shiny material can help them turn over. These shouldn't be used together because they increase the risk of sliding out of bed too quickly. A Parkinson's nurse or occupational therapist can advise.

**Find out more:** at [parkinsons.org.uk/sleep](https://parkinsons.org.uk/sleep), [parkinsons.org.uk/dystonia-and-muscle-cramps](https://parkinsons.org.uk/dystonia-and-muscle-cramps), [parkinsons.org.uk/hallucinations-symptom](https://parkinsons.org.uk/hallucinations-symptom), and [parkinsons.org.uk/information-and-support/restless-legs-syndrome](https://parkinsons.org.uk/information-and-support/restless-legs-syndrome)

### Speech and communication problems

Many people with Parkinson's have speech problems. For example, their voice may be slurred, hoarse or quieter than it used to be. People might find it hard to control how quickly they speak – this can make it difficult to start talking and may make their speech get faster. Some people with Parkinson's also find their voice can become monotone.

These problems can present difficulties when a person is talking to another person. Taking turns to speak, following fast-changing topics or interrupting might be difficult.

So people with Parkinson's may find themselves giving minimal responses or withdrawing from socialising altogether.

Some people with Parkinson's may also experience slowness of thought. So when you ask them a question, it may take a while for them to listen to what you said, think about their response and then say what they want. This can become even more difficult when people are stressed or anxious.

### **Facial expressions and body language**

Some people with Parkinson's can have issues with facial expression because it's difficult for them to control their facial muscles.

Sometimes 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. This can make it hard for people to express how they feel.

Body language may also be affected by Parkinson's symptoms, such as slowness of movement, stiffness and tremor. Starting movements may be difficult and actions can become slower and clumsier.

Involuntary movements (dyskinesia) can be a side effect of Parkinson's medication. These can be a part of the body, including the face and mouth. As a result, people with Parkinson's may be unable to control their movements well enough to speak or communicate.

### **Care plan actions:**

Difficulties with communication can be upsetting and frustrating for the person with Parkinson's and for those around them. There are some basic things you might try to make life a little bit easier.

- If you believe a person's speech or mobility is getting worse, report it to your manager. Your client may need a referral to a speech and language therapist or a change to their medication regime.
- Be patient and give your client time to talk.
- Try not to interrupt them or walk away.
- Give your client the opportunity to talk but don't pressure them to speak.
- Talk normally and don't shout.
- Listen carefully.
- Vary the tone of your voice and relax.
- Stress can be heard in your voice.
- Use short sentences and stress key words.
- Make sure they can see and hear you.
- Be reassuring and help the person affected to relax if they're visibly stressed when trying to talk. For example, they might appreciate it if you hold their hand if they're having trouble speaking.
- If you didn't understand what someone has said, ask them to repeat it but louder or in another way. Try not to pretend you have understood if you haven't.
- Try not to talk for them, unless it's absolutely necessary.
- Don't insist they pronounce each word perfectly.
- Avoid finishing their sentences for them.
- Take the lead in starting conversations.
- Don't ignore the person affected by asking someone to speak for them.
- Try to avoid speaking above noise, such as a TV or radio, and try not to be too far away. For example, in another room, when talking.



- Remember that someone may not look or sound like they're interested in talking to you, but this may not be the case.
- Try not to make a person with Parkinson's talk while doing another activity, such as walking. It can be difficult for some people to multi-task.
- Use alphabet and picture charts to help your client communicate.

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

## Depression

Depression can be common in Parkinson's. Some of the features of depression, such as slowness of thinking, can also be common symptoms of the condition.

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

Some people may be more prone to depression at times when their Parkinson's symptoms suddenly worsen or new problems emerge. For example, as a new drug becomes less effective. Sometimes, stressful life changes, such as having to stop driving, or give up a much-loved hobby, may result in a period of depression.

Depression in Parkinson's can also be a side effect of Parkinson's medication, so your client's drug regime should be reviewed by their specialist. The treatment of depression has to be tailored to each person with Parkinson's, as medication for depression can be difficult to combine with their other drug treatment.

### Care plan actions:

- Report any changes in mood to your manager, so that they can organise an appointment with the person's specialist or Parkinson's nurse. The person may need changes to their medication regime or further treatment if they're regularly unhappy or negative.

- Be aware of changes in emotions and any link with communication problems.
- Encourage your client to continue doing the things they enjoy, such as hobbies, and talk to them as much as you can.

**Find out more:** at [parkinsons.org.uk/depression](https://parkinsons.org.uk/depression)

## Anxiety

Some people with Parkinson's get feelings of anxiety. These can be intense, especially if their physical symptoms aren't under control.

Some people with the condition have anxiety related to the 'on/off' state of their motor symptoms. When 'off' and less able to move well, they may develop significant anxiety symptoms. See the 'When Levodopa wears off' section for more information about 'on/off'.

When anxiety is related to their physical symptoms, people may develop panic attacks. For example, a person may develop a fear of falling or freezing or being unable to ask for help when they freeze. This can be difficult for them to manage.

Some people may find that when their physical symptoms are better controlled by medication, their anxiety symptoms improve.

Because of this, it's important that the physical symptoms are managed effectively.

### Care plan actions:

- For mild anxiety or depression, it may be helpful to encourage the person you're caring for to avoid stimulants such as caffeine and alcohol.
- Make sure the person you're caring for has had a medical review so that their Parkinson's medication is as effective as it can be.
- Help the person to identify what triggers an anxious episode.

- Some people find that relaxation exercises, such as yoga or massage, can be helpful in relieving symptoms of anxiety.

**Find out more:** at [parkinsons.org.uk/anxiety](https://parkinsons.org.uk/anxiety)

## Mild memory problems

It may not be immediately obvious if someone with Parkinson's has mild memory problems (also known as 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 problems 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, and 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. However, they may have mild cognitive issues or other communication difficulties instead.

If your client shows signs of confusion, it's important not to always assume that their condition is simply getting worse. Symptoms can be caused by constipation, dehydration, medication or an infection. 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.

**Find out more:** at [parkinsons.org.uk/mild-memory-and-thinking-problems](https://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 those described above for mild cognitive impairment, but are more severe.

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, cooking or cleaning, 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 may 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. A person may have disturbed sleep, or experience daytime sleepiness.

They might experience difficulty in judging distances and movements, which can cause them to fall over for no apparent reason.

### Care plan actions:

- Encourage someone with dementia to keep engaging and interacting with other people.
- Keep to a daily routine as much as you can.
- Take care with communication. Use familiar phrases, speak clearly, listen carefully and give your client time to respond to you.
- Avoid speaking sharply or raising your voice, as this may distress people.
- Many people won't tell you when hallucinations or delusions happen, so ask your client if you suspect they are experiencing these symptoms. If they are, report it to your manager.
- Be respectful and keep in mind that they have the same feelings and needs as they had before developing dementia.

**Find out more:** at [parkinsons.org.uk/dementia](https://parkinsons.org.uk/dementia), and [parkinsons.org.uk/hallucinations-symptom](https://parkinsons.org.uk/hallucinations-symptom)

## How do I monitor my client's general health?

### Personal hygiene

Your client with Parkinson's may need more help with tasks such as cleaning their teeth and shaving. This is likely if they are less able to use their hands well. If your client is finding it harder to move or stand up, make sure there is seating in the shower.

Remember that Parkinson's is a fluctuating condition. So if a person can do things such as clean their teeth independently in the morning, but cannot do the same in the evening, this doesn't mean they are being difficult, or that they aren't trying.

Keep an eye on your client's eyesight, hearing and any skin conditions. Any changes may be due to the progress of their condition or because their medication regime needs adjusting. Report any changes to your manager.

If your client uses a hearing aid, glasses or false teeth, make sure that they're being used properly and are not causing any unnecessary difficulties.

### Pressure ulcers

Pressure ulcers (also known as bedsores or pressure sores) happen when the affected area of skin is under too much pressure. This pressure disrupts the flow of blood through the skin and starves it of oxygen and nutrients. This causes the skin to break down, leading to the development of an ulcer.

The parts of the body that are most at risk of developing pressure ulcers are those that are not covered by a high amount of body fat, and are in direct contact with a supporting surface, such as a bed or a wheelchair. For example, a person who spends a lot of time in bed may develop ulcers on their shoulders, elbows, heels, buttocks, the back of their head or spine.

People with Parkinson's may be at risk of developing pressure ulcers because they can't move around easily or turn over in bed.

Pressure ulcers can range in severity, from patches of discoloured skin to open wounds that expose the underlying bone or muscle. If left untreated, they can cause serious medical problems, such as blood poisoning.

### Care plan actions:

- Making regular and frequent changes to a person's position is one of the most effective ways of preventing pressure ulcers.
- If a pressure ulcer has already developed, regularly changing position will help to avoid putting further pressure on it, and give the wound the best chance of healing.

- Make sure your client takes their medication on time so they can move as easily as possible.
- If your client has continence problems, this may contribute to the development of pressure ulcers. Report any continence issues to your manager.
- If the person can't move very well, they may benefit from using equipment, such as specially designed mattresses and cushions. Report any concerns you have to your manager.
- Check your client's skin regularly for signs of pressure ulcers, such as discoloured areas of skin. If you suspect they are developing pressure ulcers, report the problem to your manager immediately.
- Help your client maintain a healthy, balanced diet and drink enough fluids, which can help to prevent skin damage. If you have any concerns, tell your manager as your client may benefit from seeing a dietitian.

## What are the main treatments for Parkinson's?

Drugs are the main treatment used to control Parkinson's symptoms.

Your client may be taking one or more of the following types of drugs. Some of these are available in generic form as well as branded options. Speak to your client's GP, specialist, Parkinson's nurse or a pharmacist if you need more information about the drugs they're taking.

### Levodopa

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

The most common forms include co-beneldopa (Madopar or unbranded) or co-careldopa (Caramet, Sinemet, Lecado, Stalevo, Duodopa or unbranded).

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.

Before dissolving ANY medication, check with your client's GP, pharmacist and your manager.

For a small number of people with Parkinson's, protein in food interferes with how well levodopa is absorbed by the body. A full stomach can also delay absorption. If this affects your client, they might benefit from taking their medication at least 30 minutes before they eat. The person would need to speak to their Parkinson's specialist about this first before making any changes.

### Dopamine agonists

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

Some other dopamine agonists are not so widely used but you may find the occasional client still taking them. These include cabergoline (Cabaser or unbranded) bromocriptine (Parlodel or unbranded) and pergolide.

### Apomorphine

Apomorphine (APO-go) is a dopamine agonist given by injection or infusion pump.

This should be set up and monitored by the apomorphine nurse. A person with Parkinson's who is using an APO-go infusion pump or APO-go pen will know how to set this.

Some people will need to have injections of apomorphine between doses of their usual tablets. These 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 when it is started. Other anti-sickness drugs can make Parkinson's symptoms worse. (See the 'Drugs to avoid' section for more information).

**Find out more:** at [parkinsons.org.uk/apomorphine](https://parkinsons.org.uk/apomorphine)

### Anticholinergics

These drugs are rarely used. Examples include trihexyphenidyl/benzhexol (Broflex or unbranded form), procyclidine (Kemadrin, Arpicolin or unbranded) and orphenadrine (Biorphen or unbranded). Benzhexol, orphenadrine and procyclidine are available in liquid form.

### Glutamate antagonist

Amantadine is mainly used to control dyskinesia. It comes in capsule or syrup form.

### COMT inhibitors

Examples include tolcapone (Tasmar) and entacapone (Comtess). Tolcapone and Entacapone should be taken at the same time as levodopa, to get the best out of the levodopa.

Stalevo is a combination drug therapy in one tablet. In addition to carbidopa and levodopa, Stalevo contains entacapone.

### MAO-B inhibitors

Examples include selegiline

(Eldepryl, Zelapar or unbranded) and 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)
- Fluphenazine (Modecate)
- Perphenazine (Fentazin/Triptafen)
- Trifluoperazine (Stelazine)
- Flupenthixol (Fluanxol/Depixol)
- Haloperidol (Serenace/Haldol)
- Metoclopramide (Maxolon)
- Prochlorperazine (Stemetil)

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 client is taking this medication, you should inform your manager, who can talk to their specialist, Parkinson's nurse or pharmacist. You should also understand what the signs of irregular heart rhythms are. These can include feeling faint, breathless or dizzy.

Other anti-sickness drugs that are generally considered useful include cyclizine (Valoid) and 5-HT<sub>3</sub> receptor antagonists like ondansetron.

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

### Surgery

Surgery doesn't cure or slow down the progress of the condition, but it can help some people control their symptoms. The most common form of surgery is deep brain stimulation.



If your client has been through this procedure, you'll need to be aware of how this works and how your client controls their symptoms. You may wish to talk about this with your client's specialist or Parkinson's nurse.

**Find out more:** at [parkinsons.org.uk/deep-brain-stimulation](https://parkinsons.org.uk/deep-brain-stimulation)

## When levodopa wears off

When levodopa is taken, a person's Parkinson's symptoms will improve. But these symptoms can sometimes return before the next dose of medication is due, causing a person's 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 advanced Parkinson's.

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 return 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 a person's 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:

- If your client is having increased periods of 'wearing off', report the problem to your manager.
- Be patient. Remember that your client's condition may fluctuate and that their ability to do things may vary from day-to-day or even hour-to-hour.

**Find out more:** at [parkinsons.org.uk/information-and-support/dyskinesia-and-wearing](https://parkinsons.org.uk/information-and-support/dyskinesia-and-wearing)

## Why is it important that people with Parkinson's get their medication on time, every time?

If people with Parkinson's are unable to take their Parkinson's medication at the right time, the balance of chemicals in their body can be severely disrupted. This leads to their Parkinson's becoming uncontrolled – increasing their care needs considerably.

This will mean that you'll need to do more for the person with Parkinson's than would otherwise have been necessary. It can take someone with Parkinson's a long time to get back to normal after this. Understandably, people with the condition may be very anxious about getting their drugs on time. These times will change from person to person and may not fit in easily with drug rounds.

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://parkinsons.org.uk/getitontime)

### Care plan actions:

- A person with Parkinson's may have a medication diary, so make sure you check it. Ask them how their symptoms change when they need medication.
- Where you can, encourage your client to look after their own medicines. Some people will self-medicate. Reassure them that you will support this routine.
- A pill timer is a box with sections for different doses. You may encourage your client to use one if they have difficulty remembering when to take their medication. Some have an alarm that sounds when different doses need to be taken.
- Keep family members informed about the medication schedule and any changes, especially if you are the sole caregiver.
- It's important to note that it's dangerous to stop medication suddenly.

## 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 these drugs can cause problems with movement, behaviour, thinking and memory. It may not be obvious that these problems are the result of medication.

### Dyskinesia

Dyskinesia can be described as unusual movements, such as jerking, twitches or spasms. They can affect any part of the body.

The strength of dyskinesia can vary from mild to severe.

They happen because of the combination of the condition and Parkinson's medication. It's most common in people who have been taking levodopa for many years. To reduce these involuntary movements, one option is to reduce the amount of drugs a person is taking. Some people may choose to live with the dyskinesia as 'off' periods can be difficult and sometimes painful.

### Care plan actions:

- If someone's experiencing increasing periods of dyskinesia, you should report it to your manager. They may also need a change in their drug treatment.
- Maintain a food and fluid diary to monitor the person's intake.
- Monitor their weight.
- Talk to your manager if you have concerns about a person's excessive weight loss or poor appetite. A dietitian may be able to advise.
- Be aware that some people may prefer to have involuntary movements, rather than have any changes made to their medication regime. It's important to understand what a person's normal range is, so talk to your client or a family member about their movement difficulties and how they want to manage their symptoms.

### Impulsive and compulsive behaviours

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 ordering and arranging objects or checking the tap is turned off, for example.

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

Impulsive and compulsive behaviour has a devastating effect 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. Also make sure they understand that these side effects can be managed effectively. You may encourage them to read our information on impulsive and compulsive behaviour in Parkinson's.
- Make sure any behavioural changes you are concerned about are reported to your manager.
- Listen to family members, friends and carers when they're worried about someone with Parkinson's.
- Make sure the person's specialist or Parkinson's nurse is also aware of these concerns.
- Inappropriate sexual behaviour could be caused by hypersexuality. Make sure your manager is aware of your concerns.
- The person's specialist or Parkinson's nurse should be contacted.
- Tell your manager if you think your client is taking too much of their medicine on purpose – this could be a sign of drug related compulsive behaviour.

**Find out more:** at [parkinsons.org.uk/icb](https://parkinsons.org.uk/icb)

## Hallucinations and delusions

Your client 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 that 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. Your client may not report them as problems, as they seem very real to them.

### 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 your manager.
- 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.

**Find out more:** at [parkinsons.org.uk/hallucinations-symptom](https://parkinsons.org.uk/hallucinations-symptom)

## Neuroleptic malignant syndrome

If any of the drugs used for treating Parkinson's need to be stopped, it's important this is done gradually. It is rare, but 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. Although it's not common, it does emphasise how important it is that people with Parkinson's get their medication on time, every time.

### **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.

Symptoms of dopamine agonist withdrawal syndrome can include anxiety, panic attacks, depression, insomnia, irritability and drug cravings.

Stopping or reducing treatment should always take place in consultation with the person's specialist and withdrawal must be done gradually.

### **Dopamine dysregulation syndrome**

This is when people have the compulsion to take more medication than they need to control their Parkinson's symptoms. This is a type of impulsive and compulsive behaviour (see the 'Impulsive and compulsive behaviour' section for more information).

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.

### **Care plan actions:**

- If you suspect a severe drug reaction, report it immediately to your manager. They should then report it to the Medicines and Healthcare products Regulatory Agency (MHRA) using their yellow card reporting scheme – call **020 3080 6000** or visit **www.mhra.gov.uk**

## **Advanced Parkinson's and end of life**

Parkinson's progresses in stages. Although Parkinson's progresses differently and at a different speed for each person, the advanced stage can potentially cover a long period of time. It's during this stage that people may need extra support from home care staff.

Someone with advanced Parkinson's may experience:

- drug treatments that are no longer effective
- a complicated drugs regime
- 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
- reduced independence
- less control of Parkinson's symptoms and symptoms being unpredictable.

### **Care plan actions:**

- If your client is having increased periods of 'wearing' off, report the problem to your manager.
- Be patient. Remember that your client's condition may fluctuate and that their ability to do things may vary from day-to-day or even hour-to-hour.

Many people with advanced Parkinson's will also experience pain, so managing pain is very important at this stage. For more information, see the 'Pain' section earlier on in this booklet.

Because of the range of symptoms and the increase in their care needs, access to a multidisciplinary team of healthcare professionals is also crucial at this point.

**Find out more:** at [parkinsons.org.uk/advanced](https://parkinsons.org.uk/advanced)

## Death and dying

Some of the more advanced symptoms can lead to increased disability and poor health. This can make someone more vulnerable 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 are dying. This may or may not be where they currently live.

### Care plan actions:

- It's important that you find out whether your client has a care plan in place regarding their preferences for how the issues surrounding advanced Parkinson's (as listed above) should be managed. This should include legal documentation such as a Lasting Power of Attorney and an Advanced Decision (also known as an Advanced Directive or Advance Decision to Refuse Treatment and Living Will). This care plan should also include information about palliative care.
- If your client is worried that they may not be able to make decisions themselves, someone they trust can do this on their behalf with a Power of Attorney. There are different types of Power of Attorney, depending on where you live in the UK. Your client with Parkinson's can read more about end of life, including Power of Attorneys at [parkinsons.org.uk/information-and-support/making-power-attorney](https://parkinsons.org.uk/information-and-support/making-power-attorney).
- If your client doesn't have a care plan in place, you should help them gather this information as soon as possible. This should be in discussion with the person themselves, their carer and family members (if relevant)

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

## How can Parkinson's UK support homecare workers?

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

The Network links key professionals and people affected by Parkinson's, bringing new opportunities to learn from each other and work together for change.

**Find out more:** at [parkinsons.org.uk/excellencenetwork](https://parkinsons.org.uk/excellencenetwork)

### Access more information and support

We provide information and support on all aspects of Parkinson's for everyone living with the condition, and those who care for them, on our website and through our publications and other resources. Visit [parkinsons.org.uk](https://parkinsons.org.uk) or call **0808 800 0303** to find out more.



## Glossary

### Bradykinesia

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

### Compulsive behaviour

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

### Cues

A prompt that triggers a movement or thought so the person can complete a task.

### 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.

### Dysphagia

Swallowing difficulties.

### 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

A drug treatment for Parkinson's. It is a chemical building block that the body converts into dopamine.

### 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.

### Non-motor symptoms

Symptoms associated with 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 symptoms recur.

### 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.

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**Our Parkinson's UK Excellence Network works together to drive change, share expertise, learning and improve Parkinson's care across the UK.**

This is your Network. Get involved at  
**[parkinsons.org.uk/excellencenetwork](https://parkinsons.org.uk/excellencenetwork)**



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