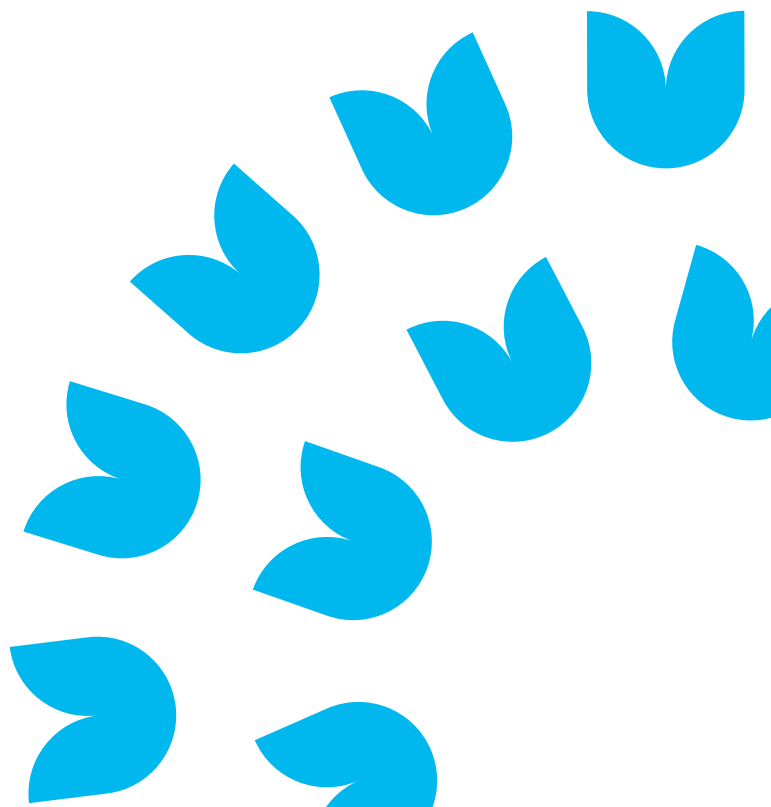


Caring for your resident with Parkinson's





This information includes key points that you will need to know when looking after someone with Parkinson's in your care home.

It'll cover what Parkinson's is, what the key symptoms are, treatments are available, and how someone with Parkinson's can prepare for end of life. Each section will focus on the actions you can take to make your resident's life comfortable, help them take control of the condition and live as independently as possible.

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. People are more likely to experience Parkinson's as they get older because the prevalence of the condition increases sharply with age. So it's likely that you'll come across residents in your care home with the condition.

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What is Parkinson's?

Parkinson's is a progressive neurological condition. It develops when cells in the brain stop working properly and die over time. These brain cells produce a chemical called dopamine. Physical symptoms start to appear when the brain can't make enough dopamine to control movement properly. As more dopamine-producing cells die, problems with movement get worse. People can start to experience other symptoms too, including pain, bladder and bowel problems and mental health issues. (Further information provided on mental health on page 10).

Parkinson's is unique to each person with the condition

Parkinson's varies from person to person. One of the challenges with Parkinson's is that symptoms can often fluctuate, or change, throughout the day. This means that someone may be stiff and move slowly in the morning, for example, but they may be able to walk by themselves later on. Other things, like stress and anxiety, can also make movement harder for people with the condition. The changing nature of Parkinson's means that the help someone with the condition will need, and the way they manage it, will be specific to them.

It's really important to monitor your resident for changes, and that you talk to them about how they're feeling and what they can manage.

It's also essential to make sure they get their Parkinson's medication on time, so that their symptoms are as controlled as possible and they can stay as independent as possible. You can find out more about getting medication on time further on in this information.

The multidisciplinary team

The multidisciplinary team of people who help your resident with Parkinson's are made up of the person with Parkinson's and health and social care professionals involved in their care.

You're an important member of this team, and can play a vital role in working with your resident and their family to understand their needs and support them day-to-day.

The person with Parkinson's and their family

The person with Parkinson's and their family are valuable members of the multidisciplinary team. Many will have lived with Parkinson's for a long time, and know how the condition typically affects them. They will be able to tell you what they feel capable of doing day-to-day.

Parkinson's specialist doctors and Parkinson's nurses

A person with Parkinson's should be under the care of a Parkinson's specialist doctor, and seen by their specialist (or Parkinson's nurse) at least once or twice a year to ensure the best management of their condition.



A large part of the role of a Parkinson's nurse is helping people to manage their symptoms and medication, so they can get the best results and fewer side effects. They can help you develop care plans for your resident, for specific Parkinson's symptoms, and give advice around Parkinson's medications. The Parkinson's nurse can also pass on information about your resident to the relevant hospital ward if they are admitted.

Your resident's Parkinson's nurse may run a telephone helpline to answer queries. This can be a particularly useful option between face-to-face appointments. The Parkinson's nurse may also be able to visit your resident within your care home.

The GP

The GP will have overall responsibility for your resident's health, but may not be too involved in their specialist Parkinson's care. If you have concerns that your resident is unwell, contact either their Parkinson's specialist, Parkinson's nurse or GP.

Therapy support

The physiotherapist, occupational therapist, speech and language therapist and dietitian can all be very helpful in supporting your resident to manage their symptoms.

You should speak to the Parkinson's nurse or GP if you think your resident would benefit from seeing a therapist.

Pharmacist

Your local pharmacist is also a useful contact within the multidisciplinary team. They can help your resident get the most out of the medication they've been prescribed. They can also advise on other drugs your resident may need to avoid taking with their Parkinson's medication.

Symptoms of Parkinson's

The three main symptoms of Parkinson's are slowness of movement, stiffness and tremor.

Slowness of movement

Slowness of movement (bradykinesia) can mean your resident might:

- walk with short, shuffling steps
- find it takes longer to do things
- have a lack of co-ordination

Care plan actions:

- Make sure your resident with Parkinson's gets their medication on time.
- Monitor for any changes to their symptoms across the day.
- Contact their Parkinson's nurse or GP if you think their symptoms are changing.
- Helping your resident to stay independent, and supporting them more when they need it, can help them build confidence to do tasks independently for when you're not around.

Stiffness

Someone with Parkinson's may have inflexible muscles in their arms and legs. This stiffness (or rigidity) can be uncomfortable. Keeping your resident as active as possible will help reduce the stiffness.

As Parkinson's can change throughout the day, your resident may need help to walk at certain times. Parkinson's medication may help this symptom.

Stiffness can also affect face muscles. This is often referred to as a mask-like expression.

So remember that if you care for someone who experiences this symptom, they can still hear and understand you, but may find it difficult to physically express how they feel.

Stiffness also impacts on posture and can affect swallowing, so it's important to monitor your resident during meal times, to make sure they're sitting upright.

Care plan actions:

- Encourage and support your resident to be as active as possible. The person you care for may benefit from seeing a physiotherapist. Speak to their Parkinson's nurse or GP for a referral.

Tremor

Not everyone with Parkinson's will have a tremor, but for those that do, it's often described as a 'resting' tremor. This is because it affects someone most when they're not doing an activity. For example, your resident will be able to pick up a cup of tea or flick through a magazine without their tremor being too noticeable.

Find out more: at parkinsons.org.uk/tremor

Common problems for people with Parkinson's

Parkinson's is a condition that gradually gets worse over time. People with Parkinson's can experience over 40 different symptoms related to their condition. The following problems are the most common that you may see.

Falls and freezing

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

They may also experience dizziness when they stand up, or low blood pressure (postural hypotension), which can lead to falls. It can be linked to their Parkinson's medication.

Freezing is a symptom of Parkinson's that often happens when someone is changing from one space to another. This happens particularly during movements that include turning. The person may not be able to move forward again for several seconds. People with Parkinson's describe it as though their feet are glued to the floor.

Care plan actions:

- Report falls to your manager.
- Make sure your resident has been assessed by a physiotherapist.
- Check that walkways and floors are clear to avoid trips and falls.
- Monitor your resident's reaction to their medication so their Parkinson's nurse or specialist can adjust their treatment if necessary.
- Try to make sure your resident can concentrate on walking without distractions, as this can make falling more likely.
- Make sure your resident has appropriate, comfortable footwear that fits well.
- There are lots of techniques that people with Parkinson's use to help them get moving again when they freeze.

Find out more: at parkinsons.org.uk/falls and parkinsons.org.uk/freezing

Eating and swallowing

The person you care for may have problems with dry mouth, posture and moving their mouth muscles. These things can make eating and swallowing more difficult. This can put people with Parkinson's more at risk of getting a chest infection or even pneumonia.

Care plan actions:

- Monitor for any coughing or choking after eating and drinking.
- Make sure your resident has the right equipment to eat and swallow properly.
- Make sure they're sitting upright with their chin neutral, so they have the right posture for swallowing more easily.
- If swallowing is a particular problem, check all food is gone from their mouth to avoid choking.
- Monitor for signs of a chest infection.

Find out more: at parkinsons.org.uk/swallowing

Diet and weight loss

A person with Parkinson's can use up a lot of energy. This can happen if they experience involuntary movements (dyskinesia), or if other symptoms mean they have to work harder to move around. Difficulties with swallowing and slowness in eating can also make it hard to eat a full meal. This can contribute to weight loss.

For some people with Parkinson's, protein (which is found mainly in meat, fish, eggs, cheese, beans and pulses) seems to interfere with how well levodopa medication is absorbed by the body. Because of this, your resident may benefit from taking their medication 30 to 60 minutes before a meal.

However, levodopa can sometimes make people feel sick. Eating a low protein snack (such as crackers) when they take their dose may help to reduce this side effect. You can read more about medication further on in this booklet.

Care plan actions:

- Monitor your resident's weight on a regular basis.

- Add high-calorie foods to healthy meals if needed. For example, you could add cream to sauces and soups.
- Check how well your resident responds to their levodopa.
- Make sure the person you care for doesn't lose too much weight and eats a healthy, balanced diet.
- Referral to a dietitian may be beneficial if they continue to lose weight.
- Your resident may need help with eating on certain days if they're struggling more than usual.

Find out more: at parkinsons.org.uk/diet

Bladder and bowel problems

People with Parkinson's may be more likely to have problems with their bladder or bowels than people of a similar age without the condition. They might need to go to the toilet with more urgency and frequency. Because of this, people might need to get up in the night to urinate. This is sometimes called nocturia and can disrupt regular sleep.

People with Parkinson's can also have problems with hand dexterity and co-ordination, so it helps if they have clothing that they can manage themselves. This will help them use the toilet more easily. Constipation can be a common bowel issue for people with Parkinson's because of muscle problems, exercising less, difficulty chewing and swallowing food, or not drinking enough.

Constipation can also be linked to Parkinson's medication.

Care plan actions:

- Your resident may benefit from using a hand-held urinal or a commode.
- Ensure your resident is wearing clothing they can manage.

- Make sure the person you care for drinks enough liquid (six to eight glasses) so they're not dehydrated or constipated. Keep a record of how much they drink to show their healthcare professionals.
- Monitor for signs of constipation and ensure laxatives are prescribed and given as needed.

Find out more: at parkinsons.org.uk/information-and-support/bladder-and-bowel-problems

Mental health problems

Hallucinations and delusions

A hallucination is when someone sees, hears or feels things that aren't there. Delusions are unusual thoughts, beliefs or worries that aren't based on reality. The person you care for may experience them because of their Parkinson's and the medication they take for it.

For many people with Parkinson's, they're just another symptom and not distressing. But for others, it can be upsetting. So it's important to let healthcare professionals know as soon as possible so that your resident can get help in managing this issue.

Care plan actions:

- If hallucinations happen suddenly, check for signs of infection or constipation and treat accordingly.
- If hallucinations or delusions become upsetting, contact their Parkinson's nurse or GP for advice.
- Monitor your resident's reaction to their medication so their Parkinson's nurse or specialist can adjust their treatment if necessary.
- Rule out other issues, such as bad eyesight or lighting problems.

Find out more: at parkinsons.org.uk/hallucinations-symptom

Depression and anxiety

People with Parkinson's may experience anxiety or depression. These can be more problematic if they've had Parkinson's for a long time.

Care plan actions:

- Check for signs of low mood.
- Monitor for signs of loneliness or isolation and engage your resident in activities within the care home. Getting their family on board with this will help.
- Encourage your resident to get involved with social support networks. They may want to join a Parkinson's UK local group, for example.

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

Dementia

Some people with Parkinson's may go on to develop Parkinson's dementia. This is different to Alzheimer's dementia. For residents with Parkinson's dementia, both physical and mental symptoms can fluctuate. This means they will be given extra monitoring and support, so it's important to get help from their specialist or Parkinson's nurse.

Find out more: at parkinsons.org.uk/dementia

Everyone's symptoms are different

Treat each resident with Parkinson's on an individual basis and develop their care plan around their needs.

If symptoms suddenly get worse, always check for signs of infection and/or constipation because this may be the cause.

Be aware of when symptoms may be more serious and may need urgent medical attention.

It's important that the symptoms of the person you care for are monitored, and that any issues are dealt with as soon as possible. This will mean they're less likely to need a stay in hospital and will be more independent day-to-day.

Treatment for Parkinson's

Having a consistent drug regime can help the person you care for manage their medication as independently as possible, day-to-day. People with Parkinson's can often have complex medication routines and take doses regularly throughout the day. It's important to understand what drug treatment your resident is taking and what side effects to look out for.

As there are a number of different drugs that someone with Parkinson's may take for their condition, we haven't listed information about them here.

Find out more: at parkinsons.org.uk/parkinsons-drugs

Importance of getting medication on time

Parkinson's medications are described as 'critical medications' and getting them on time is vital for people with the condition.

Your resident will have specific times to take their medication. This will have been carefully decided with their specialist to make sure their medication improves their symptoms as much as possible.

Your resident will need to take their medication at these specific times each day. Even being 10 minutes late can make a huge difference and mean your resident is not able to walk, move or speak.

This is because 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 will mean their Parkinson's becomes uncontrolled and you'll need to give them extra care. It can take someone with the condition a long time to get back to normal after this.

Your resident should manage their own doses of medication if they're able to. This will be the best way for them to get their medication at the times that suit their condition.

Cold remedies

Many decongestants, cold remedies and other medications can stop Parkinson's medication working properly. This is especially important to remember if your resident is taking selegiline, rasagiline and safinamide. They can also increase the risk of side effects.

Always check with a pharmacist before giving cold remedies to the person with Parkinson's you care for.

Side effects

Wearing off

A person with Parkinson's who takes levodopa for a long time may experience 'wearing off'. This is when their drugs wear off before they take their next dose, so there are times when they're stiff and slow. Wearing off is not the same as freezing.

Care plan actions:

- Make sure your resident gets their levodopa at the prescribed time.
- Monitor their reaction to medication to make sure it's working well to control their symptoms.
- Make sure your resident's specialist or Parkinson's nurse is aware if they are experiencing wearing off. They may be able to adjust their medication to reduce this side effect.

Involuntary movements (dyskinesia)

With long-term use of levodopa, your resident with Parkinson's may experience involuntary movements (dyskinesia). These are muscle movements that the person can't control. They can include twitches, jerks, twisting or writhing movements.

Dyskinesia can mean your resident will use up lots of energy from moving about. So make sure you help them to keep their weight up. See the section on diet and weight in this booklet.

Care plan actions:

- Make sure your resident's specialist or Parkinson's nurse is aware if they're experiencing dyskinesia. They may be able to adjust their medication to reduce this side effect.

Find out more: at parkinsons.org.uk/information-and-support/dyskinesia-and-wearing

Impulsive and compulsive behaviours

Impulsive and compulsive behaviours happen when someone has an overwhelming urge to behave in a certain way.

They will often carry out their behaviour repetitively as a way to reduce the worry or tension they get from their urge. Types of behaviour can include hypersexuality (a focus on sexual feelings or thoughts), gambling or binge-eating.

Care plan actions:

- Monitor for any signs of impulse control disorder.
- If they experience impulsive and compulsive behaviours, ask your resident's specialist to make changes to their medication regime or adjust the doses they take. This is the easiest way to control these behaviours while making sure their medication can still control their Parkinson's symptoms.

Find out more: at parkinsons.org.uk/information-and-support/impulsive-and-compulsive-behaviours-parkinsons

Complex therapies

Some people with Parkinson's may have had more complex therapies, such as deep brain stimulation, duodopa or apomorphine, to help manage their symptoms. Each of these need to be carefully managed and you should work with your resident's specialist and Parkinson's nurse to develop an appropriate care plan to manage them.

Find out more: at parkinsons.org.uk/apomorphine, parkinsons.org.uk/parkinsons-drugs, and parkinsons.org.uk/deep-brain-stimulation

Anticipatory care planning and end of life

Parkinson's symptoms get worse over time, so the risk of disability and poor health can increase. This can lead to infection. People don't usually die as a result of Parkinson's, but are more likely to die of an infection or another condition.

Preparing for end of life means that your resident will feel comfortable and ready for it. It can be helpful to think of the end of life in terms of having a 'good death'.

This can mean that your resident with Parkinson's will be:

- physically comfortable and free from pain
- at peace with themselves and loved ones ready to say goodbye
- able to make their wishes clear so they are respected
- treated with dignity and care

Care plan actions:

- Make sure your resident has plans in place for issues such as resuscitation or treatments (this is usually done by the GP or palliative care services).
- It's important that your resident's wishes are respected at the end of their life.
- Their family should also be involved in any decisions.
- If your resident is worried that they might 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.

Find out more: at parkinsons.org.uk/end-life

Supporting the loved ones of someone with Parkinson's

In your role, it's likely that you'll also be offering support to the family or loved one(s) of someone with Parkinson's. Caring for someone with the condition can be challenging for the person's loved one, both physically and emotionally. This can especially be the case when the person is newly diagnosed.

There are different ways that you can offer support to your resident's loved one. This can include offering a sympathetic ear to any concerns they might have, or advising them on the different information and support that's available to them.

This includes the following organisations:

- Carers UK
- Carer's Trust
- NHS.UK 'support and benefits for carers'
- Citizens Advice

You might also like to signpost residents' loved ones to our information on looking after yourself when you're a carer.

Live-in care

Most residential care agencies cannot promise to provide people with the same carers on a regular basis. Because of this, your resident might want to consider live-in care. If people chose this option, they are strongly advised to choose a company that's regulated by the Care Quality Commission (CQC).



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 way to help someone complete a task by offering prompts.

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

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.

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 symptoms recur.

Person-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 is time for a person's next dose. This may cause them to go 'off'.

More information and support for your patients

The Parkinson's UK 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.

These pages have been left intentionally blank.



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



Last updated: April 2022 | Order code: EXCEL1003

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