



**Caring for your
resident with
Parkinson's**



Introduction

This information looks at the key points that you will need to know to look after someone with Parkinson's in your care home.

It will cover what Parkinson's is, what the key symptoms are, what treatment is 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.

The number of people diagnosed with Parkinson's in the UK is about 145,000. That's around 1 adult in every 350. People are more likely to experience Parkinson's as they get older because the prevalence of the condition increase sharply with age. So it is likely that you will come across residents in your care home who have Parkinson's.

We understand that it can be difficult to look after people with Parkinson's due to the wide variety of symptoms they may have. People with Parkinson's also have a high risk of being

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admitted to hospital and often these admissions aren't planned. This means it is important for you to understand the symptoms that are most likely to cause further issues in a care home to avoid hospital admissions where possible.

This booklet can only provide a summary of information about the things that will help you care for someone with Parkinson's. It is a complex condition and you may find it useful to know further details if specific issues come up.

The best ways to find out more are listed below.

Browse our information for people with Parkinson's, their family, friends and carers to help with all aspects of the condition at parkinsons.org.uk/information-and-support

Find free courses on Parkinson's at parkinsons.org.uk/professionals/learning-hub

Download resources for professionals like you at parkinsons.org.uk/professionals/resources-professionals

There is also a more detailed presentation that accompanies this booklet available at parkinsons.org.uk/residentcare

What is Parkinson's?

Parkinson's is a progressive neurological condition. It develops when cells in the brain stop working properly and are lost over time. These brain cells produce a chemical called dopamine. Symptoms start to appear when the brain can't make enough dopamine to control movement properly. As more dopamine producing cells are lost, problems with movement get worse. People can also start to experience other symptoms too including pain, bladder and bowel problems and mental health issues. (See further on in this information to find out more.)

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. Due to the changing nature of Parkinson's it means that the help someone with Parkinson's will need, and the way they manage the condition, will be specific to them.

This means it's really important to monitor your resident with Parkinson's for changes and that you talk to them about how they are feeling and what they can manage.

Also 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.

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 are 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 the most valuable members of the multidisciplinary team because they are experts in their own condition. They will have often lived with Parkinson's for a long time, will know how Parkinson's typically affects them and be able to tell you what they feel capable of day to day.

Parkinson's specialist and Parkinson's nurse

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

A large part of the role of a Parkinson's nurse is helping people to manage their symptoms and medication, so they get the best results and fewer side effects. They can help you develop care plans, for specific Parkinson's symptoms, for your resident 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 with Parkinson's is unwell contact either their Parkinson's Specialist, Parkinson's Nurse or their own GP.

Therapy Support

The Physiotherapist, Occupational Therapist, Speech and Language Therapist and Dietitian can all be really helpful in improving and managing some of the symptoms that your resident with Parkinson's may have. Please 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 as part of the multidisciplinary team. They can help your resident with Parkinson's to get the most out of the medication they've been prescribed. They can also give advice on other drugs your resident may need to avoid taking with their Parkinson's medication (see further on in this information).

Symptoms of Parkinson's

The 3 main symptoms of Parkinson's are slowness of movement, stiffness and tremor.

Slowness of movement

Slowness of movement 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:

- 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.
- Help your resident stay independent and support them more when they need it will mean they stay independent.

Stiffness

Someone with Parkinson's may have inflexible muscles in their arms and legs, this stiffness 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.

Care plan:

- 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 is often described as a resting tremor. This is because it affects someone most when are 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.





Common problems for people with Parkinson's

Parkinson's is a condition that gradually gets worse over time. People with Parkinson's can experience at least 40 different symptoms related to their condition. The following problems are the most common that you may see. For more information and advice on symptoms management visit parkinsons.org.uk/parkinsons-symptoms

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. Someone with Parkinson's 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. They 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:

- Report falls to your manager.
- Make sure your resident has been assessed by a physiotherapist.
- Make sure that walk ways 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 footwear that fits well and is comfortable.
- 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/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 make people with Parkinson's more at risk of getting a chest infection or even pneumonia.

Find out more at parkinsons.org.uk/eating-swallowing-and-saliva-control.

Care plan:

- Monitor for any coughing or choking after eating and drinking
- Make sure your resident has the right equipment to eat and swallow properly. Do they need a straw? Do they need to eat thickened or pureed food?
- Make sure they are 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.

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.

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

See more about medication further on in this information.

Care plan:

- 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 medication and the timing of their dose.



- It's important to make sure the person you care for doesn't lose too much weight and eats a healthy, balanced diet.
- Referral to a dietician may be beneficial if they continue to lose weight

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.

People with Parkinson's can have more urgency and frequency in going to the toilet. This can mean that people need to get up more in the night to urinate. This is sometimes called nocturia and can disrupt regular sleep.

They can also have problems with hand dexterity and co-ordination so it helps if they have clothing they can manage themselves. This will help them use the toilet more easily.

Constipation can be a common bowel problem for people with Parkinson's because of muscle problems, exercising less, difficulty chewing and swallowing food or not drinking enough. Parkinson's medication can also be linked to constipation.

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

- 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 are not dehydrated or constipated. Keeping a record of how much they drink will mean you can show their healthcare professionals
- Monitor for signs of constipations and ensure laxatives are prescribed, and given, as needed.

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 Parkinson's medication they take.

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

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

Care plan:

- 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.

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.

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

Care plan:

- Monitor for signs of low mood and anxiety, refer to their GP if necessary.
- 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 social support networks. They may want to join a Parkinson's UK local group for example.

Dementia

For some people with Parkinson's they 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 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



someone with Parkinson's may take for their condition, we haven't listed information about them here. For our full information on drug treatments for Parkinson's visit parkinsons.org.uk/drug-treatments

Below we have included information on some of the key issues linked to medication that it is important to be aware of.

Importance of Getting medication on time

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

Your resident will have specific times they 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 Parkinson's a long time to get back to normal after this.

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

Everyone's Parkinson'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.

Find out more at parkinsons.org.uk/symptoms

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 are 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 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 with Parkinson's is taking and what side effects to look out for.

As there are a number of different drugs that

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:

- Make sure your resident gets their levodopa at the prescribed time
- Monitor your resident's reaction to medication to make sure that it is 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.

Care plan:

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

Impulsive and compulsive behaviours

Impulsive and compulsive behaviours happen when a person 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.



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 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 is 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:

- 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 that they take. This is the easiest way to control these behaviours while making sure their medication can still control their Parkinson's symptoms.

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/treatments-and-therapies

Care plan:

- 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 is 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 may not be able to make decisions themselves, someone they trust can do this on their behalf with a Power of Attorney. Your resident with Parkinson's can read more about end of life including Power of Attorneys

Find out more at parkinsons.org.uk/making-power-attorney

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**.

We run a peer support service if your patient would like to talk on the phone with someone affected by Parkinson's who has faced similar issues to them. The service is free and confidential –our helpline can talk to your patient about being matched with a volunteer.

Our helpline can put your patients in touch with one of our Parkinson's local advisers, who give one-to-one information and support to anyone affected by 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 **parkinsons.org.uk/localtoyou**

Your patients can visit **parkinsons.org.uk/forum** 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 sheet.

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

This is your Network. Get involved at parkinsons.org.uk/excellencenetwork

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