

**PARKINSON'S<sup>UK</sup>** CHANGE ATTITUDES. FIND A CURE. JOIN US.

# CARING FOR YOUR RESIDENT WITH PARKINSON'S

Information for care home staff



**Parkinson's is one of a range of conditions you may come across when working with people in a care home.**

This booklet looks at the symptoms of Parkinson's, the treatments for the condition and the potential side effects of those treatments.

It also suggests actions you can take to make sure your residents with Parkinson's receive the highest quality of care.

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# KEY MESSAGES

- Parkinson's affects everyone in different ways. Listen to the person with Parkinson's and their family (if they are involved in your resident's care) about how the condition affects them – they are the experts.
- Remember that how the condition affects your resident can vary from hour to hour and day to day. The amount of help and support you give them will need to vary, too.
- Taking medication at exactly the right time is crucial for people with Parkinson's. Make sure you give Parkinson's medication on time, every time, so that your resident with Parkinson's stays as independent as possible.
- It is vital that a person's Parkinson's medication is not stopped abruptly at any time.
- People with Parkinson's should have regular medical reviews by a specialist and access to any therapy support they need. Make sure this happens.
- A safe, stimulating environment is important for people with Parkinson's.
- Exercise sessions can be really helpful with pain and stiffness.
- Make sure that your resident has access to a varied and balanced diet, and remember to account for any swallowing or movement problems that could stop them from getting the nutrients they need.
- Talk to your resident regularly and give them time to answer. It may take them time to respond, but this doesn't mean they are not listening or don't understand.

“ When I first came into the home I hated it. I was in a lot of pain and the staff did not know how to care for me or cope with my Parkinson’s. I am unable to move for myself, so even the smallest adjustment to my position has to be made by others. I have to be turned every two hours as I am ‘locked’ into position and must remain however I am left when moved.

Because I have a tremor and other involuntary movements, the carers think I am able to move freely. But this isn’t the case. If they do leave me, the pain becomes unbearable. It also increases my tremor, which causes additional stress.

I feel that no one around me seems to know much about Parkinson’s, which leaves me feeling isolated.

As my Parkinson’s progresses, I am producing extra saliva. I need a constant supply of tissues and a bowl that I can, whenever possible, spit into. This causes problems at night, as I am unable to see either the bowl or the tissues. Simple things that most people take for granted are impossible without help. Even watching television is difficult.

I enjoy visits from friends and family. My husband, Tony, visits me twice a day. Visits keep me informed and allow me to participate in life, as I still enjoy talking to people.”

**Carmina, diagnosed in 2003**

# 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 lack of dopamine means that people can have great difficulty controlling movement.

About one person in every 500 has Parkinson's. That's about 127,000 people in the UK.

Most people who get Parkinson's are aged 50 or over, but younger people can get it too. Statistics show that 5-10% of people who live in care homes have Parkinson's.

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

But the condition doesn't only affect mobility. People living with the condition can also experience tiredness, pain, memory problems, sweating, excessive saliva production, sleep problems, dizziness and constipation.

These symptoms can have a huge impact on the day-to-day lives of people with the condition. These non-motor symptoms are present at all stages of the condition but they can dominate in the later stages of Parkinson's.

Not everyone with Parkinson's experiences the same combination of symptoms – they can vary from person to person and progress at a different speed. This means that no two people will follow exactly the same medication routine.

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

## It's 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 progress more quickly.

Generally, Parkinson's has four stages: diagnosis, maintenance, complex and palliative.

### It can fluctuate

The way Parkinson's affects someone can change from day to day, and even from hour to hour – symptoms that may be noticeable one day may not be a problem the next. This can either be caused by Parkinson's or the medication used to treat it.

This can cause frustration for both the person with Parkinson's and their carers or families.

Symptoms will get worse when someone's Parkinson's drugs are wearing off and improve again after Parkinson's 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'. Parkinson's is the most common form of parkinsonism.

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

**Find out more:** see our [information sheet \*Parkinsonism\*](#).



# HOW SHOULD I APPROACH CARING FOR A PERSON WITH PARKINSON'S?

Ideally, good practice would be to assess a client before they enter residential care. The team could then be briefed and make the necessary preparations for a person's arrival.

If this has not been done, assess the symptoms of your resident with Parkinson's when they first arrive, but remember that because of the fluctuating nature of the condition, this may be quite difficult.

Keep in mind that people with Parkinson's will have good days and bad days, but symptoms can also change from hour to hour or minute to minute. Their condition and their individual care plan should be reviewed regularly to take their changing needs into account.

It's good practice for an expert to carry out a medical usage review. Ask your resident's GP, specialist or Parkinson's nurse to do this a couple of months after they have arrived. This will make sure that the

medication is tailored to their current needs, as these may be different to when they were at home.

## Person-centred care

It's important to adopt 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 that their life is not defined by the condition.

People with Parkinson's and their carers (if they have one) are experts in their own condition and should be consulted on what they think their needs are.

Anyone involved in the care of a person with Parkinson's should help them to focus on what they can do, not what they can't do.

Encourage your resident to be more independent when they can, but offer them extra help when things aren't going so well. For example, some mornings your resident might need help with all of their needs,



including washing, dressing and eating, but in the afternoon they might need no help at all.

The care plan needs to be Parkinson's-friendly and reflect these fluctuations, with lots of room for regular change.

Although at times life can be challenging, a combination of modern treatments and a high standard of care will help you to give residents with Parkinson's the best quality of life possible.

“ My dad is 70 years old and has recently moved to a nursing home. This has been a long, challenging process and it takes time for the care staff to fully understand the wants, needs and capabilities of a person with Parkinson's.

I have a white board in his room where I leave messages and notes for the staff. Parkinson's is a hard condition to explain because each person is different. My dad can hardly move. He can't walk and has to be fed.

I keep in constant contact with the staff and a member of the family visits every day. Handing care of a loved one over to others is not easy to do, but when you can no longer meet the person's needs at home, you have no choice.

It takes time to build trust with the care staff and you will always feel guilty. Finding good quality care is the key. ”

**Sue, whose father has Parkinson's**

## Multidisciplinary working

Of course, you will not be the only person involved in the care of a person with Parkinson's.

Collaborative health and social care is essential to manage Parkinson's, and people with the condition will need the expert, professional help of a multidisciplinary team.

This booklet will help you to recognise when a person with Parkinson's needs support and care from various health and social care professionals.

And, when you suspect that someone needs additional support, it is vital that you tell your manager or supervisor, so that they can report the issue to the person's GP, specialist or Parkinson's nurse (if they have one).

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

As you're in close contact with your resident between clinical appointments, you'll see subtle changes in their symptoms and wellbeing. Share the information

with other staff at team meetings and when you change shifts. Keep a record to give to your resident's GP, specialist or Parkinson's nurse.

## 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 Parkinson's and the 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 resident's GP or Parkinson's specialist if there is a Parkinson's nurse near you.

You can find out more at [parkinsons.org.uk/nurses](https://parkinsons.org.uk/nurses)

## Family involvement

It is also important that a person's family are involved in their care when they enter residential care.

Families should be encouraged to participate in care planning and to communicate regularly with residential care staff.

If you see any changes in your resident's condition, if their health deteriorates or if you're having difficulty managing their symptoms, it's good practice to inform their carer or family.

## Care plan actions

- Take your time to talk to your new resident and their family to understand their needs
  - If you know how the condition affects each individual, it will help you to plan their care. By understanding and managing
- their needs, you can help to reduce the impact of the condition on their quality of life.
  - Make sure your care is person-centred. People with Parkinson's and their carers should always be asked about what they think their needs are, as they know their condition best.
  - Make contact with your local Parkinson's nurse (if you have one).
  - Report any issues or concerns about your resident's condition to your manager or supervisor.



# ADVANCED PARKINSON'S AND END OF LIFE

Although the condition progresses differently and at a different speed for each person, the advanced stage can potentially cover a long period of time.

Someone will be in the advanced stage when they experience two or more of the following.

- Drug treatments are no longer effective.
- Drugs regimen is complicated.
- More 'off' periods and dyskinesia.
- Increased mobility problems and falls.
- Problems with swallowing.
- Mental health symptoms such as depression, anxiety, hallucinations, delusions and dementia.
- Reduced independence.

- Less predictability and control of Parkinson's symptoms.

Many people with advanced Parkinson's will also experience pain, so at this stage, management of pain is crucial.

Because of the range of symptoms and the increase in their care needs, it is important that the person with Parkinson's has access to a multidisciplinary team of healthcare professionals.

This will include their specialist, Parkinson's nurse, physiotherapist, occupational therapist, speech and language therapist, continence nurse and dietitian.

You are also a key part of this team, as someone who can monitor the condition on a regular basis and raise any issues with the relevant healthcare professional.

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

## 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.

The care plan of someone with Parkinson's 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 be at their previous home or with relatives.

## Making decisions about end of life

The law says that every reasonable effort should be made to support residents to make their own decisions about the care and treatment they receive.



If your resident has lost the ability to make their own decisions, then any actions or decisions about their care and treatment must be taken in the person's best interests.

This means taking into account their wishes, feelings, values and beliefs, and any views they may have expressed in the past.

The views of family, carers and other relevant people should also be considered, if this is practical and appropriate. If your resident has granted a personal welfare Lasting Power of Attorney to someone, this person will be able to make decisions on the resident's behalf.

Some people with Parkinson's may have made an Advance Decision, also known as an Advance Decision to Refuse Treatment, Living Will or an Advance Directive in Scotland.

This sets out their wishes about receiving a specific medical treatment, should they lose the capacity to make the decision for themselves in the future.

For example, it could be a decision not to be fed by tube when they become seriously ill or close to dying. Advance Decisions are legally binding and must be followed.

### Care plan actions

- If your resident does not have a care plan, you could talk to them about the benefits of putting one in place.

- It is important that you find out whether your resident has a care plan in place regarding how they want the issues surrounding advanced Parkinson's to be managed. This should include legal documentation, such as Lasting Power of Attorney and an Advance Decision. The care plan should also include information about palliative care.

We have information that gives people with Parkinson's more detail about preparing for the practical and emotional aspects of death and dying. You may also find these useful.

**Find out more:** see our booklet *Preparing for end of life*.



# HOW CAN I HELP PEOPLE WITH PARKINSON'S MANAGE THEIR SYMPTOMS?

Here is some guidance about how you can help people with Parkinson's to manage their symptoms and make their daily life a bit easier.

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

## Stiff or rigid muscles

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

It is important to check if the person you are caring for is taking or needs pain relief for these symptoms. If you think they do need pain relief report this to your manager.

Generally the person's GP or Parkinson's nurse will be able to prescribe adequate and appropriate

medication. If this does not help, they may need to see their specialist.

## 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 (eg 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 strategies to help them when they freeze.

## Care plan actions

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

- Often it is the start of a movement that is hard, such as taking the first step to walk. A physiotherapist can give your resident tips to help with this.

- A physiotherapist can advise on 'cues': techniques your resident can use to restart or continue a movement after freezing. These include counting steps, using trigger words or asking the resident to step over your foot to start movement.

- If you see the person you are caring for with Parkinson's regularly 'switching off' or freezing, speak to your manager about arranging a medication review with their GP, specialist or Parkinson's nurse.

- Encourage your resident 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 regularly freezes, try not to talk to them while they are walking because this can make it worse. If you need to discuss something with your patient do it while they are sitting down.

- Make sure the person receives their medication at the right time, as this will help keep them mobile.

**Find out more:** see our information sheet *Freezing in Parkinson's*, and our exercise animations at [parkinsons.org.uk/exercise](http://parkinsons.org.uk/exercise)

## Slow movements (bradykinesia)

It can 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 may include problems getting out of a chair or turning over in bed. They may lack co-ordination in their hands.

## Care plan actions

- Give people plenty of time, support and patience.
- Remember that it might also take some people longer to answer questions because of speech and swallowing problems.



- Find out how well a person can move around. You may need to tell your manager about any mobility problems, so that they can contact a physiotherapist.

## 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 will 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. Medication may help.
- Remember that anxiety or 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.

**Find out more:** see our information sheet *Tremor and Parkinson's*.

## Bladder problems

Incontinence is a common problem for people with Parkinson's. The most common problems associated with the condition are urge incontinence 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 warning. They may benefit from using a hand-held urinal or a commode, especially at night.



- If your resident 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—many people have difficulties with fine finger movements, such as unbuttoning clothes or using zips.
- Allow plenty of time so they feel comfortable and are unhurried.
- It's important that a person does not cut down on the amount of fluid they drink, which may lead to dehydration. Six to eight glasses of fluid a day are recommended. Any fluid is suitable, including water, fruit juice, milk, tea, coffee and squash.
- Report bladder problems to your manager as your resident 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 resident to fill out a fluid chart. This will help to specify their needs and help healthcare professionals find out what the appropriate treatment should be.

## 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.
- Some people have difficulty chewing and swallowing food. This can make it harder for them to include fibre in their diet, which helps to keep stools soft and easy to pass.
- Some people do not drink enough fluid and this can cause the motions to be harder and more difficult to pass. This may be a particular problem during very hot weather.
- Some Parkinson's medication can make constipation worse.

It is important that people with Parkinson's do not 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 resident need to be seen by the relevant member of the multidisciplinary team, such as a dietitian.
- Make sure your resident drinks enough fluids.
- Make sure your patient maintains a healthy, balanced diet that is 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 resident has difficulty moving around, you may need to help them to visit the toilet.
- Allow plenty of time so they feel comfortable and are unhurried.

- Help your resident to 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.

When increasing a person's intake of fibre, it is important to do so gradually to avoid bloating or flatulence (wind). Introduce one new fibre food every three days.

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.

**Find out more:** see our booklet *Looking after your bladder and bowels when you have Parkinson's*.

### Speech problems

Many people with Parkinson's have speech problems. These may make everyday activities, such as talking to friends or using the phone, difficult.

For example, their voice may be slurred, hoarse or unsteady, 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 make it hard when a person is talking to other people. Taking turns to speak, following fast-changing topics or interrupting might be difficult, and so people with Parkinson's may find

themselves giving minimal responses or withdrawing from socialising altogether.

People with Parkinson's can also experience slowness of thought. When you ask a person with Parkinson's a question it can often take much longer for them to listen to what you said, think about their response and then articulate it than it does for people without Parkinson's.

This can become even more difficult when people are stressed or anxious.



## Problems with facial expressions and body language

Some people with Parkinson's can have issues with facial expression because of difficulty controlling 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 can also be affected by Parkinson's symptoms. Slowness of movement, stiffness and tremor can reduce body or hand gestures and make head and neck movements more restricted.

Starting movements can be hard and can become slower and clumsier.

Involuntary movements (also known as dyskinesia) can be a side effect of Parkinson's medication. These can affect any 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.

Difficulties with communication can be upsetting and frustrating for the person with Parkinson's and for those around them. In a care situation, if you don't understand the communication problems caused by Parkinson's, this can often result in misunderstandings.

But there are some basic things you might try to make life a little bit easier.

### Care plan actions

- If you believe a person's speech or movement is getting worse, report it to your manager. Your resident may need a referral to a speech and language therapist or a change to their medication regime.
- Make sure that all care staff know about any communication problems and make the effort to speak to the resident, as it's vital for their resident's wellbeing.
- Be patient and give the person affected time to talk. They may need extra time to talk and respond, so try not to interrupt them or walk away.
- Give people the opportunity to talk and encourage them to join in the conversation if it's appropriate, 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. It will also help not to ask difficult questions or more than one question at a time.
- Make sure they can see and hear you.
- Be reassuring and help the person affected to relax if they are visibly stressed when trying to talk. For example, they might appreciate it if you hold their hand if they are 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.
- 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.
- Take the lead in initiating conversation.
- Remember that someone may not look or sound like they are 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 multitask.

**Find out more:** see our [information sheet](#) *Communication and Parkinson's*.

## Mild memory problems

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

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

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

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

It is vital that a person's condition is reviewed by a specialist because sometimes it may seem like they are experiencing dementia symptoms, but they may have mild memory problems or other communication difficulties instead.

Also, if a person with Parkinson's shows signs of confusion it is important not to always assume that their condition is simply getting worse.

These symptoms can be caused by a combination of Parkinson's and the long-term use of Parkinson's drugs. Cognitive problems can be made worse by other illnesses, infection or anaesthetic.



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.

## Parkinson's dementia

Dementia is not uncommon in Parkinson's, particularly if people have had the condition for many years. Symptoms may include slow thought processes and difficulty concentrating.

Some of the problems are similar to those described above for mild cognitive impairment but they are more severe.

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 increasingly hard.



People can also experience changes in their appetite, energy levels and sleep 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 motor symptoms may develop at all. It tends to progress at a faster rate than Parkinson's.

Dementia with Lewy bodies affects a person's memory, language, concentration and attention. It also affects their ability to recognise

faces, carry out simple actions and their ability to reason.

People with this form of dementia commonly experience visual hallucinations, which can be quite vivid. This can happen early on in the condition. They might also experience difficulty in judging distances and movements, which can cause them to fall over for no apparent reason.

The condition can also cause someone to experience episodes of confusion, which can change a lot from hour to hour or over weeks or months.

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

## Care plan actions

- If you notice any changes in your resident's condition or have any concerns about their mental health, report it to your manager. Your resident may need adjustments to their medication regime, or a mental health referral may be required.
- Keep to a daily routine as much as you can.

- Some people with Parkinson's will be taking medications for dementia.
- If your resident does have an infection, it must be treated early. Report any concerns to your manager.
- Encourage someone with dementia to keep engaging and interacting with other people.
- Maintain a familiar environment that helps your resident to feel comfortable.
- Take care with communication. Use familiar phrases, speak

clearly, listen carefully and give your resident time to respond to you.

- Many people won't tell you when hallucinations or delusions happen, so ask your resident if you suspect they are experiencing hallucinations or delusions. If they are, report it to your manager.

**Find out more:** see our information sheets *Dementia and Parkinson's*, *Dementia with Lewy bodies*, *Hallucinations and delusions in Parkinson's* and *Mild memory and thinking problems*.



“ My mam went into care in 2011, and lived in two different care homes until her death last summer. The staff were caring and compassionate, but did lack specific knowledge about Parkinson’s.

Due to my mam’s health issues, which included dementia later in her life, the staff did not always have an easy time with her. I let them know that I understood how she could be and how difficult this was to deal with on a daily basis.

I didn’t want them to hesitate in having an honest and open discussion with me. I wasn’t distressed by my mother’s behaviour because I knew it was not within her control.

I wanted to be able to agree strategies with the staff. I could also give them tips on what to look out for – for example, subtle changes in her behaviour that indicated a downturn in her physical and emotional health.

A friend said to me ‘our loved ones are in care because we can’t look after them’. This needs to be acknowledged along with the issues that can go with conditions like Parkinson’s. There needs to be open dialogue between all parties.”

**Geraldine, whose mother had Parkinson’s**

## 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 Parkinson's. With that in mind, remember that it is important not to make assumptions about a person's condition. Instead they should be seen by their GP, specialist or Parkinson's nurse.

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 slow thinking or difficulty concentrating.

Some people may be more prone to depression at times when their Parkinson's symptoms suddenly worsen or new problems emerge, perhaps as a drug begins to become 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 resident's drug

regimen should be reviewed by their Parkinson's 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 a change in drug treatment, but if they are regularly unhappy or negative, they may need further treatment.
- Be aware of changes in emotions and any link with communication problems.
- Encourage your resident to continue doing the things they enjoy, such as hobbies, and talk to them as much as you can.
- Encourage your resident to take part in activities and talk to them as much as you can.

**Find out more:** see our [information sheet \*Depression and Parkinson's\*](#).

## 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 Parkinson's 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. Sometimes anxiety can come on and disappear suddenly.

When anxiety is related to their physical symptoms people may develop panic attacks, whether that's a fear of falling, freezing or being unable to communicate. This is something many people find very difficult to manage.

Some people may find that when their physical symptoms are better controlled by medication, they feel less anxious. So it is 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 are caring for to avoid stimulants such as caffeine and alcohol.
- Help the person to identify what triggers an anxious episode.

- Make sure the person you are caring for has had a medical review to make sure their Parkinson's medication is as effective as it can be.
- Some people find that relaxation exercises, such as yoga or massage, can be helpful in relieving symptoms of anxiety.

**Find out more:** see our [information sheet \*Anxiety and Parkinson's\*](#).

## Eating, swallowing and saliva control

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

Drooling is one of the first signs of a swallowing problem. This will happen because the person can't close their lips properly, they find it hard to swallow regularly, or because they aren't sitting in a good position. This can cause saliva to collect in the mouth, which can cause overspill, leading 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.



This can lead to problems such as aspiration pneumonia.

People with Parkinson's may show signs of a swallowing problem 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 experiencing weight loss
- have trouble swallowing their medication
- have heartburn, acid reflux or lots of chest infections

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 without any of the usual signs of coughing or choking.

In these circumstances, a referral to a speech and language therapist is vital. They can assess the person and make appropriate suggestions for treatment, such as exercises to strengthen the lip, tongue and throat muscles. They can also advise on ways to improve breathing techniques.

A dietitian can help by giving advice to your resident 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.
  - Make sure that medication is taken on time so the person can swallow well at meal times. If your resident is having problems swallowing their medication report it to your manager immediately.
  - Changes to a person's medication regime or Botox injections may help. Your resident may need to see their GP, specialist or Parkinson's nurse.
  - 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, report it to your manager as your resident may need to see a dentist.
  - Make sure they drink enough fluids. Six to eight glasses a day are recommended.
- Look at how well they can use and co-ordinate their hands.
  - Your resident may need a lot of time to enjoy eating on their own, or they may need your help at every meal.
  - Your resident may use specially designed cutlery or cups. Ask their carer, family member or friend to bring them in. An occupational therapist can also provide advice on the best ones to use.





- If it takes a long time for someone to eat, you could give them half of the meal and keep the other half warm until they are ready to eat it.
- Avoid giving your residents hard, dry or crumbly foods. Liquids may be thickened with powdered thickeners, milk powder, instant potato powder or plain yoghurt, as thicker liquids move more slowly and are easier to control.

For some people, these solutions will not be enough and a different feeding method might be needed.

## Dry mouth

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

**Find out more:** see our information sheet *Eating, swallowing and saliva control*.

## Weight loss

If a resident with Parkinson's leaves their food because of difficulties eating, this can lead to weight loss.

## Care plan actions

- If you notice your resident has lost weight, report it to your manager. A referral to a dietitian or speech and language therapist may be required. A dietitian can offer advice about getting a good diet and about the types of food that may be easier to swallow. They may also recommend nutritional supplements.
- It could also be that their dentures are loose and uncomfortable, so they'll need to see a dentist.
- Make sure your resident is drinking enough fluids.
- If your resident'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 to suggest ways to manage weight.

**Find out more:** see our booklet *Diet and Parkinson's* and our information sheets *Eating, swallowing and saliva control*, *Dental and oral health in Parkinson's*.

## 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 when they stand up owing 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 resident may benefit from physiotherapy, so a referral may be necessary.
- If your resident 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 resident do it while they are sitting down.

There are many things that could be hazardous and make people more likely to fall, including slippery floors, loose carpets and general



clutter. Here are some tips on how to help your resident reduce hazards in their environment.

- Clear away clutter 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.
- Make sure the 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 your resident has 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:** see our information sheet *Falls and Parkinson's*.

## Pain

Many people with Parkinson's experience pain. This can include dystonia – involuntary muscle contractions most commonly experienced when a person's drugs are wearing off.

## Care plan action

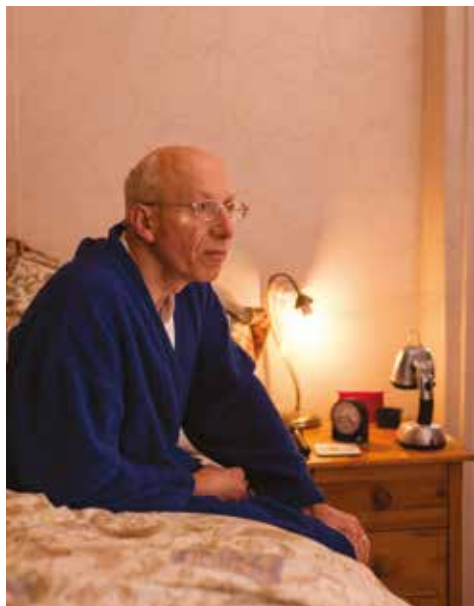
- Your resident with Parkinson's might take pain relief as part of their drugs regimen. Speak to your manager if your resident is not happy with what they take, or if pain relief needs to be added to their regimen. They may need a review of their medication with the specialist or Parkinson's nurse.

**Find out more:** see our information sheet *Pain in Parkinson's*.

## Sleep problems and tiredness

Sleep and night-time problems are common in Parkinson's. These may include insomnia, pain and nocturia.

These difficulties can leave people feeling tired and lethargic (sleepy) during the day. Your resident's symptoms may get worse when they are tired.



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 or delusions.

Turning over in bed can be difficult for people with Parkinson's because of rigidity, so you should see if they need any care for pressure ulcers. 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 some Parkinson's drugs, drugs 'wearing off' or by restless leg syndrome. Your resident's Parkinson's symptoms may get worse when they are tired.

### Care plan actions

- You may find your resident gets tired more quickly than someone without Parkinson's, so let them rest when they need to.
- Put a night-time call bell in reach of your resident with Parkinson's, so they know help is at hand.
- They will need reassurance if they are experiencing nightmares. These can be very distressing.
- Make sure people have adequate pain relief.
- Help them to keep a sleep diary so they can explain their symptoms to a specialist or Parkinson's nurse.

**Find out more:** see our [information sheets \*Sleep and night-time problems in Parkinson's and Hallucinations and delusions in Parkinson's.\*](#)

# WHAT ARE THE MAIN DRUG TREATMENTS FOR PARKINSON'S?

Drugs are the main treatment to control Parkinson's symptoms. There are drugs that work by replacing or mimicking the actions of dopamine, the chemical that is lacking in the brains of people with Parkinson's.

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

## Levodopa

The most common examples include co-beneldopa (Madopar) and co-careldopa (Sinemet, Duodopa, Lecado or generic form).

Stalevo is a combination drug therapy in one tablet. It contains a substance that enhances the benefits of levodopa.

There are different forms of each drug. There is a dispersible form of Madopar that can be swallowed whole or dissolved in water. Note that Madopar capsules should NOT be broken. Duodopa is an intestinal gel. The drug is pumped continuously through a tube that is surgically inserted in the intestine.

For details of controlled-release (CR) options, see our booklet, *Drug treatments for Parkinson's*.

For a small number of people with Parkinson's, protein in food interferes with the way levodopa is absorbed by the body. A full stomach can also delay absorption. If this affects your resident, 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

The most common examples include ropinirole (Requip, Adartrel, Spiroco, Ralnea or generic form), rotigotine (Neupro), and pramipexole (Mirapexin, or generic form).

The following dopamine agonists are not so widely used but you may still find the occasional person taking them. These include cabergoline (Cabaser or generic form) bromocriptine (Parlodel or generic form) and pergolide.

## Dopamine agonists (injection or infusion pump)

Apomorphine (APO-go) is given by injection or infusion pump. This should be set up and monitored by the Parkinson's nurse or an APO-go nurse. A person with Parkinson's who is using an APO-go infusion pump or APO-go pen, or their carer if they have one, will know how to set this.

Some people will need to have injections of apomorphine between doses of their usual tablets. Injections of apomorphine 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 weeks when it is started. Other anti-sickness drugs can make Parkinson's symptoms worse.

**Find out more:** see our [information sheet \*Apomorphine\*](#).

Impulsive and compulsive behaviour is a side effect that affects some people taking dopamine agonists. It can also affect some people taking other Parkinson's drugs, including levodopa. See page 45 for more information.

## Anticholinergics

These drugs are rarely used. Examples include trihexyphenidyl/benzhexol (Broflex or generic form), procyclidine (Kemadrin, Arpicolin or generic form) and orphenadrine (Disipal, Biorphen or generic form).

## Glutamate antagonist

Amantadine (Symmetrel) controls tremor and stiff muscles. It comes in capsule or syrup form.

## COMT inhibitors

Examples include tolcapone (Tasmar) and entacapone (Comtess).

Tolcapone and entacapone have to be taken at the same time as levodopa, otherwise they will be ineffective.

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

## MAO-B inhibitors

Examples include selegiline (Eldepryl, Zelapar or generic form). This drug is a stimulant, and should be taken in the morning so it doesn't disturb sleep. Rasagiline (Azilect) should also be taken in the morning.

## 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)

- Fluphenazine with nortriptyline (Motival)
- 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. 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:** see our booklet *Drug treatments for Parkinson's*.





# WHY IS IT IMPORTANT THAT PEOPLE 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 will 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 Parkinson's may be very anxious about getting their drugs on time.

It's important that you support residents to maintain as much independence as possible. One way to do this is to give your resident control over when they take their medication if this is appropriate.

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)

“ Getting their medication on time is one of the most basic, important things for people living with this condition. ”

**Judi, whose husband has Parkinson's**

# WHEN LEVODOPA WEARS OFF

When levodopa is taken, a person's Parkinson's symptoms will improve. But these symptoms can sometimes recur 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 are feeling at their most capable.

Being 'off' is when Parkinson's symptoms recur and are at their most debilitating. Some people have described this as like a light

switch being turned on and off, or going up-and-down like a yo-yo.

As well as having an effect on a person's motor symptoms, people may also experience feelings of anxiety, sleepiness, low mood or pain 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 are still able to reach for a cup.

## Care plan actions

- Make sure all staff know you have a resident with Parkinson's, and that drugs may have to be given outside of usual drug rounds.

- A person with Parkinson's may have a medication diary, so check it as soon as they move in. Ask them how their symptoms change when they need medication.
- Make sure staff know how important the timing of Parkinson's medication is.
- It's important to note that it is dangerous to stop medication suddenly.
- Set up a training session on Parkinson's and medication with Parkinson's UK. See page 53 for more about education and training.
- A pill timer is a box with sections for different doses. It might have an alarm that sounds when different doses need to be taken. You can use pill timers or alarm clocks to remind staff about residents whose medication is due at different times from set drug rounds.
- Where you can, encourage your resident with Parkinson's to look after their own medicines. Some Parkinson's residents will self-medicate. Reassure them you will support this routine and offer pill timers or reminders to help them.



# WHAT ARE SOME OF THE POTENTIAL SIDE EFFECTS OF PARKINSON'S MEDICATION?

We cannot list all of the side effects of all Parkinson's drugs, but some of the drugs used to treat Parkinson's can cause problems with movement, behaviour, thinking and memory. It may not be obvious that these problems are the result of medication.

Make sure all staff are aware of these potential drug side effects.

## Dyskinesia

Dyskinesia happens because of the combination of the condition and Parkinson's medication. It is most common in people who have been taking levodopa for many years.

It can be described as unusual movements, such as jerking, twitches or spasms. They can affect any part of the body. The strength of dyskinesias can vary from mild to severe.

In order to reduce these involuntary movements the only option is to reduce the amount of drugs a

person is taking. But this can lead to a reduction in their general mobility. Some people may choose to live with the dyskinesia rather than compromise their ability to take part in their usual activities.

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

## Care plan action

- 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.

## Impulsive and compulsive behaviour

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

Impulsive behaviour is when a person can't resist the temptation to carry out certain activities that could lead them to harm themselves or others. This includes a strong urge to gamble, shop or binge eat.

Some people with Parkinson's experience hypersexuality, where they become so preoccupied with sex that it can cause problems with their work or personal life.

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

“ I went from being organised, in a routine, to being a crazy party man. My life was out of control and I couldn't focus on anything – I was thrill-seeking all the time.

Some months later, my specialist found out from research about how impulsive and compulsive behaviour can be a side effect of some dopamine agonists.

These drugs are a useful medication and can do a lot of good, but people with Parkinson's, and all health and social care professionals involved in their care, must be aware of the side effects. ”

**Stephen, diagnosed in 2001**

In a lot of cases, this behaviour is out of character. The person experiencing this behaviour may experience distress, and possibly 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 sheet *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 and make sure the person's specialist or Parkinson's nurse is 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 they're taking too much of their medicine on purpose – this could be a sign of drug-related compulsive behaviour.

You can find more information for professionals about impulsive and compulsive behaviour at [parkinsons.org.uk/icbresources](https://parkinsons.org.uk/icbresources)

### Hallucinations and delusions

Your resident 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 they 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, is not causing the symptoms.

Research shows that hallucinations and delusions often happen when someone with Parkinson's also has problems with memory or thinking, dementia, depression, sleep problems or very strong Parkinson's movement symptoms.

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

**Find out more:** see our [information sheets \*Impulsive and compulsive behaviour in Parkinson's\* and \*Hallucinations and delusions in Parkinson's\*](#).



## Neuroleptic malignant syndrome

If any of the drugs used for treating Parkinson's need to be stopped, it is important this is done gradually.

Abrupt withdrawal of certain drugs can result, albeit rarely, in neuroleptic malignant syndrome.

This is a very serious condition that may cause death from complications of the respiratory, cardiovascular or renal system. This is rare, but it does emphasise the importance of medication management in Parkinson's.

## 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.

Stopping or reducing treatment should always take place in consultation with the person's specialist. Symptoms of dopamine agonist withdrawal syndrome can include anxiety, panic attacks,

depression, insomnia, irritability and drug cravings.

To avoid dopamine agonist withdrawal syndrome, people with Parkinson's must get help from a specialist in Parkinson's and withdrawal must be done gradually.

## Dopamine dysregulation syndrome

When people have the compulsion to take more medication than is needed to control their Parkinson's symptoms this is known as dopamine dysregulation syndrome. This is a type of impulsive and compulsive behaviour (see page 45 for a fuller explanation).

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

## 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 **[mhra.gov.uk](http://mhra.gov.uk)**



# WHAT ELSE DO I NEED TO THINK ABOUT WHEN I HAVE A RESIDENT WITH PARKINSON'S?

## Surgery

Surgery is a treatment option for a small number of people whose symptoms aren't controlled by drugs.

The most common form of surgery is deep brain stimulation, and if your resident has been through this procedure, you will need to be aware of how this works and how your resident controls their symptoms. You may wish to talk about this with your resident's specialist or Parkinson's nurse.

**Find out more:** see our booklet *Surgery for Parkinson's*.

## General health and personal hygiene

Your resident 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 they find 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 does not mean they are being difficult, or that they are not trying.

It's important to keep an eye on your resident's eyesight, hearing and any skin conditions.

Any changes could be because of the progress of their Parkinson's, or because their medication needs adjusting. Report any changes to your manager.

If your resident uses a hearing aid, glasses or false teeth, make sure they are being used properly and are not causing any unnecessary difficulties. Also make sure shoes or slippers are comfortable and safe. This will reduce the likelihood of falls.

## Seeing and reporting change

Your resident's condition should be monitored by their GP, specialist or Parkinson's nurse, but record any changes yourself.

At your resident's next medical review, they'll talk about changes in general care and medication needs. Make sure you give a carer's view, to help the specialist to make their decisions. Tell them what is going well and what isn't.

## 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 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, are at the most risk of developing pressure ulcers.

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, pressure ulcers can cause serious medical problems, such as blood poisoning.

## Actions to take

- 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 resident takes their medication on time to ensure maximum mobility.
- If your resident has continence problems, this may contribute to the development of pressure ulcers. Report any continence issues to your manager.
- If your resident has limited mobility they may benefit from using equipment, such as specially designed mattresses and cushions. Report any concerns you have to your manager.
- Check your resident'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 resident maintain a healthy, balanced diet and adequate hydration, which can help to prevent skin damage. If you have any concerns, tell your manager as your client may benefit from seeing a dietitian.

“ My grandfather was so badly treated that he had sores from not having his incontinence pad changed for almost two weeks. The sores became infected and he never really recovered.

We moved him to another home after he was well enough. He was well cared for there, but infections plagued him from that day until his death. ”

**Thomas, whose grandfather had Parkinson's**

“ I became a volunteer educator for Parkinson’s UK three years ago. After I was diagnosed with Parkinson’s, my sole objective was to raise awareness and understanding of my condition.

I deliver Parkinson’s awareness courses to care home staff across my county. The feedback I get has been really positive. The staff really appreciate being trained by someone who has the condition. ”

**John, diagnosed in 2008**



# HOW CAN PARKINSON'S UK SUPPORT RESIDENTIAL CARE WORKERS?

## Courses and seminars

Parkinson's UK runs courses and seminars for care home workers. These cover the symptoms, medication, side effects and myths about Parkinson's, and how to look after people with the condition. To find out more, see our website: [parkinsons.org.uk/education](https://parkinsons.org.uk/education)

## Join the Parkinson's UK Professionals' Network

We work closely with professionals who support people with Parkinson's. Professionals play a vital role in signposting people to us for further support and information. It's important that we work together to reach everyone affected by Parkinson's, to make sure they don't feel alone with their condition and have the highest quality services and support.

Join our Professionals' Network to receive the latest information about Parkinson's UK and share knowledge with your professional peers to help develop your practice.

Simply register at [parkinsons.org.uk/professionalsnetwork](https://parkinsons.org.uk/professionalsnetwork) or call **0808 800 0303**.

Further resources for professionals are available online at [parkinsons.org.uk/professionals](https://parkinsons.org.uk/professionals)

## Access further information

We provide information on all aspects of Parkinson's for everyone affected by the condition on our website and through our publications and other resources. Visit [parkinsons.org.uk](https://parkinsons.org.uk)

# GLOSSARY

## Bradykinesia

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

## Cognitive processes

Mental processes involving thinking and memory.

## Compulsive behaviour

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

## Cues

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

## Deep brain stimulation

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

## Delusions

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

## Dopamine

A neurotransmitter or chemical messenger. This chemical helps to

control the messages the brain sends to the muscles to help people perform sequences of movement. Dopamine also contributes to some thinking and memory processes.

## Dopamine agonist withdrawal syndrome

A syndrome that occurs when a person's dopamine agonist treatment is abruptly stopped or reduced.

## Dopamine dysregulation syndrome

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

## Dysphagia

Swallowing difficulties.

## Dyskinesia

Involuntary movements, 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.

## Get It On Time

A Parkinson's UK campaign to make sure that people with Parkinson's get their medication on time, every time.

## Hallucinations

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

## Hypotension

Low blood pressure.

## Illusions

When a person sees things in a different way from how they look in real life.

## Impaction

When the bowel is loaded with hard stools causing obstruction and overflow. Caused by constipation.

## 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 that replaces dopamine, the chemical that is lost causing the development of Parkinson's.

## Motor symptoms

Symptoms related to movement.

## Multidisciplinary team

A group of healthcare professionals with different areas of expertise who can unite and treat complex medical conditions. Essential for people with Parkinson's.

## Neuroleptic malignant syndrome

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

## Neurological

Involving the nervous system (including the brain, spinal cord, the peripheral nerves, and muscles).

## Non-motor symptoms

Symptoms of 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.

## Parkinsonism

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

## Patient-centred care

A focus on the needs of a person with a long-term condition as an individual who is expert in 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'.



## Caring for your resident (B114/2013)

Do you have any feedback about this information? Your comments will help us ensure our resources are as useful and easy to understand as possible. Please return to [Information Content team, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ](#), or email [publications@parkinsons.org.uk](mailto:publications@parkinsons.org.uk). Thank you!

### 1. Please choose the option that best fits you.

- I have Parkinson's and was diagnosed in
  - I care for someone with Parkinson's
  - I have a friend or family member with Parkinson's
  - I'm a professional working with people with Parkinson's
  - Other (please specify)
- 
- 

### 2. Where did you get this information from?

- GP
  - Parkinson's nurse
  - Parkinson's UK local adviser
  - Call to the helpline
  - Other (please specify)
  - Specialist
  - Parkinson's UK local group
  - Ordered directly from us
- 
- 

### 3. Has it answered all your questions?

- Yes, completely
- Yes, mostly
- Partly
- Not sure
- Not at all

### 4. How easy was it to understand?

- Very easy
- Easy
- Not sure
- Quite difficult
- Very difficult

Continued over the page



## 5. Has it helped you manage your condition better, or make choices that have improved your life in some way?

- |   |   |
|---|---|
| <input type="checkbox"/> It helped a lot    | <input type="checkbox"/> It didn't help       |
| <input type="checkbox"/> It helped a little | <input type="checkbox"/> It made things worse |
| <input type="checkbox"/> No change          |   |

## 6. What is your ethnic background?\*

- |   |  |
|---|--|
| <input type="checkbox"/> Asian or Asian British | <input type="checkbox"/> Mixed         |
| <input type="checkbox"/> Black or Black British | <input type="checkbox"/> White British |
| <input type="checkbox"/> Chinese                | <input type="checkbox"/> White other   |
| <input type="checkbox"/> Other (please specify) |  |
- 

\*We ask about your ethnicity to ensure our information is reaching a broad range of people. However, this question is optional.

## Want to hear more from us?

- I would like a response to my feedback
- I would like to be a member of Parkinson's UK
- I'm interested in joining the Information review group, to offer feedback on Parkinson's UK information

## If you've answered yes to any of these options, please complete your details below.

Name

---

Address

---

Email

---

Telephone

---

## How would you prefer us to contact you?

- Email    Post    Phone

We will not pass on your details to any other organisation or third party. To find out more, read our privacy policy at [parkinsons.org.uk/termsandconditions](https://parkinsons.org.uk/termsandconditions)



Thank you to everyone who contributed to or reviewed this booklet:

**Dr Richard Grunewald, Consultant Neurologist, Division of Clinical Neurosciences, Royal Hallamshire Hospital, Sheffield**

**Annemarie Booth, Clinical and Care Governance Lead, Care UK**

**Sally Hawthorne, Senior Care Assistant, Ponteland Manor Care Home, Newcastle**

**Helen Bentley, Senior Care Assistant, Grangewood, Houghton-le-Spring**

All of the photographs in this booklet feature people affected by Parkinson's, health and social care professionals involved in caring for people with Parkinson's and Parkinson's UK staff. Thank you to everyone involved for letting us use their photograph.

### **Our information**

All of our most up-to-date information is available at **[parkinsons.org.uk/information-support](https://parkinsons.org.uk/information-support)** If you'd prefer to read one of our printed leaflets or booklets, find out how to place an order at **[parkinsons.org.uk/ordering-resources](https://parkinsons.org.uk/ordering-resources)** or by calling **0300 123 3689**.

We make every effort to ensure that our services provide current, unbiased and accurate information. We hope that this will add to any professional advice you receive and help you to make any decisions you may face. Please do continue to talk to your health and social care team if you are worried about any aspect of living with Parkinson's.

If you'd like to find out more about how we put our information together, including references and the sources of evidence we use, please contact us at **[publications@parkinsons.org.uk](mailto:publications@parkinsons.org.uk)**

### **Can you help?**

At Parkinson's UK, we are totally dependent on donations from individuals and organisations to fund the work that we do. There are many ways that you can help us to support people with Parkinson's. If you would like to get involved, please contact our Supporter Services team on **0800 138 6593** or visit our website at **[parkinsons.org.uk/donate](https://parkinsons.org.uk/donate)**. Thank you.

Every hour, two people in the UK are told they have Parkinson's – a brain condition that turns lives upside down, leaving a future full of uncertainty.

Parkinson's UK is here to make sure people have whatever they need to take back control – from information to inspiration.

We want everyone to get the best health and social care. So we bring professionals together to drive improvements that enable people to live life to the full.

Ultimately, we want to end Parkinson's. That's why we inspire and support the international research community to develop life-changing treatments, faster. And we won't stop until we find a cure.

**Together we can bring forward the day  
when no one fears Parkinson's.**

Parkinson's UK  
215 Vauxhall Bridge Road  
London SW1V 1EJ

Free confidential helpline **0808 800 0303**  
(Monday to Friday 9am–7pm, Saturday 10am–2pm).

Interpreting available.

NGT Relay **18001 0808 800 0303** (for use with smart phones, tablets, PCs and other devices). For more information see **[www.ngts.org.uk](http://www.ngts.org.uk)**

**[hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk)**  
**[parkinsons.org.uk](http://parkinsons.org.uk)**

Order code: PKB114

Last updated May 2013. We review our information within three years. Please check our website for the most up-to-date versions of all our information.

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