

# Parkinson's: a guide for home care workers



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

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

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

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

There is a glossary on page 54 that explains terms you may not be familiar with. The first time a glossary term appears in the booklet, we have highlighted it in bold for you.

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## General care plan actions

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- Parkinson's affects everyone in different ways. Listen to the person with Parkinson's and their family (if they are involved in your client's care) about how the condition affects them – they are the experts.
  - How Parkinson's affects a person can vary from hour to hour and minute to minute.
- So if a person can carry out an activity once but isn't able to do it again – even on the same day – this doesn't mean they are being difficult, or that they aren't trying.
- The amount of help and support you give your clients will need to vary, according to what they are able to do each time you see them.

- If you have any concerns about your client's condition, report them to your manager or follow your company's procedure for doing this.
- Taking medication at exactly the right time is crucial for people with Parkinson's. Make sure your client is taking their Parkinson's medication on time, every time.
- It is vital that a person's Parkinson's medication is not stopped abruptly at any time.
- Some people may benefit from taking medication for symptoms that are not related to movement problems. Speak to your manager about arranging a medication review for your client if you have any concerns.
- Give your client time to answer when you talk to them. It may take them time to respond, but this doesn't mean they aren't listening or don't understand.
- People with Parkinson's should have regular medical reviews by a specialist and access to the multidisciplinary care team. Make sure this happens and let your manager know if you have any concerns.
- Make sure that your client has access to a varied and balanced diet. If they have any swallowing or movement problems that could stop them from getting the nutrients they need, report this to your manager.

“ Every morning I wake up hours earlier than I need to, because my body is so stiff. It’s so painful. I struggle to get out of bed – even turning over is extremely difficult. There are always aches and pains present in my body – in my back, legs and feet.

My husband gives me my medication in the morning and then I wait for 20 minutes before getting up for a shower. Standing is easier than sitting in the bath, but keeping my balance is tricky.

For a person with Parkinson’s, getting their day started can be full of problems. It is a struggle for me every morning just to get up and dressed. I struggle getting my clothes and shoes on. I can’t bend down to do laces anymore.

Then I go to work. As my day goes on my movements and body become less stiff. I take medication again at lunchtime, and by the afternoon my movements are a little better.

In the evening, I take more medication. I watch TV in a comfortable armchair that has been modified with raised box feet, which helps me get out of the chair more easily. Usually I play bowls two to three times a week. Exercise makes me sleep better, but I often wake up stiffer as a result.

By 9pm, I am uncomfortably stiff again and I find it hard to get out of my chair and up the stairs to bed. I dread going to sleep, because all my symptoms will be back in the morning.”

**Sharon, diagnosed in 2009**

# What is Parkinson's?

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## It's neurological

People get Parkinson's because some of the nerve cells in their brains that produce a chemical called **dopamine** have died. This loss of dopamine means that people can have great difficulty controlling movement.

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

But the condition doesn't only affect movement. People living with Parkinson's can experience a range of **non-motor symptoms** that can have a greater impact on their lives than movement difficulties. Non-motor symptoms include depression, sleep problems, anxiety, excessive sweating, constipation and pain. They are present at all stages of the condition but they can dominate in the later stages of Parkinson's.

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 develop it too.

## 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.

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

## It can fluctuate

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

Also, how Parkinson's affects someone can change from hour to hour, and even from minute to minute – symptoms that may be noticeable one day might not be a problem the next. This can either be caused by Parkinson's itself or the medication used to

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

## Parkinsonism

The main symptoms of Parkinson's are also the main symptoms of a range of conditions that together are called '**parkinsonism**'. Idiopathic Parkinson's is the most common form of parkinsonism. Idiopathic means the cause is unknown.

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

**Find out more:** see our information sheet *Parkinsonism*.





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

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

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

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

### **Person-centred care**

It's important to take a **person-centred approach** to caring for a person with Parkinson's. This means focusing on someone's needs as an individual and the fact that their life is not defined by the condition. People with Parkinson's and their carers

“Some home carers thought my husband didn't know what he was talking about. But believe me, he is more on the ball than they are at times. So my advice is to listen to the person – don't ignore what they say they want.”

### **Teala, whose husband has Parkinson's**

(if they have one) are experts in their own condition – they should be asked about their needs and how they manage their symptoms.

### **Multidisciplinary working**

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

The multidisciplinary team can include a person's specialist, Parkinson's nurse (if they have one), physiotherapist, occupational therapist, and speech and language therapist.

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

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

As someone who can monitor a person's condition on a regular basis, you are a key part of this team. If you think a person you're caring for needs extra support, it's vital that you tell your manager or supervisor so they can report the issue to the person's GP, specialist or Parkinson's nurse.

By reporting any issues or concerns, you can help to provide the standard of care needed to

make a positive difference to the lives of people with Parkinson's.

## **Parkinson's nurses**

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

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

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

## Care plan actions

- Speak to the person with Parkinson's and their carer about their individual needs. They are expert in how Parkinson's affects them.
- Make sure your client's care plan is Parkinson's-friendly and reflects the changing nature of the condition.

- Make contact with your local Parkinson's nurse (if you have one).
- Report any issues or concerns about your client's condition to your manager or supervisor.



“ I have had both good and bad experiences of home care. I have two care visits a day. Fortunately, my morning carer is excellent – very friendly, committed and highly professional. She always arrives on time, if not early, and makes sure I have everything I need.

She always notices when my symptoms are worse and supports me in finding solutions to any problems. She is sensible, trustworthy and never gives the impression she is rushed.

I have had several care workers whom I’ve not been happy with. Often, on a first visit, care workers don’t even ask what difficulties I have. They see two legs and assume I must be able to walk. Some have been in a rush, or late, and don’t seem to concentrate on what they’re doing.

I sometimes have another care worker who I don’t feel understands my condition or my needs. She always seems rushed. As a result, I’m reluctant to ask her to do certain things, such as help me to shower. I don’t feel I can trust her to concentrate on the task at hand.

It’s important that care workers encourage the people they care for to look for manageable ways to cope with challenging situations. They should look for ways to help – perhaps using aids or equipment, or further professional help.”

**Diana, diagnosed in 2004**

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

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

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

### **Stiff or rigid muscles**

Simple movements, such as getting up from a chair, rolling over in bed or moving fingers to write or fasten a button, can be difficult or painful for someone with Parkinson's. Stiff and painful joints, especially shoulders, are also 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 give them appropriate medication. If this does not help, they may need to

see their specialist. See page 24 for more information about pain.

### **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 'cueing' strategies to help them when they freeze. These are techniques or prompts that the person can use to restart or continue a movement after freezing, such as counting steps and using trigger words to encourage movement.

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



### Care plan actions

- Find out if the person has any problems with freezing by observing them or asking them. If they do, report the problem to your manager. Their medication may need adjusting or they may benefit from seeing a physiotherapist.
- Often it is the start of a movement that is hard, such as taking the first step to walk. A physiotherapist can give tips to help with this.
- A physiotherapist can advise on 'cues'.
- Make sure the person is receiving their medication on time, every time.

- Encourage people to take regular exercise, if appropriate. This can help to strengthen muscles, increase mobility in their joints and build up their general fitness and health.
- If a person experiences freezing, try not to talk to them while they are walking because this can make it worse. If you need to discuss something with your client, do it while they are sitting down.

**Find out more:** see our information sheet *Freezing in Parkinson's* and our exercise booklet and DVD *Keeping moving*.

## **Slow movements (bradykinesia)**

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

Some people's ability to move might change very quickly, so at times they can move well, but within minutes they may slow down or stop.

Difficulties moving may include getting out of a chair or turning over in bed. A person may also lack co-ordination in their hands.

### Care plan actions

- Give people plenty of time, support and patience.
- Find out how well a person can move around. You may need to tell your manager about any mobility problems, so that they can contact a physiotherapist.
- Walking aids may be helpful – but always get advice from a physiotherapist before buying anything.

- Remember that it might also take some people longer to answer questions because of speech and swallowing problems (see page 19).

## **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 stress can make a tremor worse, so try to help people with Parkinson's find ways to stay calm and relaxed, such as exercise or complementary therapies.
- Make sure your client's medication is taken on time.
- If your client has problems moving around, you may need to help them visit the toilet. Keep in mind that people with Parkinson's may have practical problems using the toilet – many people have difficulties with fine finger movements, such as unbuttoning clothes or using zips.

**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 (an urgent need to pass urine before having time to visit the toilet) and nocturia (the need to get up during the night to urinate).

#### Care plan actions

- Be aware that someone with Parkinson's might need to urinate often and may need to visit the toilet without much warning. They may benefit from using a hand-held urinal or a commode, especially at night.
- Allow plenty of time so they feel comfortable and 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 a day are recommended. Any fluid is suitable, including water, fruit juice, milk and squash.
- Report bladder problems to your manager as your client may need to be seen by the relevant member of the multidisciplinary team, such as a continence adviser. Medication may be an option for some bladder problems.
- Help your client fill out a fluid chart. This will help to specify their needs and help healthcare professionals find out what the appropriate treatment should be.



## 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 makes 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 bowel motions to become harder and more difficult to pass.
- 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 client needs to be seen by the relevant member of the multidisciplinary team, such as a dietitian.
- Make sure they drink enough fluids. Six to eight glasses a day are recommended.

- Make sure your client maintains a healthy balanced diet which 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 client has difficulty moving around, you may need to help them visit the toilet. Allow plenty of time so they feel comfortable and unhurried.
- Help your client fill out a diet or stool chart. This will help to specify their needs and find out what the appropriate treatment should be when they are seen by their healthcare professional.

Remember that some people with Parkinson's may have problems chewing and swallowing. This can make it difficult to eat a diet with plenty of fibre. There are some soluble varieties available and even some high-fibre drinks. A dietitian or a speech and language therapist can give advice about this.



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

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

## **Eating, swallowing and saliva control**

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

People with Parkinson's may show signs of 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 losing weight
- have trouble swallowing their medication

- have heartburn, acid reflux or lots of chest infections

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

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

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

People who have swallowing problems are also at risk of chest problems as food or liquid from the mouth can go into the lungs, rather than the stomach.

In some cases, people with Parkinson's can have what's called '**silent aspiration**'. This is when food enters the windpipe and goes down into the lungs.

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

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

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

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

## Care plan actions

- Report any chewing or swallowing problems to your manager.
- Your client may benefit from seeing a speech and language therapist, occupational therapist or dietitian.
- Make sure that medication is taken on time so the person can swallow well at meal times. If your client is having problems swallowing their medication report it to your manager immediately.
- Changes to a person's medication regimen may also help and there are drugs that may control saliva production.
- Try making changes to the person's posture when they're eating or drinking – having their head tilted forwards will make it harder for food to go into the lungs.
- If the person's dentures are loose and uncomfortable, they may need to see a dentist.
- If they want to eat on their own, allow them lots of time as they may be slow.

- Make sure they drink enough fluids. Six to eight glasses a day are recommended.
- Your client might find specially designed cutlery or cups useful. If they don't already have any, an occupational therapist can advise on the best ones to use.
- Hard, dry or crumbly foods should be avoided. Liquids may be thickened with powdered thickeners, milk powder, instant potato powder or plain yoghurt, as thicker liquids are often easier to control. A dietitian may also recommend nutritional supplements.

For some people, these solutions will not be enough and a different feeding method might be needed. The Royal College of Physicians has a publication, *Oral feeding difficulties and dilemmas*, that you may find useful. Visit [www.rcplondon.ac.uk](http://www.rcplondon.ac.uk)

### Dry mouth

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

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



## Weight loss

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

**Dyskinesia** (involuntary movements) can also lead to weight loss. For more information, see page 44.

### Care plan actions

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

basis, you should record their weight, food and fluid intake on a chart. This will help other members of the multidisciplinary team suggest ways to manage the situation.

**Find out more:** see our booklet *Diet and Parkinson's* and our information sheets *Eating, swallowing and saliva control* and *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 or fainting when they stand up due to low blood pressure (postural **hypotension**). This can cause people to fall. Sometimes the medication taken for Parkinson's can make blood pressure problems worse.

**Find out more:** see our information sheet *Low blood pressure and Parkinson's*.

## Care plan actions

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

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

- Try to clear away as much clutter as you can and arrange the furniture so that moving around is as easy as possible.
- Hand or grab rails may be useful in tight spaces, such as in toilets, bathrooms or by the stairs. Putting non-slip mats in the bathroom will also help.
- Always make sure a person's environment is well lit.

- If possible, apply strips of coloured tape to the edge of steps to reduce slipping and to make them more visible.
- Make sure they have commonly used items close to hand.
- Floor coverings can sometimes be a hazard. For example, carpet patterns can be visually confusing. Speak to an occupational therapist or physiotherapist about applying strips of tape or plastic footsteps on the carpet. These can guide people in places they may be more likely to fall, such as a tricky turn on stairs, or in doorways.

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



## Pain

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

### Care plan actions

- People with Parkinson's might take pain relief as part of their drugs regimen. Speak to your manager if your client 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 their specialist or Parkinson's nurse.

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

## Sleep problems and tiredness

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

These difficulties can leave people feeling tired and sleepy (lethargic) during the day.

Parkinson's, or the medication that treats it, can cause vivid dreams or trouble sleeping.

Not getting enough sleep can cause problems similar to the symptoms of depression.

These difficulties can also make someone with Parkinson's confused or irritated and can make it more likely that they will experience hallucinations 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 (see page 35 for details). They may also need access to appropriate equipment to help their mobility in bed.

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

### Care plan actions

- You may find that your client gets tired more quickly than someone without Parkinson's, so let them rest when they need to.





- They will need reassurance if they are experiencing nightmares. These can be very distressing.
  - Keep a sleep chart. This can be taken to the person's next appointment with their specialist to assess their difficulties.
  - Keep a call bell within their reach, so they know help is at hand at night when it's harder to move.
  - Make sure people have adequate pain relief. Seek advice from an appropriate medical professional.
  - There is no specific bed or mattress recommended for people with Parkinson's, but an occupational therapist can provide advice about aids to help people get in and out of bed.
  - Some people with Parkinson's use satin pyjamas or satin sheets because the shiny material can help them turn over. These shouldn't be used together because they increase the risk of sliding out of bed too quickly. A Parkinson's nurse or occupational therapist can advise.
- Find out more:** see our booklet *Sleep and night-time problems in Parkinson's* and our information sheets *Hallucinations and delusions in Parkinson's* and *Restless legs syndrome in Parkinson's*.

## Communication problems: Speech

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

These problems can make it hard when a person is talking to another person. 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.

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

## Facial expressions and body language

Some people with Parkinson's can have issues with facial expression because it's difficult for them to control their facial muscles. Sometimes a person may make an expression that they didn't plan to make. At other times they may find it difficult to smile or frown. This can make it hard for people to express how they feel.

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



may be difficult and actions can become slower and clumsier.

Involuntary movements (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.

### Care plan actions

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

- If you believe a person's speech or mobility is getting worse, report it to your manager. Your client may need a referral to a speech and language therapist or a change to their medication regimen.
- Be patient and give your client time to talk. Try not to interrupt them or walk away.
- Give your client the opportunity to talk but don't pressure them to speak.
- Talk normally and don't shout.
- Listen carefully.
- Vary the tone of your voice and relax. Stress can be heard in your voice.
- Use short sentences and stress key words.
- Make sure they can see and hear you.
- Be reassuring and help the person affected to relax if they 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 for them.
- Take the lead in starting conversations.

- Don't ignore the person affected by asking someone to speak for them.
- Try to avoid speaking above noise, such as a TV or radio, and try not to be too far away, for example in another room, when talking.
- Remember that someone may not look or sound like they 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 multi-task.
- Use alphabet and picture charts to help your client communicate.

**Find out more:** see our information sheet *Communication and 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.

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

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

Depression in Parkinson's can also be a side effect of Parkinson's medication so your client's drug 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 changes to their medication regimen or further treatment if they are regularly unhappy or negative.

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

**Find out more:** 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. See page 41 for more information about 'on/off'.

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

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

## 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 include problems with planning, multi-tasking, moving quickly from one activity to another or doing tasks in a particular order. They may also have a tendency to start a task and not complete it, and may also experience slow thought processes.

While many people can experience mild memory problems, this 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.

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



be caused by medication or an infection. They can also be made worse simply because a person has been taken away from their normal surroundings and routine, for example, if they've had a stay in hospital.

### **Parkinson's dementia**

Dementia is not uncommon in Parkinson's, particularly if people have had the condition for many years. Many of the problems are similar to those described above for mild cognitive impairment but are more severe.

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

People can also experience changes in their appetite, energy levels and sleeping patterns, so they may find themselves sleeping more during the day. They may become less engaged with what's going on around them and have

a lack of motivation or interest in things they previously enjoyed.

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

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

### **Dementia with Lewy bodies**

Dementia with Lewy bodies is diagnosed when someone has the symptoms of dementia first and then develops Parkinson's-like symptoms. In some cases of dementia with Lewy bodies, no Parkinson's-like symptoms may develop at all.

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

People with this form of dementia commonly experience visual hallucinations, which can be quite vivid. This can happen early on in

the condition. A person may have disturbed sleep, or experience daytime sleepiness.

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

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. 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 client's condition or have any concerns about their mental health, report it to your manager. Your client may need adjustments to their medication regimen or a mental health referral.
- If your client does have an infection, they should be referred to their doctor, because they may need antibiotics. Report any concerns to your manager.
- Think about other reasons for your client to be confused, such as dehydration.

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

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





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

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### **Personal hygiene**

Your client with Parkinson's may need more help with tasks such as cleaning their teeth and shaving. This is likely if they are less able to use their hands well. If 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 aren't trying.

“ My wife Kate was diagnosed with Parkinson’s more than 25 years ago. She was a teaching assistant and bookkeeper, before retiring 10 years ago.

She now has a live-in carer, who helps her to bed, through the night when unable to move unaided, and in the morning when washing and dressing.

With her help, Kate recovers strength through the morning, takes gentle exercise and together they prepare nutritious and balanced meals. Kate enjoys a gentle life of surprisingly good quality and variety through the caring, professional, yet friendly help she is given.

I help with her daily life, providing creative stimulation and doing the ‘fetching and carrying’. Kate and I also go to the local Parkinson’s UK support group, which Kate enjoys, and she goes to Women’s Institute meetings.

Having a live-in carer is the only practical way to give Kate the essential help she needs, though it does require some consideration and adjustment in the home.

Live-in care has undoubtedly and substantially given Kate a better life than could have been expected – as well as an endearing friendship.”

**Alan, whose wife has Parkinson’s**

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

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

## **Pressure ulcers**

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

The parts of the body that are 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.

## Care plan actions

- Making regular and frequent changes to a person's position is one of the most effective ways of preventing pressure ulcers.
- If a pressure ulcer has already developed, regularly changing position will help to avoid putting further pressure on it, and give the wound the best chance of healing.
- Make sure your client takes their medication on time so they can move as easily as possible.

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

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

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

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

### Levodopa

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

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

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

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

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

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



## **Dopamine agonists**

These work in a similar way to dopamine to improve movement symptoms.

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

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

## **Apomorphine**

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

This should be set up and monitored by the 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 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 days when it is started. Other anti-sickness drugs can make Parkinson's symptoms worse. See below for details of drugs to avoid.

**Find out more:** see our information sheet *Apomorphine*.

## **Anticholinergics**

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

## **Glutamate antagonist**

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

## COMT inhibitors

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

Tolcapone and Entacapone should be taken at the same time as levodopa, to get the best out of the levodopa.

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

## MAO-B inhibitors

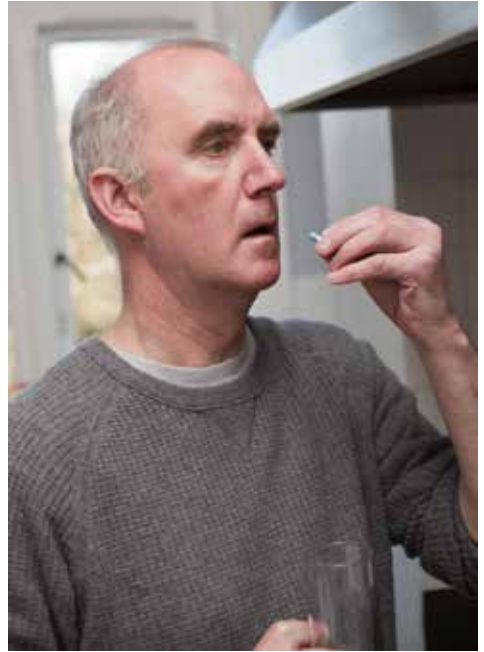
Examples include selegiline (Eldepryl, Zelapar or unbranded) and rasagiline (Azilect). This drug is a stimulant, and should be taken in the morning so it doesn't disturb sleep.

## Drugs to avoid

Some drugs can bring on Parkinson's-like symptoms and should be avoided, unless they're recommended by a specialist.

These are some (but not all) of the drugs to avoid.

- Chlorpromazine (Largactil)
- Fluphenazine (Modecate)



- Perphenazine (Fentazin/Triptafen)
- Trifluoperazine (Stelazine)
- Flupenthixol (Fluanxol/Depixol)
- Haloperidol (Serenace/Haldol)
- Metoclopramide (Maxolon)
- Prochlorperazine (Stemetil)

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

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

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

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

## **Surgery**

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

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

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



## When levodopa wears off

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

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

Sometimes the effects of wearing off happen quickly – this is called on/off. Being 'on' describes when a person's symptoms are controlled and they are feeling at their most capable. Being 'off' is when Parkinson's symptoms return and are at their most debilitating. Some people have described this as like a light switch being turned on and off, or going up and down like a yo-yo.

As well as having an effect on a person's motor symptoms, people may also experience non-motor symptoms including sleepiness or low mood as their medication wears off.

'On/off' is different from 'freezing'. There are different ways of managing freezing and 'on/off' swings, so they must be seen as separate problems. During 'off' periods a person will hardly be able to move at all, so walking, going up stairs or reaching for a cup will be impossible. But when a person freezes, it only affects certain movements. So they may not be able to walk, but they are still able to reach for a cup.

### Care plan actions

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



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

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It's really important to make sure that people with Parkinson's take their drugs at the right 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. These times will change from person to person and may not fit in easily with drug rounds.

Parkinson's UK runs a campaign called Get It On Time to highlight the importance of people with Parkinson's getting their medication on time, every time. For more information visit [parkinsons.org.uk/getitontime](https://parkinsons.org.uk/getitontime)

### Care plan actions

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



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

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

### **Dyskinesia**

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

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

To reduce these involuntary movements, one option is to reduce the amount of drugs a person is taking. Some people may choose to live with the dyskinesia as 'off' periods can be difficult and sometimes painful.

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 actions

- If someone is experiencing increasing periods of dyskinesia, you should report it to your manager. They may also need a change in their drug treatment.
- Maintain a food and fluid diary to monitor the person's intake.
- Monitor their weight.
- Talk to your manager if you have concerns about a person's

excessive weight loss or poor appetite. A dietitian may be able to advise.

- Be aware that some people may prefer to have involuntary movements, rather than have any changes made to their medication regimen. It is important to understand what a person's normal range is, so talk to your client or a family member about their movement difficulties and how they want to manage their symptoms.

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

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

have. Impulsive and compulsive behaviour has a devastating effect on people with Parkinson's and those around them.

### Care plan actions

- Make sure that people with Parkinson's and their families know about this potential side effect of Parkinson's medication. Also make sure they understand that these side effects can be managed effectively. You may encourage them to read our information 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 client may experience hallucinations, where they see, hear, feel or taste things that aren't there.

They may also experience delusions, when they have thoughts or beliefs that aren't based on reality. These can include paranoia, jealousy or extravagance (the belief that a person has special powers that they do not).

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

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

## Care plan actions

- Don't rely on someone telling you they are experiencing hallucinations or delusions. They may not realise what they are, or they might not want to tell you. If they seem to be behaving or reacting in a strange way, gently ask them what the matter is.
- If you know or suspect that a person is experiencing these symptoms, report it to your manager.

- If hallucinations or delusions are very severe, questioning them or doubting their existence (by telling the person experiencing them that they aren't real) may not help. It could lead to conflict and further distress.

**Find out more:** see our information sheet *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. It is rare, but abrupt withdrawal of certain drugs can result in neuroleptic malignant syndrome.

This is a very serious condition that may cause death from complications of the respiratory, cardiovascular or renal system. Although it is not common it does emphasise how important it is that people with Parkinson's get their medication on time, every time.





## **Dopamine agonist withdrawal syndrome**

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

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

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

## **Dopamine dysregulation syndrome**

This is when people have the compulsion to take more medication than they need to control their Parkinson's symptoms. This is a type of impulsive and compulsive behaviour (see page 45 for more information).

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

### Care plan actions

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



## Advanced Parkinson's and end of life

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

Someone with advanced Parkinson's may experience:

- drug treatments that are no longer effective
- a complicated drugs regimen
- more 'off' periods and dyskinesia
- increased mobility problems and falls
- problems with swallowing
- mental health symptoms such as depression, anxiety, hallucinations and delusions and dementia
- reduced independence
- less control of Parkinson's symptoms and symptoms being unpredictable

Many people with advanced Parkinson's will also experience pain, so at this stage, managing pain is very important.

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

**Find out more:** see our information sheet *Thinking about advanced Parkinson's*.

### Death and dying

Some of the more advanced symptoms can lead to increased disability and poor health. This can make someone more vulnerable to infection. People with Parkinson's most often die because of an infection or another condition.

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

## Care plan actions

- It is important that you find out whether your client has a care plan in place regarding their preferences for how the issues surrounding advanced Parkinson's (as listed above) should be managed. This should include legal documentation such as a Lasting Power of Attorney and an Advanced Decision (also known as an Advanced Directive or Advance Decision to Refuse Treatment and Living Will). This care plan should also include information about palliative care.
- If your client does not have a care plan in place, you should help them gather this information as soon as possible. This should be in discussion with the person themselves, their carer and family members (if relevant).

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 this useful.

**Find out more:** see our information sheet *Preparing for the end of life*.

## How can Parkinson's UK support home care workers?

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

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

Through the Excellence Network a range of online and facilitator-led learning programmes for health and social care professionals. Details of these, and courses run by independent training companies across the UK, can be found in the education and training directory.

To find out more, visit **[parkinsons.org.uk/excellencenetwork](https://parkinsons.org.uk/excellencenetwork)**

### **Access further information and support**

We provide information and support on all aspects of Parkinson's for everyone affected by the condition and those who care for them on our website and through our publications and other resources. Visit **[parkinsons.org.uk](https://parkinsons.org.uk)** or call **0808 800 3030** to find out more.

## Glossary

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### Bradykinesia

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

### Compulsive behaviour

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

### Cues

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

### Delusions

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

### Dopamine

A neurotransmitter or chemical messenger. This chemical helps to control the messages the brain sends to the muscles to help people perform sequences of movement. Dopamine also contributes to some thinking and memory processes.

### Dysphagia

Swallowing difficulties.

### Dyskinesia

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

### Dystonia

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

### Freezing

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

### Hallucinations

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

### Hypotension

Low blood pressure.

### Impulsive behaviour

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

### Lewy bodies

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

### Levodopa

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

### Multidisciplinary team

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

### Motor symptoms

Symptoms related to movement.

### Neuroleptic malignant syndrome

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

### Non-motor symptoms

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

### 'On/off'

A potential side effect of levodopa and some other Parkinson's medication. 'On' means the drugs are working and symptoms are well controlled and 'off' is when symptoms recur.

### Parkinsonism

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

### Person-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'.





## Parkinson's: a guide for home care workers (2016)

If you have comments or suggestions about this booklet, we'd love to hear from you. This will help us ensure that we are providing as good a service as possible. We'd be very grateful if you could complete this form and return it to:

**Editorial and Creative Services, Parkinson's UK,  
215 Vauxhall Bridge Road, London SW1V 1EJ.**

Or you can email us at [publications@parkinsons.org.uk](mailto:publications@parkinsons.org.uk). Thanks!

### Please tick...

- I have Parkinson's. When were you diagnosed? .....
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Where did you get this booklet from?

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- Parkinson's UK local group or event
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Has this resource given you information that might help you manage your client's condition better?

- NA  It hasn't helped  It has helped a little  It has helped a lot

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Continued over the page

What aspects did you find most helpful? .....

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

**Maria Curphey, Parkinson's Specialist Nurse, Stepping Hill Foundation Trust**

**Zoe Elkins, Head of Care, The Good Care Group**

**Richard Walker, Consultant Physician, North Tyneside General Hospital**

**Thanks also to our information review group and other people affected by Parkinson's who provided feedback.**

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.

We make every effort to make sure that our services provide up-to-date, unbiased and accurate information. We hope that this will add to any professional advice you receive and will 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.

References for this booklet can be found in the Microsoft Word version at **[parkinsons.org.uk/professionals/resources](https://parkinsons.org.uk/professionals/resources)**

### **How to order our resources**

**0845 121 2354**

**[resources@parkinsons.org.uk](mailto:resources@parkinsons.org.uk)**

Download them from our website at **[parkinsons.org.uk/professionals/resources](https://parkinsons.org.uk/professionals/resources)**

### **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 **020 7932 1303** or visit our website at **[parkinsons.org.uk/support](https://parkinsons.org.uk/support)**. Thank you.

**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.**

The tools, education and data it provides are crucial for better services and professional development.

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

Visit [parkinsons.org.uk/excellencenetwork](http://parkinsons.org.uk/excellencenetwork)

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