

# SUPPORTING SOMEONE WITH PARKINSON'S

A guide for family,  
friends and carers



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

## When you're supporting or caring for someone with Parkinson's, it can be hard coming to terms with the changes this can make to your life.

This booklet aims to answer some of the questions you may have about your role. This may be around getting help for yourself, any benefits you're entitled to or how changes might affect your relationship with the person you're supporting. It has practical tips and information that can help, along with ways to get emotional support and look after your own health.

Some people don't like to be called a carer as they don't feel it sums up their relationship with the person with Parkinson's and the support they're giving them. You may prefer to think of yourself as the partner, family member or friend of someone close who has been living with the condition for a while, or is newly diagnosed.

You may be supporting someone with Parkinson's alongside caring for other people close to you, such as young children, parents or grandparents. We have tried to include a wide range of information that is relevant to as many people as possible – whatever stage of life you're at.

You don't need to read all of the information in this booklet at once. You can skip to the sections that are most relevant to you, or read parts only when you feel ready to.

As Parkinson's affects people differently, you may find that some of the information in this booklet doesn't relate to the current situation or care needs of the person you support.

This booklet is an overview of some of the subject areas that may be relevant if you're supporting someone with Parkinson's. To get more detailed information, see the 'Find out more' sections throughout this booklet. These sections will point you in the right direction for extra information if or when you need it.

## **Disclaimer**

This booklet includes information on benefits and social care that is correct at the time of going to print, but is subject to change. Our most up-to-date information on benefits is on our website at **[parkinsons.org.uk/benefits](https://parkinsons.org.uk/benefits)**

Our helpline can also give advice on benefits.

Call **0808 800 0303** or email **[hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk)**

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# WHAT IS PARKINSON'S?

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## In this section:

- What causes it?
- What are the symptoms?
- Does everyone have these symptoms?

Parkinson's is a progressive neurological condition. This means that it causes problems in the brain and gets worse over time.

## What causes it?

People with Parkinson's don't have enough of a chemical called dopamine because some of the nerve cells in the brain that produce it have died.

We don't know yet exactly why people get Parkinson's, but researchers suspect it's a combination of genetics and environment that cause the dopamine-producing nerve cells to die.

## What are the symptoms?

The main symptoms of Parkinson's affect movement and balance. These include tremor, stiffness and slowness of movement. These are sometimes called 'motor symptoms'.

**People with Parkinson's may also experience other symptoms, including:**

- thinking and memory changes
- sleep problems
- pain
- bladder and bowel problems
- mental health problems, including anxiety and depression

These are often referred to as 'non-motor symptoms'.

You can find a fuller list of Parkinson's symptoms on our website.

## Does everyone have these symptoms?

Everyone's Parkinson's progresses differently. Not everyone with Parkinson's has the same combination of symptoms – they vary from person to person.

Also, how Parkinson's affects someone can change from day to day, and even hour to hour.

Symptoms that may be noticeable one day may not be a problem the next.

As time goes by and Parkinson's symptoms develop, the person with the condition may rely on you more for support. Because of this, it's important to know how you can get the support you need. (See the 'Looking after yourself' section for more information.)

**Find out more:** see our information on how Parkinson's progresses, and Parkinson's symptoms.

# LOOKING AFTER YOURSELF

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## In this section:

- Making sense of your feelings
- Taking care of your own mental health
- Physical activity and exercise
- Getting support from others
- Our helpline and Parkinson's advisers
- Elaine's story
- Recognising the signs of depression
- Taking care of your own health needs
- Other types of support from your GP
- Tips from others who support someone with Parkinson's

Thinking about yourself may be the last thing on your mind as you support someone close with their Parkinson's. But it's important to look after your own health and mental wellbeing too.

## Making sense of your feelings

It's normal to experience a mix of emotions as you adjust to their diagnosis – along with the change and uncertainty it brings.

At first, you might not even be sure how you're feeling. Your feelings will change over time, as you understand more about the diagnosis and think about how their Parkinson's may progress.

### **It's common to experience the following feelings at different times:**

- Feelings of isolation and uncertainty – you're not sure where to turn or how you're going to cope with the situation.
- Denial, where you find it hard to accept the situation, or feel it isn't fair.
- Fear about the future or worries about practical things, including your finances and care needs.
- Sadness or depression.
- Anger – you may question why this is happening to you, or feel it isn't fair.
- Confusion, or feelings of loss or grief, about the changes to your relationship – such as, any plans you had and what you expected life together to be like in the future.
- Guilt – you may feel you should be doing more for the person you support, or worrying that you're more concerned about the effect on your own life.
- Frustration – wondering whether you could be doing more for them.
- Overwhelmed – you may feel that you're having to cope with so much.

### **Coping with change**

It can be difficult if you and the person with Parkinson's are at different stages in coming to terms with the diagnosis. One of you may wish to face it and gather the information you need to get on. The other may not feel ready to – and that's normal.

**Dealing with change can take time. You may need support to:**

- understand and come to terms with Parkinson's
- live with the changes it might bring to your personal relationships, relationships with others and your working life
- manage the stress Parkinson's may create

## **Taking care of your own mental health**

Following a Parkinson's diagnosis, you're likely to feel an impact on your own mood and emotional health. It can leave you feeling lost because you feel the needs of the person you're supporting should come first. These feelings may come up over time too.

So from the start, and as their Parkinson's progresses, try to take some time out of your day to look after your own mental wellbeing.

You may feel that putting them first is the right thing to do at the moment. But taking care of yourself and having a good quality of life means that you're better able to offer support when it's needed.

**Here are some ideas to help you start thinking about ways you can take care of your own mental health.**

- Try to take a break when you need it. Keeping your social life as normal as possible and doing things you enjoy can help you recharge your batteries. Accepting support from others is important too.
- Talk to other people. Join online support groups, forums or check what is available to you locally. (See the 'Getting support from others' section.)

- If you're still working, speak to your employer. Find out what support they may offer you. This may be flexible working opportunities, specific leave arrangements (paid or unpaid), access to advice and information (a staff website or support network) or an employee assistance programme, if available where you work.
- Don't shut off from family and friends – they will hopefully be there to support you where they can.
- Help yourself to relax. Meditation, yoga or massage are just some ways to relax. But find what suits you best. Activities that absorb your concentration, such as gardening or reading, can be therapeutic.

## Physical activity and exercise

Being physically active can help improve your mental and physical wellbeing. It can give you some time away from your supporting responsibilities.

**Finding ways to stay active can benefit you in many ways, including:**

- improving your confidence and self-esteem, especially from the social benefit of being active with others
- helping your brain work more efficiently, so you can learn and remember more
- reducing feelings of anxiety and depression, and increasing happiness – especially if you can be active outdoors
- increasing your energy levels and giving you better sleep
- lowering your stress levels and blood pressure
- reducing your risk of developing other health problems, such as heart disease, stroke, diabetes, osteoarthritis, dementia and some cancers

Being active is also beneficial for the person you support. It can help to manage symptoms of Parkinson's. So finding types of physical activity you can do together can benefit you both and help them not to feel left out.

Depending on your level of fitness, there are lots of activities you can do, including walking, cycling, dancing and swimming.

You may want to spend some time doing what you enjoy with the person you support, or have some time on your own.

**Find out more:** see our information on physical activity and exercise.

## Getting support from others

Talking to others who understand what you're going through and getting support can help you understand Parkinson's and how it affects you too.

Connecting with others will also help as Parkinson's progresses. And sharing how you're feeling with others who are having similar experiences can help you recognise any challenges and pressures in your life.

### **You may also want to get support to help you:**

- live with the changes it might bring to your personal relationships, relationships with others and your working life
- make time for friends and hobbies
- keep up with work, training or volunteering
- try to take a break when you need it (See the 'Taking a break' section for more information)

We all deal with things in our own way and at our own pace. So if you don't feel ready yet to reach out for support or connect with others, you can come back to the information here when you feel able to.

It's easy to feel isolated, alone or cut off. Getting emotional support from others and staying connected is important and can make a difference to how you feel.

**Think about:**

- getting support from Parkinson's UK in your own right – our activities and services are open to everyone affected by Parkinson's
- joining a Parkinson's UK group in your local area or a Parkinson's cafe, to meet like-minded people and get peer support
- using apps like FaceTime, WhatsApp, Skype or Zoom, or your landline phone or mobile, to stay in touch with others for emotional support remotely if getting out is difficult
- getting professional help, such as counselling, if you need to talk to someone about how your feelings are affecting your mental health and wellbeing
- joining the Parkinson's UK Facebook Community Group, where you can talk to those in a similar situation
- joining other Facebook communities so you can connect with others
- the Parkinson's UK forum ([forum.parkinsons.org.uk](https://forum.parkinsons.org.uk)) – a space for family and friends of someone with a diagnosis to share tips, advice or to get emotional support

## Our helpline and Parkinson's advisers

Our helpline is a free confidential service providing support to anyone affected by Parkinson's. You can call our helpline on **0808 800 0303**.

Our trained advisers, including specialist Parkinson's nurses, can provide information and advice about all aspects of living with Parkinson's.

### **This includes:**

- medical issues, including symptoms and treatments
- employment and benefits
- health and social care
- emotional support
- local activities
- signposting to other sources of information

They can also put you in touch with a Parkinson's adviser if you need more local or in-depth support.

You can find out more about our support services in the 'More information and support' section at the end of this booklet.



Elaine supports her partner David who has Parkinson's. She describes how she looks after herself and gets support from others.

## ELAINE'S STORY

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“ Caring is constant, even the little things – I never sit down at a table in a cafe first for example, it’s me that gets the coffee. I am always considering David. Hybrid working has been great though – I love it as I get a social life at work. It’s difficult to take that time for yourself, but looking after yourself is so important.

As well as regular reflexology sessions, which I describe as ‘life-giving’, the beach close to where David and I live offers solace for both of us. We have a one-year-old Springer spaniel, Duke, who is very healing. Getting out with him for a walk on the beach is great for us.

I’m also a member of my local sea swimming club. The group has been my saviour. Everyone is very kind and will ask, ‘How are you?’ I don’t hide what has been happening from my friends. I’m a talker and if I can talk to people, I learn more and can help David more.

Sharing is vital and people are always understanding and supportive. ”

Elaine

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## Recognising the signs of depression

Supporting someone with Parkinson's can be challenging, and it's common for this to impact your own mental health. Seeing the impact of Parkinson's symptoms on someone you care about, and their increasing need for help and support, may make you feel helpless at times. It could even alter your mood. So it's important to look out for stress, anxiety and depression, and to get support if you need it.

Depression may come on slowly and the symptoms can be complex. So it may take time for you to recognise the early signs. This can mean that someone else notices things aren't quite right and suggests that there's something wrong.

Depression may interfere with your work, social and family life.

### Symptoms can include:

- continuous low mood or sadness
- feelings of hopelessness, helplessness and guilt
- feeling tearful
- low self-esteem
- lacking motivation
- having little interest in things you used to enjoy

If you think you might be depressed, speak to your GP who can refer you to further help if necessary. You may also wish to contact our helpline on **0808 800 0303**. Our trained advisers can provide emotional support and information.

For details of other organisations you can speak to, see the 'More information and support' section at the end of this booklet.

## Taking care of your own health needs

Thinking about your physical health may be lower down on your list of priorities. This can be the case whether a diagnosis is recent or you've both been living with Parkinson's for some time.

But making sure you stay on top of your own health needs is important.

### Your health

If you're busy supporting someone with Parkinson's, taking care of yourself and your own health needs will help you to continue to have a good quality of life. This will benefit both of you, and help you to support them well.

You can prioritise your own health needs by making sure you attend your regular check-ups and screenings.

Eating well and healthily can be a challenge when you're supporting someone with Parkinson's. But it's important for both of you to eat a healthy, balanced diet.

If you're providing physical support for someone, be aware of your own abilities and get support where you need it. If their symptoms are more complex, you may need help to lift or move them, for example.

Ask your GP, district nurse or an occupational therapist for advice on lifting, turning or moving aids to assist you. They can also offer advice on equipment and living aids to help the person you care for move around the house more easily without your help. (See the 'Help from health and social care professionals' section.)

The Carers UK website has free useful information on looking after yourself, including how to look after your back when you're lifting or helping someone to move around, for example. Go to [www.carersuk.org](http://www.carersuk.org) and search for 'Protecting your back' to find out more.

If you're concerned about your health, talk to your GP about any issues you might be having. This means that any problems are managed as quickly and effectively as possible.

### **Getting the most from health services**

Along with your Parkinson's specialist or Parkinson's nurse, your GP will be a crucial part of your support team.

Speak to your Parkinson's nurse, GP, and your local social services department in England and Wales about the services you need. This will be the social work service in Scotland or health and social care trust in Northern Ireland. You can also ask your Parkinson's adviser (see the section 'Our helpline and Parkinson's advisers' for details of how they can help you).

### **Register as a 'carer' with your GP surgery**

When you let your GP know that you're supporting someone with Parkinson's, you may be entitled to extra support. This includes things like flexible appointments.

You may not feel that the word 'carer' best describes the support you give. But registering as a 'carer' is the way to let your GP know. It may help you get the support and access to services you need to help you look after them, as well as your own wellbeing.

Some GP surgeries have a carers' register or database. If you're on this, you'll be given special consideration because you're supporting someone with Parkinson's.

### **Many GP surgeries use this register to:**

- give you access to appointments quickly if you need them and help to get the services you need at the right time. This is so that you don't have to tell everyone, every time, about your caring responsibilities
- give you up-to-date information about events for people like you who are supporting someone with a condition
- offer appointments for more appropriate times
- making sure any hospital or clinic outpatient appointments and admission letters state that you're a carer
- offer free flu vaccinations

## **Other types of support from your GP**

**Your GP can provide other forms of valuable support, advice and information, including:**

- arranging home visits for you, and the person you support
- arranging appointments for you both at the same time
- supplying repeat prescriptions to be delivered to your local pharmacy

When you talk to your GP, be honest about your needs, your feelings, and what you think would help.

## **Making the most of your own GP appointments:**

- As soon as you notice an issue, book an appointment. This helps make sure any problems are managed as effectively as possible.
- Prepare for your appointment. Keep a diary of how you (and the person you support) have been, your feelings and any issues that have come up.
- Make a list of things that you want to talk about. Keep the list short and put things in order of importance.
- Be honest about your needs, your feelings and what you think would help.
- If you're not feeling confident, take someone with you – a friend, for example. Having someone else with you can help you to remember what is said. Making notes can help too.

## **Getting enough sleep**

It's important to sleep well, although it can be difficult if the person you support has sleep problems or needs care overnight.

People with Parkinson's can be more likely to have insomnia because of the symptoms of the condition, such as tremor, stiffness, pain and restless legs syndrome. Disturbed sleep can also be a direct symptom of Parkinson's without these other symptoms. It can also be linked to Parkinson's medication.

Sleep and night-time problems are very common among carers of people with Parkinson's too. These sleep disturbances may lead to an increased risk of depression and stress.

It may be difficult sometimes, but it's important to have good sleeping habits. This will help improve your health, wellbeing and general quality of life.

Talk about this with your GP. You can also ask them for advice on helping the person you support with any sleep problems linked with their Parkinson's. Be sure to raise any night-time care issues at your carer's assessment. (For more information on having a carer's assessment, see the 'Carer's assessment' section.)

We have lots of information on the difficulties people with Parkinson's may have with their sleep, why they happen and what can help. This information applies to you as well as the person you support.

**Find out more:** see our information on sleep and night-time problems in Parkinson's.

## Tips from others who support someone with Parkinson's

Whatever support you give, even if you feel you're coping, it's important to get the help you need.

### Here are some tips from other carers of people with Parkinson's:

- Plan ahead where you can, to help reduce uncertainty.
- Acknowledge your feelings. Talk about what you're doing and how you're feeling to the person you support, family, friends or others in a similar situation.
- Tell friends, colleagues (and your children's school if relevant) how your role fits with the rest of your life and how they can help you.
- Make it clear what you are and are not willing to do – this prevents unrealistic expectations and resentment building up.
- Build small pleasures into your routine, like reading a book in the garden, having coffee with a friend or going for a walk.
- Encourage independence. It's important to let the person you're supporting be as independent as possible, even if tasks take much longer. Resist the temptation to take over. Try to avoid giving too much advice and practical help.
- Enjoy life as much as you can.
- Look after yourself and keep time aside for you. Make sure you don't neglect your own health and quality of life, and accept support from others. This way you can try to keep your social life as normal as possible and do things you enjoy.

- Get to know another carer – ideally someone who also supports a person with Parkinson’s so they understand the issues. You can share advice, hear what new treatments are available or what support or events are in the area. Most areas have some sort of carers’ group. There may also be a local Parkinson’s group for carers.
- Make changes to how you divide your roles and responsibilities – these can still be shared. This means that neither person carries all the responsibility.
- Get support as soon as you can so problems don’t reach crisis point. Ask your GP, Parkinson’s adviser or a social worker what help they can give you. This way you’re prepared, even if you don’t think you need help right now. (For more information on planning for an emergency, see the ‘Emergency support’ section.)
- Meet up with your friends. They will genuinely want to help by doing something, such as shopping, giving you lifts to appointments, or sitting and talking over coffee.
- Plan things together – try not to let Parkinson’s take over. Do things you enjoy together, even if this means doing them differently.

# DRUG TREATMENTS FOR PARKINSON'S

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## In this section:

- Supporting someone with their Parkinson's medication
- Side effects
- Taking other medications

## The Parkinson's medication the person you support is taking does one or more of the following:

- Increases the amount of dopamine in the brain. Dopamine allows messages to be sent to the parts of the brain that coordinate movement.
- Acts as a dopamine substitute. It will stimulate the parts of the brain where dopamine works.
- Blocks the action of other factors (enzymes) that break down dopamine.

When the person you support was diagnosed with Parkinson's, their specialist will have talked to them about their symptoms and how they affect them. Their specialist may have advised them to start taking Parkinson's medication. There'll be specific times to take it which the person you're supporting should stick to.

This is particularly important if the person you're supporting has to go into hospital. (See the 'Supporting someone in hospital' section.)

There are many types of drugs used to treat Parkinson's, and they work in different ways to make symptoms better. Which medication the person you support is taking depends on how much their symptoms affect them as well as other factors, such as their age and lifestyle. Most people are given a type of medication called levodopa to start with.

Their treatment will be kept under review as their Parkinson's symptoms develop over time. Planning a medication routine is something that should be a joint decision between a person with Parkinson's and their healthcare professional.

**When the person you're supporting is prescribed medication, make sure they ask about:**

- what they're taking
- when to take it
- any side effects

Sometimes Parkinson's medication can have significant side effects. The person themselves may not be aware of them. It can be helpful for you to look out for any medicine issues, such as new symptoms or changes to mood or behaviour.

Before leaving the clinic, they should get the contact details of their Parkinson's nurse or the number of the clinic. This is in case they have any problems with side effects.

## **Supporting someone with their Parkinson's medication**

Helping someone close to you with their Parkinson's medication every day can feel like a big responsibility. They may have a complicated medication regime, taking a number of different tablets each day at specific times. So helping them to manage their medication may feel quite daunting, especially as their Parkinson's progresses.

Ask for support from their GP, specialist, Parkinson's nurse or pharmacist to get a good understanding of the type and timing of medication. A chart or diary may be useful to help record this. Having this information written down will help the person you're supporting to discuss their medication with the relevant healthcare professional.

It also means you can plan the drug regime around what you're both doing. This way, you can both continue to enjoy a good quality of life.

It can help when you have to plan for special occasions, such as holidays, too.

**Find out more:** see our information on drug treatments for Parkinson's.

## Side effects

Like any drugs, the Parkinson's drugs the person you're supporting is taking can have side effects. The most common ones are always listed on the information leaflet that comes with the medication.

### **They can include:**

- tiredness and sleepiness
- feeling sick
- dizziness
- hallucinations and delusions
- impulsive and compulsive behaviours

## Hallucinations and delusions

Hallucinations and delusions can have a big impact on daily life. A hallucination is when you see, hear, feel, smell or even taste things that aren't there. Delusions are unusual thoughts, beliefs or worries that aren't based on reality.

They can happen with any Parkinson's medication but are more common with dopamine agonists. They are a type of drug to treat Parkinson's. Not everyone will experience this side effect and it's more common in the later stages of Parkinson's.

These side effects can feel worrying, so it's important to get clear information about hallucinations and delusions before the person with Parkinson's starts their medication.

If there is an issue, the person you support should talk to their healthcare professional about hallucinations and delusions. Their healthcare professional can then adjust the dose of their medication to help manage the symptoms.

**Find out more:** see our information on hallucinations and delusions.

## Impulsive and compulsive behaviours

Impulsive and compulsive behaviour is a possible side effect of some Parkinson's drugs. It's important to know about it when you're supporting someone close with Parkinson's, as it can be difficult to manage.

Impulsive and compulsive behaviour is when a person can't resist the temptation to carry out certain activities that could lead them to harm themselves or others. It's often one that gives instant reward or pleasure. This behaviour might be unusual for that person.

Behaviours can include gambling, becoming a shopaholic, binge eating or focusing on sexual feelings and thoughts.

**Here are some of the signs to look out for:**

- Have they recently put on weight? There may be a number of reasons for this, but you might want to look for the signs of binge eating.
- Are they being more private than usual about their finances?
- Have they started collecting or organising certain objects?
- Have you noticed any repetitive behaviour? This could be carrying out some tasks repeatedly.
- If the person with Parkinson's is your partner, have you noticed an increase in their sex drive? Or a change in their sexual behaviour, either towards you or anyone else?
- Are they going shopping more often than usual?
- Are they spending more time than usual on their computer, phone or tablet. This could be on shopping or gambling websites, or websites with sexual content, for example. This may be during the night or early hours of the morning.
- Are they taking more of their Parkinson's medication than they should?
- Have you noticed them becoming more aggressive or angry?
- Is there a family history of gambling or alcoholism, or any of the behaviour above?

If you suspect impulsive and compulsive behaviours, encourage the person you support to contact their healthcare professional. If you're really worried about their behaviour, you could try speaking to their health team yourself. But, it may be that their specialist or Parkinson's nurse isn't able to discuss the situation with you without their consent.

**Find out more:** see our information on drug treatments for Parkinson's, and impulsive and compulsive behaviours in Parkinson's.

## Taking other medications

Pharmacists can offer health advice and over-the-counter medicines for a range of minor illnesses, such as coughs, colds or stomach problems. If the person you support is ill and needs to take medication, your pharmacist can guide you on how to take these alongside their Parkinson's medication. They can also help you both understand the Parkinson's medication prescribed and explain how to take it correctly.

They may also be able to put medication into a dosette box or dosette-style blister pack. This means that each tablet has its own section linked to the correct time and day. This helps to remind you and the person you support of their dose and when to take it.

If they're taking any other long-term medication, it's also important for them to tell their specialist or Parkinson's nurse. This is because this can interact with Parkinson's medication.

# HELP FROM HEALTH AND SOCIAL CARE PROFESSIONALS

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## In this section:

- Professionals who make up a multidisciplinary team
- Training

There are many different professionals who may become involved in helping the person you support manage their Parkinson's. This group of professionals from different areas of health and social care is called a multidisciplinary team.

They can make a big difference to the quality of life of people with Parkinson's. Many also provide support directly to carers.

The more support the person with Parkinson's gets from these professionals, the more you will be able to support them in turn. It's important to know about the different people who can help the person you support.

As a carer, you're an important part of the multidisciplinary team. Sharing your insights and knowledge will help health and social care professionals do their best for the person you're supporting. It may help others with Parkinson's too.

Their GP, specialist or Parkinson's nurse can make referrals to other health and social care professionals in a multidisciplinary team. They can help you and the person you're supporting. In some areas, you may also be able to self-refer.

## Professionals who make up a multidisciplinary team

Health or social care professionals or organisations that can help include:

### GPs

A GP is the first healthcare professional the person you support would have seen about their Parkinson's symptoms. Their GP would have referred them to a Parkinson's specialist doctor for diagnosis.

A GP may also refer to a range of other healthcare professionals that make up a multidisciplinary team, such as psychologists, occupational therapists and physiotherapists.

### Parkinson's specialists

Parkinson's specialists are doctors – usually neurologists or geriatricians (specialists in the care of older people), with a particular interest in Parkinson's. It's likely the specialist will have diagnosed them with Parkinson's.

The person you're supporting should see their specialist once every six months to a year. They will check how their Parkinson's symptoms are affecting them and may suggest changes to their treatment.

When they see their specialist will depend on NHS waiting times locally. However, if you and the person you support feel that there's a change in their Parkinson's symptoms, request a review ahead of the next appointment.

As the partner, family member or friend of the person with Parkinson's, it can be helpful for you to attend appointments with them. They will need to give consent for you to attend.

## Parkinson's nurses

Parkinson's nurses have specialist experience, knowledge and skills in Parkinson's. They can support with symptoms, side effects and any other medical issues.

A large part of their role is helping to manage medication so people get the best results and fewer side effects.

After diagnosis, it may be that the person you support sees their Parkinson's nurse more regularly, who will monitor their treatment and care.

## Occupational therapists

Occupational therapists who have experience of working with people with Parkinson's can help the person you support stay as independent as possible. They can also help them to do everyday tasks and activities.

They assess how able they are to carry out day-to-day activities. They can suggest ways of making both home and workplace (if relevant) safer or more manageable.

They may recommend equipment for the home, such as grab rails. Or discuss bigger changes such as a stair lift or a wet room.

You can usually contact an occupational therapist through your GP, your social services department, social work service (Scotland) or health and social care trust (Northern Ireland).

An occupational therapist may be able to offer advice on making everyday tasks easier and leisure activities more accessible as needs change.

**Find out more:** see our information on occupational therapy and Parkinson's.

## Physiotherapists

Physiotherapists (sometimes called physios) with experience of Parkinson's can help people with the condition keep moving and functioning as much as possible.

They can help you and the person you support maintain general levels of fitness and mobility. They can also help people with Parkinson's maintain good posture and balance. Physiotherapists can suggest ways to get the most out of physical activity and exercise. (See the section on physical activity and exercise.)

They can also advise you as someone supporting a person with Parkinson's on safe ways to help you care for them if they have problems moving. Physiotherapists can suggest ways to prevent falls too.

Referral to a physiotherapist may be made by their GP, specialist or Parkinson's nurse.

**Find out more:** see our information on physiotherapy and Parkinson's.

## Speech and language therapists

Speech and language therapists specialise in all aspects of communication. This includes speech, facial expression, problems with eating or swallowing, body language, and using technology.

They can help people to improve speech quality and minimise problems such as low volume or lack of clarity.

A speech and language therapist can also work with you, to help improve how you communicate with the person with Parkinson's.

They can also advise on the best food and drink options for people who are having issues with swallowing. Speak to a GP, specialist or Parkinson's nurse about what is available where you live.

**Find out more:** see our information on speech and language therapy and Parkinson's.

## Dietitians

Dietitians can help with diet issues, such as weight changes or digestive problems, like constipation. A GP can help with access to a dietitian.

**Find out more:** see our information on diet and Parkinson's.

## Pharmacists

Pharmacists can help you and the person you're supporting understand the medication prescribed and explain how to take it.

If they take medication for other illnesses or conditions, their pharmacist can guide them on how to take these alongside their Parkinson's medication.

## Counsellors and therapists

Counsellors and therapists can help you and the person you're supporting manage your mental health. This may include any feelings of anxiety, low mood or depression.

## Social workers

Social workers are experts in helping individuals and families when they have issues that make taking part in their community more difficult.

They may be a central point of contact between you and your local council or health and social care trust (in Northern Ireland) services, such as social care support. They may also have links with your Parkinson's adviser.

## Training

As Parkinson's progresses, you may get more involved in practical care. This may be helping with medication or physical tasks. Training can help you to take care of your own health (especially your back). It can also give you confidence to do these tasks and improve the quality of life for the person you support.

You can find details of training programmes for carers by contacting your local carers centre or carers organisation. See the 'More information and support' section for details of carer organisations.

# CARERS' NEEDS AND RIGHTS

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## **In this section:**

- How can I get support?
- Carer's assessment
- Personal budgets and direct payments
- Jane's story

Some people don't like to be called a carer. This is because they don't feel it sums up their relationship with the person with Parkinson's and the support they're giving them.

You might not think of yourself as a 'carer', either, when you're supporting someone close with their Parkinson's – as their partner, family member or friend. But recognising your role as a carer may mean you can claim benefits, get support and access services that can help you care for yourself and the person you support.

For example, you can get help to take a break from caring (see more in the 'Taking a break' section). This is important for you and the person you're supporting. It can take many forms – from a few hours a week doing something you enjoy to a respite break where you go away for a few days.

## **Other services you may be able to get include:**

- support – such as local carers' groups or projects
- advice and information – for example on benefits

- equipment and aids – to help make tasks easier when giving support training. For example, in lifting and handling (see the section on ‘Training’)
- counselling

## How can I get support?

Your local council will arrange and provide support services. This is usually through its social services department, or your local health and social care trust in Northern Ireland.

The services are not just for older people in need or those with disabilities. They’re also for carers.

The person you support can get an assessment to find out what services they need. And if you regularly support someone, you also have a right to an assessment to see what help you might need, too. This is known as a carer’s assessment. It doesn’t cost anything to be assessed.

## Carer’s assessment

A carer’s assessment can help you to get the support or services you need in your caring role. In Scotland, they’re called an adult carer support plan. In Wales, they’re called a carer’s needs assessment.

It will assess the impact that supporting someone with Parkinson’s may have on your own life. It will also take into account any physical, emotional or psychological needs you might have.

### Who can have an assessment?

You can have a carer’s assessment to help you with supporting the person with Parkinson’s. This is regardless of how much money you have or the type or amount of support you give.

It's not charged for and you don't have to live with the person you support.

The assessment will look at your needs separately from the needs of the person you support with Parkinson's.

You can have an assessment even if they don't have a needs assessment. But you can choose to have an assessment that looks at the needs of you both. This combined assessment can be done at the same time. You and the person you support will need to agree to this.

You will usually be offered an assessment by the local council social services department, social work service (Scotland) or local health and social care trust (Northern Ireland).

Alternatively, you can contact them if they haven't offered you one already.

(You will normally find social services in England listed as 'adult social care' services.)

### **Why do I need a carer's assessment?**

An assessment is important because it's an opportunity to show the impact the support you're giving may have on you. It also gives you a chance to talk about your own health and any effect it has on your supporting role.

The assessment will help to look at how much support you give and what support you might need to continue in your caring role – if that is what you want to do. The assessment will also look at what help you can get. It takes into account any pressures on you created by the support you give.

It will help the relevant authority to provide the right services to support you.

You can also look at how to balance other aspects of your life, such as work, family and hobbies. A carer's assessment has to consider whether you want to work, as well as your education, training and leisure activities.

### **Preparing for a carer's assessment**

Preparing ahead can help you get the most out of the assessment. It will give you the best chance of getting the services and support you need.

Your carer's assessment will take at least an hour.

Assessments may take place face to face, in person, or by phone or online. They should take place at a time that suits you.

For a face-to-face assessment, this should take place at a location that is convenient for you. If you feel it would help, ask if you can include a friend or relative at your assessment..

### **Ahead of your assessment, you may want to consider:**

- What services you think would really help you. This may include information, equipment and aids, a meal delivery service (if available in the area where the person you support lives), or help with personal tasks, such as dressing or shopping, someone to talk to or counselling. It could also include time for yourself to see family or friends, or for hobbies you enjoy.

- Showing the assessor a diary of all the tasks you currently do to help the person you care for. This could be the support you're providing, emotionally or physically. If you can, include the daily time that your supporting role takes, any night-time problems and time taken to give medication. Think about the practical tasks you do, too, such as ordering prescriptions and arranging appointments.
- Talking about your feelings, and how supporting the person with their Parkinson's fits into and affects other parts of your life.
- Asking someone else to be with you during the assessment, such as a friend or Parkinson's local adviser.
- Telling the assessor how you feel about how you support the person with their Parkinson's. Think about any areas where support can help you.
- Telling the assessor about any particular cultural or religious needs you have. This may be time needed to go to pray, for example.
- Talking to other carers via our local groups or carers' organisations.

**Find out more:** see our information on keeping a diary for carers.

After your assessment, you should be told, in writing, its outcome and what services will be provided.

If you think your circumstances have changed, you can arrange to have another assessment.

## During your assessment

A social worker, healthcare professional, such as an occupational therapist, or a local voluntary organisation will carry out your carer's assessment. Be honest about the amount of support you give and any impact this has on you and your family.

A carer's assessment is your time to talk about your own needs and any concerns you have about the support you're giving. The focus of the assessment will be on you, not the person you're caring for.

You may be sent a checklist before the assessment meeting.

### **The assessor will talk about the following with you:**

- How you support the person who has Parkinson's with their needs, such as help with washing and dressing, medication, doing the laundry and shopping, and managing money and bills.
- Any feelings you may have about the support you give.
- How you feel about continuing to support the person with their Parkinson's.
- Your health.
- Any other caring responsibilities you may have, for example children, grandchildren or other members of your family.
- The things you enjoy doing to help you relax.
- What your plan is in any emergencies.
- Housing, especially if it's suitable and meets your needs. For example, if the person you support has difficulties moving around.

- Any work responsibilities. If you work, how many hours a week? Is your employer aware you're caring?
- How you manage and provide care.
- What would make things easier?

### **After your assessment**

Following a carer's assessment, your local council or health and social care trust (in Northern Ireland) will decide if your needs are 'eligible' for support. The support may be for you directly, for the person you support or both.

The range of services available varies across the UK and the level of help available will vary by area.

If your local council or health and social care trust thinks you're not eligible for support they should give you further information on getting help elsewhere.

### **If you're not happy with your assessment, or its outcome:**

- Speak to the authority responsible for care services where you are, and ask for another assessment if necessary.
- Ask your local carers' organisation, our helpline or speak to your local advocacy service for further advice. You can find the contact details for our helpline in the 'More information and support' section at the end of this booklet.
- Get details of the local council or health and social care trust complaints procedure so that you can make a formal complaint if need be.

## Types of extra support you could get

The sort of help you may be able to get will depend on your needs.

### It could include:

- help with housework or gardening – depending on where you live, this support may not be available in your part of the country.
- help with their personal care, bathing or washing and laundry
- training to help you with moving and handling the person you support
- home alterations or equipment
- counselling to help give you emotional support
- respite care, such as daycare, for the person you support
- benefits advice
- access to classes and activities to help improve your wellbeing

Depending on where you live in the UK, your carer's assessment and the way your local council or health and social care trust (in Northern Ireland) offers help and support for you and the person with Parkinson's will be slightly different.

Carers UK has factsheets explaining carer's assessments in England, Scotland, Wales and Northern Ireland. For contact details, see the 'More information and support' section at the end of this booklet.

## Paying for services

Following your carer's assessment, your local council or health and social care trust may carry out a financial assessment. This is to work out the ability of the person with Parkinson's to pay for any new or additional 'package' of care services they have agreed to supply.

The resources of other family members and carers aren't considered – it's just the resources of the person with care support needs. This applies to respite care as well as help in the home, daycare and other support.

Some people will be eligible for financial support from their council or health and social care trust, and some (known as 'self-funders') won't. The financial help they agree to supply can be given in different ways. (See the 'Personal budgets and direct payments' section.)

The council or health and social care trust can put in place any extra support or care agreed following a carer's assessment. If the person you're supporting is already getting help with the cost of their care, they may not need to pay any more for any extra support the council or trust offers following your carer's assessment. Or it may even be free, with the council or health and social care trust covering all the costs.

Even if you go on to arrange and pay for care yourselves, it's worth both you and the person you're supporting with their Parkinson's having a carer's assessment. This is so that you don't miss out on any other useful services, free equipment or local information.

## Personal budgets and direct payments

Following a needs assessment, your local council or health and social care trust (in Northern Ireland) will carry out financial assessments to work out how much they'll pay towards the care and support needs the person with Parkinson's is eligible for.

### Personal budgets

Your local council or health and social care trust will draw up a care plan for the person you support with Parkinson's that will include a personal budget. This is what it will cost overall for your local authority to give or arrange care and support.

The personal budget will also show how much the council will pay and how much the person with Parkinson's would pay towards the cost of the care and support they'll receive.

Following a carer's assessment, if your local council or health and social care trust thinks you're eligible, they may give you a carer's personal budget to cover costs for support you're assessed to need.

This could include support from a wellbeing service, practical help, such as a laundry service, funding for an exercise class, or whatever is needed to support you in your caring role.

Some of the services your local authority suggests may be voluntary ones.

Any costs for you to have time off from caring (respite care) will be charged to the personal budget of the person you support.

How much money their local council or health and social care trust gives them will depend on the results of the financial assessment.

Those entitled to help with care costs following the financial assessment may choose for the council to arrange services and have a reduced bill to reflect the council contribution to costs.

## **Direct payments**

The local authority can directly commission and arrange services on your behalf or they may offer you a direct payment. A direct payment allows you to buy services that may not be on their 'approved provider lists'. This could be using a day service they don't commission or employing a personal assistant, for example.

This can allow greater flexibility and a bigger choice of services. There may be some extra paperwork needed if you employ somebody or manage the account yourself. But most local authorities will have support set up to help you manage this and it may be helpful for you to discuss this with them.

Arrangements for personal budgets and direct payments are different for Scotland, Wales and Northern Ireland.

For more information, contact your local council social services department, social work service (Scotland) or health and social care trust (Northern Ireland), or our helpline on **0808 800 0303**.

Age UK has a useful information sheet about personal budgets and direct payments in social care. See the 'More information and support' section at the end of this booklet for details of how to contact them.

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Jane and Jim have been married for over 40 years. As Jim's Parkinson's has progressed, Jane has taken on more responsibility.

## JANE'S STORY

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“ At home, our responsibilities and roles have slowly begun to change as Jim’s Parkinson’s has progressed.

I know Jim doesn’t like the fact I’ve taken on more responsibility for things he might have done in the past. But if something needs to be done, it needs to be done, and I don’t mind that. Stress is bad for Parkinson’s, so anything I can do to reduce stressful situations does help. We are a team.

The word ‘carer’ has a number of connotations. ‘Carer’ is a warm term, but it can also imply that the other person is incapable – and Jim certainly isn’t!

But I do care, so it’s a difficult one. I don’t object to the word, but I don’t know if there is an alternative that really encapsulates all that it entails. ”

Jane

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# PLANNING AHEAD

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## In this section:

- Why plan for the future?
- Making a Will and power of attorney
- Emergency support
- Supporting someone in hospital
- Care following a hospital stay
- NHS continuing healthcare (CHC)

When you're supporting someone with Parkinson's, it's understandable that you might not be ready to start thinking about your plans for the future. Or feel that it's relevant for you at the moment.

Planning ahead may help both you and the person you're supporting feel more reassured. We have some tips and further information, below.

If you don't feel ready now, you can always come back to this information and take a look when it's the right time for you both.

## Why plan for the future?

For many of us, thinking about issues around the future can feel difficult, so we put it off. Arranging a Will or power of attorney is on most to-do lists, but can seem less of a priority depending on what stage of life you're at.

But when you're supporting someone close with Parkinson's, early discussions and planning – if you're both feeling up to it – can help you feel prepared emotionally and practically. It can also give you both peace of mind.

It can help to be aware of what arrangements and choices you may want to make in the future, so you're feeling one step ahead. It can also take away the burden for other people in your lives, so that they feel more confident and reassured about what lies ahead.

## **Getting organised**

Practically, it's helpful to keep important documents, like bank details and statements, in a safe place. Being organised and knowing where these documents are, can help make life easier and help you feel that you're keeping on top of things. It also helps if other members of your family know where to find any of these documents.

Think about things like finances, employment, housing and leisure, so you can be ready for important decisions – as and when you need to make them.

## **Making a Will and power of attorney**

Making a Will is important for everyone. It means that you can decide what happens to property and belongings. Not having one may cause problems for relatives in the future. Without a Will, your assets, including savings, investments or property, will be divided using legal rules rather than a person's wishes.

It's also a good idea to set up a power of attorney at the same time as making a Will.

A power of attorney is a written legal document giving someone else the authority to take actions and decisions on your behalf. There are different types of power of attorney depending on where you live in the UK.

## Some things to think about

- It's a good idea to talk about this with the person you support with Parkinson's. So you know how they would like to be cared for and who should look after their affairs.
- They may want to think about having someone to act for them when they can no longer make decisions.
- More than one person can be an attorney using a power of attorney.

## Further help and support

Thinking about the future can feel difficult and you may want to get further practical and emotional help. You can call our helpline on **0808 800 0303** to talk things through.

**Find out more:** see our information on putting your affairs in order, and making a Will and power of attorney.

## Emergency support

You may worry what will happen to the person you support, if you were suddenly unable to do so. This may be due to illness or a change to work commitments, for example.

So it's a good idea to think ahead by putting together an emergency plan and finding out what support is on offer if you need it in an emergency in the future.

- Ask your local council or health and social care trust (in Northern Ireland) if they can give you emergency respite care for carers.

- Set up an emergency plan so that support for the person with Parkinson's can continue in the same way. Carers UK has useful tips and ideas to help you plan ahead and think about what you need to include in your emergency plan (visit [carersuk.org](https://www.carersuk.org)).
- Keep key telephone numbers, such as your employer, in an easy-to-find place.
- Use a community care alarm service if you need to – ask your local social services department, social work service or health and social care trust.
- Use technology to help you, such as smartphones for video calls and apps.
- Make sure your carer's assessment takes into account what support you will need in an emergency (see the 'Carer's assessment' section for more information).
- Speak to your relatives or neighbours about any support they can give you in an emergency. Consider installing a key safe, and give the code to a relative or trusted neighbour. This way, they can access your home in an emergency.

## Supporting someone in hospital

If the person with Parkinson's you support goes into hospital, it's really important that hospital staff understand that they need their medication on time. Speak to hospital staff about this.

Getting Parkinson's medication on time will mean the symptoms of the person you support are well controlled. It will also mean that they're likely to have fewer complications from being in hospital.

Our *Get It On Time* resources can help you and the person with Parkinson's to remind staff about the importance of getting medication on time in hospital.

**Find out more:** see our information on going into hospital, and range of *Get It On Time* resources.

## Care following a hospital stay

When the person you support is ready to come out of hospital a discharge coordinator will work with them and you on their discharge plan. For some this may mean simply returning home with all the support they had previously.

But if their needs have increased or you're concerned you may need support then discuss this with the discharge co-ordinator. They should make arrangements with both of you about what can be put in place to support you both. They should involve you and the person with Parkinson's you support in any decisions they make.

If the person with Parkinson's needs some support to help them recover once they leave hospital, they may get 'intermediate care'. This short-term care, at home or in a care home, is free and can be for up to six weeks.

During this time further assessments, including financial assessments and NHS continuing healthcare (see the 'NHS continuing healthcare' section for more information), can be carried out.

Before discharge or soon after returning home, the discharge team or social services should work with you and the person you're supporting to agree on the next steps. This will take place before any intermediate care provided comes to an end.

### **This may include:**

- fresh needs and carer's assessments, home care support or other care needed
- information on further support and equipment
- what to do if things change and the person you support needs a referral back to their hospital healthcare team again
- what to do if something goes wrong
- financial assessments to see if the local authority should help with ongoing care costs
- an NHS continuing healthcare assessment where needs are complex

## **NHS continuing healthcare (CHC)**

NHS continuing healthcare (CHC) is a package of care that may be available for people who have a high level of long-term healthcare needs. It's arranged by the NHS and is free.

If the person you support has advanced Parkinson's, they will most likely have a high level of healthcare needs. So it may be worth checking if CHC is available for them. It means that people with Parkinson's and their family get the full package of care they need free of charge.

If somebody you support is leaving hospital, they need to speak to a hospital social worker about their move back into the community and have an assessment.

### **Getting CHC funding**

To be able to get this type of funding, the care the person with Parkinson's needs has to mostly be for 'complex healthcare needs' that local council social care services or the health and social care trust couldn't provide.

A Parkinson's diagnosis doesn't guarantee CHC funding. It's also worth keeping in mind that there's no application form. Instead, the healthcare or social care professionals involved in the care of the person you support, such as a social worker, occupational therapist, Parkinson's nurse or nursing home staff, carry out a CHC checklist.

Carers of people receiving CHC funding are still eligible for a carer's assessment.

For an in-depth guide to NHS continuing healthcare where the person you support lives, see the contact details for Age UK, Age Cymru, Age NI and Age Scotland in the 'More information and support' section at the end of this booklet.

# TAKING A BREAK

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## In this section:

- What types of respite care are there?
- How do I arrange respite care?
- How do I pay for respite care?
- Les's story

When you're supporting someone with Parkinson's, it can be easy to put your own needs to one side. But taking time to follow your own interests, take a break, meet friends or enjoy a hobby is important for your emotional and physical wellbeing. Short breaks from caring are sometimes known as respite.

## What types of respite care are there?

How you take a break will be personal to you. You may prefer to take a few hours or a day a week for time to yourself. You may also want to take a week or longer for a holiday.

The needs of the person you support will play a part in the type of break you have, too. You may want to go away with the person you support for a break. Or you may want to stay at home while they're cared for in a care home or nursing home. Alternatively, you may want to stay with friends or book your own break away.

There may be the chance to go on holiday together where care is given to the person with Parkinson's. To find out if there are any schemes available in your area, you can call our helpline on **0808 800 0303** or email **hello@parkinsons.org.uk**

## Here are a few other ways you can get respite care:

- Care for the person with Parkinson's in your home

Someone visits your home regularly to give you time to do your own thing. This can be at home or somewhere else. It can be a short period – just two to three hours a day, or overnight. And it can be occasional or frequent.

- Day care for the person with Parkinson's outside of the home

The person you support with Parkinson's spends some time at a day centre, giving you the chance to have a break. Some respite options, such as day centres, offer activities the person you support can take part in. It also offers them a change of scene, company and the chance to meet other people. If personal care needs mean that a day centre can't manage, day care in a care home may also be possible.

- Care away from home for the person with Parkinson's

The person you support could have short stays in residential care.

- Night-sitting

A paid carer stays overnight so that you can have a night's sleep.

## How do I arrange respite care?

### To get help with a break:

- In England and Wales, contact your local council's social services department.
- In Scotland, contact your local council, or health and social care partnership.
- In Northern Ireland, contact the social services department of your local health and social care trust.

Residential respite care may be provided by your local social services or social work department, or charities and organisations. You can get more information from your local authority or carer's organisation on local charities and organisations that can help you arrange a break or offer services to give you or the person you support a break.

### **Organising respite care yourself**

You can organise support so you can have a break with the help of a direct payment, or pay for this yourself. Contact your local social services, social work service or social services department for more information.

You can also arrange care directly with a care worker or by using an agency. You may choose to employ a care worker yourself, rather than go through an agency. If you do this, be aware that you're then taking on employer responsibilities.

You may decide to organise short-term respite care for the person you support through a care home. If so, you can find out what is available in your area by going to your local council website (health and social care trust in Northern Ireland). They can also give you details of organisations that can help you decide which residential care provider to go for.

You can also find out more about what grants might be available for your situation or where you live using the Turn2us grants search tool at **[www.turn2us.org.uk](http://www.turn2us.org.uk)**

Carers UK has detailed information on taking a break and respite care. You can find their contact details in the 'More information and support' section at the end of this booklet.

## How do I pay for respite care?

The person you care for could have a care and support plan set up from adult social care that allows for some respite. Alternatively, you could discuss this in a carer's assessment to see if this could be part of a carer's care and support plan.

You will be financially assessed to see how much you have to pay towards this.

You could also make arrangements independently of adult social care and pay for this privately.

Respite care can form part of the package of care that results from the needs assessment of the person with Parkinson's you support and your carer's assessment. Any financial help for respite care will depend on their financial assessment.

If respite care is added on to a package that is already funded, there could even be no further charge.

Respite care can be funded in different ways. This can be by you, your local council or health and social care trust (in Northern Ireland), or charities. But how respite care is paid for will vary depending on where you live in the UK.

### Benefits and respite care

If you take a break from caring, any benefits payments you receive may be affected. This will depend on things like how long your break is for, say. The rules affecting benefits and respite care are complex.

Call our helpline adviser for employment and benefits on **0808 800 0303** to find out if your benefits may be affected, or email **hello@parkinsons.org.uk**

See the 'More information and support' section at the end of this booklet for links to other helpful organisations.

## **Help with paying for a break**

There may also be local grants or schemes to help you with the cost of a break. Contact your local council or health and social care trust (in Northern Ireland), or local carer's centre, for information on any financial support that you may be able to get.



Les lives in rural Scotland with his wife, Jo, who was diagnosed with Parkinson's in 2016.

## LES'S STORY

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“ I am conscious that it's important to have some activities outside of our home and relationship, which gives us both a bit of space.

I enjoy restoring old motorbikes in my workshop, which gives us both time apart. I also have an allotment and a garden to look after. I do try to involve Jo with this, although that usually involves me doing a lot of digging while she happily supervises!

It's hard to judge exactly how much help to give someone you care for without taking away too much independence, but having some outside activities has given us a structure to work around.

Looking back, we feel lucky, not in having Parkinson's, but in being forced to re-evaluate our lives and find a kind of harmony that works for us.

We are both grateful that Jo's health meant us making a major change to our lifestyle sooner than we would have done. We have been able to enjoy having an extra five years of retirement together while Jo's health is manageable.

We are lucky we have a strong relationship. But keeping active, not taking things too seriously and learning to accept what is possible helps both of us to work together and support each other on this journey. //

Les

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# BENEFITS AND OTHER FINANCIAL SUPPORT

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## In this section:

- Benefits help and advice
- Benefits for carers
- What benefits can the person I support claim?
- Help paying Council Tax
- Grants, loans and other support
- Useful contacts for financial help and support

If you're supporting someone with Parkinson's, you might be worried about how you'll manage financially. Whether you're of pension age or still working, you may want help with day-to-day needs – for you both. This can lead to extra costs.

There's some financial support available if you're supporting someone with Parkinson's. This includes benefits, allowances or grants.

So it's important to find out what benefits and other financial assistance you're both entitled to. This can be for you as a carer, and to meet the care needs of the person with Parkinson's you support.

## Benefits help and advice

The welfare benefits system can be complex. Finding out what benefits or financial help you're both entitled to can be confusing.

As everyone's financial situation is different, it's important to get advice about what benefits you and the person you support can claim. We have more detailed information on our website, including information on specific benefits.

You can also use the online benefits calculator at **[www.turn2us.org.uk/get-support](http://www.turn2us.org.uk/get-support)** to check what you can claim. Carers UK and Age UK have information on benefits for carers – see contact details in the 'More information and support' section at the end of this booklet.

If you're claiming benefits as a carer, be sure to check all the options for both you and the person you look after.

### **Some things to think about include:**

- As a carer, you may be able to get means-tested benefits, or increases in means-tested benefits, depending on your situation. These include Universal Credit, Pension Credit and Housing Benefit.
- Carers and people with disabilities may be able to pay less Council Tax - see the 'Help paying Council Tax' section.
- In some cases Carer's Allowance can reduce the benefit the person you look after gets. So it's a good idea to check before claiming it.
- Even if Carer's Allowance isn't paid to you, claiming it can sometimes help you get other benefits, or increases of other benefits.
- There are different benefits for carers in Scotland.

If you would like more information about benefits you both may be able to get, or help with benefit claims or challenging any decisions about benefits, call our free confidential helpline on **0808 800 0303**. The helpline can put you in contact with a benefits and employment adviser.

**Find out more:** see our range of booklets on the different benefits you and the person you support with Parkinson's may be entitled to.

## Benefits for carers

### Carer's Allowance

Carer's Allowance is for people who regularly spend 35 hours a week or more caring for someone who gets a 'qualifying benefit'.

A qualifying benefit is Attendance Allowance, Personal Independence Payment (PIP) daily living component, Adult Disability Payment (ADP) daily living component (Scotland only) or Disability Living Allowance care component (at either the middle or highest rate). You don't have to be related to the person you're caring for or be living with them.

In Scotland, Carer's Allowance is being replaced by Carer Support Payment.

You can still qualify for Carer's Allowance even if you've never been employed or paid National Insurance contributions. Carer's Allowance isn't means-tested, which means it isn't affected by your savings. But there's an earnings limit and it's taxable.

If you're receiving the state pension or some other benefits, you will not receive a Carer's Allowance payment. But it may still be worth applying because it might entitle you to other, or additional, means-tested benefits, depending on your circumstances.

If you're thinking of applying for Carer's Allowance you should check with the person you look after because in some, but not all, cases it could reduce the benefit they get.

### **Carer's Allowance Supplement**

If you live in Scotland and receive Carer's Allowance or Carer Support Payment, you get a Carer's Allowance Supplement. This is paid every six months in June and December.

You will be paid Carer's Allowance Supplement automatically – you won't need to apply for it.

**Find out more:** see our information on Carer's Allowance.

### **Carer's Credit**

This protects the State Pension rights of people who aren't able to pay National Insurance contributions, aren't entitled to Carer's Allowance, and are looking after a disabled or ill person. Go to [www.gov.uk/carers-credit](http://www.gov.uk/carers-credit) for more information and how to claim.

## What benefits can the person I support claim?

There are a range of benefits that the person with Parkinson's may be able to claim, depending on their circumstances.

### **These include:**

Attendance Allowance – people who have reached State Pension age, have a disability or illness and need help with personal care or safety may be able to claim this benefit. It's based on what help the person you support needs, not the help they're actually getting.

It can be paid in addition to most other social security benefits. It can sometimes increase the amount of any means-tested benefits they get.

Attendance Allowance is paid to the person who needs care or supervision, not to a carer.

In Scotland, Attendance Allowance is being replaced by Pension Age Disability Payment.

**Find out more:** see our information on Attendance Allowance.

Personal Independence Payment (PIP) – in England, Wales and Northern Ireland or Adult Disability Payment (ADP) in Scotland. This is for people who start their claim when under pension age and who may need extra help with day-to-day activities or have trouble getting around due to their health or disability. New claims in Scotland are now being transferred to ADP.

PIP and ADP are not taxable or based on National Insurance contributions. They can be paid in addition to most other social security benefits. They can also sometimes help you get, or get an increased amount of, means-tested benefits.

Both PIP and ADP have two parts – a daily living component for help with everyday life, and a mobility component for help getting around.

If the person you support is already getting PIP when they reach pension age, then so long as their disability continues they should be able to keep getting it after pension age.

PIP and ADP have a mobility component and Attendance Allowance doesn't. So if there is a possibility that they qualify for a mobility component and are under pension age, they should start their claim before reaching pension age

Those of State Pension age or over who have care or supervision needs, should consider claiming Attendance Allowance instead.

**Find out more:** see our information on Personal Independence Payment (PIP) and Adult Disability Payment (ADP).

## Help paying Council Tax

You may be able to get help with paying Council Tax. This means that you, or the person you support, may be able to get help with your Council Tax through a Council Tax discount, the Disability Reduction scheme, or through a Council Tax Support scheme managed by your local authority.

## Grants, loans and other support

There are various grants, loans and schemes to help you and the person you're supporting. These can help with certain one-off or occasional expenses, or help if you're in financial need.

### They include:

- Support at work. Can your employer help or make adjustments so that being a carer is easier? Are there policies around this where you work?
- Grants and loans, such as Disabled Facilities Grants. This is from the local council if the person you're supporting is disabled and needs to make changes to their home. For example, widening doors, installing ramps, improving access to rooms and facilities, such as adding stairlifts or a downstairs bathroom.
- Hardship Payments Scheme. This is paid when certain benefits have been stopped or reduced, such as Universal Credit, Employment and Support Allowance or Jobseeker's Allowance, and you face hardship as a result. These apply when someone's benefit is 'sanctioned'. This is when you either lose your benefit or it's reduced. If this happens to you, call our free confidential helpline on **0808 800 0303**. The helpline can put you in contact with a benefits and employment adviser for help and whether you can challenge the decision.
- Help getting around, including the Blue Badge parking scheme, and various travel discounts and exemptions.
- Parkinson's UK Personal Grants. People with Parkinson's or other forms of parkinsonism, as well as you as the person supporting them, can apply for a Parkinson's UK Grant up to £1,500.

## How do I access one-off grants?

Charitable funds and trusts offer grants and can support daily costs for people in need. Some provide regular help, advice and practical support. Your local Citizens Advice (or local advice agency in Northern Ireland) may have information on these.

Occupational charities, for those who work or have worked in particular industries, and those for ex-service people can also be helpful.

## Useful contacts for financial help and support

- Carers UK has a lot of information about benefits you may be entitled to claim.
- GOV.UK has useful information about financial help, including Carer's Allowance, direct payments and pensions.
- Turn2us Benefits Calculator.
- nidirect has information about benefits for people who live in Northern Ireland.

(See the 'More information and support' section at the end of this booklet for contact details for these organisations.)

Call our helpline on **0808 800 0303** to find out more about what grants or loans you may be able to get. We also do benefit checks and help challenge benefit decisions that people don't agree with.

**Find out more:** see our information on grants, loans and other support.

# WORK

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## In this section:

- Supporting someone while working
- Your rights at work
- Should I stop doing paid work?
- What about my finances?

## Supporting someone while working

You may be working as well as supporting someone with Parkinson's.

### **Paid work can provide:**

- financial independence and money to help with caring
- a break from your supporting role
- new social networks and friendships
- a boost to your self-esteem
- a better pension

If you're in paid work, you may find that, as time goes on, combining your responsibilities can be challenging. You may also need to make changes to maintain your own general health and wellbeing.

Your employment needs should be taken into account in any assessment from your local council or health and social care trust in Northern Ireland (see the 'Carers' needs and rights' section for more information).

## **Are you protected against discrimination at work?**

If you support someone with a long-term condition like Parkinson's, you're protected from being discriminated against or harassed at work.

This means that as a carer, you shouldn't be treated less favourably than another employee who isn't a carer. You should still get the flexibility you're legally entitled to.

## **Should you tell your employer you're supporting someone?**

You don't have to tell your employer you're supporting someone with Parkinson's. But it may help if you need to take time off to look after the person you support.

You might make this decision depending on whether your employer has a policy to support carers, or they would be open to looking at ways to support you. Find out what's available before you approach your manager.

### **Possible support options:**

- Special leave arrangements to cover any time you need to care for the person with Parkinson's (paid or unpaid). This would be at your employer's discretion.
- An employee assistance programme, if your workplace has one. This will be designed to deal with any personal or work-related problems you have that may affect your ability to do your job.
- Access to advice, support and information, perhaps on a staff website or carers' network.

## Your rights at work

You may have a statutory (legal) right to ask your employer if you can work flexibly. This may mean changing your hours or working from home.

You will be able to request flexible working from your first day in a new job. Your employer must give serious consideration to your request, but they can refuse it if there's good business reasons for doing so. To find out more about the statutory right to ask for flexible working, visit [gov.uk/flexible-working](https://www.gov.uk/flexible-working)

Carers UK has some useful information on your rights at work when you're supporting someone, see the 'More information and support' section at the end of this booklet.

Remember there's nothing stopping you from talking to your employer informally. This may be something you may wish to do if you need a temporary change to your role.

The Carer's Leave Act 2023 gives employees the right to one week's unpaid leave each year to provide or arrange care for a dependent with a long-term care need. The Act gives rights to carers in England, Wales and Scotland.

### Where can I get support?

If you're a member of a trade union, ask them for help. A local, or regional, union representative may be able to talk to your employer on your behalf and attend meetings with you.

If you're not in a union, you have the right to invite a colleague to attend certain types of meeting with you.

## Can I get time off in an emergency?

Employees can take a 'reasonable' amount of time off work to deal with an emergency involving a dependant.

### A dependant can include a:

- husband, wife or partner
- child
- parent
- friend or family member who lives with you, but doesn't pay rent
- person who reasonably relies on you to care for them (for example, an elderly neighbour)

You should not be victimised or dismissed by your employer for using this right. Your employer can decide whether the leave is paid or unpaid.

### You might need to take leave because of:

- an emergency, such as a fall, that results in an ambulance being called
- unexpected problems with care arrangements
- the person you care for falling ill
- the need to make longer-term arrangements for a dependant

You should also find out how unpaid time off might affect your work rights, National Insurance record, pension and working tax credit eligibility.

## Should I stop doing paid work?

If you decide you have to leave work, think about other options available to you other than resigning. This could be a career break or retirement, for example.

Employers are keen to keep skilled, experienced and committed staff. So they may be open to changing your role to fit around your caring duties. You may consider part-time working or job sharing, working from home, or paid or unpaid leave that allows you to think about long-term options.

## What about my finances?

If you're thinking of leaving work to spend more time to support someone with Parkinson's, you may be concerned about your finances. But there are things you can do to ease any worries, such as making sure you're claiming all the benefits you're entitled to.

Call the employment and benefits adviser on our helpline on **0808 800 0303** to talk things through.

# MORE INFORMATION AND SUPPORT

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## Mind and Mind Cymru

For confidential help, contact Mind Infoline on **0300 123 3393** (9am-6pm, Monday-Friday, except bank holidays). You can also find information and support on the Mind website, including how to find therapy or counselling.

**info@mind.org.uk**  
**www.mind.org.uk**  
**www.mind.org.uk/about-us/mind-cymru**

## Carers UK

The charity offers a wide range of information and advice on caring. Carers UK can also help you connect with other carers.

You can contact the helpline on **0808 808 7777** or **advice@carersuk.org** (9am-6pm, Monday-Friday, excluding bank holidays).

**www.carersuk.org**

## Carers Wales

**www.carersuk.org/wales**

## Carers NI

**www.carersuk.org/ni**

## Carers Scotland

**www.carersuk.org/scotland**

## Carers Trust

A charity that works to improve support and services for people who are caring, unpaid, for a friend or member of the family. Carers Trust Network are independent local services for carers of all ages.

They support carers by giving carers access to advice, help and a break from caring.

Find the Carers Trust Network Partner in your area for local support on the website or on **0300 772 9600** (9am-5pm, Monday-Friday).

**info@carers.org**  
**www.carers.org**

**Carers Trust Scotland**  
**0300 772 7701**  
**scotland@carers.org**

**Carers Trust Wales**  
**0300 772 9702**  
**wales@carers.org**

At the time of going to press, Carers Trust work has paused direct services for unpaid carers in Northern Ireland.

### **GOV.UK**

For information on benefits and financial support that you may be able to claim, and flexible working.

**www.gov.uk**

### **nidirect**

For benefits and financial support, and flexible working if you live in Northern Ireland.

**www.nidirect.gov.uk**

### **Mygov.scot**

For information on benefits if you live in Scotland.

**www.mygov.scot**

### **Turn2us**

Offers a free Benefits Calculator for help finding out what benefits you may be able to claim.

It also has a free Grants Search to see if you can get a charitable grant.

**turn2us.org.uk**

### **Age UK**

Age UK Advice Line for older people is free and confidential, and can give you advice on money and benefits, as well as retirement and care. Call **0800 678 1602** (8am-7pm everyday).

**www.ageuk.org.uk**

## Age Cymru

To contact Age Cymru Advice Line, call **0300 303 4498** (9am-4pm, Monday-Friday). Calls are charged at a local rate.

**advice@agecymru.org.uk**  
**www.agecymru.org.uk**

## Age NI

Call freephone **0808 808 7575** (9am-5pm, Monday-Friday) for advice and information.

**advice@ageni.org**  
**www.ageuk.org.uk/northern-ireland**

## Age Scotland

Call the free, confidential phone service on **0800 124 4222** (9am-5pm, Monday-Friday). Or fill in the online enquiry form to email for advice.

**www.ageuk.org.uk/scotland**

## Citizens Advice

England  
**www.citizensadvice.org.uk**

Wales  
**www.citizensadvice.org.uk/wales**

Northern Ireland  
**www.citizensadvice.org.uk/about-us/northern-ireland**

Scotland  
**www.citizensadvice.org.uk/scotland**

## Parkinson's nurses

Parkinson's nurses have specialist experience and knowledge of Parkinson's. They can:

- support people coming to terms with their Parkinson's diagnosis
- help people to manage their medication, so they get the best results and fewer side effects

- make referrals to other professionals such as speech and language therapists and physiotherapists

Some nurses are based in the community, such as your GP surgery. Others are based in hospital settings and clinics.

Talk to your GP or specialist for more details on speaking to a Parkinson's nurse.

### **Parkinson's UK information and support**

You can read our most up-to-date information at **[parkinsons.org.uk](https://parkinsons.org.uk)**

You can order printed information by calling **0330 124 3250** or visiting **[parkinsons.org.uk/orderingresources](https://parkinsons.org.uk/orderingresources)**

If you'd like to speak to someone, our specialist adviser team can provide information about any aspect of living with Parkinson's.

They can talk to you about managing symptoms and medication, social care,

employment rights, benefits, how you're feeling, and much more.

Call our team on: **0808 800 0303** or email **[hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk)**

We'll provide expert information over phone or email or put you in touch with an adviser locally.

If you'd like to meet other people living with Parkinson's in your local area, you can find friendship and support through our network of volunteers and local groups. Go to **[parkinsons.org.uk/localgroups](https://parkinsons.org.uk/localgroups)** or call our helpline to find out more.

Our forum is also a very active space to share and chat with others who really understand, at a time that suits you. Visit **[parkinsons.org.uk/forum](https://parkinsons.org.uk/forum)**

### **Thank you**

Thank you very much to everyone who contributed to or reviewed this information.

### **Ian Adams**

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Parkinson's UK

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Employment Adviser at  
Parkinson's UK

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

### **Feedback**

If you have any comments  
or feedback about our  
information, please call  
**0800 138 6593**, email  
**feedback@parkinsons.  
org.uk**, or write to us at

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

If you'd like to find out  
more about how we put  
our information together,  
please contact us at  
**healthcontent@parkinsons.  
org.uk** or visit our website.

### **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 Care team  
on **0800 138 6593** or visit  
our website at **parkinsons.  
org.uk/donate**

Thank you.

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We are Parkinson's UK.  
Powered by people.  
Funded by you.  
Improving life for everyone  
affected by Parkinson's.  
Together we'll find a cure.

**PARKINSON'S<sup>UK</sup>**

Free confidential helpline **0808 800 0303**  
Monday to Friday 9am–6pm, Saturday 10am–2pm  
(interpreting available)  
NGT relay **18001 0808 800 0303**  
(for textphone users only)  
**hello@parkinsons.org.uk**  
**parkinsons.org.uk**

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



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