

# Getting the right healthcare

---

## About Parkinson's

Understanding health professionals,  
how to access healthcare and how  
we can support you.



# Introduction

---

**Everyone's experience of Parkinson's is different. Getting the right care from health professionals after diagnosis is important to make sure your symptoms are managed well, right from the start.**

**But Parkinson's is complex and can change over time. So it's also important to get support as your symptoms change and your Parkinson's progresses.**

**This booklet gives you the information to help you understand more about Parkinson's healthcare. It will:**

- introduce some of the health professionals you might see on your Parkinson's journey
- explain how to access them and what to do if you can't
- give you some tips on how to manage your condition yourself
- point you to other resources or support.

## Health professionals

Health professionals who can help manage your condition include Parkinson's nurses, specialist doctors (for example neurologists or geriatricians), physiotherapists, occupational therapists, speech and language therapists, mental health professionals and dietitians.

Each one will have a different role to play in supporting you. Some may have specialist knowledge in Parkinson's. For example, a neurophysiotherapist can tailor care more than a general physiotherapist.

Who you may need to see depends on your symptoms, how they affect you and how they progress. We talk more about how to get an appointment with these professionals on page 9.

### General practitioner (GP)

Your GP should refer you to a Parkinson's specialist doctor for diagnosis. A GP can also refer you to a range of other health professionals, such as mental health professionals and physiotherapists.

Your GP may know you well, which can be helpful. But the average GP will only have a few patients with Parkinson's. It's unlikely they will know as much about the condition as specialists do.

Your GP will continue to be important outside of your Parkinson's care. They can help with other ways to stay well, including offering a flu vaccine. They will also be able to give you support with your general health.

### **Parkinson's specialist doctor**

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

You will be invited to see your specialist around once every six months to a year, although this can vary. They will check how your Parkinson's symptoms are affecting you and may suggest changes to your treatment.

### **Parkinson's nurse**

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

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

Your specialist doctor would usually refer you to them once you get your diagnosis. If they haven't, you can follow up and ask whether you will be referred to a Parkinson's nurse. If you are told there is no Parkinson's nurse in your area, please contact our helpline to find out your options.

### **Pharmacist**

Pharmacists can help you understand the medication you are prescribed, the potential side effects and explain how to take it. There are two different types of pharmacists, hospital and community.

A hospital pharmacist is a specialist pharmacist based in a hospital who monitors side effects

from medication. They can work with other health professionals to suggest changes to your medication.

A community pharmacist can help you if you have other illnesses or conditions you need medication for. They can guide you on how to take these alongside your Parkinson's medication.

### **Speech and language therapist**

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

They will be able to give you techniques or tips to help prevent or reduce problems.

They can give you useful information about problems that may occur in future, how to spot them and what can be done about them.

### **Occupational therapist**

Occupational therapists can help you stay as independent and as safe as possible.

They assess how able you are to carry out day-to-day activities and suggest ways of making your home and workplace safer or more manageable. They may recommend equipment for your home, such as grab rails. Or discuss bigger changes such as a stair lift or a wet room.

They may be able to help you find strategies to deal with fatigue, communication and anxiety. And to help plan and pace yourself throughout the day.



## Physiotherapist

Physiotherapists (sometimes called physios) can help you keep moving and functioning as much as possible through movement and exercise, manual therapy, education and advice. They can also help you maintain good posture and balance.

Being active with Parkinson's is important. It can help manage your symptoms and lift your mood. A physiotherapist can suggest ways you can get the most out of physical activity and exercise.

Together you can work out what is important for you, and they can help you to continue to carry out daily tasks for as long as, and as safely, as possible.

## Dietitian

Dietitians can help if you have problems with your diet. They can help you maintain a healthy weight and advise on what foods you should be eating more or less of.

They can also help with common problems such as constipation, and if your symptoms are making it harder to eat or drink.

## Mental health professionals

There are different mental health professionals that can help with mental health issues you might experience including anxiety, apathy or depression. Talking therapies are the main approach to these issues and can take different forms.

Cognitive behavioural therapy (CBT) is an example of a talking therapy. It can help you manage your problems by changing the way you think and behave.

Counselling is another talking therapy. It involves a trained therapist listening to you and helping you deal with any emotional difficulties you're experiencing. A counsellor can work with you to understand any underlying issues that may be contributing to your depression or anxiety.

## Other health professionals

There are other health professionals who you may need to see depending on your symptoms and how they progress. These can include:

- urologists, who can help with bladder or bowel issues, which are more common in people with Parkinson's

- gastroenterologists, who can help with any gastrointestinal issues such as constipation, digestive issues, nausea or diarrhoea
- podiatrists, who can help with foot problems caused by Parkinson's.

### A multidisciplinary team

Sometimes, a team of health professionals will work together to plan the treatment that is best for you. This is called a multidisciplinary team, or MDT for short. You're at the centre of this team, and your treatment should be tailored to your specific needs.

Not everyone will have an MDT. This depends on how your symptoms affect you, and what services are available in your area.

#### Our information

Our website, booklets and magazines can help you better understand which health professionals can help you and how.

- Read our information online at **[parkinsons.org.uk/health-team](https://parkinsons.org.uk/health-team)**.
- Order free printed information at **[parkinsons.org.uk/shop](https://parkinsons.org.uk/shop)**.
- Or order by phone on **0330 124 3250**.

## Accessing a health professional

Typically your GP will refer you to a Parkinson's specialist if you have symptoms. If you are diagnosed, you should then have access to a Parkinson's nurse or an initial appointment with one.

Your GP, specialist, or Parkinson's nurse can refer you to see other health professionals and explain how they can help. In some areas, you might be able to self-refer and make an appointment yourself. If you're unsure, ask about this at your next appointment.

In some areas, Parkinson's services are accessed through patient-initiated follow-up (PIFU). This means that you need to contact the team and organise an appointment, rather than the healthcare team organising one automatically.

It's important to be aware that how you access a service or get an appointment can look different everywhere. This depends on things like your Parkinson's symptoms, and where you live. Your experience might be very different to someone else's.

Our helpline can give you more information on your specific situation.

### Private care

Everyone is entitled to NHS care. But we know that people with Parkinson's sometimes choose to pay for some services privately.

Using the NHS is usually best for people with Parkinson's as care can be joined up and your health professionals

can talk and refer to each other. Some treatments or medication may also only be available on the NHS.

You may choose to get a diagnosis privately. You can then choose to access and be referred to NHS services after a private diagnosis, but you will still have to go through the same NHS processes as someone who has not received a private diagnosis. Or you can opt to continue with private care if that option is possible for you.

Some people access private healthcare like physiotherapists or occupational therapists if they are struggling to access certain NHS services. This could be due to long waiting times for appointments or lack of services in their area.

### **Accessing private healthcare**

You can ask your GP, specialist or nurse about private care options, and they may be able to point you in the right direction.

You can also search online yourself. You must make sure any health professional is accredited and registered with the relevant body or organisation. For example, you should check that a physiotherapist is chartered, and registered with the Health and Care Professions Council (HCPC).

Our information on specific health professionals tells you how to find them in more detail.

You may still need a referral or referral letter, for example from your GP, to see a private health professional.

### **Paying for private care**

You will need to pay for any private care and it can be expensive. You may have to pay for any further medication or treatment. Some providers may offer payment plans to help you.

You may be able to get a diagnosis through private health insurance but usually it doesn't cover ongoing care for long term health conditions like Parkinson's. It's always best to check with your provider.

### **Problems with Parkinson's services and accessing healthcare**

You are entitled to the right care from health professionals. But getting access to this can be frustrating or difficult, and everyone's experiences will vary. Some people may access healthcare in a hospital, and some people may access it in community settings. Accessing care might not be straightforward, or happen in the way you would expect.

There may be long NHS waiting lists, or you might live somewhere where services aren't available. The health professionals you see may change due to staff turnover. Sometimes it can be tricky to know what help you should be getting in the first place.

### **What to do if you're unhappy with your care**

If you're unhappy with the level of care you are receiving, there are things you can do to try and improve the situation. This includes raising your concerns informally with the NHS or making a complaint.



We can talk you through the processes involved which can be different across the UK. Get in touch with our helpline for any help or advice about raising concerns with the NHS.

## Reach out to us

Our friendly expert advisers can talk to you about which health professionals can help, the type of care and support you should be getting and what to do if you're having problems in your area.

This includes our team of 90 local advisers, who can give you more in depth and personal support. You can do the same if you're a partner, friend or family member of someone with Parkinson's.

Call our helpline on **0808 800 0303** or email **hello@parkinsons.org.uk**.

This information is also available on page 25 of this booklet as a tear-out section. You can keep it with you or put it somewhere safe for when you need it.

## Managing your own condition

The health professionals we've covered play a key role in your Parkinson's. But you can be active in managing your own condition too.

There are many things you can do yourself, from joining local groups and connecting with others, to doing regular physical activity and maintaining a healthy, well-balanced diet.

We've listed a few things that you can do that may help with your Parkinson's. But this will be different for everyone.

There are lots of other things you can do to manage your symptoms and we can help you find what works best for you.

### Physical activity and exercise

Being active for 2.5 hours a week can help manage your Parkinson's symptoms.

Physical activity has a positive impact both physically and mentally. It can be as important as getting the right dose of medication.

The right physical activity is different for everyone. But being active is always most effective when you push yourself and you do something you enjoy. Whether that's playing tennis for an hour. Taking a long walk with the dog. Or practising everyday movements, like walking up the stairs.



### Staying social and keeping in touch with people

It's important to stay in touch and connected with other people, including your friends and family. It can give you a sense of belonging, while knowing there's other people you can turn to for emotional support.

Our local groups are a great way to meet other people with Parkinson's. Some host weekly informal meetings or coffee catch-ups, others host singing sessions and exercise classes.

Our online forum and Facebook community group are very active spaces. They're another great way to connect with other people who have similar experiences.

### Looking after yourself

**Maintain a healthy diet.** If you have Parkinson's, there is no specific diet that you should follow. But

it's recommended that you maintain a healthy and balanced diet. This will improve your health and may help to ease problems, such as constipation, low mood, reduced bone density and weight changes.

Certain foods can interfere with the absorption of some of your medication, so it's important to understand which foods do this and how to time them with your medication.

**Stay hydrated.** Drinking plenty of fluids can help remove waste products in urine, carry nutrients around and control body temperature. Being dehydrated with Parkinson's can make some symptoms worse, such as constipation, low blood pressure and swallowing problems.

**Getting enough sleep is important for everyone.** But sleep problems can be common in Parkinson's. Try to get as much quality sleep as possible.

Things that may help can include choosing the right bed and mattress, avoiding screens before bed and keeping your bedroom at a cool temperature.

Get more information. We have lots of tips and information on all of these topics, and other ways you can manage your condition yourself.

- Read our information about everyday life online at [parkinsons.org.uk/everyday-life](https://parkinsons.org.uk/everyday-life).
- Order free printed information at [parkinsons.org.uk/shop](https://parkinsons.org.uk/shop).
- Or order by phone on **0330 124 3250**.



## How to feel prepared

When you have an appointment with a health professional, you might find it useful to have some notes, prompts or questions to take with you.

You could make a list of questions you want to cover or what you want to get out of it. You can take any documents, a diary or a notebook with you. We have a handy section in the back of this booklet to do this.

Be as honest as possible. Give them as much detail as you can about how you're feeling and what your symptoms are. It can be helpful to have a list of things you want to talk about, and note down the top three things.

You can take someone with you to an appointment for support, such as a close friend or family member.

### Questions to ask your health professional

Some more specific questions you may want to ask include:

- I'm concerned about a particular symptom. What can help?
- What type of side effects might I get from my medication?
- I have another medical condition as well as Parkinson's. What should I do?
- Which other health professionals can help me?
- I'm feeling stressed and down about my diagnosis. What help can I get?

- How often will I see you?
- Can I have more time with you?
- When will I have my next appointment?
- How long is the waiting list for this service, and when can I expect to hear from them? (They may not know the answer, but might be able to provide you with the service contact details to enquire directly with them).

### Keeping track of your health professionals

Making a list of health professionals you're in contact with, or things you'd like to ask about at your next appointment, can be helpful.

Doing this and making a note of what they do and how to reach them can help you feel more prepared and organised throughout your Parkinson's journey.

We've provided a template for you where you can add their details but feel free to use whatever works best for you. There are some other notes pages for you to use too.

**Address book**

<b>NHS number:</b>		<b>Hospital number:</b>	
<b>Health professional, eg Parkinson's nurse</b>	<b>Name</b>	<b>Name</b>	<b>Contact information</b>

<b>Health professional, eg Parkinson's nurse</b>	<b>Name</b>	<b>Contact information</b>



## More information and support

### Parkinson's UK information and support

Whatever your journey with Parkinson's, you're not alone.

From the moment you or someone you care about is diagnosed, we have information and support for you.

**Speak to one of our friendly expert advisers, including specialist Parkinson's nurses, care advisers, and benefits and employment advisers.** We've got information and advice on all aspects of living with Parkinson's.

**Get help managing your diagnosis.** Our information packs, webinars, courses and support groups can help you and your loved ones understand your Parkinson's diagnosis and better manage your symptoms.

**Read our up to date, reliable health information.** Our website, booklets and magazines can help you better understand Parkinson's. They're full of tips and advice on managing your condition and supporting a loved one.

**Find ways to get active, stay active and live well with Parkinson's.** Whatever your fitness level, we'll help you find the right activities for you.

**Connect with other people with Parkinson's, families, friends and carers.** Across the UK, in your local area or online. We'll help you meet others who understand what you're going through, because they're going through it too.

### Find out more

- Call our helpline on **0808 800 0303** or email **hello@parkinsons.org.uk** to speak to an expert adviser.
- Visit **parkinsons.org.uk/information-and-support** to read our information or find support that's local to you.
- Call **0330 124 3250** or visit **parkinsons.org.uk/order-print-booklets** to order free printed information.

### Thank you

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

Mrs Miriam Parry  
Parkinson's Disease Nurse Consultant  
King's College Hospital

Fiona Lindop MBE  
Specialist physiotherapist in Parkinson's  
Derby Parkinson's Service

Professor Richard Walker  
Consultant Physician, Northumbria Healthcare NHS  
Foundation Trust and Honorary Professor of Ageing and  
International Health, Newcastle University

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

All of our information is checked by experts and other people with Parkinson's, so you know it's information you can trust.

## 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, 50 Broadway, London, SW1H 0BL.

If you'd like to find out more about how we put our information together, or be part of the team that reviews our health content, please contact us at **healthcontent@parkinsons.org.uk** or visit our website at **parkinsons.org.uk/health-content**.

## 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.

## Tear-out section

Cut this section out and stick it on your fridge or keep it with you.



### Our helpline

Speak to one of our friendly expert advisers, including specialist Parkinson's nurses, care advisers, and benefits and employment advisers. We've got information and advice on all aspects of living with Parkinson's. They can also put you in touch with one of our local advisers, who can meet up with you and help you.

- Call **0808 800 0303**
- Email **hello@parkinsons.org.uk**



This page have been left intentionally blank.



### **Our information**

Our website, booklets and magazines can help you better understand Parkinson's. They're full of tips and information on managing your condition or supporting a loved one.

- Read our information online at **[parkinsons.org.uk/information-and-support](https://parkinsons.org.uk/information-and-support)**.
- Order free printed information at **[parkinsons.org.uk/shop](https://parkinsons.org.uk/shop)**
- Or order by phone on **0330 124 3250**



**INFOB1057**

Getting the right healthcare

**We're Parkinson's UK,  
the charity that's  
here to support every  
Parkinson's journey.  
Every step of the way.**

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

Parkinson's UK, 50 Broadway, London SW1H 0DB



Patient Information Forum

Registered with



**Last updated: January 2025. Next review due 2028 | Order code: INFOB1057**

Parkinson's UK is the operating name of the Parkinson's Disease Society of the United Kingdom.  
A charity registered in England and Wales (258197) and in Scotland (SC037554). © Parkinson's UK  
11/24 (10493)