

PARKINSON'S AND YOU

A guide for
people who are
newly diagnosed



PARKINSON'S^{UK}
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

Getting a diagnosis of Parkinson's affects everyone differently. Some people feel shocked or confused – others feel angry or anxious. Some people feel relieved to have an explanation for their symptoms.

This booklet aims to answer the most common questions you may have if you've just been diagnosed with Parkinson's. You may also find it helpful if someone you know, like your partner, friend or family member, has been diagnosed.



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WHAT IS PARKINSON'S?

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

Because Parkinson's affects everyone differently, people will have different experiences of how their condition changes or progresses.

For many people, the condition can take years to progress to a point where it has a real impact on daily life.

In this section:

- What causes it?
- What are the symptoms?
- Does everyone have these symptoms?
- How old are people when they get Parkinson's?
- Is there a cure?

What causes it?

People with Parkinson's don't have enough of the chemical dopamine because some of the nerve cells in their brain have stopped working. Without dopamine people can find their movement is affected and it takes longer to do things.

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 your movement and balance. These include tremor, stiffness and slowness of movement. These are sometimes called 'motor symptoms'. Not everyone gets these symptoms.

Tremor

Parkinson's may cause your hands and body to shake, which can make everyday activities difficult.

Unlike other types of tremor, which affect people while they are moving, a Parkinson's tremor is more likely to be a resting tremor. This tends to affect people while they are still. It may also become more noticeable if you become anxious or excited.

Stiffness

Parkinson's may cause your muscles to become stiff. This can make it difficult to turn around, get out of chairs, turn over in bed or make fine-finger movements, like writing or fastening a button. Stiff muscles can also make your posture worse and cause problems with facial expressions.

Slowness of movement

Parkinson's may affect how easily you can move. You may find that you walk with short, shuffling steps, that it takes you longer to do things or that you have problems with coordination and balance.

Non-motor symptoms

You may also experience other symptoms such as:

- mild memory and thinking problems
- sleep problems
- pain
- constipation
- mental health problems, including anxiety and depression

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

Does everyone have these symptoms?

Not everyone with Parkinson's experiences 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 from hour to hour. Symptoms that may be noticeable one day may not be a problem the next.

How old are people when they get Parkinson's?

The risk of developing Parkinson's increases with age. Most people who get Parkinson's are aged 50 or over, but younger people can get it too.

We have information specifically for younger people on our website at **parkinsons.org.uk/youngerpeople**

Is there a cure?

While a lot of progress has been made in our understanding of the condition, there is currently no cure for Parkinson's.

Parkinson's UK is committed to funding the right research into the most promising treatments, bringing us closer to a cure. Turn to page 38 to find out how you can get involved with research.



HOW IS PARKINSON'S TREATED?

Although there's currently no cure, there are many drugs, treatments and therapies that can help manage Parkinson's symptoms.

Medication is usually the main treatment for Parkinson's. But you may also see other health and social care professionals from different teams, who can offer different types of help. Physical activity and exercise can also help manage your symptoms.

You can find out more information in the section 'What health professionals might I see?' on page 16.

In this section:

- Drug treatments
- Will I have side effects from the drug treatment?
- Alan's story
- What health professionals might I see?
- Questions to ask your specialist or nurse
- How does physical activity and exercise help?
- Should I change my diet?
- How does protein affect my diet?



Drug treatments

When you're diagnosed with Parkinson's, your health professional will talk to you about your symptoms and how they affect you.

If your symptoms are impacting your daily life, they may recommend you start medication. If you have very mild symptoms, you and your health professional may agree to wait until symptoms become more difficult.

For a lot of people who have just been diagnosed, Parkinson's drugs can be really helpful. There are many types of drugs used to treat Parkinson's, and they work in different ways to make your symptoms better. Most people are given a type of medication called levodopa to start with.

After a few weeks, you may be invited for a follow-up appointment to check how your medication is working. This is when your health professional will review or change the

dose or frequency, or add new drugs until your symptoms are as controlled as possible. It may take some time to get this right. Your treatment will usually need reviewing as your Parkinson's symptoms develop over time.

Planning a medication routine is something that should be a joint decision between you and your healthcare professional. If you are prescribed medication, make sure you ask about what you are taking, when to take it, and any side effects.

Will I have side effects from drug treatment?

Like any drugs, Parkinson's drugs 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

Impulsive and compulsive behaviour is a possible side effect of some Parkinson's drugs. It's important to know about it as it can be difficult to manage.

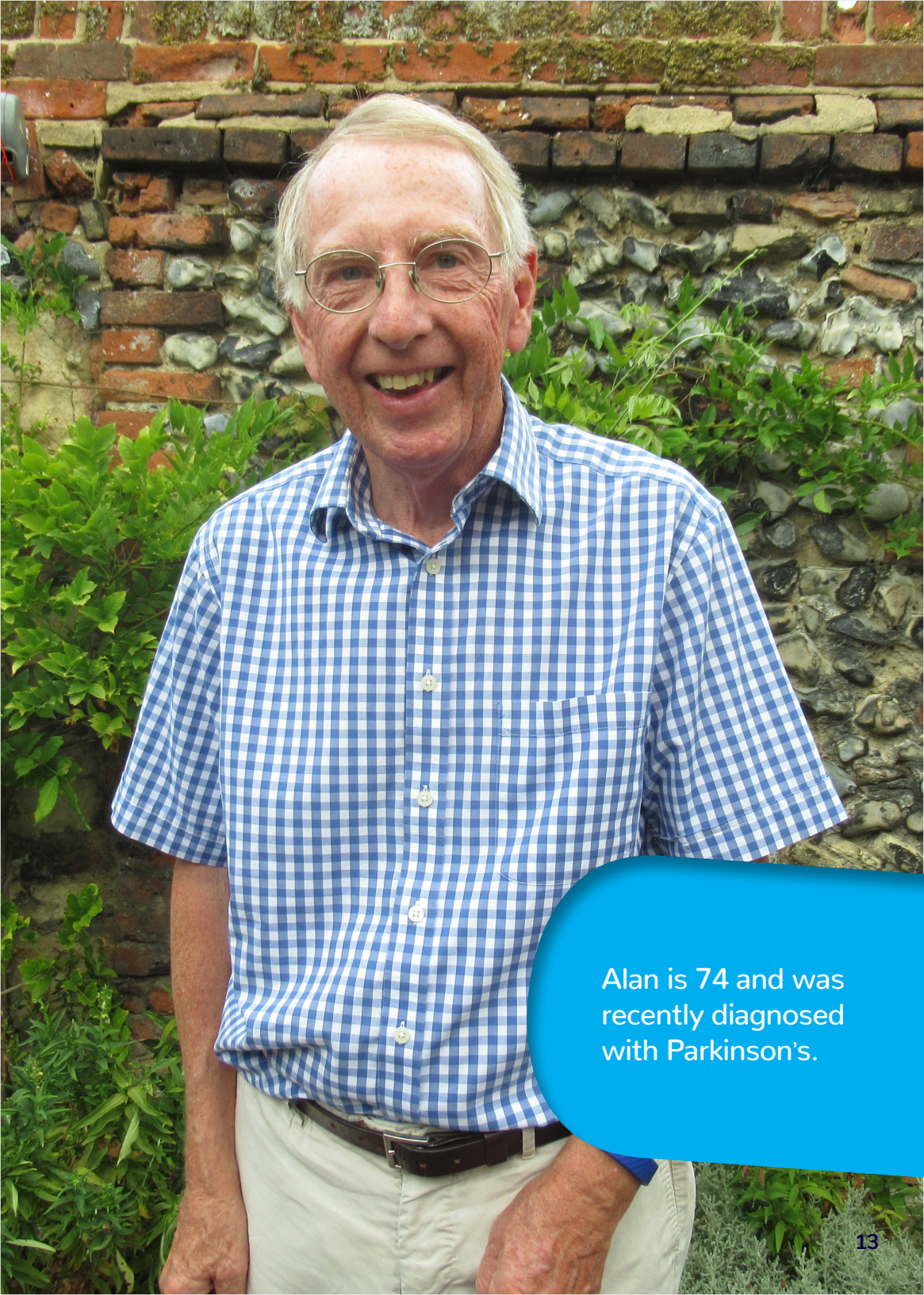
Impulsive and compulsive behaviour is when a person can't resist the temptation to carry out certain activities that could lead them to harm themselves or others. This behaviour might be unusual for that person. Behaviours can include gambling, becoming a shopaholic, binge eating or focusing on sexual feelings and thoughts.

Although only a small number of people experience these side effects, they can have a big impact on the person affected and those around them.

If you think you or the person you care for are experiencing these side effects, tell your healthcare professional as soon as possible. Asking your specialist or Parkinson's nurse to make changes to your medication regime or adjusting the doses that you take is the easiest way to control them.

If you are not able to get through to your healthcare professional, you can call our Parkinson's UK helpline on **0808 800 0303**. We have information on what behaviour to look out for and further information on what to do next.

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



Alan is 74 and was recently diagnosed with Parkinson's.

ALAN'S STORY

“When I was diagnosed I was told my symptoms were mild and that medication would help. It was a relief to hear that, but I also knew that it meant sticking to a medication routine every day.

I have to take my tablets at least 30 minutes before a meal, three times a day. So every morning I knew I had to do three things when I woke up – feed our cat, make a cup of tea and take a tablet. Then I would leave the other two pills for that day in a bowl on the side in the kitchen. I knew that once that bowl was empty, I'd taken all my medication for that day.

Last year, my routine was disrupted when we were having some work done to our house. I forgot to take a tablet, and my hand started shaking.

I decided to buy a digital watch and use it to set alarms to remind me to take my medication.

Since I've been doing that, I've never forgotten a dose. It can be difficult to get into a routine, but I've found this watch really helpful.

They say that with Parkinson's everyone is different and I am so pleased that the small amount of medication I take each day really does make a difference.

I also go to a weekly exercise class for people with Parkinson's and across the week I try to fit in a 30-minute daily walk, or an hour's cycle ride. I love playing croquet, and I've even won the competition at my local club. In the past, I have exercised, but never with any routine in mind. Now, I am active every day.

It may seem like a strange thing to say, but – for me – being diagnosed with Parkinson's is good news. Giving it a name meant everything. I could get treatment and get my symptoms under control.

Alan

What health professionals might I see?

Many different health professionals may be involved in helping you manage your Parkinson's. Some will have a bigger role than others, depending on your symptoms.

This group of health professionals that support you to live with Parkinson's is called a multidisciplinary team.

Parkinson's specialists are doctors. They 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. They will check how your Parkinson's symptoms are affecting you and may suggest changes to your treatment.

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 you might be having problems with. A large part of their role is helping to manage your medication, so you get the best results and fewer side effects. Your specialist would usually refer you to them once you get your diagnosis.

Pharmacists can help you understand the medication you are prescribed and explain how to take it. If you have other illnesses or conditions, you need medication for, your pharmacist can guide you on how to take these alongside your Parkinson's medication.

Physiotherapists (sometimes called physios) can help you keep moving and functioning as much as possible. They can help you with your fitness levels and to maintain good posture and balance. They can suggest ways you can get the most out of physical activity and exercise.

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.

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.

Dietitians can help if you have problems with your diet – for example, if you have problems with your weight or have digestive problems, such as constipation.

Counsellors and therapists can help you manage any feelings of anxiety, low mood or depression.



Questions to ask your specialist or nurse

If you've just been diagnosed with Parkinson's, you may find it helpful to think about questions to ask your specialist or Parkinson's nurse at your next appointment.

Some 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?

Many health professionals and services offer phone and video calls for your appointments. We have information online on how best to prepare for this type of appointment. Visit **parkinsons.org.uk/phoneandvideo** to read more.

How does physical activity and exercise help?

Being active is important for everyone. If you have Parkinson's, being active for 2.5 hours a week can help manage Parkinson's symptoms, and has a positive impact both physically and mentally.



Some physical activity is good, more is better

Just like Parkinson's, the right physical activity is different for everyone. But being active is always most effective when you push yourself. That could be:

- playing tennis for an hour
- taking a long walk with the dog, if you have one
- practising everyday movements, like walking up the stairs

Get active doing something you love

Whatever you do to get active, it's important to do it regularly. And if you enjoy the physical activity you're doing, you're more likely to keep doing it. Find something you love and that makes you feel good.

Make it social

Taking up a sport or joining a class is a good way to meet up with friends, or make new friends. Whatever it is that gets you moving, it's good for your health and mood.

Challenge your mind

Whether it's focusing on a fast-paced game of table tennis or memorising a full dance routine, physical activity that challenges your brain as well as your body can help your mental and physical health.

How do I get started?

If you're new to physical activity and exercise, ask your GP or specialist to make a referral to a physiotherapist, or an exercise professional with experience working with people with Parkinson's. They can give you advice and help plan the right exercise routine for you.

Many of our local groups across the UK offer exercise classes specifically for people with Parkinson's, at all stages of the condition. We also have lots of YouTube videos and advice on how to stay active at home on our website. Visit **parkinsons.org.uk/exercise** to find out more.

Should I change my diet?

If you have Parkinson's, there is no specific diet that you should follow. But it's recommended that you maintain as healthy a diet as you can. Eating a balanced diet will improve your health and may help to ease problems you may experience, such as constipation, low mood and weight changes.

Generally, the rules for following a healthy diet are:

- eating a varied diet
- eating healthy portions of foods

- eating the right balance of food groups
- eating regular meals
- drinking plenty of fluid
- eating at least five portions of fruit and vegetables a day

How does protein affect my diet?

For some people, protein (which is found mainly in meat, fish, eggs, cheese, yoghurt, nuts, beans and pulses) can affect how levodopa works in your body. This is the most common type of drug prescribed when someone is newly diagnosed with Parkinson's. Because of this, it's best to take your Parkinson's medication at least 30 to 45 minutes before meals.

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

PRACTICAL THINGS TO KNOW ABOUT

In this section:

- Can I still drive?
- Can I still work?
- Genna's story
- Can I get help with my finances?

Can I still drive?

Having Parkinson's doesn't necessarily mean that you will have to stop driving or that your licence will be affected. But there are some things you need to do if you would like to continue driving and stay safe on the roads.

- When you are diagnosed with Parkinson's, you must tell your licensing agency straight away. This is a legal requirement. You need to tell the DVLA in England, Scotland and Wales, or the DVA in Northern Ireland.
- You also need to tell your insurance company.
- To decide whether you're fit enough to drive, the licensing agency will need to find out more about your condition and ask you to fill out a form.

- They may be able to make their decision from the information you give them. But if they need more information, they will write to your GP or specialist. You may also be asked to go for a medical examination that will usually be with your own GP or specialist.
- If the licensing agency decides you cannot have a licence, it will give you a medical reason why, as well as details of if and when you can reapply.

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



Can I still work?

If you've been diagnosed with Parkinson's, it doesn't mean you have to stop working. If your treatment is carefully managed and you have plenty of support, it's possible to continue working for many years, depending on the type of job you have and how your symptoms progress.

Sometimes, you may need to make changes to your working life. This could be something relatively simple like asking for more flexibility with your hours. Or it may be something more significant like making changes to your job role.

The most important thing is to stay as informed as you can about your rights in the workplace, and use all the support available to you.

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



Genna has young onset Parkinson's. She was diagnosed while on maternity leave.

GENNA'S STORY

“ My main symptoms are muscle stiffness in my right arm and right leg, and I get a tremor which varies day to day. I take slow release tablets, and at night time I can be quite unsteady on my feet and lose my balance.

I work as a childrenswear designer for a high street fashion chain and have a lovely team. My work has been really good and supportive. But there are times I find things difficult.

On a bad day I'm tired in the morning and it takes me a while to get going. I really struggle with getting the girls ready, getting to work on time and taking my medicine, which takes a while to kick in.

At work we stand for a lot of our meetings, which I find hard. I will often sit down or lean on the chair. It probably looks like I'm not interested, but I'm trying to keep my balance!

It's tricky because people see me and I seem well so they expect me to carry on and keep going.

My company is very inclusive and I have a good relationship with my boss. I've reduced my hours, but having Parkinson's has made me realise that I have to think of work as just work. Parkinson's makes you put things into perspective.

Genna

Can I get help with my finances?

After diagnosis you might be worried about how you'll manage financially. If you can't work or if you need help with your day-to-day needs, this can lead to extra costs.

There is financial support available, so it's important to find out what benefits, grants, loans and other support you're entitled to.

To find out what support you can get:

- read our information about the different types of benefits available
- call our helpline on **0808 800 0303**
- use the online Turn2us Benefits Calculator and Grants Search tools to check what you can claim at **www.turn2us.org.uk**

HOW DO I COME TO TERMS WITH THE DIAGNOSIS?

In this section:

- Finding out you have Parkinson's
- What can help?
- Adjusting to change
- What do I do if I'm still struggling to come to terms with the diagnosis?
- Daxa's Story

Finding out you have Parkinson's

For many people, it can take time to adjust when you're diagnosed with Parkinson's. Getting used to living with a condition you may know little about can be difficult.

You may also feel lots of different emotions, including:

- shock – you may not have expected the diagnosis or believe it's true
- relief – at getting the diagnosis after a period of not knowing what the symptoms were, or that it isn't something more serious
- anger, sadness or worry – you may have anxiety about what the diagnosis means for you or how symptoms might progress

After getting a diagnosis you may question what causes Parkinson's and why you have it. It can be hard to hear that we don't yet know why people get Parkinson's. It can also be hard to live with the uncertainty of how your condition will progress.

You may find that you experience different emotions from one day to the next. It's also very common to try to ignore the diagnosis completely. All of these responses are completely normal.

What can help?

It's important to get the right information and support – when it's the right time for you. This can include simple things like reading this booklet, or talking to friends and family for support. Health professionals, like a Parkinson's nurse, can also provide a lot of useful information and support. Rather than ignoring or suppressing normal feelings, try to acknowledge and accept them.

Hearing how other people have coped and navigated their diagnosis can also help. There are many ways to meet or chat to other people to share how you're feeling, and who will know what you're going through.

- Our Parkinson's UK local groups are a great way to meet other people affected by Parkinson's.
- Parkinson's cafes are informal meet ups set up and run by people all across the UK.
- Our online forum or Facebook community group are very active spaces and a great way to connect with other people.

It's important to remember to look after yourself and make time for self-care during this time. Some people find calming activities like mindfulness or deep breathing helpful, or relaxing exercises like yoga or tai chi. These can help reduce stress and improve your wellbeing.

Physical activity and exercise can also help, as regular exercise can boost your mood. We talk about this more on page 18 of this booklet.

Adjusting to change

With time and support, people often feel more in control of their symptoms and find ways to manage their condition.

But adjustment can be an ongoing process. You may feel better or worse depending how your symptoms are affecting you and what else is going on in your life. For example, if you develop new symptoms, you may once again feel shocked or angry. These feelings may then go away as you get more used to the symptoms and get the right support to manage them.

What do I do if I'm still struggling to come to terms with the diagnosis?

For some people, the distress can be hard to shift. You may have lasting feelings of anxiety or low mood. It's normal to have feelings of worry and uncertainty about what the future holds, or feelings of low mood after being diagnosed with Parkinson's.

At this stage, talking therapies or medication can be useful. If you're struggling with feelings of anxiety or low mood, it's important to reach out for help.

- Talk to your GP, specialist or Parkinson's nurse. They'll be able to look at what treatment options are best for you.
- Talk to your partner, family or friends. They may be able to support you by helping you reach out to others.
- Call our helpline on **0808 800 0303**. We can offer further information and emotional support.





Daxa was 55 when she was diagnosed with Parkinson's.

DAXA'S STORY

“ I often remind myself that my future is in my hands – I’m in control of my own life.

My medication is helping, although some of the side effects like feeling dizzy, drowsy and nauseous are hard to cope with. I’ve been trying out different alternative therapies too, including reiki, meditation, yoga and herbal treatments. Making other positive changes in my life is helping – I’m eating more healthily and pushing myself to walk as much as possible.

I have plans to start dancing, travelling and volunteering again. My Parkinson’s might make this challenging, especially as it’s so different every day, but I’m determined to try.

What I’d really like is to be a positive role model for other people going through their own journey to diagnosis.

In the Indian community in particular, there is a lot of reluctance to talk about disabilities – I'd love to help change people's attitudes and inspire more people to share their stories.

Everyone's life is different, and this is mine. I'm learning more every day and gradually adapting to life with Parkinson's.

Daxa

WHEN YOU'RE READY

In this section:

- Read more about Parkinson's
- Read our magazine
- Join First Steps
- Take part in research

Read more about Parkinson's

We have a range of other booklets you might find helpful if you've just been diagnosed with Parkinson's.

These include

- Drug treatments for Parkinson's (order code INFOB0009)
- Physiotherapy and Parkinson's (order code INFOB0055)
- Diet and Parkinson's (order code INFOB0007)
- Driving and Parkinson's (order code INFOB0008)
- Speech and communication problems and Parkinson's (order code INFOB0058)
- Anxiety and Parkinson's (order code INFOB0028)
- Work and Parkinson's (order code INFOB0024)
- Relationships, sex and Parkinson's (order code INFOB0020)
- General information about benefits (order code INFOB0042)

You can order online, by phone or by email. Just mention the order code as listed above.

- Visit the Parkinson's UK shop at **parkinsons.org.uk/shop**
- Call **0330 124 3250**
- Email **resources@parkinsons.org.uk**

Or you can read all of our information on our website at **parkinsons.org.uk**

Read our magazine

The Parkinson is our free, high-quality print magazine, packed full of articles to help you live well and manage your condition.

It includes:

- real life stories and experiences from people living with or caring for someone with Parkinson's
- tips from people with Parkinson's on managing the condition day to day
- Q&As with experts

The Parkinson comes out three times a year. Call **0800 138 6593** or email **team@parkinsons.org.uk** to sign up.

Or, go to **parkinsons.org.uk/magazine** to read our magazine online.

Join First Steps

First Steps is our online programme for people recently diagnosed with Parkinson's and their family, friends and carers.

In three sessions, we'll help you to take the first steps in making sense of your diagnosis. And we'll empower you to start living well with Parkinson's by providing you with the information and support you need.

This programme is for you if:

- you're looking for ways to make sense of your diagnosis
- you don't know what information and support is available to you
- you feel ready to meet other people who have also been recently diagnosed with Parkinson's, and their family, friends and carers.

To take part, you will need access to a device with a webcam and a reliable internet connection. If you're not feeling confident using Zoom, we offer support in how to get started and use the key features.

To find out more about this programme, please contact the First Steps team on **020 7963 9381** or email **firststeps@parkinsons.org.uk**

Take part in research

When you take part in research you are helping to drive forward better treatments for everyone with Parkinson's. From at-home surveys to clinical trials of new treatments. Whatever you're ready for, you can make a difference by taking part.

The 'Take Part Hub' on our website can help you find local research studies that are recruiting people with and without Parkinson's now. Visit **parkinsons.org.uk/takepartinresearch**

MORE INFORMATION AND SUPPORT

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**

You can order printed information by calling **0330 124 3250** or visiting **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**

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** 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**

Thank you

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

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^{UK}

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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