

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

PARKINSON'S AND YOU

A GUIDE FOR PEOPLE NEW TO THE CONDITION.



Being diagnosed with Parkinson's can be a very emotional experience. Some people feel shocked or confused – others feel angry or anxious. Some people even feel relieved to have an explanation for their symptoms.

This booklet aims to answer questions about what Parkinson's is, how the condition can be treated and how it might affect your everyday life. It also has details of where you can find useful information and support.

When you're ready to find out more, our booklet *Living with Parkinson's* looks at how the condition might affect different aspects of your life, including work, relationships and parenting. It also goes into a lot more detail about symptoms and how they can be managed.

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QUICK FACTS

- Parkinson's is a progressive neurological condition.
- We are still trying to understand why people get Parkinson's.
- Around one person in every 500 has Parkinson's.
- Most people who get Parkinson's are aged 50 or over, but younger people can get it too.
- Parkinson's is not infectious and doesn't usually run in families.
- Everyone's experience of Parkinson's is different.
- Although there's currently no cure, there are a range of medicines and treatments available to manage the symptoms of the condition.
- Although at times life with Parkinson's can be difficult, many people with the condition lead active, fulfilling lives.

“ I sat in front of the mirror and tried to see what was different. Nothing. Not a single thing had changed. I still had to comb my hair, take a shower, eat as normal. That's when the truth began to dawn on me – of course I was still me! I looked the same, I am the same. ”

Dave, diagnosed in 2010



ABOUT PARKINSON'S

What is Parkinson's and what causes it?

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

People with Parkinson's don't have enough of the chemical dopamine because some of the nerve cells in their brain that make it have died. Without dopamine people can find their movements become slower so 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 genetic and environmental factors that cause the dopamine-producing nerve cells to die.

What are the symptoms?

The symptoms most often associated with Parkinson's are tremor, stiffness and slowness of movement.

“ I don't have much of a tremor. Instead I sway, and make rather exaggerated gestures as though I was in a boat on a gently billowing sea. ”

Caroline, diagnosed in 2009

Tremor

Parkinson's may cause some people's hands and bodies 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 and tends to affect people while they are still. It may also become more noticeable if someone with the condition is anxious or excited.

The tremor usually starts on one side of the body and may spread to the other side, as the condition progresses.

This is probably the most well known of Parkinson's symptoms, but not everyone with the condition has a tremor.

Muscular rigidity or stiffness

Because their muscles are stiff, some people with Parkinson's have problems turning around, getting out of chairs, turning over in bed or making fine-finger movements, such as writing or fastening a button.

Some people find that over time their posture becomes stooped or the muscles in their face become stiff or rigid, making facial expressions more difficult.

Slowness of movement

Starting to move can be more difficult for people with Parkinson's. They can find it takes longer to do things and they get tired more easily. A lack of co-ordination can also be a problem.

Other symptoms

As well as difficulties with movement, people with Parkinson's might experience other symptoms such as tiredness, pain, depression, problems with memory, swallowing and sleep, problems urinating, anxiety, and constipation. These are often referred to as non-motor symptoms and can have an impact on people's day-to-day lives.

Find out more: we produce more detailed information about all the symptoms associated with



Parkinson's. You can find these at parkinsons.org.uk/publications. Alternatively, see page 36 for details of how to order a catalogue.

Parkinson's symptoms can be affected by stress or illness. So, if you are worried, anxious, stressed, nervous or become ill, your Parkinson's symptoms may become more noticeable. If you notice a change in your symptoms, speak to your GP, specialist or Parkinson's nurse (if you have one) to rule out any other problems.

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 is Parkinson's diagnosed?

Parkinson's tends to develop gradually and it can be a number of months, or even years, before the symptoms become obvious to someone with Parkinson's – or their family – and for them to talk to their doctor.

“ My GP was reluctant to refer me in the beginning. Eventually, he wrote a letter to a specialist. After four months, I had blood tests and an MRI scan. In all, it took two years to get the diagnosis. ”

Kris, diagnosed in 2004

It is not easy to diagnose the condition, so it's important to see a Parkinson's specialist to get an accurate diagnosis.

The specialist will usually look for slowness of movement plus at least one of the other main symptoms of Parkinson's tremor and stiffness.

They will also consider your medical history and carry out an examination before making a diagnosis. Your symptoms may have other causes and you may be referred for further tests and scans to rule these out.

How quickly does the condition progress?

The symptoms someone might have and how quickly the condition develops will differ from one person to the next.

For many people, the condition can take years to progress to a point where it can have a real impact on daily life. Many of the symptoms can be treated or managed with medication.

Is there a cure?

There is no cure for Parkinson's at the moment. Researchers and scientists are making advances in understanding the condition, its causes and how best to treat it.

In fact, research has made more progress towards finding a cure in the last decade than ever before. There have also been some exciting new areas of research, including gene therapy and stem cell therapy.

Parkinson's UK is the largest charity funder of Parkinson's research in Europe. We've already made enormous strides in our understanding of the condition and developed better treatments and therapies. But despite recent progress we're still searching for a cure. You can find out more

“ I find my tremor is linked to periods of anxiety or excitement and to cold weather. One trick which often helps is to turn the hand so the palm is facing the ceiling. Holding this position for a couple of minutes helps still the tremor. ”

John, diagnosed in 2005

about our current research at parkinsons.org.uk/research

You may also be interested in joining our Research Support Network. If you join, we'll send you emails with the latest opportunities to support Parkinson's research. For information email research@parkinsons.org.uk

Can people die from Parkinson's?

For most people, their life expectancy won't change much because of Parkinson's. However, some of the more advanced symptoms can lead to increased

disability and poor health, which can make someone more vulnerable to infection.

The most important thing is to try to manage your condition as best as you can with the support of specialist healthcare professionals.

Are my children at risk of Parkinson's?

It's rare to find more than one person in a family who has Parkinson's. Researchers believe the condition can sometimes be inherited, but this only happens in rare cases.

Is Parkinson's infectious?

No, Parkinson's can't be caught like

the flu or measles. No one knows what causes it, but experts agree that it is not infectious.

How many people have Parkinson's?

In the UK, there are around 127,000 people with the condition, and each year, about 10,000 people are diagnosed.

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.





TREATMENTS AND THERAPIES

How is Parkinson's treated?

Although there's currently no cure, a range of drugs, treatments and therapies are available to manage many of the symptoms.

Medication is usually the main treatment for Parkinson's, but you should also have access to health and social care professionals from different teams, who can offer different types of therapy, such as speech and language therapy and physiotherapy. See page 15 for more information.

There are several types of drugs used to treat Parkinson's, and they work in different ways to relieve some of the symptoms.

For a lot of people who have just been diagnosed, Parkinson's drugs can be a great help. However, if your symptoms are mild, you might decide, together with your specialist, to postpone drug treatment until your symptoms increase. This is because Parkinson's drugs can become less effective

over time, or you might start to develop side effects after taking them for a while.

Whether or not you decide to take medication in the early stages, it's important to make sure your lifestyle is as healthy as possible, focusing on exercise, relaxation and diet.

If you do need medication you might need to take several different drugs, and the dosages you take may increase as your symptoms change. It will be important to set up a good system for getting your prescriptions and for ensuring you take your drugs at the right times.

If you do choose, alongside your healthcare professionals, to take medication for your condition, it is important that you don't stop taking it without first discussing it with your specialist or Parkinson's nurse.

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

What is impulsive and compulsive behaviour?

Impulsive and compulsive behaviour is a possible side effect of some Parkinson's drugs. Although only a relatively small number of people experience it, it can have a big impact on the person affected and those around them.

Impulsive behaviour is when a person can't resist the temptation to carry out certain activities that could lead them to harm themselves or others. In a lot of cases, this behaviour is out of character.

Compulsive behaviour is when a person has an overwhelming drive to act in a certain way, often repetitively, to reduce the worry or tension that they get from their urge. These behaviours can include addictive gambling, eating and shopping, or an increase in sexual thoughts and feelings. Often, people may have more than one of these behaviours.

Talk to your healthcare professional about these side effects, when you are prescribed Parkinson's medication.

If you think you're experiencing impulsive and compulsive behaviour, or if you are a family member, carer or friend of someone with

Parkinson's and notice them behaving differently, don't be afraid to seek help. Your healthcare professional will have spoken to others who have experienced these symptoms, and everything you tell them remains confidential.

Remember, it is important to take your medication as prescribed. If you are worried about any symptoms, speak to your specialist or Parkinson's nurse before changing your medication.

You can call our free confidential helpline on **0808 800 0303** (calls are free from UK landlines and most mobile networks) or email **hello@parkinsons.org.uk**

Find out more: visit parkinsons.org.uk/icb for more information about impulsive behaviour, including a video explain the symptoms, or see our information sheet *Impulsive and compulsive behaviour in Parkinson's*. We also have an *Impulsive and compulsive behaviour in Parkinson's* information tool, which you can use to discuss any concerns with your healthcare professional.

What surgical options are there?

Deep brain stimulation is a form of surgery used to control some of the symptoms of Parkinson's. It involves passing small electrical currents through electrodes that are implanted in the brain.

This isn't a suitable option for everyone and, like any surgery, there are some risks involved. It is normally only considered as an option if your medication no longer helps with your symptoms. Talk to your specialist for more details.

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

Which professionals can help me?

Many people may be involved in helping you manage your condition. Some will have a bigger role than others, depending on your symptoms.

Your GP, specialist or Parkinson's nurse can make referrals to the health and social care professionals listed here. In some areas, you may be able to refer yourself.

Parkinson's UK information and support workers can also provide information about, and links to, your local services. See page 36

for details of how to find your local information and support worker.

Assessing the full range of Parkinson's symptoms – especially those not related to movement – can be difficult. Parkinson's UK has a questionnaire available to help you and your GP, specialist or Parkinson's nurse look at your non-motor symptoms.

You can download the questionnaire from our website – **parkinsons.org.uk/nonmotor** – or use the copy included on page 43.

At the back of this booklet, there's also a space for you to keep details of all the professionals you see. You can take this along to your GP, specialist or Parkinson's nurse appointments to remind you which professionals you would like to be referred to.

Dietitians can help if you have problems with your diet, for example if you are under or overweight or have digestive problems, such as constipation.

GPs can refer you to a range of healthcare professionals, such as hospital specialists, psychologists and physiotherapists.

Your GP may know you well, which can be helpful. But the average GP, generally, has only three or four patients with Parkinson's, and it's unlikely they will know as much about the condition as specialists do. We recommend you see a specialist for advice about your Parkinson's.

Occupational therapists (often known as OTs) can help people with disabilities to stay as independent 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 can advise you about appropriate adaptations, aids or equipment. Occupational therapists can also tell you about leisure activities that can help you stay fit and that you may enjoy.

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

Parkinson's nurses have specialist experience, knowledge and skills in Parkinson's. They have an important role in the care of people with Parkinson's, including offering guidance on managing medication.

Currently, not all areas have access to a Parkinson's nurse. If you want to find out more about the

healthcare services available in your area you can ask your GP, or your local Parkinson's UK information and support worker can help you. See page 36 for details of how to find your local information and support worker.

Parkinson's specialists are doctors, usually neurologists or geriatricians (specialists in the care of older people) with a particular interest in Parkinson's.

Make sure you are referred to a specialist because Parkinson's is a complex condition that is difficult to diagnose, and can require complex drug treatment. The clinical guidelines on Parkinson's recommend that people are referred to a specialist by their GP without treatment.

Check that your neurologist or geriatrician is a Parkinson's specialist as not all of them are.

If you are referred for an appointment with a specialist in England, you are able to choose where you are treated, and where appropriate, which named specialist-led team you would like to be treated by.

If you live in Northern Ireland, Scotland or Wales and you're not

happy with the specialist you're referred to, tell your GP. They may be able to make an appointment for you with another specialist, either at the same hospital or elsewhere. But it's important to keep in mind that this may delay your treatment.

Find out more: see our [information sheet *Talking to your GP, specialist or Parkinson's nurse about Parkinson's.*](#)

You may find that access to other professionals, such as Parkinson's nurses, therapists and dietitians, might be easier through your specialist, as they often work in teams with other related healthcare professionals.

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.

They can also advise on dispensing aids, such as pill timers, and offer advice if you find opening bottles difficult.

Physiotherapists use physical treatments, including exercise, to

“ The Parkinson's nurse was immensely helpful – coming to my house when I was newly diagnosed and explaining Parkinson's to me so well and clearly that I remember many of her exact words. ”

Diana, diagnosed in 2004

help manage any stiffness in joints and to restore muscle strength and mobility. They can also advise your carer (if you have one) on safe ways to help you if you have problems moving and suggest ways to prevent falls. Seeing a physiotherapist can make a real difference, so we recommend that you ask to be referred.

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

Practice nurses work in GP practices. They carry out regular checks and run advice sessions. They can be a useful source of information, particularly about general health problems.

Psychologists and counsellors

can support people who might need help coming to terms with their condition. They can also help you manage any feelings of anxiety, low mood or depression.

Social workers can advise on home support, claiming benefits and respite care. They are also responsible for your community care assessment and for carers' assessments. Contact your local Social Services Department, or Social Work Department if you live in Scotland, for access to a social worker.

Speech and language therapists

(often known as SALTs) are healthcare professionals who specialise in all aspects of communication, from facial expression and body language to speech and communication aids. They are also experts in swallowing problems. Speech and language therapists can be extremely helpful, so we recommend you speak to one as soon as you can.

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

Do complementary therapies have any benefit?

There is no simple answer to

“ For the past six years I have been having one-to-one Pilates lessons, which have been extremely helpful. I enjoy it immensely and it makes me feel refreshed and ready to go. My instructor is always thinking up new exercises to try and keep my brain and body alert! ”

Thelma, diagnosed in 1983

this question. We've heard from many people who feel they have benefited from using these therapies. For example, some people have told us they can help to manage symptoms, reduce stress, and provide an overall sense of wellbeing. Many of our local groups organise complementary therapy sessions at their meetings to encourage people to give them a try.

However, there has not been a lot of medical research about their effectiveness to treat Parkinson's

symptoms. So there isn't enough scientific evidence to say for certain that complementary therapies have benefits for Parkinson's symptoms. And, because there are so many types of therapy, it is impossible to generalise as to whether they work or not.

It will also depend on what you expect from them. For example, you may not feel a particular therapy is having a positive effect on your Parkinson's symptoms, but you may enjoy the experience. In this case, you may feel this is enough of a benefit for you to continue.

We recommend you consult your GP, specialist or Parkinson's nurse for advice if you're interested in trying complementary therapies, to find out if they are suitable for you. This is particularly true of herbal medicines or any therapy that involves taking vitamins, as some of these might interfere with Parkinson's medication.

It is also important to use a qualified complementary therapist – GP surgeries can often provide a list of local practitioners.

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



I have another medical condition as well as Parkinson's. What should I do?

If you have another medical condition and are concerned about how this will affect your Parkinson's or vice-versa, speak to your GP, specialist or Parkinson's nurse.

Make sure that all the healthcare professionals involved in your care are aware of your health issues. Also, tell them about any treatments that have been suggested or prescribed any other healthcare professional you may have seen. This will ensure you receive the best all-round care.



LIVING WITH PARKINSON'S

Will I be able to carry on working?

For people who are in full- or part-time work, being diagnosed with Parkinson's may be a concern. Work is an important source of income, but can also build confidence, self-esteem and personal satisfaction.

Just because you've been diagnosed with Parkinson's, it doesn't mean you have to stop work.

If you do need or want to carry on working, it is really important to work out the most effective treatment for your symptoms with your specialist.

If work causes practical problems, an occupational therapist can do an assessment and help you to find solutions. Speak to your employer about getting an assessment.

Of course there are some jobs that might cause problems for you. For example, if your job requires a lot of energy or physical strength or if your tremor interferes with

your ability to use your hands for writing. If this is the case, you might need to consider an alternative role.

Your employer has a legal duty to make 'reasonable' adjustments and make changes to your employment where necessary. This might include being flexible about your hours or getting equipment to help you with your role.

If you do decide to stop working, it is important to think carefully about the financial, emotional and practical implications.

Our advice is not to rush into a decision – give your treatment time to settle down.

Even if you're happy with your decision to stop working early, it's worth talking to employers and professional or trade organisations to establish the best terms for you, and decide exactly when you want to leave.

You may find it useful to be more informed about your employment rights and what the duties of your employer are (if this is relevant to you).

If you have questions about working with Parkinson's, contact our helpline on **0808 800 0303** or email **hello@parkinsons.org.uk**. You can also get advice and information from your local Citizens Advice Bureau (see page 39 for contact details) and your local welfare benefits service.

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

Am I entitled to any benefits?

Having enough money to support yourself is essential and you might be eligible for financial help. The rules about access to benefits are complex and can change. For more information and guidance contact:

- our helpline on **0808 800 0303**
- our information and support workers (call our helpline or visit **parkinsons.org.uk/isw**)
- your local Citizens Advice Bureau (see page 39 for contact details)

- your local benefits office (found in the telephone directory under 'Government')
- benefits advice agencies
- disability rights officers from your social services/social work department

Find out more: we have a range of information sheets covering a variety of benefits. Details of what is available and how to order or download any of our resources are on page 36.

Will I still be able to drive?

Having Parkinson's doesn't necessarily mean your licence will be affected. However, you may need to have a medical or driving assessment.

Do I have to tell my driving licensing agency that I have Parkinson's?

Yes. Anyone applying for a driving licence has to complete a section on the application form indicating any health problems they may have.

If you already have a licence, you are required by law to inform your licensing agency of any medical condition that may affect driving, including Parkinson's. In England, Scotland and Wales the licensing agency is the DVLA and in Northern

Ireland it is the DVA. See page 39 for contact details.

Do I have to tell my insurance company that I have Parkinson's?

Anyone who knowingly drives while unfit may invalidate their insurance cover, so it is essential to inform your insurance company of any change in your health that might affect your ability to drive.

It is against the law to make a false statement or withhold information in order to get car insurance.

Will my medication affect my driving?

Drowsiness is a side effect of some Parkinson's drugs and this can sometimes be severe. Some Parkinson's medications can also

cause excessive daytime sleepiness or sudden onset of sleep.

This may be more likely in people with advanced Parkinson's on multiple medications and when increasing certain types of medication.

Although this is concerning, the DVLA has stated that the risk of sudden onset of sleep is low and that taking Parkinson's drugs should not automatically mean you have to stop driving. However, if you experience any excessive daytime sleepiness or sudden onset of sleep you should not drive and you should inform your GP, specialist, or Parkinson's nurse.

Find out more: see our booklets *Driving and Parkinson's* and *Drug treatments for Parkinson's*.



What should I do if I live alone?

For some people with Parkinson's living alone is a concern, but many people with the condition live on their own and manage very well.

A common concern is fear of falling, but a lot can be done to make the home less hazardous, including:

- rearranging furniture to make rooms safer
- removing loose mats or rugs
- adding grab rails around the house (stairs, bath or shower, for example)
- making lighting brighter to make moving around much safer

You may find it useful to discuss these ideas and where to get help to carry them out with an occupational therapist.

Find out more: see our [information sheet *Living alone with Parkinson's*](#).

Should I change my diet?

There are no specific changes you need to make but, like everyone, you will benefit from eating as healthily as possible.

A balanced and nutritious diet including three meals a day (or four

smaller meals) is recommended. You should aim to eat a mix of starchy foods (such as bread, rice, potatoes, noodles, cereal, crackers, oats, yams), fruit and vegetables, dairy products, and proteins (meat, fish, eggs, beans or pulses). Fatty or sugary foods should be eaten in moderation.

It is also important to drink plenty of fluids. Unless your doctor has advised you otherwise, alcoholic drinks in small amounts are not harmful.

Many people with Parkinson's find that they get constipated. Exercise, combined with a regular intake of fluids and fibre-rich foods, such as cereal grains, wholemeal bread and pasta, brown rice, seeds, nuts, fruit, vegetables and pulses, will usually help.

If you are overweight, you may need to cut down on fatty foods and carbohydrates. Losing weight will also help you to move around, as it will ease the strain on your joints.

If, as sometimes happens, you lose weight without trying to, you may need special dietary supervision and supplements. Make sure you talk to a doctor or dietitian before considering any changes to your diet.

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

Can protein affect Parkinson's medication?

A small number of people taking a Parkinson's medication called levodopa (one of the main drugs used to treat the condition) may find a meal that's high in protein affects how well their medication works.

If you notice this, we recommend talking to your specialist or Parkinson's nurse. Some people may find taking their medication about 30 minutes before their meals is more effective.

Can I still exercise?

Yes. In fact, exercise is especially important for people with Parkinson's. Keeping fit will help muscles and joints from becoming stiff and rigid.

As well as helping with mobility, exercise can lift your mood. It can also be a social experience if you join a local group or sports club for example.

There are also a number of 'low-key' exercise options to keep you flexible and active and which may also reduce the risk of falls, such as yoga, t'ai chi, walking, gardening, golf and daily stretches.

“ Exercise is really important for people with Parkinson's and there is growing evidence that it can bring many benefits. Exercise doesn't necessarily mean having to go to the gym – you can do exercises at home, and can even do them sitting down. Fitting some form of exercise into your daily routine is most beneficial. ”

Fiona, a physiotherapist

If you are unsure about the suitability or safety of any exercise you would like to do, talk to your GP or ask for a referral to a physiotherapist.

The main thing is to try to stay active, but do things at your own pace, even if it takes longer than expected.

Find out more: see our booklet and DVD *Keeping moving*.

Are there any other ways I can improve my mobility?

Exercise, medication and generally staying active are the best ways to stay as mobile as possible. But, depending on your symptoms, there is a wide range of equipment available that might also help.

What sort of equipment might I need?

It can be difficult to accept the need to start using aids, but many people find specialist equipment, for example grab rails or walking sticks, actually help them become more independent.

There are all kinds of aids and equipment available to help people

who might have problems doing things, such as washing, bathing, reaching, eating and drinking.

If you are thinking about buying equipment to help you day to day, we strongly advise you have an assessment from the relevant therapist first.

A physiotherapist or occupational therapist can advise on what is available to suit your needs.

If the therapist suggests equipment, he or she should be able to advise you on suppliers and any funding that may be available. Talk to your GP about referrals to these services.



MY RELATIONSHIPS WITH OTHERS

How will my family be affected?

Everyone copes with life in different ways, but if someone in the family is diagnosed with Parkinson's, it can have a big effect on everyone.

If you or your loved ones have any concerns or worries, you might find talking to a counsellor helpful.

They can also call our helpline on **0808 800 0303** for information and support.

You or your family may also find speaking to one of our information and support workers helpful. You can ask the helpline for the details of your local information and support worker or visit **parkinsons.org.uk/isw**

Roles within families may gradually change as your Parkinson's progresses because you might need more help. These changes can be difficult for everyone, but discussing them openly with your family may make things easier.

You may also find it useful to tell people when you're having difficulties so they can help you.

Make sure you also let them know when you're not having any problems – your family and friends will want to help you as much as they can, but it's important for you to stay as independent as possible.

Try to keep doing the things you have always enjoyed as a family. Remember that Parkinson's shouldn't dominate everything.

You may find it helpful to discuss your wishes with your family or friends about your care should your condition worsen. This could help reduce their fears and worries as they may be reluctant to bring up the conversation with you.

Find out more: see our information sheet *Talking to people about Parkinson's*.

How do I tell my children or grandchildren about my condition?

Having a loved one with Parkinson's can be difficult for some children or young people. It might help for them to have someone to talk to and ask questions about Parkinson's, such as a GP or Parkinson's nurse. It also helps if they can get hold of information about the condition easily.

Parkinson's UK has several publications that may help you talk about your condition with the young people in your family. For children aged three to seven, we have a range of children's books:

- *My grandad has Parkinson's*
- *My mum has Parkinson's*
- *My dad has Parkinson's*
- *My gran has Parkinson's*

These could also be read by older children alone. For teenagers we have *Parkinson's in your life: a guide for teenagers*. You may also find our information sheet *Talking to children about Parkinson's* useful.

You may also find our *A quick introduction to Parkinson's* leaflet useful for facts about the condition. Our easy read booklet *Information*

“ I firmly believe that once I accepted myself as a person with Parkinson's, and did not think of myself as a lesser person because of this, then other people did the same. It is not the most important thing about me. ”

Caroline, diagnosed in 2003

about Parkinson's can be used to explain the condition to anyone with learning difficulties or for anyone who wants a simple guide to the condition.

How do I tell people I have Parkinson's?

Telling people you have Parkinson's can be daunting. It's hard to find the right words, especially if you're worried about how people may react. You might worry that if people know you have Parkinson's, they'll judge or identify you by what they know or think about the condition.

Who you tell and what you tell them is up to you. But you might find the following tips helpful.

- Tell at least one person close to you. This will give you someone to talk to about your Parkinson's. They may also be able to help you tell other people.
- Choose carefully when and how you tell people. You may want to get everyone together to tell them all at once, or to tell people only when you need to. Some people find it easier to tell people in a letter or an email, rather than face to face.
- Practise what you want to say. Prepare yourself by thinking through the possible reactions you may get and how you might feel.
- Talk to people with Parkinson's about how they told others about their condition.
- They may be able to give you tips. You can try contacting them through your local Parkinson's UK group, or our online forum, parkinsons.org.uk/forum

Find out more: see our [information sheet *Talking to people about Parkinson's*](#).

How will my intimate relationships be affected?

Having Parkinson's doesn't necessarily mean you'll have difficulties, but sometimes the condition can have an effect on intimate relationships.

Parkinson's can make it harder to move freely and make spur-of-the-moment gestures. A spouse or sexual partner might also find it hard to switch from supporting you to being



intimate in a sexual way. Stress and anxiety can also have an effect.

If you experience any of these problems, there are ways to manage them. Talking to your partner about how you feel can help. If tiredness is a problem you could try changing the time you have sex.

Other problems may arise due to the emotional change in the relationship. As Parkinson's progresses, you may find you and your partner taking the roles of carer and cared for. Some couples find it hard to see each other as equal partners in these new roles. Keep talking to each other about any concerns you have.

Discussing any issues with your specialist or Parkinson's nurse may also be useful and they can refer you to other sources of help, such as a couples counsellor or psychosexual therapists.

Remember that Parkinson's shouldn't stand in the way of an enjoyable and fulfilling sex life.

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



How does Parkinson's affect pregnancy?

It's hard to know for certain what happens to women with Parkinson's when they get pregnant, because of the small numbers involved in research. Some women's symptoms get worse and some do not. It is encouraging that the majority of cases written about ended in full-term delivery of healthy babies.

If you are worried about being or becoming pregnant with Parkinson's, speak to your Parkinson's nurse or specialist.

Find out more: see our booklet *Living with Parkinson's* and our website for information about pregnancy and Parkinson's.

EMOTIONAL ISSUES

Staying positive

Many people with Parkinson's lead active and fulfilling lives, not by pretending that nothing is wrong, but by understanding how their Parkinson's affects them and working around it. Although living with your condition may be difficult at times, exploring what having Parkinson's means for you and trying to think positively about what you can still do may help.

Staying active

Spending time socialising also helps keep many people positive and active. The attitude of family and friends can influence this. They need to encourage you to lead as normal and active a life as possible.

Finding leisure activities you enjoy and feel benefit from is essential for leading a healthy life. This is true whether you have Parkinson's or care for someone with the condition.

You might like playing sports or going to the gym, spending time

on hobbies such as art or music or taking part in drama groups. There are also a lot of educational opportunities you might like to think about, from crafts, languages or martial arts through to university degrees.

I'm feeling down – is there anything I can do?

Most people with Parkinson's struggle with their emotions from time to time. It's natural to feel angry, depressed or anxious – particularly when you are first diagnosed. As time goes on, these feelings may subside, but they can also reappear from time to time as your condition progresses.

Stress and anxiety

If you are feeling stressed, it might help to speak to your GP, specialist or Parkinson's nurse about your concerns. They may help to ease your mind by offering information and by signposting you to professionals who can help. Talking to your family and close friends might also make you feel better.

Anxiety or stress can make symptoms worse. They can also interfere with sleep, leaving you feeling tired and worn down, so it's really important to find ways to relax.

Exercise can help you unwind and improve your sense of wellbeing. Some people have also found complementary therapies, such as aromatherapy, yoga, reflexology and music and art therapy, have helped improve their mood and relieved feelings of anxiety and stress. See page 25 for more information.

It's important to get advice if you find feelings like anxiety or stress are seriously interfering with your life. Speak to your GP, specialist or Parkinson's nurse if you have any concerns.

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

Depression

A lot of people with Parkinson's experience feelings of depression at some point. This can be due to the chemical changes in the brain caused by the condition. It's also an understandable reaction to the effect Parkinson's has on your life. Symptoms of depression may include low mood or self-esteem, a lack of interest in things you

“ I do the things I can. The things I can't ... well, someone else can do. Don't hide away. You must keep going. Take one day at a time and smile. ”

Derek, diagnosed in 2009

usually enjoy, tiredness and difficulty sleeping.

Your GP may suggest you take antidepressants, which can be very effective as long as they are compatible with any medication you are taking for Parkinson's. Counselling and cognitive behaviour therapy can also be beneficial. Exercise can also help ease feelings of depression.

It can be hard for family or close friends if someone has serious depression, especially if they are involved in their care. Being aware of the symptoms and learning a bit more about the condition is important, and can make the situation easier to manage. This is especially important if you've had depression before being diagnosed with Parkinson's.

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

Frustration

If you are having problems moving, the extra effort it takes to do things can make you feel frustrated.

It is difficult to avoid this frustration altogether, but finding the best possible treatment and support, keeping active and learning how to organise your day can help.

Many people ask: "Why me?" Unfortunately there is no answer to this question, but there are lots of people living with Parkinson's who have found ways to accept the situation as best as they can and get on with their lives.

There is no one way to do this, but your frustration (and any other emotional difficulties) may be eased by talking to someone who understands. This might be a close friend, someone else with Parkinson's or an expert, such as your Parkinson's nurse.

Emotional support

You can meet other people in a similar situation at your local Parkinson's UK group.

“ As a couple who often had weekends away, Sheila found packing hard, so we would prepare a list together, and tick things off as we packed them. I have also found friends and family to be very supportive, which has been good for my self-confidence. ”

David, whose wife has Parkinson's

To find out about your nearest group, visit parkinsons.org.uk/localgroups. You can also contact our helpline on **0808 800 0303** or at hello@parkinsons.org.uk

You could also speak to your local Parkinson's UK information and support work. You can find their details by contacting our helpline or by visiting parkinsons.org.uk/isw

You can also join our online forum to share your experiences and chat to other people. Visit parkinsons.org.uk/forum

Counselling

Even the most optimistic and energetic person may find it difficult to be positive after they've been diagnosed. Others who are prone to worry might always find it hard, but it is certainly worth trying the positive approach.

If you're finding it difficult being positive, you should talk to your GP, specialist or Parkinson's nurse who may be able to give you details of local counsellors. They may also be

able to refer you for psychological support, if this is available.

Your local information and support worker may be able to give you further information about services in your area.

There are also organisations you can contact if you wish to speak to a counsellor. See the More information and support section on page 36 for details of who to contact for counselling.



FOR FAMILY, FRIENDS AND CARERS

If you provide support to someone who has Parkinson's, you are sometimes considered to be their 'carer'. Not everyone likes this term, and it can mean different things to different people. You may provide emotional support, practical help or personal care for someone for a varying amount of time each week.

It's important to recognise how the condition affects someone can change from day to day. Think about when to allow them to rest and when to offer help. These are not easy judgements to make, so don't be discouraged if you sometimes get it wrong. And make sure you think about your own needs as well as those of the person you care for.

Here are some tips:

- Try to maintain your own support network outside of your relationship with the person you care for. It's important to have someone you can talk to. This may be a family member, trusted friend or other carer.
- Think about your feelings and try to talk about them with the person you care for.
- Be clear about what you are able or willing to do as a carer so there are no unrealistic expectations.
- Find help for the tasks you are not able or willing to do before any difficulties crop up.
- Look after yourself, particularly your health, and keep some time for your own social life, hobbies or pastimes.
- Try to carry on doing the things you both enjoy together.
- Try to keep your sense of humour and keep things in perspective.
- As a carer, you may be entitled to financial support. Call our helpline on **0808 800 0303** or Carers UK on **0808 808 7777** for more information.

Find out more: see our booklet *The carer's guide*.

MORE INFORMATION AND SUPPORT

Support and information from Parkinson's UK

Knowing where to find answers to your questions or having someone to talk to can make a real difference to life with Parkinson's.

You can call our free confidential helpline for general support and information. Call **0808 800 0303** (calls are free from UK landlines and most mobile networks) or email **hello@parkinsons.org.uk**

Our helpline can also put you in touch with one of our local information and support workers, who provide one-to-one information and support to anyone affected by Parkinson's. They can provide links to local groups and services as well.

Our website **parkinsons.org.uk** has a lot of information about Parkinson's and everyday life with the condition. You can also find details of your local support team and your nearest local group meeting at **parkinsons.org.uk/localtoyou**

You can also visit **parkinsons.org.uk/forum** to speak with other people in a similar situation on our online discussion forum. In addition, you can find us on Facebook and Twitter. Visit: **www.facebook.com/parkinsonsuk**
www.twitter.com/parkinsonsuk

Information resources

Another great way to find out more about living with Parkinson's is through our publications, DVDs and audio tapes.

They cover a range of topics, including symptoms, treatments, benefits and emotional issues. And you can ask us about translating our resources into other languages.

You can download the publications from our website at **parkinsons.org.uk/publications** or contact us for a catalogue and order form of everything that's available. **0845 121 2354**
resources@parkinsons.org.uk

Peer support service

If you'd like to talk things through on the phone with someone affected by Parkinson's, you can use our peer support service. We can put you in touch with a trained volunteer who has a similar experience of Parkinson's to you.

This could be anything to do with Parkinson's, such as:

- personal experiences of treatments
- ways of coping with the condition
- ways of caring for someone with Parkinson's

Call our helpline to access the peer support service.

A path through Parkinson's

This is a self-management programme developed by Parkinson's UK and people living with the condition. It aims to give you information, an opportunity to think, and help to decide what your priorities are.

We run self-management groups for people fairly recently diagnosed; those who have been living with Parkinson's for longer; and for mixed groups. All groups are also for carers and partners.

Come along and you'll have the opportunity to learn from others with a similar experience of Parkinson's. The groups will discuss:

- what self-management is
- looking ahead and plans for the future
- relationships, feelings and emotions
- what's important
- top tips
- taking care of yourself
- support from Parkinson's UK

Self-management groups are run by trained volunteers, who have first-hand experience of Parkinson's, and run for two, three or six weeks.

For more information on dates and locations in your area or to book a place please visit **parkinsons.org.uk/selfmanagement** email **selfmanagement@parkinsons.org.uk**, or call our helpline.

USEFUL CONTACTS

Age UK

0800 169 6565

www.ageuk.org.uk

Age Cymru

0800 022 3444

Age NI

0808 808 7575

Age Scotland

0845 125 9732

Action on Depression (Scotland)

0131 243 2786

admin@actionondepression.org

www.actionondepression.org

The Afya Trust

This voluntary organisation aims to remove the disadvantage in health care services experienced by black and Asian groups and other minority communities in England.

020 7803 1180

info@afiya-trust.org

www.afiya-trust.org

British Association for Counselling and Psychotherapy

01455 883 300

Textphone **01455 560 606**

bacp@bacp.co.uk

www.bacp.co.uk

Carers Trust

England **0844 800 4361**

Scotland **0300 123 2008**

Wales **0292 009 0087**

info@carers.org

www.carers.org

Carers UK

advice@carersuk.org

www.carersuk.org

Adviceline (England, Scotland,
Wales) **0808 808 7777**

(Monday-Friday, 10am-4pm)

Adviceline (Northern Ireland)

028 9043 9843

Cause (Northern Ireland)

Cause is a unique peer-led regional charity offering services to families, partners and friends across Northern Ireland caring for a loved one who has experienced serious mental illness.

0845 603 0291

www.cause.org.uk

Citizens Advice England

0844 411 1444

Wales

0844 477 2020

Text Relay

0844 411 1445

www.citizensadvice.org.uk

Website for online advice:

www.adviceguide.org.uk

Northern Ireland

www.citizensadvice.co.uk

Scotland

03454 040 506

www.cas.org.uk

Depression Alliance

Charity supporting people with depression and their families.

0800 123 2320 (voicemail only)

info@depressionalliance.org

www.depressionalliance.org

Disability Action (Northern Ireland)

This organisation works to ensure that people with disabilities attain their full rights as citizens, by supporting inclusion, influencing government policy and changing attitudes in partnership with disabled people.

028 9029 7880

Textphone **028 9029 7882**

hq@disabilityaction.org

www.disabilityaction.org

Disability Living Foundation

0300 999 0004 (Monday–Friday, 10am–4pm)

helpline@dlf.org.uk

www.dlf.org.uk

Disabled Parents Network

07817 300103

disabledparentsnetwork.org.uk

Disability Pregnancy and Parenthood International

0800 018 4730 (Tuesdays, Wednesdays and Thursdays, 10.30am–2.30pm)

info@dppi.org.uk

www.dppi.org.uk

Driver and Vehicle Agency (DVA) (Northern Ireland)

0845 402 4000 (Monday–Friday, 9am–5pm)

028 7034 1380 (textphone)

dva@doeni.gov.uk

Driver and Vehicle Licensing Agency (DVLA) (England, Scotland, Wales)

0300 790 6802 (driver licensing enquiries) (Monday–Friday, 8am–7pm, Saturday 8am–2pm)

18001 0300 123 1278 (text phone)

www.dvla.gov.uk

Local health services

Find your nearest primary care trust (in England), Health Board (in Scotland or Wales) or Health and Social Care Trust (Northern Ireland) in your local phone book or on the following websites:

England

www.nhs.uk

Northern Ireland

www.hscni.net

Scotland

www.show.scot.nhs.uk

Wales

www.wales.nhs.uk

Mind

0300 123 3393

info@mind.org.uk

www.mind.org.uk

Northern Ireland Association for Mental Health

028 9032 8474

info@niamhwellbeing.org

www.niamhwellbeing.org

No Panic

A charity that helps people to overcome anxiety disorders.

0800 138 8889

admin@nopanic.org.uk

www.nopanic.org.uk

The Outsiders

A club for people who are isolated because of their disability. Also offers advice for people who have concerns about sexual or personal relationships.

07074 990 808

info@outsiders.org.uk

www.outsiders.org.uk

Sex and Disability Helpline

07074 993527

(Monday–Friday, 11am–7pm)

sexdis@outsiders.org.uk

www.outsiders.org.uk

Relate

Provides relationship counselling and support services, delivered at 400 locations, by phone and online.

0300 100 1234

www.relate.org.uk

Relationships Scotland

0845 119 2020 (Monday-Friday,
9am-5pm)

enquiries@relationships-
scotland.org.uk

www.relationships-scotland.org.uk

Scottish Association for
Mental Health

0141 530 1000

enquire@samh.org.uk

www.samh.org.uk



My contacts

GP

Specialist

Parkinson's nurse

Information and
support worker

Physiotherapist

Occupational
therapist

Speech and
language therapist

Parkinson's UK local
group contacts

Local authority

Other

In an emergency
please contact

Non-motor symptoms questionnaire

Assessing the full range of Parkinson's symptoms – especially those not related to movement – can be difficult. It may be helpful to fill in this questionnaire before you visit your specialist or Parkinson's nurse so they can assess any non-motor symptoms you have.

Tick anything that affects you and use this to build a list of priorities to talk about at your next appointment with your specialist or Parkinson's nurse.

- 1 Dribbling of saliva during the daytime.
- 2 Loss or change in your ability to taste or smell.
- 3 Difficulty swallowing food or drink or problems with choking.
- 4 Vomiting or feelings of sickness (nausea).
- 5 Constipation (less than three bowel movements a week) or having to strain to pass a stool.
- 6 Bowel (faecal) incontinence.
- 7 Feeling that your bowel emptying is incomplete after having been to the toilet.
- 8 A sense of urgency to pass urine makes you rush to the toilet.
- 9 Getting up regularly at night to pass urine.
- 10 Unexplained pains (not due to known conditions such as arthritis).
- 11 Unexplained change in weight (not due to change in diet).
- 12 Problems remembering things that have happened recently or forgetting to do things.
- 13 Loss of interest in what is happening around you or in doing things.

- 14 Seeing or hearing things that you know or are told are not there.
- 15 Difficulty concentrating or staying focused.
- 16 Feeling sad, 'low' or 'blue'.
- 17 Feeling anxious, frightened or panicky.
- 18 Feeling less interested in sex or more interested in sex.
- 19 Finding it difficult to have sex when you try.
- 20 Feeling light-headed, dizzy or weak standing from sitting or lying.
- 21 Falling.
- 22 Finding it difficult to stay awake during activities such as working, driving or eating.
- 23 Difficulty getting to sleep at night or staying asleep at night.
- 24 Intense, vivid or frightening dreams.
- 25 Talking or moving about in your sleep, as if you are 'acting out' a dream.
- 26 Unpleasant sensations in your legs at night or while resting, and a feeling that you need to move.
- 27 Swelling of the legs.
- 28 Excessive sweating.
- 29 Double vision.
- 30 Believing things are happening to you that other people say are not.

Parkinson's and you (2014)

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

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

Or you can email us at publications@parkinsons.org.uk. Thanks!

Please tick...

- I have Parkinson's. When were you diagnosed?
- I'm family/a friend/a carer of someone with Parkinson's
- I'm a professional working with people with Parkinson's

Where did you get this booklet from?

Please tick...

- GP, specialist or Parkinson's nurse
- Parkinson's UK local group or event
- Our website
- Information and support worker
- Ordered from us directly
- Other

How useful have you found this booklet?

(1 is not useful, 4 is very useful) 1 2 3 4

Has this resource given you information that might help you manage your condition better?

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

Have you found the publication easy to read/use? Yes No



Continued over the page

What aspects did you find most helpful?

Were you looking for any information that wasn't covered?

Do you have any other comments?

If you would like to become a member of Parkinson's UK, or are interested in joining our information review group (people affected by Parkinson's who give us feedback on new and updated resources), please complete the details below and we'll be in touch.

- Membership
- Information review group

Name

Address

Telephone

Email

What is your ethnic background?

Please tick...

- Asian or Asian British
- Black or Black British
- Chinese
- Mixed
- White British
- White other
- Other (please specify)



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

John Hindle, Consultant Physician, Care of the Elderly, Betsi Cadwaladr University Health Board and Bangor University

Gina Robinson, Academic Senior Nurse and Senior Lecturer at Sunderland University

Claire Hewitt, Information and Support Worker, Parkinson's UK

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

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

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

References for this booklet can be found in the Microsoft Word version at parkinsons.org.uk/publications

How to order our resources

0845 121 2354

resources@parkinsons.org.uk

Download them from our website at parkinsons.org.uk/publications

Can you help?

At Parkinson's UK, we are totally dependent on donations from individuals and organisations to fund the work that we do. There are many ways that you can help us to support people with Parkinson's. If you would like to get involved, please contact our Supporter Services team on **020 7932 1303** or visit our website at parkinsons.org.uk/support. Thank you.

Every hour, someone in the UK is told they have Parkinson's. Because we're here, no one has to face Parkinson's alone.

We bring people with Parkinson's, their carers and families together via our network of local groups, our website and free confidential helpline. Specialist nurses, our supporters and staff provide information and training on every aspect of Parkinson's.

As the UK's Parkinson's support and research charity we're leading the work to find a cure, and we're closer than ever. We also campaign to change attitudes and demand better services.

Our work is totally dependent on donations. Help us to find a cure and improve life for everyone affected by Parkinson's.

Parkinson's UK

Free confidential helpline **0808 800 0303**

Monday to Friday 9am–7pm, Saturday 10am–2pm. Interpreting available.

Text Relay **18001 0808 800 0303**

(for textphone users only)

hello@parkinsons.org.uk

parkinsons.org.uk

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The Information Standard

Certified Member