

# LIVING WITH PARKINSON'S

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



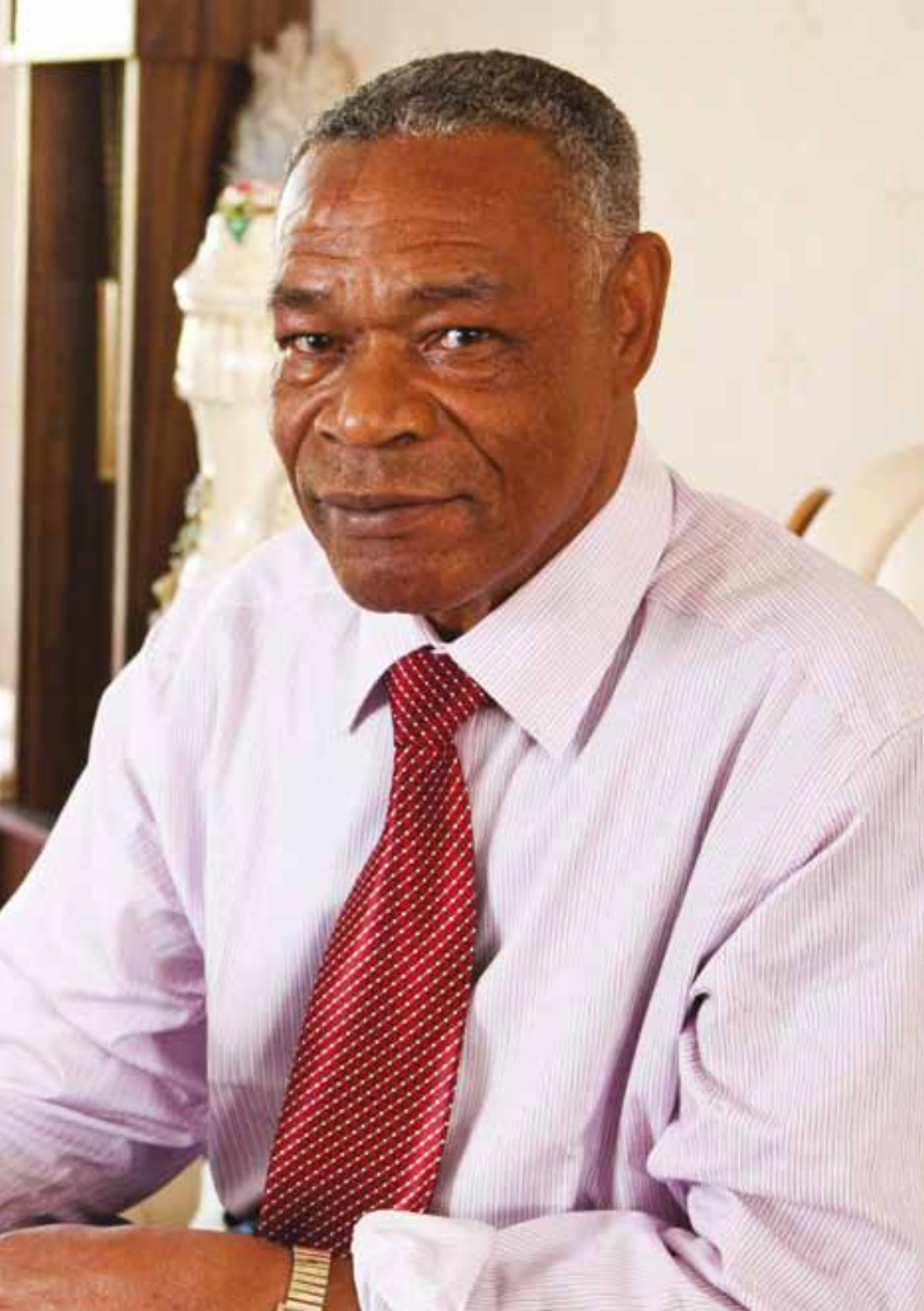
**This booklet is for people who are looking for in-depth information about how Parkinson's may affect their day-to-day lives – and how to manage the condition. It covers aspects such as treatments, relationships, work and travel.**

Everyone's experience of Parkinson's is different, and how the condition may affect your day-to-day life can vary. But by providing practical information about life with Parkinson's, we hope this guide answers some of your questions. Through the voices of others with the condition, we also hope it provides some inspiration to encourage you to continue living life to the full. It also has information that may be helpful for family members, carers and friends.

Contact details for all of the organisations mentioned, details of how to order other resources and a list of useful words can be found at the back of this booklet.

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# WHAT IS PARKINSON'S?

## What is parkinsonism?

Parkinsonism describes a range of conditions whose main symptoms include tremor, stiff muscles and slow movements.

Parkinson's, also known as idiopathic Parkinson's, is the most common form of parkinsonism. Idiopathic means that the cause is unknown. Most people with parkinsonism have Parkinson's, but other types include multiple system atrophy (MSA) and progressive supranuclear palsy (PSP).

**Find out more:** see our information sheet Parkinsonism. We offer support to all people with parkinsonism, but if you've been diagnosed with MSA, you can also contact The Multiple System Atrophy Trust. If you've been diagnosed with PSP, you can contact the PSP (Europe) Association. Contact details are on pages 127-8.

## What is Parkinson's?

Parkinson's is a progressive neurological condition. People with Parkinson's don't have enough of

the chemical dopamine because some 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.

## What causes Parkinson's?

We don't yet know exactly why people get Parkinson's, but researchers think that a combination of genetic and environmental factors cause dopamine-producing nerve cells to die.

## Can certain types of medication cause Parkinson's?

There is a risk that some medications used for other conditions, such as drugs used to treat serious mental health problems, dizziness, nausea and high blood pressure, can bring on Parkinson's-like symptoms. This type of parkinsonism is called drug-induced parkinsonism. This happens with drugs that block dopamine

(the chemical that is in short supply in the brains of people with Parkinson's). If you're worried about the drugs you are taking, speak to your GP.

**Find out more:** see our information sheet [Drug-induced parkinsonism](#).

## How many people have Parkinson's?

About one person in every 500 has Parkinson's. That's about 120,000 people in the UK. Most people who get Parkinson's are aged 50 or over, but younger people can get it too.

## What are the symptoms of Parkinson's?

Not everyone with Parkinson's has the same symptoms. You won't experience all of the possible symptoms and they won't happen in a particular order. Everyone with Parkinson's is different, so how a symptom affects you, the time it takes to progress and how it is treated may be different for you than for other people with the condition. Parkinson's symptoms may change from day to day and even hour to hour, as well as over a longer period of time.

The symptoms most often associated with Parkinson's are:

### Tremor

Parkinson's can cause some people's hands and bodies to shake. It usually begins in one hand or arm. If you have a tremor, it will be easier to notice when your affected body part is resting, or if you are angry or excited. Your tremor may decrease or stop altogether when the body part is used. This is the symptom that many people associate with Parkinson's, but not everyone with the condition has a tremor.

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

### Rigid or stiff muscles

Rigid muscles can make it hard to do everyday things and can be very painful. You may have problems turning around, getting out of a chair or making fine finger movements such as fastening buttons or touch-typing. Some people find that their posture becomes stooped or their face becomes stiff, so it's harder to make facial expressions.

### Slowness of movement

You may find that it gets harder to make movements and that they take longer. Some people's arms stop swinging when they walk, their heel doesn't hit the ground smoothly and they take smaller steps.

These symptoms may be mild in the early stages of Parkinson's, but this can change as the condition progresses. You could also have problems with:

- balance and walking – this can sometimes lead to falls
- freezing – this is when people with Parkinson's stop suddenly while walking or when starting a movement. If you freeze, you may find you're not able to move again for some time

You may find that your symptoms are worse during an 'off' period, when your Parkinson's medication level is low and isn't working so well. When you next take your medication, your symptoms may be less noticeable because you are 'on' again.

**Find out more:** see our information sheets [Falls and Parkinson's](#), [Foot care and Parkinson's](#), [Freezing in Parkinson's](#) and [Motor fluctuations in Parkinson's](#).

## What are the other symptoms of Parkinson's?

For a long time, Parkinson's was seen as a condition that mainly affects movement. But symptoms that aren't directly related to movement are very common – these are called non-motor symptoms.

Everyone with Parkinson's has a different experience of the condition, and it's important to remember that not everyone will experience these symptoms. The speed at which the condition develops and how strongly you experience any symptoms also changes from person to person. But problems you may experience include:

### Depression

This is common in Parkinson's. The symptoms of depression include low mood, lack of sleep, problems with appetite, trouble concentrating and a lack of energy. Depression may be difficult to recognise, as many symptoms overlap with the symptoms of Parkinson's itself.

**Find out more:** read [page 35](#) and see our information sheet, [Depression and Parkinson's](#).

### Anxiety

People with Parkinson's can often experience feelings of anxiety or panic attacks. Mood changes may be caused by your medication level. If you're 'on' you might feel better, but if you're 'off', your negative thoughts may increase.

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

## Apathy

You may experience apathy, and not feel like you want to do very much. You may be content to stay at home and do very little without necessarily feeling sad about this.

## Bladder and bowel problems

Not everyone with Parkinson's will experience these, but difficulties including incontinence and constipation can affect some people.

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

## Dental problems

It's important to keep your mouth and teeth healthy. You may experience problems such as excess saliva and dribbling, or a dry mouth.

Movement problems may make it more difficult to clean your teeth or dentures or to get to the dentist.

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

## Excess saliva and swallowing problems

If you've had Parkinson's for several years, you may find it hard to swallow. This can cause problems with excess saliva.

**Find out more:** see our information sheets [Eating, swallowing and saliva control in Parkinson's](#) and [Speech and language therapy and Parkinson's](#).

## Fatigue

You might find you get very tired, lack energy or feel exhausted. This can affect what you can do and how well you can concentrate.

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

## Pain

Many people with Parkinson's experience pain in some form, often due to muscle spasms (dystonias – see glossary on page 131).

**Find out more:** see our information sheets [Pain in Parkinson's](#) and [Muscle cramps and dystonia](#).

## Skin and sweating problems

Parkinson's can cause the glands in your skin to make too much of a substance called sebum, which can make your skin and scalp greasy and scaly. Sweating, especially at night, can be caused by the condition or some Parkinson's medications.

**Find out more:** see our information sheet [Skin, scalp and sweating problems in Parkinson's](#).

## Sleep and night-time problems

You may experience problems sleeping that will leave you feeling tired during the day. There are many different reasons for these problems, including changes in how you react to your medication, muscle spasms (dystonia) and restless legs syndrome.

**Find out more:** see our information sheets [Sleep and night-time problems in Parkinson's and Restless legs syndrome and Parkinson's](#).

Speak to your GP, specialist or Parkinson's nurse (if you have one) if you are concerned about any of these issues. We have a non-motor symptoms questionnaire available to help with this discussion. You can order a free copy of this and our other resources by using the details listed on the inside back cover. You can also download them from our website at [parkinsons.org.uk](http://parkinsons.org.uk)

To find out more about Parkinson's nurses, see page 17.

## Does Parkinson's cause thinking and memory problems?

For some people, Parkinson's affects thinking and memory. This could be caused by the condition,

a side effect of your Parkinson's medication or by other medical conditions you may have. You may have problems remembering things or concentrating for a long time. You may need extra time to answer when someone is speaking to you. It won't be that you don't understand, it just may take you longer to organise your thoughts and answer questions. You may also find it hard to do more than one thing at a time.

Some people with Parkinson's will go on to get dementia. This is more common in people who develop Parkinson's later in life.

Some people with Parkinson's also get hallucinations and delusions. These can be caused by the condition or can be a side effect of Parkinson's drugs. It is important to talk about any of these problems with your GP, specialist or Parkinson's nurse.

**Find out more:** see our information sheets [Parkinson's dementia, Dementia with Lewy bodies and Hallucinations and delusions in Parkinson's](#).

## How is Parkinson's diagnosed?

Parkinson's tends to develop gradually and it can be a number of months, or even years, before your symptoms progress enough for you to contact your GP.

It is not easy to diagnose the condition, so it's important that you see a Parkinson's specialist to get an accurate diagnosis. A Parkinson's specialist will usually be a consultant or geriatrician with a special interest in Parkinson's. The specialist will usually look for two or more of the main symptoms of tremor, rigidity or slowness of movement.

They will also consider your medical history and carry out an examination before making a diagnosis. The symptoms of Parkinson's can have other causes. When a specialist thinks that someone has Parkinson's, they will rule out other possible conditions, such as MSA, PSP or Wilson's disease, which is a rare, inherited condition that affects the brain and is similar to Parkinson's.

## How does Parkinson's progress?

Parkinson's is a progressive condition, but each person with

the condition is different, so each individual will get different symptoms that won't develop at the same speed or in a set order. It may take years for them to have an impact on your life.

There aren't any treatments available that can stop the progression of Parkinson's, but there are medications that can help manage your symptoms effectively.

New research and treatments mean that people with Parkinson's have a much better quality of life compared with a few years ago.

If you've had Parkinson's for a while and you're worried about any of your symptoms or how well your treatment works, talk to your GP, specialist or Parkinson's nurse. You can also call our free helpline on **0808 800 0303** for information and support.

## Can people of all ages get Parkinson's?

People can get Parkinson's at any age, but the chance of getting Parkinson's increases as you get older. Most people affected by Parkinson's are aged over 65 when they are diagnosed. But young people can get Parkinson's, too. It is estimated that one in 20 people with Parkinson's are under 40 when

they are diagnosed. 'Young-onset Parkinson's' means a diagnosis of Parkinson's in someone who is under 40, but the term is often used to refer to anyone of working age (up to 65).

## Will my symptoms be different if I'm diagnosed with Parkinson's at a younger age?

Younger people with Parkinson's are less likely to have a tremor. However, depression and dystonia, which are muscle spasms that cause unusual body positions such as turned in and arching feet, are more common.

Many younger people will have concerns about how Parkinson's may affect other areas of their lives, such as money, their job, relationships and bringing up children.

## How does Parkinson's treatment change depending on my age?

Your age can have a big effect on which treatments are best for you and how well your medication works.

The treatment for Parkinson's is similar whatever your age, but if you're younger, your Parkinson's

specialist will take two things into account: that you will be living with Parkinson's for many years, and that you're more likely to have some side effects from medication.

If you're a younger person with Parkinson's, your treatment plan might involve the following:

- Not starting your medication straight away. This may be possible if you have mild symptoms.
- Starting with dopamine agonists or MAO-B inhibitor drugs, rather than levodopa. These drugs control symptoms well in the early stages of Parkinson's, and tend to cause fewer side effects. But they generally don't work as well as levodopa. Levodopa is usually prescribed as Parkinson's develops, but it might be used from the start if it helps you control your symptoms so you can still work. You may take a combination of different drugs to treat your symptoms.
- Having surgery for Parkinson's, if your motor symptoms can't be controlled by drugs. See page 31 for more information.

## Can children get Parkinson's?

Very rarely, children and young people aged under 21 can get Parkinson's symptoms. This is known as 'juvenile Parkinson's'. If you think someone might have juvenile Parkinson's, ask your GP for a referral to a neurologist who specialises in treating children, or a movement disorders specialist. The symptoms of juvenile Parkinson's can be caused by rare conditions, including Wilson's disease, dopa-responsive dystonia (Segawa's syndrome) or an unusual form of Huntington's disease.

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

## Can women's menstrual cycles affect their Parkinson's?

There isn't a lot of information on menstruation and Parkinson's, but many women with the condition say their symptoms get worse before and during their period. Some movement symptoms may mean you have problems with the practical aspects of having a period, such as changing sanitary towels or tampons. If you have difficulties with your period or other gynaecological issues, speak to your GP or Parkinson's nurse.

## Why do fewer women get Parkinson's than men?

Slightly more men than women get Parkinson's, especially in younger people. Research suggests that women may be less likely to get Parkinson's, or it may develop later in life and symptoms may be milder, because of higher levels of dopamine in the brain. This is thought to be because of the activity of oestrogen (the female sex hormone).

Although there isn't a lot of information on the menopause and Parkinson's, some studies have shown that Parkinson's symptoms might develop when a woman reaches menopause, which causes the level of the hormones oestrogen and progesterone to fall. It has been suggested that hormone replacement therapy (HRT) may help, but other studies couldn't find enough evidence to show the effects of HRT, so more research is needed.

If you're worried about your symptoms, talk to your GP, specialist or Parkinson's nurse.

# My life with Parkinson's

By Andrea, diagnosed in 2007 at the age of 34

A week after my 21st birthday, I gave birth to my son, Ben. Shortly afterwards, my leg started to shake, particularly if I was stressed, tired or unwell. I was reassured it was a nerve damaged in childbirth and thought no more about it.

Apart from depression and tiredness, I didn't really notice anything more until 2005. By this time I was married to my partner Pablo and had my daughter, Isabel. I was becoming increasingly tired in the afternoon and my arm shook if I did anything energetic. Then I started to stutter and my leg began to drag when I walked. I couldn't write very well, use a computer mouse easily or even brush my teeth with a manual toothbrush.

My GP thought it could be a benign tremor and prescribed me some high blood pressure tablets to try to ease my symptoms. But the tremor didn't really change and as I already had low blood pressure, I ended up passing out at the top of the stairs and falling from top to bottom.

I was then referred to a specialist. There was mention of Parkinson's, but it was not high on anybody's list.

After waiting for what seemed like an eternity, and an MRI scan later, I met the neurologist who said without a doubt it was Parkinson's. In a way, finding out I had this condition was a relief, but in all honesty, I knew next to nothing about it or the implications of having it. As far as I was aware, it was an illness for older people. Well, that was obviously wrong.



# HEALTHCARE PROFESSIONALS

## Which healthcare professionals can help me?

### Your GP

If you think you have Parkinson's, the first person you'll see is your GP. The average GP only has a small number of patients with Parkinson's, and their knowledge of the latest diagnostic and treatment options available may be relatively limited, so your GP should refer you quickly to a doctor who has a special interest and experience in Parkinson's (a Parkinson's 'specialist').

If you are diagnosed with Parkinson's, your GP will be important in your long-term care. They can give you treatment and health advice, and help to access the services you need. They should work closely with your specialist.

Your GP will work with a team including practice nurses, district nurses, health visitors, therapists and counsellors. Together they provide a service called primary care.

### Your specialist

Parkinson's specialists will either be neurologists, or consultants with an interest in the care of older people. Secondary care is the service given by your specialist and the other healthcare professionals in a hospital.

Decisions on your treatment should be agreed between you and your specialist and should consider your abilities, personal situation and your individual needs. Your family might also be involved in making decisions about your treatment.

### The multi-disciplinary team

For you to get the best care for Parkinson's, health and social care professionals from different teams need to work together. Specialists will often run Parkinson's clinics with other health professionals, including doctors, Parkinson's nurses and therapists, such as:

**Occupational therapists** who give advice on daily living, including washing, bathing, dressing, eating, reading and leisure.

**Physiotherapists** who advise on movement problems at home and elsewhere (an occupational therapist can also help you with equipment for this).

**Speech and language therapists** who give advice on anything to do with communication and also on swallowing problems.

### **I find it hard to talk to my GP or specialist. Can you give me any tips?**

Many people find it difficult to talk to their doctor about problems they are experiencing. To make sure you get the best treatment, it's important that you can speak to your doctor about any problems or anything you don't understand. These are some things you can try:

- Prepare yourself for your appointment and think about what you want to get from it.
- Make a list of the questions you want to ask your doctor. Keep them as short as possible. You might want to give them the list to read.
- Take a leaflet or other information with you about the problem you want to talk about.
- Keep a diary of symptoms, side effects and other problems you

have. This can help you to talk about them with your doctor.

- If the doctor says things you don't understand, ask them to explain them to you. It is much better to admit that you don't understand than to pretend you do, and then find you don't know what you need to do when you get home.
- Take someone with you to give you moral support, to speak for you if you find it hard to communicate and to take notes.
- Take your medication with you, including the bottles or packaging. It can be hard to remember the names of each one, particularly if you take a number of different medicines.
- Remember that, however embarrassing you think your worry is, you won't be the first to ask. Doctors are used to dealing with all kinds of problems. They can't help you if they don't know what is really worrying you.

If you really can't talk to your doctor or you find them unsympathetic, you might want to change your GP. You can do this at any time without giving a reason. You could change to another doctor in the same surgery or go to another GP practice and ask to register.

The GP practice doesn't have to accept you, but this doesn't mean you can't approach another surgery in your area.

You can get advice from your local primary care trust's Patient Advice and Liaison Service (PALS) in England, your local Community Health Council (CHC) in Wales, the Independent Advice and Support Service (IASS) in Scotland and the Patient and Client Council in Northern Ireland.

### Find out more

- See our information sheets Talking to your doctor and Keeping a diary, and our Non-motor symptoms questionnaire, which will help your doctor diagnose any symptoms not related to movement.
- The Patients Association's booklet You and Your Doctor is available to download from its website at **[www.patients-association.org.uk](http://www.patients-association.org.uk)**
- **[www.embarrassingproblems.com](http://www.embarrassingproblems.com)** is a website that has information and advice on embarrassing health problems that you might find hard to talk about.

## What does a Parkinson's nurse do?

Parkinson's nurses are experts on the condition and its treatment. They can work in hospitals, the community or both. Unfortunately, there isn't a Parkinson's nurse in every area. We believe it's very important that you have access to specialist nursing care. Not everyone has access to a Parkinson's nurse so we are actively campaigning to make this happen.

You can join our National Campaigns Network to receive regular updates about our national campaigning work and ways you can get involved. To find out more, call **020 7963 9332** or email **[campaigns@parkinsons.org.uk](mailto:campaigns@parkinsons.org.uk)**

Parkinson's nurses support you and your family by:

- finding out what your needs are – they can help you to see the professionals and services that you need
- making a care plan for you
- helping you with your drug treatment
- giving information and education about the condition to you, your carer (if you have one) and health and social care professionals

- solving problems
- giving you emotional and lifestyle help
- supporting you if you're admitted to hospital

To find out if there is a Parkinson's nurse in your area, contact your GP, specialist or Parkinson's UK information and support worker (see page 119 for details).

### Is there a certain standard of treatment I should expect?

The National Institute for Health and Clinical Excellence (NICE) advises the NHS in England and Wales on the most effective treatment and care. The NICE guidance on Parkinson's advises the NHS on what it should do to diagnose and treat Parkinson's, whether someone with Parkinson's is at home, in hospital or in a care home.

The NICE guideline has been reviewed and endorsed by the Department of Health, Social Services and Public Safety for use in Northern Ireland.

In Scotland, NHS Quality Improvement Scotland has produced Clinical Standards

for Neurological Health Services. These guidelines make recommendations about the standard of care that people with any neurological condition should receive from the NHS, and include specific standards about Parkinson's.

The Scottish Intercollegiate Guidelines Network (SIGN) has also produced an evidence-based guideline about the most effective treatments for Parkinson's, but this mainly relates to the diagnosis and drug treatment of Parkinson's.

Recommended treatment standards include:

#### Quick referral to a specialist for diagnosis and regular check-ups

A Parkinson's specialist, not a GP, should diagnose Parkinson's. If your GP thinks you have Parkinson's, they should refer you to a neurologist or, if you're older, a geriatrician, before you start taking medication. NICE recommends you should see a specialist within six weeks and you should have check-ups every six to 12 months. This doesn't apply in Scotland, where the NHS Clinical Standards recommends regular reviews, at least annually. However, there is an 18-week 'referral to treatment' pathway that applies.

## Information and choices

You should be able to talk through your treatment and care options and your healthcare professionals should help you to make decisions.

## Access to a Parkinson's nurse, or the same level of care

NICE states that you should be given someone to contact if you have any concerns or need more information. This might be a Parkinson's nurse (if there is one in your area), who can check your medication and refer you to other health professionals. In Scotland, access to a Parkinson's nurse is required.

## Access to appropriate treatments

NICE advises on medical treatments including drugs and surgery that should be available to you.

The Clinical Standards in Scotland outline the NHS services that you should have access to, including surgery options for Parkinson's, where appropriate.

SIGN will make recommendations about the most effective medical treatments that are available.

Another body, the Scottish Medicines Consortium makes decisions about the cost-effectiveness of

medications and whether they should be routinely offered in the NHS. You should discuss with your specialist or Parkinson's nurse what is suitable for you.

## Treatment for other health problems associated with Parkinson's

You should be offered treatment if you experience other health conditions or problems related to your Parkinson's.

## Access to care in the later stages of Parkinson's

You should be able to get help for issues that affect your quality of life. Your GP, specialist or Parkinson's nurse can help if you want to talk about the support and choices available to you and your carer in the advanced stages of Parkinson's.

## Other support

You should have access to services including physiotherapy, occupational therapy, speech and language therapy and mental health professionals to help with issues such as problems with movement, speech, swallowing and day-to-day activities. Ask your GP, specialist or Parkinson's nurse to refer you.

## What if my care doesn't meet these standards?

If your care doesn't meet these standards, ask your GP, specialist or Parkinson's nurse why. Ask whether they're aware of the guidelines. To complain about your NHS services, contact:

- Your local Patient Advice and Liaison Service (PALS) if you live in England.
- Your local Community Health Council (CHC) if you live in Wales. You can find details of your local CHC by contacting the Wales Board. See page 124 for details.
- The Independent Advice and Support Service (IASS) if you live in Scotland. The IASS is part of the Scottish Citizens Advice Bureau Service and is funded by local NHS Boards. It aims to support patients, their carers and relatives in their dealings with the NHS and in other matters affecting their health.
- In Scotland, Health Rights Information Scotland (HRIS) has a useful leaflet called Making a complaint about the NHS. It is available at [www.hris.org.uk](http://www.hris.org.uk)

- In Northern Ireland, the Patient and Client Council provides advice, information and supports those who want to complain about health and social care services. See page 128.
- You can also get help to make a complaint from your local Citizens Advice Bureau. See page 124 for contact details.

## Find out more

Call our helpline on **0808 800 0303** for information and support, or to find out how to contact your local information and support worker, who can give you information about healthcare services in your area.

Read more about the NICE and SIGN guidelines for Parkinson's at [parkinsons.org.uk](http://parkinsons.org.uk). Call the NHS Response Line (**0870 1555 455** quoting N1053) to order a free copy of the leaflet 'Understanding NICE guidance: Parkinson's disease'. You can download NHS Healthcare Improvement Scotland's Clinical Standards for Neurological Health Services at [www.healthcareimprovementscotland.org](http://www.healthcareimprovementscotland.org)

# My life with Parkinson's

By Tina, diagnosed in 2003 at the age of 43

I worked with people with Parkinson's before I was diagnosed myself. When I was employed as an occupational therapist, the main thing that hit me whenever I was working with a person with Parkinson's was the importance of the timing of medication. Often it takes some time to set up the most appropriate drug treatment for someone, and even then, it is the best choice for a variable length of time, because the condition is ever-changing and progressive.

Over time, someone with Parkinson's may experience increasing periods when the effect of the most recent dose wears off before the next one is due or has begun to work. Involuntary movements may appear and there may be sudden switches from being 'on' and able to move to being 'off' and immobile. One minute the individual would be able to go about their day-to-day activities, and the next they would be completely frozen.

This would obviously impact on my work as an occupational therapist and how effective I could be. I would find that if a person had taken a dose late or missed a dose before I saw them, there would be next to nothing I could do as a therapeutic intervention to make an immediate difference to their wellbeing.

Having Parkinson's myself has made it clear how vitally important medication is to somebody with the condition. About an hour before a dose is due, I start getting jittery and if I take a dose late, day-to-day tasks become increasingly difficult for me to do.



# MEDICAL TREATMENTS

There is no cure for Parkinson's yet, but there are treatments that can help you to control the symptoms and enjoy a better quality of life. These include drugs, surgery, physiotherapy, speech and language therapy, and occupational therapy.

## Parkinson's drugs

This section looks at the medication used to treat Parkinson's, what surgical options are available, and answers some of the questions you may have on these topics.

Medication is usually the main treatment for Parkinson's. There are several types of drugs used to treat Parkinson's, and they act in different ways to improve some of the symptoms.

## What drug treatments are there?

This table shows the drugs most often used to treat Parkinson's. The generic (or common) names are shown, as well as the brand names that have been given by the companies who market them.

**Find out more:** see our booklet [Drug treatments for Parkinson's](#).

Generic name	Brand names
<b>Levodopa</b> This drug is always combined with either benserazide or carbidopa to make sure it enters the brain more efficiently. It can be used at all stages of Parkinson's.	
Co-beneldopa (benserazide plus levodopa)	Madopar® Madopar® CR

Table continued on next page

Generic name	Brand names
<b>Levodopa</b> continued	
Co-careldopa (carbidopa plus levodopa, available in generic form)	Caramet® CR Duodopa® Sinemet® Sinemet® CR Half Sinemet® CR
Co-careldopa plus entacapone (see opposite)	Stalevo®
<b>Dopamine agonists</b> These drugs may be given on their own or prescribed alongside levodopa or other drugs.	
Bromocriptine (available in generic form)	Parlodel®
Cabergoline (available in generic form)	Cabaser®
Pergolide (available in generic form)	Celance®
Pramipexole (available in generic form)	Mirapexin® Mirapexin® prolonged release
Ropinirole (available in generic form)	Requip® Requip® XL
Rotigotine	Neupro®
Apomorphine (available in generic form)	APO-go® PEN APO-go® PFS
Unlike other dopamine agonists, apomorphine is usually reserved for late Parkinson's when symptoms are severe and levodopa is not working well all the time.	

Generic name	Brand names
<p><b>Monoamine oxidase type B (MAO-B) inhibitors</b></p> <p>These drugs are sometimes used alone in early Parkinson's, or with levodopa and sometimes other drugs, in late Parkinson's.</p>	
Rasagiline	Azilect®
Selegiline (available in generic form)	Eldepryl® Zelapar®
<p><b>Catechol-O-methyltransferase (COMT) inhibitors</b></p> <p>In late Parkinson's, COMT inhibitors are used alongside levodopa to help it work more smoothly.</p>	
Entacapone	Comtess®
Tolcapone	Tasmar®
<p><b>Glutamate antagonist</b></p> <p>This is mostly used with other Parkinson's medication and has an effect on tremor and stiff muscles.</p>	
Amantadine	Symmetrel®
<p><b>Anticholinergics</b></p> <p>These drugs are not used very often for Parkinson's but sometimes they are used for reducing tremor and stiff muscles.</p>	
Orphenadrine (available in generic form)	Biorphen® Disipal®
Procyclidine (available in generic form)	Arpicolin® Kemadrin®
Trihexyphenidyl (benzhexol) (available in generic form)	Broflex®

## Getting it right

You and your specialist or Parkinson's nurse will discuss the medication options that are right for you. You may take one drug on its own, or you might take a combination of different types. Because each person with Parkinson's is different, everyone will have different symptoms and will respond to treatment in a different way. So the type and amount of medication, and the times you take them each day, may not be the same as someone else with the condition.

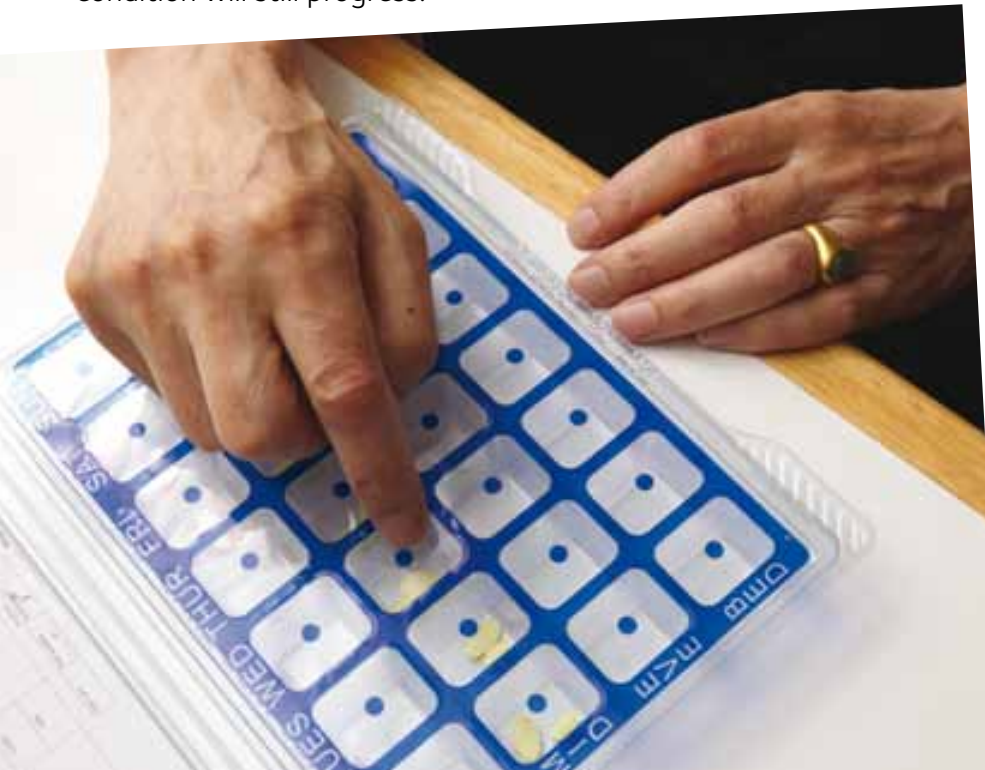
Parkinson's drugs can work well, but they aren't a cure and your condition will still progress.

So the drugs you take will need to be changed or added to so that your symptoms can be controlled.

## Medication timing

Getting used to taking medication every day can be a challenge. Make sure you have the information you need about your drugs. Ask your GP, specialist or Parkinson's nurse if you're unsure of anything.

Whichever Parkinson's drugs you take, it's very important to take them at the right time of the day. This will let you manage your symptoms as well as possible.



## Using pill timers

If you have many different drugs to take or you find it hard to remember when to take them, you might want to use a pill timer. This is a box with a number of sections that separate the tablets that you take at different times of the day. Some have an alarm that will remind you when you need to take the next dose.

## Side effects

Many people find their Parkinson's medication works very well when they start taking it. But this can change over time and side effects of some Parkinson's drugs can develop. Some people's side effects will have a big impact on their lives and have to be kept under control along with the symptoms. Speak to your GP, specialist or Parkinson's nurse, as changing or adding to your medication might help.

People with mild symptoms who have just been diagnosed might not start taking Parkinson's drugs until their symptoms get in the way of their daily life. The current trend is for Parkinson's specialists to start treating symptoms within a year of diagnosis. It's important to talk about your options with your GP, specialist or Parkinson's nurse.

## I have read that some Parkinson's drugs make people want to gamble. Is this true?

Impulsive and compulsive behaviour is a potential side effect of some types of Parkinson's drugs. A relatively small number of people develop impulsive and compulsive behaviour, which can have a big effect on their lives and the lives of those around them. Most of these take dopamine agonist medication, but it can affect people taking some other Parkinson's drugs, too.

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. Some examples are gambling, becoming a 'shopaholic' or binge eating.

Hypersexuality is where someone is focused on sexual feelings and thoughts. Sexual impulses become more intense and may be felt at inappropriate times. With hypersexuality, there is a risk someone may behave in a way that is socially unacceptable, or may even break the law.

Compulsive behaviour is when a person has an overwhelming drive or urge to act in a certain way, often repetitively, to reduce the worry or tension that they get from their drive or urge. This behaviour includes punding, which is repetitive collecting and sorting of objects.

If you're experiencing this behaviour, speak to your GP, specialist or Parkinson's nurse as soon as possible. Your family should also know about this potential side effect so they can spot any unusual signs.

Treatment may include changing your medication, or you may want to talk to a professional about the effects this behaviour is having. Speak to your GP about accessing psychotherapy or counselling in your area. You can also contact the British Association for Counselling

and Psychotherapy for details of private therapists (see page 123 for details).

**Find out more:** see our [information sheet Impulsive and compulsive behaviour in Parkinson's](#).

### **Dopamine agonist withdrawal syndrome**

Recent research has discovered dopamine agonist withdrawal syndrome, which can happen when someone very suddenly stops taking dopamine agonists, perhaps because they are experiencing impulsive and compulsive behaviour. It can lead to symptoms including depression, anxiety or pain. Any withdrawal from Parkinson's drugs needs to be done in a tapered way, under the supervision of a health professional, to avoid the risk of this syndrome.



## **I was in hospital recently and had a lot of trouble getting my medication on time. How can I stop this from happening again?**

Unfortunately this is a common problem and one that Parkinson's UK continues to campaign on. We want to make sure that people with Parkinson's get their medication on time – every time.

As part of our Get It On Time campaign, we encourage care home and ward staff to:

- tell all team members when they have a patient with Parkinson's
- use pill timers or alarm clocks to remind themselves when people with Parkinson's have to take medication outside of normal drug rounds
- encourage patients to self-medicate, when the hospital has a policy in place for this
- make sure everyone knows how important the timing of Parkinson's medication is
- set up training sessions on Parkinson's and medication
- order our Get It On Time resources

If you have a Parkinson's nurse, they can give you more help on what to do if and when you go into hospital. If you have the chance to plan ahead for your hospital stay, you should be able to talk about your needs to staff before you go. Your Parkinson's nurse may be able to do this for you.

### **Find out more**

- See our Get It On Time materials and Going into hospital and Anaesthesia information sheets.
- Our booklet Caring for your patient with Parkinson's will give ward staff more information about your condition. You can take it to any meetings you have before admission.

## **How can I make sure people know I have Parkinson's and what medication I take if I have an accident?**

If you're taken to hospital in an emergency, the professionals looking after you need to know about your condition as soon as possible, so they can give you the right care.

It's a good idea, especially if you live on your own, to fill in the form in the information sheet Going into hospital. On this you can list your drugs and your needs, and anything

else, such as animals that need to be looked after, your emergency contact and the name of your GP, specialist, Parkinson's nurse and any other health and social care professionals involved in your care, such as your physiotherapist or occupational therapist. This is useful in an emergency if you can't tell people these things. Keep it in an easy-to-find place, such as your handbag, wallet, by the telephone or in a special 'bottle in the fridge' (see next column).

Other items you may find useful:

### ['Bottle in the fridge'](#)

The 'bottle in the fridge' scheme is an emergency information service that is provided free of charge by some local charities. The bottle may contain details of your medical conditions and a list of the drugs you take. It is stored in the fridge as most households have one, and it is usually easy to find.

### [Parkinson's UK Medication card](#)

You can also order our Medication card to carry in your purse or wallet.



You can write details of the drugs you are taking, your GP's number and your emergency contact details on this.

### Parkinson's UK Alert card

You can order our Alert card, which has some brief messages that will explain you have Parkinson's if you have trouble speaking. This is useful for when you're out and about. You can also wear an item of jewellery (such as a MedicAlert bracelet or pendant) that holds contact details and medical information. Medical staff will use these if you're taken to hospital in an emergency.

## Surgery for Parkinson's

### What surgery is available to treat Parkinson's?

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

Because of the risks involved in surgery on the brain, surgery for Parkinson's is mainly used to treat people who have had Parkinson's for a long time or whose symptoms can't be controlled by drugs. It may also be used if you are experiencing strong involuntary movements (dyskinesias). It may not be an option if you have uncontrolled

high blood pressure, heart and lung disease, severe depression, confusion, dementia or psychosis.

There are two main types of surgery used to treat Parkinson's. One type is lesioning. This involves damaging certain cells within specific parts of the brain (by making a lesion). These lesions are known to have a good effect on some Parkinson's symptoms. The other type is deep brain stimulation.

### What is deep brain stimulation?

Deep brain stimulation is a type of surgery used to treat Parkinson's. It involves inserting very fine wires, with electrodes at their tips, into the brain. This is done under local anesthetic so the person is awake and the site for stimulation can be correctly found. When it is found, an electric current is passed through the wires, and this will have an effect on the person's symptoms. The wire is then connected to a unit that is implanted under the skin of the chest, like a pacemaker. This is done under general anesthetic.

Talk to your Parkinson's specialist about whether surgery is an option for you.

**Find out more:** see our booklet [Surgery and Parkinson's](#).



# EMOTIONS AND MENTAL HEALTH

For many people with Parkinson's, the condition has a big effect on their thoughts and feelings. How it affects you will depend on:

- your symptoms and how they affect the activities you do
- your response to treatment
- your age when you're diagnosed
- your personal circumstances
- your personality and approach to life
- what matters most to you – practically, emotionally, psychologically and spiritually – and how this is affected by Parkinson's
- the support that is available to you
- how the condition affects your relationships

Everyone with Parkinson's is different and people's reactions to a diagnosis will vary, but you may:

- feel relieved there is a reason for the problems you've been having
- feel devastated, angry, depressed or anxious
- not accept what is happening, hide it or have trouble telling people

Realising you have these feelings and accepting the diagnosis is the first major step in living successfully with Parkinson's. If you've just been diagnosed, give yourself time to digest the information. Don't make any big choices about your life until you've had time to accept the diagnosis and you've found the right information and support.

In the early stages of Parkinson's, many people find that their symptoms are mild and can be managed well with the available treatments. But as the condition progresses, it will have a bigger effect on your life. When this happens, you may find that your thoughts and feelings change a lot.

You might have low times when you feel down, especially if you have to make big changes, like giving up work.

People close to you may also experience a range of reactions to your diagnosis. See the relationships section on page 47.

## **I sometimes find it hard to cope with Parkinson's. Who can I talk to?**

Talking to someone else about your feelings can help you to realise what's really worrying you. Then you can focus on ways to deal with any difficulties you might face. If you're finding it hard to cope, it's really important to get help before the situation gets worse. Finding ways to cope with your thoughts and feelings can help you cope better with all the practical issues that Parkinson's throws at you every day.

Who you talk to depends on your personal situation, what you're finding hard to deal with and who you feel most comfortable with. You may choose to talk to someone who knows you well, such as a partner, relative or friend. But some people like to speak to someone who is not close to them. This could be a health or social care professional. It might

be a Parkinson's nurse, a therapist or your local Parkinson's UK information and support worker.

You could also speak to a professional counsellor. They will help you look at your life and the feelings you have in a safe environment. They won't give you medical advice, but they'll give you space and time to consider your feelings and actions to give you an idea of what you find hard and why. This can help you to sort out your feelings, accept your situation or make changes to your life.

Many GP surgeries have counsellors attached to their practice or can give you information about other local counsellors. There are also other counselling organisations that can give you information and details of private counsellors. These include Relate and the British Association for Counselling and Psychotherapy.

You may also meet someone at your local Parkinson's UK group that you can speak to about living with the condition. See page 119 for more details.

If you don't want to meet people face to face, or if you live in an area with no local Parkinson's UK groups nearby, you can call our helpline on

**0808 800 0303** for information and support. There are also online forums where you can talk to other people, including our online forum at [parkinsons.org.uk/forum](http://parkinsons.org.uk/forum)

**Find out more:** the mental health charity Mind has a guide, *Making Sense of Counselling*. This covers what counselling is, how it can help, what it involves, the types available and how to find a counsellor. There is a small charge for this booklet.

## Do people with Parkinson's get depression and why?

Depression affects some people with Parkinson's. It can make you feel low and can stop you wanting to do things. It can affect your sleep, appetite and energy levels and make it hard to concentrate.

Many people will get depressed because of the effect living with Parkinson's has on their lives. Some people are more likely to get depression as their Parkinson's symptoms become more noticeable. You may also be affected by change, for example if you need to give up work or activities you used to enjoy. Others have depression even before being diagnosed with Parkinson's and it is thought that depression may be a symptom of Parkinson's.

Changes to your Parkinson's medication might help with depression. You might need to take antidepressants (be aware that some of these may not be suitable for you) or have counselling or other mental health therapies. Speak to your specialist or Parkinson's nurse about making any changes to your medication. Taking exercise and learning how to relax may help.

## Find out more

- See our information sheet *Depression and Parkinson's*.
- Our information and support workers and helpline advisers offer a listening ear if you'd like to speak to someone about how you are feeling. Call **0808 800 0303**.
- Support is available from mental health organisations, such as the Depression Alliance or Mind in England and Wales, Action on Depression in Scotland or the Scottish Association for Mental Health, or the Northern Ireland Association for Mental Health or Cause in Northern Ireland.
- The Royal College of Psychiatrists has accessible guides to mental health issues, including depression. See page 119 for contact details of all organisations.

## Are panic attacks common in Parkinson's?

Panicking is the body's natural reaction to fear or danger. A chemical called adrenaline is released that makes you alert and ready for action.

But some people have panic attacks for no clear reason. A panic attack is an overwhelming feeling of fear or terror that comes out of the blue. Someone having a panic attack might feel sweaty, have a racing heart and feel short of breath.

People with Parkinson's may be more likely to suffer from panic attacks and these may be affected by certain medications. They can also happen at times when your medication is 'wearing off' or working less well. You might have a panic attack because you're worried about Parkinson's and how you'll cope in certain situations.

Panic attacks won't harm you, but they can be frightening, and unless they're controlled, they can stop you doing things because you're worried about having an attack. Talk about this problem with your GP, specialist or Parkinson's nurse. They might also suggest medication or some types of therapy. Exercises to help you



relax might help, such as counting slowly in your head, listening to soothing music, taking a warm bath or doing yoga or meditation.

### Find out more

- See our information sheet [Anxiety and Parkinson's](#).
- The mental health organisation Mind has a booklet, [How to cope with panic attacks](#), and a shorter leaflet, [Troubleshooters: panic attacks](#), both available to order for a small charge. See page 127 for contact details.
- Other organisations that can help you include [No Panic](#) and [Anxiety UK](#). See page 122 for contact details.

# My life with Parkinson's

By Susan, diagnosed in 1997 at the age of 43

I was diagnosed on 6 March 1997 – you don't forget dates like that. I was working as a registered general nurse on a busy surgical ward, having embarked on a new career after a period of staying at home and looking after our three children. It had been a challenge studying to be a nurse – little did I know that I was about to face a bigger challenge in having Parkinson's.

Initially, I coped very well. After ringing Parkinson's UK – and reading what was in the library – I got on with life. I wasn't hiding my condition, but I wasn't mixing with others with Parkinson's either.

Only recently did I feel that the condition was having more of an effect on my life. Strangely enough it was depression, not Parkinson's – although it is associated with the condition – that made me wave the white flag and surrender.

Fortunately I have an excellent GP and during a consultation, he spotted my low mood. I admitted I was not very happy, but I didn't think I was depressed. I had an assessment that would tell me if I needed medication and a prescription – just in case. To my surprise, I was moderately depressed and started taking yet another lot of pills!

It has taken over seven months to be back to 'normal' and fighting the good fight yet again. I can now focus on the positive aspects of my life with Parkinson's – such as quality time with my two-year-old grandson. I am here for my daughter and her young family, spend more time with my husband and still have an active social life.

# My life with Parkinson's

By Jenni, diagnosed in 2001 at the age of 51

Everyone experiences some challenges in life – perhaps divorce, redundancy or hitting the big '50', even being diagnosed with Parkinson's – I just managed to do them all at once. But my pragmatic nature helped me to accept 'that's life' and that I may as well get on with it. A sense of humour has helped too!

Having been a divisional director in the insurance industry for many years, it was a shock to find my brain as well as my body slowing down. Fatigue was affecting my ability to drive and fulfil my job, so I had to accept early retirement at just 57.

I've been involved with the local music society for 25 years – I've been a dancer, a soloist, a chorus girl and now the all-important Wardrobe Mistress, so I'm not going to let Parkinson's stop me doing what I love. I've also taken on the challenge of being Secretary of the Newport Branch of Parkinson's UK. These two roles give me a huge sense of personal worth and achievement, and keep me occupied and amused. You may find me planning a monthly meeting or creating 20 hats for a performance. The bonus is, I can do these sitting down. I live alone and these social connections add to my support network.

Somehow I fit in regular swimming, keep fit classes, flower arranging, numerous family visits and the treat of holidaying with friends in South Africa and Turkey each year. I don't have time to feel sorry for myself. A positive mental attitude is essential. Although I admit that Parkinson's impacts on my life, I consider myself fortunate that with modern medication, it certainly doesn't dominate it.

# SELF-HELP

## What self-help strategies can help me cope with Parkinson's?

When you're living with a long-term condition such as Parkinson's, self-help strategies can be as important in helping you cope with the condition as the support you receive from medical treatments and health and social care. Below are some strategies that have worked for other people with Parkinson's.

### Having a positive attitude

Although it won't be easy, especially if you've just been diagnosed, this is a big part of coping with Parkinson's. It can be hard to do all of the time, but many people with Parkinson's say that a positive attitude makes a big difference to how they lead their lives. Some people find that thinking about what they can do, rather than what they can't, helps too. Developing a positive attitude can take time and be affected by your condition and other things in your life.

If you're dealing with difficult emotions or are depressed, it's important to speak to your GP, specialist or Parkinson's nurse before the situation gets worse. They can refer you to services, such as counsellors and psychotherapists, who can support you.

### Keeping stress under control

Try to keep a sense of perspective, as stress can affect Parkinson's symptoms. Seeing problems as challenges and breaking them down into smaller stages can help. You could try using relaxation techniques, or some complementary therapies.

**Find out more:** see our booklet [Complementary therapies and Parkinson's](#).

### Staying active and enjoying your interests

Make sure Parkinson's doesn't become your only focus in life. Try to get plenty of exercise and continue to enjoy the hobbies and interests

you had before you were diagnosed, or develop new ones. Don't give up if you find a much-loved activity is hard to do – get advice from an occupational therapist. They might be able to suggest ways of making things easier, perhaps by changing the way you do something or by using equipment.

### Being creative

Many people enjoy expressing themselves through creative therapies such as writing, art and music. They might help you to express your feelings about your life and having Parkinson's. You can read more about this in our booklet on complementary therapies, mentioned previously.

Some local Parkinson's UK groups offer regular creative sessions such as art, dance and singing groups. Find your local group at [parkinsons.org.uk/localgroups](http://parkinsons.org.uk/localgroups)

You can also enter your art work in our annual Mervyn Peake awards. Find out more about the benefits of creative activities on page 94.

### Staying informed about Parkinson's

Read our website, information sheets and booklets to discover more about the latest news and

“My father began Pilates at the age of 78, and hasn't looked back! He visits a local studio on a weekly one-to-one basis. The teacher is a specialist in Pilates for older people, and he is not her oldest client! He insists that the sessions have helped his mobility, and would recommend them to anyone.”

### Sarah, whose dad has Parkinson's

research. You can also go along to talks at your local Parkinson's UK group. This will help you to be more informed about your condition and treatment, which will help you to make informed decisions about your care.

### Meeting others in a similar position

Many people find it helps to meet other people with Parkinson's, and their families, through their local group. Call our helpline on **0808 800 0303** or visit [parkinsons.org.uk/localgroups](http://parkinsons.org.uk/localgroups) to find your local group.

## Helping others

Many people say that they gain a lot of satisfaction from helping others with Parkinson's. You can do this by raising awareness of the condition, working as a volunteer for your local group, or by fundraising. Find out how to contact your area's regional fundraiser by calling **0808 800 0303** or visiting **[parkinsons.org.uk/localtoyou](http://parkinsons.org.uk/localtoyou)**

**Find out more:** [Living with a Long-term Illness: the facts](#) by Frankie Campling and Michael Sharpe focuses on self-help and maintaining a positive attitude when you have a long-term health condition.

## Can I take more control of the care I receive?

There are websites that provide information about medical conditions and can point you in the right direction for further support:

- England: NHS Choices (**[www.nhs.uk](http://www.nhs.uk)**)
- Northern Ireland: **[www.nidirect.gov.uk](http://www.nidirect.gov.uk)**
- Scotland: **[www.nhs24.com](http://www.nhs24.com)**
- Wales: Health in Wales (**[www.wales.nhs.uk](http://www.wales.nhs.uk)**)

“ I have been going to t'ai chi classes for about four years and find them helpful for balance and co-ordination as well as the companionship. ”

### **Caroline, diagnosed in 2003**

You can also use the relevant website to find services in your area, including GP surgeries, hospitals and pharmacies. If you do not have access to the internet, you can find contact details for health and social care services in your local phone book.

## Personal budgets and individual budgets

Across the UK, new ways are being tried that will give people greater choice over the support they receive. Most commonly, this includes an offer of direct payments.

A personal budget is the amount of money social services makes available for a person's care and support needs. You know how much is available upfront and the money can be spent in any way you choose, so long as it meets the needs identified in your support plan and it doesn't put you at risk.

An individual budget is very similar to a personal budget, but includes funding from other services such as healthcare, housing-related support and disabled facilities grants.

Both individual and personal budgets can be paid to you in different ways.

In England, personal budgets, given partly or completely as 'direct payments', are going to become the main way of delivering and funding social care services in the future. In Northern Ireland, Scotland and Wales, direct payments may be offered as an option for people assessed as needing care services.

Direct payments are cash payments made by local authorities straight to the person who has been assessed as needing social care services. They allow the person to buy the support they need instead of care being arranged for them. The local authority will monitor that the money is being spent to meet the person's needs, as set out in their support plan.

The aim of this scheme is to give people greater choice and control over their lives, and will help them to make their own decisions about how their care and support is

delivered and paid for. Payments could go towards respite care or caring support. The amount of the direct payment will depend on your financial position when you are assessed. Part of the assessment will determine how much you will need to contribute towards your personal budget.

The authority responsible for care where you live should offer direct payments to people who meet the necessary criteria, but direct payments don't have to be used if you would prefer the local authority to arrange services for you.

### Find out more

- Contact your local council social services, social work department or health and social care trust, your information and support worker, or our helpline on **0808 800 0303** for more information.
- In England and Wales, visit the website **[www.direct.gov.uk](http://www.direct.gov.uk)** to find out more about direct payments.
- The Department of Health in England has produced an information guide to direct payments. This, and an easy-read version, can be downloaded from **[www.dh.gov.uk/publications](http://www.dh.gov.uk/publications)** or call **0300 123 1002** (Textphone **0300 123 1003**).

- In Northern Ireland, find out more at [www.nidirect.gov.uk](http://www.nidirect.gov.uk). There are guides to direct payments available to download on the website. You can also order these by calling **028 9052 2910**.
- In Scotland, you can find out more about direct payments on the publications section of the Scottish Government Health Directorates website at [www.sehd.scot.nhs.uk](http://www.sehd.scot.nhs.uk)

## What is the Expert Patients Programme?

The Expert Patients Programme is an NHS-based training scheme in England that recognises the importance of patient empowerment. Set up for people with long-term chronic conditions, it aims to help people to develop new skills to help them to manage their condition on a daily basis.

The NHS describes an ‘expert patient’ as someone with a long-term condition who “can take more control over their health by understanding and managing their condition, leading to an improved quality of life”.

The programme is based on research from the UK and the USA over the past 20 years, which shows that people living

with chronic illnesses often know the best way to manage their condition. If they are given the skills they need to do this, it can have a big effect on their quality of life. The benefits include:

- feeling confident and in control of your life
- being able to manage your condition and its treatment in partnership with healthcare professionals
- being able to talk confidently with professionals and being willing to share responsibility on treatment
- being realistic about the impact of your condition on yourself and your family
- using the skills and knowledge you have to lead a full life

To become an ‘expert patient’, you take a six-week course (two and a half hours a week), which is led by someone who lives with a long-term condition themselves.

**Find out more:** in England, visit the website [www.expertpatients.co.uk](http://www.expertpatients.co.uk) or call **0800 988 5550**. Similar programmes are available in Northern Ireland, Scotland and Wales. Contact your Parkinson’s UK country team to find out more about these.

## What are complementary therapies and how can they help?

Complementary therapies are non-conventional health treatments, often based on ancient systems, which may be used in addition to conventional medicine. Examples include acupuncture, the Alexander technique, aromatherapy, Ayurveda, creative therapies (involving art, music, dance or drama), chiropractic, conductive education, herbal medicine, homeopathy, osteopathy, Pilates, reflexology, t'ai chi and yoga.

Complementary therapies are often popular with people who have long-term conditions, such as Parkinson's. There is not very much evidence available about the benefits, but many people report that complementary therapies help them with things like controlling their posture, fitness, relaxation, social interaction and personal development. Relaxation therapies have been found to be very helpful, as stress can make Parkinson's symptoms worse.



If you are thinking of trying a complementary therapy, talk about it with your GP, specialist or Parkinson's nurse to make sure the therapy is right for you. This is very important if you want to use herbal medicines, as some cannot be used with, or have bad effects on, Parkinson's medication.

You should also make sure that the therapist you use is properly trained and is linked to a professional organisation that ensures they work to certain standards.

**Find out more:** see our booklet [Complementary therapies and Parkinson's](#).

## How do illegal drugs affect Parkinson's?

Some illegal drugs can cause drug-induced parkinsonism. In the early 1980s, some people who took a chemical called MPTP (a synthetic version of heroin) developed parkinsonism. In addition, recent research has suggested that people who use methamphetamine (the recreational drug crystal meth) or other amphetamine-like drugs may be more likely to develop Parkinson's.

Some people with Parkinson's ask us whether cannabis could help

their condition, because reports have suggested that it helps people with multiple sclerosis, another condition that affects the brain. Studies have looked into the benefits of cannabis on dyskinesia (uncontrollable movements) caused by taking levodopa, but no significant benefits have been found.

Although there is still no consensus on the effect of cannabis on Parkinson's, the way it affects mood means that it's likely to have a negative effect on everyday life.

Research continues into whether the parts of ecstasy that don't cause harm could be used on their own to create new treatments for Parkinson's.

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

# My life with Parkinson's

By Adrian, diagnosed in 2007 at the age of 61

I worked as a toastmaster for several years after leaving the armed services, and it was while pouring wine into glasses that I became aware that something was wrong with me. My dominant hand is my right one, yet the wine bottle kept tapping on the rims of the wine glasses as I was pouring. Several people made jokes about it, saying that I must have had too much to drink myself, but I became concerned enough to see my GP.

We did some tests, such as placing the tips of my index fingers, in turn, on the tip of my nose while my eyes were closed. She then said, "I think you have Parkinson's," and referred me to a neurologist to confirm the diagnosis.

I knew a person who'd had Parkinson's for 18 years, but I must admit I felt scared that my life was about to be cut short. My wife sent off for the Parkinson's UK DVD for newly diagnosed people, and it that showed me that many of my fears were unfounded. There were many people with various stages of Parkinson's who were leading very fulfilling lives. One important message was that not all people with Parkinson's end up in wheelchairs.

I don't like to put my health entirely in the hands of medical doctors and I decided that I would take responsibility for myself. So I cleaned up my diet and lifestyle. I do realise that the time may come when I have to start taking Parkinson's medication, but this will be my decision after taking advice from my neurologist.

There are things I can't do without help, such as buttoning my shirt. My decorative painting is also out of the question now, but I don't dwell on it too much, because there are many things that I still enjoy, such as canoeing.

# RELATIONSHIPS

When you have Parkinson's, your relationships with partners, family, friends and colleagues can change. This can happen at any stage of the condition. You may find you can adapt to these changes and fit them into your life, or you may find them difficult. You may find that family relationships are most affected.

This section looks at how relationships can be affected by Parkinson's and gives practical ways to manage these changes.

Relationships can be affected by:

## Reaction to diagnosis

People react to a diagnosis of Parkinson's in different ways, and expect different things of the condition. You may be afraid you'll become disabled very quickly, or you may not expect it to affect you at all. If you have ideas of what's going to happen that are different to what your partner or family think, this can lead to problems. You should get as much information about Parkinson's as possible to

make sure that what you expect is realistic. Talk about your expectations with your partner, family, friends and the health social care professionals involved in your care.

## Changing roles in a relationship

When someone has Parkinson's, the positions or roles that people have in partnerships and families can change over time. This is because people take on different tasks. A carer may have to take on more jobs around the house. The person with Parkinson's may have to give up work, and their partner could become the main earner.

Your partner and family members may feel under pressure, and you may miss your old role, or feel you don't have one anymore. It is no one's fault, but this can make you or your family members feel hostile, resentful, guilty, powerless or lost.

## Communication

Parkinson's can affect all types of communication – speaking, facial expressions, body language

and writing. Changes in how you use these skills can have a big effect on your personal and professional relationships.

If you are less able to use facial expressions or body language, this can confuse people. They might think you are not interested or don't want to talk to them, when this isn't true. Some people find it hard to do intimate things that are part of their relationship with their partner, such as squeezing a hand.

### Social isolation

You might find you become withdrawn and less confident, especially if you don't have support and you have trouble speaking to people. If you feel as though you've lost your social position in your family group or workplace, this might lead you to feel lost or less important.

You might not want to take part in social activities, especially if you think your symptoms make you stand out or you're embarrassed by them. It can be worse if you don't have the support of family and friends or if strangers are unsympathetic to you.

If you're feeling embarrassed about your symptoms, you could go along to one of our local groups, where you can get used to socialising with others in a relaxed way.

### Parkinson's symptoms

Depression and fatigue, which are common Parkinson's symptoms, may have a big effect on your relationships. You may also experience mood swings when levels of dopamine in the brain go up and down. This might be linked to the times you take your drugs. Mood changes can be very dramatic.

When your medication is working, you can feel relaxed and positive about your situation. But when it's not working, you might feel worried or low. This can affect you and your family.

If you are having these feelings, speak to your GP, specialist or Parkinson's nurse. They can direct you to any further help you may need. You can also call our helpline on **0808 800 0303** for support and information.

### How to cope with changes in your relationships

You may want to try some of the following:

- Talk about your feelings with those close to you without blaming each other.
- Tell your family or partner the attitude you want to have to your condition and how they can help you with this.

- Some roles may have to change, but you may be able to share work so that no one has to do everything.
- Work together to solve problems so that everyone is happy. This may mean having to be flexible and coming to a compromise.
- Decide what your priorities are and focus your energies on these. Don't make the condition the whole focus of your life.
- Drop, change or find help with activities that are not so important.
- Don't be afraid to look for help if you find it hard to sort out problems. Professionals, such as occupational therapists, Parkinson's nurses, our information and support workers, our helpline advisers (on **0808 800 0303**), counsellors and psychologists, may be able to offer you support.
- Talk to other people with Parkinson's and their families who have been through problems like yours.
- Keep your sense of humour. This will help you to keep things in perspective and will make stressful times better.
- Don't let Parkinson's get in the way of everything you do. Make sure you enjoy activities together, even if you have to change them to make them easier.
- Get help before your problems have the potential to reach breaking point.
- If you're a carer or family member, help the person with Parkinson's to be as independent as possible, even if things take longer. Make sure you have the support you need, too.
- Remember that Parkinson's doesn't always cause problems for relationships. We've met many couples and families who say that coping with Parkinson's together has made their relationships stronger.

### Find out more

- See our information sheets Communication and Parkinson's, Depression and Parkinson's and Fatigue and Parkinson's.
- Living with a Long-Term Illness: the facts by Frankie Campling and Michael Sharpe has sections on emotions and relationships.
- Read actor and Parkinson's research campaigner Michael J Fox's autobiography Lucky Man. In it he describes how, after he'd

got over the shock of his diagnosis, his family relationships improved and he appreciated his family more.

## How does Parkinson's affect intimate relationships?

Sex is important to most people, whether they have Parkinson's or not. Being diagnosed with Parkinson's may affect your sex life, but it doesn't mean you'll definitely have sexual problems. The main causes of problems in the sex lives of people with Parkinson's are often the same as those that affect other people. Our sex lives can be affected by:

- tiredness
- stress and anxiety
- money worries
- worries about the future
- worries about self-image
- lack of communication

Having Parkinson's can make things more difficult. The condition will make it harder for you to move freely. It can stop you from making spontaneous movements. You may find it physically hard to show affection, for instance, feeling steady enough to give a hug or to lean over to give a kiss.

Your spouse or partner might also find it hard to switch from being in a supportive role to being intimate in a sexual way.

Other problems you might experience include:

- a lack of interest in and desire for sex
- lack of arousal
- physical problems, including trouble having an orgasm

These can affect both men and women, but research has shown that sexual problems are more likely to be experienced by men than women. For example, men may have erection problems – your GP might prescribe drugs such as Viagra®, Cialis® or Levitra® for this. Speak to your GP or Parkinson's nurse about any problems you are experiencing.

Another side effect of some Parkinson's drugs is an increased interest in sex. This is called hypersexuality (see page 27). This can have a big effect on personal and professional relationships. You should speak to your GP, specialist or Parkinson's nurse if you have this problem.

## Tips for managing problems with intimacy

- Talk to your partner about any difficulties you're having, as soon as they happen. Talking about concerns is an important part of any good relationship. This may help you solve problems before they get worse.
- Many people say that keeping a sense of humour reduces tension and keeps things in perspective.
- You may be able to get over the physical problems that happen as a result of having Parkinson's. Try changing the times of the day you have sex, or experiment with different positions.
- Talk to a professional about your problems. This could be your GP, specialist, Parkinson's nurse, a counsellor at an organisation like Relate or an adviser on our helpline (**0808 800 0303**). Realising you need this type of help and asking for it can be hard. But don't feel embarrassed. These people are used to dealing with these problems and you won't be the first to ask.
- Above all, talk to each other. You might have a different attitude to sex, but Parkinson's shouldn't stop you enjoying it.

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

## I am single. How will Parkinson's affect any future relationships I may have?

Parkinson's doesn't mean you can't have good emotional, sexual and intimate experiences in the future. You can tell future sexual partners about your condition, as much as you want to and when you want to. Many people who have been in this situation say it's best to be honest.

Some of the most common causes of relationship and sexual problems happen to everyone, with or without Parkinson's. You might want to talk to other single people with Parkinson's at your local Parkinson's UK group (find your nearest group at **parkinsons.org.uk/localgroups**), or on our online forum at **parkinsons.org.uk/forum**

# My life with Parkinson's

By Catherine, diagnosed in 1996 at the age of 25

My mum and I were asked into the consultant's office and it was there that my life changed for ever. "You've got Parkinson's," he said. "I've got what? At 25, I've got what?" I replied.

As my mum sighed with relief, knowing that I wasn't terminally ill, I could hear nothing and was in shock. We headed home to tell my dad and sister. There were plenty of tears. We had been told something that would change our lives for ever and were all in complete shock. We wanted to carry on as if nothing had changed ... for a short time anyway.

Years later, my Parkinson's has progressed. I can be off work for months at a time, but life is what I make it. I have been through a divorce and a miscarriage, and have experienced things in life that most people could never imagine. There's no denying, living with Parkinson's is hard. But each day is different and although I can feel low at times, through everything I stay strong.

In February 2006, I met a person who I never dreamt existed for me. He has changed my life completely. He is my perfect partner. He's kind and loving, he is there every step I take, and supportive of my every decision. We married in September 2007 and now have a little boy – Jacob Isaac.

It is really hard to imagine the future – I don't know what it holds, because the condition is so different for everyone. I live for today, and cram as much into life as I possibly can. I just have to live with my Parkinson's and that's what I intend to do.

# Our lives with Parkinson's

By Roger, diagnosed in 2002 at the age of 52

I decided in the beginning that I would try to carry on living as normally as possible, although soon I realised that I would need more help from my wife, Del. I found I would get annoyed when I couldn't do some tasks and Del could do them easily. As time went on and with Del's help, we began to laugh about the difficulties I had, and this brought us closer together.

And Delphine, who has been married to Roger for 40 years

Although it was really hard to deal with the diagnosis, it didn't come as a complete shock as Roger's father had Parkinson's. Has it changed us? We are closer now than ever and have more time for each other.

In the beginning, Roger had problems keeping his medication down. I felt so helpless and would go for a shower so I could have a good cry. My capable husband was now struggling with simple tasks and needed my help to complete them. Life became different. It took two years before I could tell Roger how difficult it was for me after his diagnosis.

Now though, we're just the same as we were before Roger's diagnosis. We love each other, we look after each other and most of all, we are there for each other. Round one to us – round two, we will have to wait and see.



# BEING A PARENT OR GRANDPARENT

## How do I talk to my children or grandchildren about Parkinson's?

If you have children or grandchildren, they'll want to ask questions about Parkinson's and how it will affect you in the future. Many parents and grandparents wonder if they should tell their children or grandchildren about the condition and what the best way to do this is.

These tips from parents, grandparents and psychologists may help you:

- Be open, honest and realistic with your children or grandchildren. Don't hide the condition from them. They may worry more about what they don't know than what they do.
- Explain Parkinson's simply and in the right way for their age (see the next page for booklets and leaflets that can help you).
- Talk about the condition in a clear and specific way and try not to assume anything. You may know people can't catch Parkinson's, but would a child?
- Children need to feel in control about how much information they receive and when. Don't tell them too much at once, but make sure they know they can talk about Parkinson's with you and ask questions at any time.
- Reassure them that it's very unlikely that they'll get Parkinson's.
- Call our helpline on **0808 800 0303**, speak to your local information and support worker, your GP or Parkinson's nurse if you are finding it hard to tell your children, or if you're worried about their reaction and how they are coping with the news.
- Speak to parents or grandparents in a similar position – contact them through your local Parkinson's UK group.

## Young carers

If you're under 18 and help to support a relative with Parkinson's, you'll be described as a 'young carer'. You might support your relative alongside other family members, or you might care for them on your own. Whether you give practical care or not, if you have a parent or grandparent with Parkinson's, you'll still benefit from support. This includes somewhere you can get more information and someone you can ask questions and talk to.

## Find out more

- See our information sheet Talking to children about Parkinson's. This also has contact details for organisations who can give information and advice on young carers and children's issues.
- Our booklet The carer's guide has a section for young carers.
- Our publications for children and young people include story books for children with a parent or grandparent who has Parkinson's. We also produce Parkinson's: The Facts – a guide for young people aged 11–17 years.



- I'll Hold Your Hand, So You Won't Fall: a Child's Guide to Parkinson's Disease is a book by Muhammad Ali's daughter, Rashida.

## Will I be able to father children?

We know of several men with Parkinson's who have fathered children since their diagnosis. This includes the actor and Parkinson's campaigner Michael J Fox. But there hasn't been any scientific research that looks at how Parkinson's affects male fertility.

## 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. The evidence available isn't very helpful – it just says that 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're pregnant and have Parkinson's, this advice might help with some of the problems you might face:

## Balance problems

Talk to your health visitor for advice on posture. You could also speak to a physiotherapist for advice on balance and whether you need a walking aid.

## Slowness of movement

Give yourself more time to do daily tasks. Remember that you'll also feel more tired than usual.

## Sickness and vomiting

Talk to your GP or hospital team for advice. You should tell them, as they may not be aware, that Maxolon and Stemetil should NOT be given to anybody with Parkinson's. It's advisable to eat small, frequent meals, six to eight times a day. Also, avoid high-fat and very spicy foods. Starchy foods, such as bread (toast) or dry breakfast cereals can help with nausea.

## Constipation

Remember to drink plenty of fluids and have a fibre-rich diet to reduce the chance of constipation (but don't eat too much fibre, as this can make the problem worse). Avoid caffeine in drinks such as tea, coffee and cola as this can make you want to pass water more often.

## Fatigue

Try to get eight hours sleep every night, and rest during the day if you can.

If you're a woman with Parkinson's who becomes or wants to become pregnant, speak to your neurologist, obstetrician and Parkinson's nurse as soon as you can.

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

## **I am a single parent with Parkinson's. How will I cope?**

Many people cope very well, and there's no reason why you shouldn't, too. Many lone parents find it helps to share ideas and tips with others.

Speak to people through your local Parkinson's UK group. You can also contact an organisation that supports lone parents, such as Gingerbread, Gingerbread Northern Ireland or One Parent Families Scotland. See page 122 for contact details.



# Our lives with Parkinson's

By Andrew, diagnosed in 2006 at the age of 42

I saw my GP because of stiffness in my left leg and arm – I was referred to a neurologist who diagnosed Parkinson's. After this, I fell into a deep depression that lasted about six months. It took over my life, turning me into a recluse in a zombie state: unshaven and not wanting to do anything.

I have three girls, who were aged 14 to 17 at the time. My youngest took it the hardest: "Why my dad? He hasn't done anything to hurt anybody." But with the help of booklets, we got a better understanding, bringing my family closer. My girls would be my minders, looking out for me when we went places.

There is no easy way around Parkinson's, but tell your children – don't hide it, don't bury your head in the sand. Your life will change, but through Parkinson's UK I now have many more friends than ever.

Andrew's daughter Jennifer, who was 16 when her dad was diagnosed with Parkinson's

When I found out that my dad had Parkinson's, I was very unsure about what it was and how it would affect him. Once my parents explained to me what Parkinson's was, I was very upset and didn't know what to say or do to help my dad. But in a short time, I learnt that he hadn't really changed, except he would have a bad day now and again. On these days, I try to help out as much as possible.

The main way I found to deal with the feelings I had about Parkinson's was to just talk to my dad. It was hard at first, but the overall effect Parkinson's has had on the family is that it has brought us closer together.



# LIVING ON YOUR OWN

## How can I manage my Parkinson's if I live on my own?

Many people with Parkinson's live alone and manage very well. But it's natural to worry about how you will cope as your Parkinson's changes. Some parts of your life may become more difficult, but there's no reason why you can't keep living on your own, as long as you have help when you need it.

Speak to your local social services or social work department if there are parts of living with Parkinson's you find hard to cope with. They may be able to assess you for support such as practical help with tasks such as cleaning or ironing.

Contact our helpline on **0808 800 0303** for further information and support. They can also give you details of your local Parkinson's UK information and support worker.

## Physical problems

These can make you less independent and make it harder to cope at home. An occupational therapist can give you ways to make daily tasks easier. They can also suggest aids and equipment to help.

## Finances

Living alone can be hard financially, whether you are working or receiving a pension or disability benefits. Make sure you are getting the financial support you are entitled to. Remember that even if you are still working, you may be entitled to certain benefits if you live alone. These include reduced council tax (not applicable in Northern Ireland). You can speak to our advisory officer for benefits and employment on **0808 800 0303**.

## Emotions

Anyone who is living alone and has a long-term health condition can be prone to depression, loneliness and isolation. If you have a strong network of family and friends

to support you, this can help. If you find it hard to cope emotionally, you don't have to struggle on alone. Contact your GP, specialist, Parkinson's nurse or our helpline (on **0808 800 0303**) for support.

Many people who live on their own find friendship and support through local Parkinson's UK groups. You can also join internet discussion groups such as our online forum at **[parkinsons.org.uk/forum](http://parkinsons.org.uk/forum)**

These tips might help:

- Don't assume that living alone is impossible when you have Parkinson's – many people cope very well with the right support.
- Talk with your GP, specialist or Parkinson's nurse about any problems you have because you live alone.
- Speak to an occupational therapist if you find any home, work or leisure tasks hard to do.
- Check you're getting all the benefits you're entitled to. You can ask your Parkinson's UK information and support worker or speak to our helpline's dedicated adviser for benefits and employment on **0808 800 0303**. We also have a range of information sheets about benefits.

- You can also speak to your local Citizens Advice Bureau for advice about benefits and financial support.
- Make the most of the support you have from family and friends.
- Our local groups, including those for younger people, can give you friendship and support.
- Share your experiences with others in a similar place through our online forum and other internet support sites.
- Our website has details of local Parkinson's support and upcoming events. Take advantage of events, activities and support that are available to you locally. You can get information from your local library, local paper and Citizens Advice Bureau.

**Find out more:** see our information sheets [Living alone with Parkinson's and Depression and Parkinson's](#). We also have a range of sheets [on rights and benefits](#).

# My life with Parkinson's

By Duncan, diagnosed 1997 at the age of 59

I lived alone for many years, but I did have some concerns about living alone as my condition progressed. As much as I liked being in my lovely garden flat and doing things on my own, this is no good to me if I suddenly go 'off' – when my medication stops working. On one occasion, I tripped up and fell over a chair. When this happened, I began employing an overnight carer, but this became too expensive.

When I went into hospital last year for an operation, a friend suggested I move into a care home. I wanted a solution where someone would be there to help if I fell or hurt myself. It was up to me to make the decision, but I knew I couldn't delay.

I moved into a care home with just over thirty residents and a number of full-time staff. I had previously had a care assessment with social services. They couldn't fund my accommodation, so I pay full 'bed and board'. The home offers specialist care for people with conditions such as Parkinson's.

It doesn't have the nursing support you get in a nursing home, but there are carers on duty at all times. Some mornings I can get up and feel fine, and on others, when my medication isn't working so well, I can't get out of bed. It's good to know that someone is there to help me if I need them.

I've always been very independent, but I enjoy my new home. It has a nice garden, it has a relaxing environment and it's located close to town. I like living here.



# SPEAKING, WRITING AND COMMUNICATING

## How can Parkinson's affect the way I communicate?

### Handwriting

Problems with writing can be one of the first signs of Parkinson's. This can be caused by muscle stiffness, tremor and a lack of co-ordination. Your handwriting may become small, cramped and hard to read.

### Speech

Many people with Parkinson's experience problems with speaking. You may find your speech slurs or the tone of your voice is dull, without any change in expression. Your voice may also become very quiet.

### Body language and facial expressions

If you have rigid muscles and slow movement, you'll find non-spoken communication more difficult. This includes making facial expressions such as smiling or frowning, or using body language such as nodding. This can have a big effect

on your relationships, as people can misunderstand you or think you're not listening or interested.

### What can I do?

- Changes to your medication may help, so speak to your GP, specialist or Parkinson's nurse.
- A speech and language therapist can advise on speech and non-verbal problems.
- An occupational therapist can help with handwriting.

## How can a speech and language therapist help me?

Speech and language therapists can assess and treat any communication and swallowing problems you may have. They can give you breathing and posture techniques to help with speech problems, non-verbal communication (including facial expression and body language), and eating, swallowing problems and excess saliva. They can also help you with ways around tasks that

may be a problem, like being able to communicate using the telephone.

Referral is often via your GP, specialist or Parkinson's nurse, although in some places you can refer yourself to a speech and language therapist through your local hospital or health centre. Speech and language therapists may also work in private practice, where you have to pay.

## What tips can you give me to improve my handwriting?

Some people find that when they start writing, the size of their handwriting is not affected, but as they write across the page it becomes smaller and smaller (known as micrographia). The writing may be 'spidery' and hard to read. Some people find it hard to write because their hand shakes too much.

An occupational therapist can help you with these problems. The following tips may also help:

- Using pens and pencils with a thick or padded barrel may help you get a better grip.
- If you have a tremor, a weighted cuff may give you more control.
- It's important that you try to take your time. After writing

a line, try to stop, relax, breathe deeply and stretch using wide arm movements. Push down through your arms before starting again.

- Use a clipboard or a non-slip mat to stop the paper from sliding away.
- You could try using a dictation machine or tape recorder to record voice messages instead of writing. Some mobile phones are also able to record and play back speech.
- Some people find electronic typewriters, word processors and computers can be useful. Using the internet and email is also a useful way to communicate.
- Computer software programmes are available that act like a dictation machine, letting you send dictation by email or the internet.
- If you need to sign a cheque or document you could ask someone else to fill in the details for you, so that you just have to add your signature.

## Find out more

- See our information sheets Communication and Parkinson's, Eating, swallowing and saliva control and Speech and language therapy and Parkinson's.

- You can also carry one of our Alert Cards in your purse or wallet for when you have problems speaking. This credit card-sized card explains that you have Parkinson's and that you may have problems communicating.

## I can't keep my signature the same on things like cheques. What can I do?

It can be hard to write signatures on cheques and official documents, or to keep it always looking the same. This can lead to it being questioned in shops or by the bank. An occupational therapist can advise on ways of improving your handwriting. You can also talk to your bank about any problems you have. Alternatives can include the following:

### Credit or debit card templates

This is a plastic guide with a hole where the signature should be. It can help make it easier to sign in the right place. Talk to your bank about whether they provide these.

### Changing your signature

Speak to your bank about accepting a simpler signature. For example, you might find it easier to write your first initial and surname, instead of writing your name in full.

## Identification cards

Some banks offer credit cards that can show your photo next to the signature – you might also use a passport or driving licence as proof of identification.

## Rubber stamps

You might find it useful to use a signature stamp. Some banks provide them and you can buy them in most stationery shops for about £20.

Please note, however, that in Scotland rubber stamp signatures are not generally accepted.

## Avoid using cheques for payments

An increasing number of companies are no longer accepting payments by cheque. Try to use Direct Debits or standing orders to pay regular bills, subscriptions or regular donations. Many utility companies give a discount for payment by Direct Debit so it may be useful to make enquiries.

## Chip and pin cards

Although the main purpose of the system is to cut credit card fraud, it may also help people who have trouble writing signatures.

## Telephone or internet banking

Many people manage their finances in this way, which avoids the need for signatures.

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

## How could a computer help me?

It can help you in different ways:

- with day-to-day contact, especially if you have problems with handwriting
- for work
- for keeping in touch with your friends and for making new ones through internet forums
- for finding out information about Parkinson's and other subjects of interest

- for online banking and shopping, which can be helpful if you have severe movement problems

You can find out more from an occupational therapist or AbilityNet, a voluntary organisation that helps disabled people to get and use computer technology. It has links with centres in England, Northern Ireland, Scotland and Wales.

Your local adult education college should offer computer courses. You can also do them with Learndirect, an adult education service that hosts online courses and has a network of centres across the UK. See page 126 for contact details.

**Find out more:** see our information sheet [Computers, the internet and useful websites](#).



# My life with Parkinson's

By Judy, diagnosed in 1990 at the age of 49

After the initial shock of learning I had Parkinson's, there was a brief period of relief to finally discover the cause of the problems I had been having with everyday activities. What I wanted most was more information, so that I could plan for my future and also cope with the problems to come. In the first few years, with the help of medication, life continued at a near normal pace, but my independence slowly diminished as the drugs began to wear off before the next dose was due. My main symptoms are rigid muscles and slow movement. I now get severe muscle cramps and spasms, which are painful.

It's hard for people without Parkinson's to understand the problems that are unique to the condition. At one time you may not be able to move, but then an hour or so later you could be walking around. Losing balance when walking can also make people think you're drunk. Educating the public is important, but I've also developed a thick skin!

One problem area I've encountered is going into hospital. It's crucial to stress to ward staff the importance of getting your drugs on time. You or your carer (if you have one) should give staff information about the condition from Parkinson's UK. I've found my contact with the charity invaluable. They are always willing to offer support via the helpline, and if you live alone (I am widowed) it is comforting to know there is someone to turn to.

I'm always looking for alternative ways of coping. I find music great to move to, even when I'm 'off'. Swaying from side to side and lifting alternate feet helps me to move. I always have someone to help me with this. The love and support from my family and friends has helped me to adjust to life with Parkinson's.



# INDEPENDENCE AND DAILY LIVING

## I want to be as independent as possible. How can a physiotherapist help me?

Physiotherapists are trained health professionals who use physical treatments, including exercise, to help treat people who have physical problems because of illness, injury or age. The methods they use include exercise, massage or physical pressure (manipulation), heat or movement in water (hydrotherapy).

A physiotherapist can look at and treat the effects that Parkinson's has on your mobility. This includes walking, posture, balance, how well you can use your hands and fingers (dexterity) and 'transfers', such as moving in and out of bed. They might also help you to manage non-motor symptoms, such as pain and sleep problems.

When you're in the early stages of the condition, your physiotherapist will use exercise and relaxation to help keep you moving. As your

symptoms progress, they can help you with other possible problems such as freezing, balance problems, falls and not being able to move.

You'll be referred to a physiotherapist by your GP, specialist or Parkinson's nurse. In some areas, you can refer yourself. You may also choose to see a physiotherapist privately, for a fee. If you do this, make sure that they are properly trained. To be sure of this, they will have the letters MCSP (Member of the Chartered Society of Physiotherapy) after their name. The Chartered Society of Physiotherapy can give you details of qualified physiotherapists. See page 124 for contact details.

Make sure you see a physiotherapist who focuses on neurology or the care of older people, and who has treated people with Parkinson's before.

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

## How can an occupational therapist help me?

When you're diagnosed with Parkinson's, you may have to make many life changes. An occupational therapist can help you to adapt to these changes. They help you get the most out of life by helping you carry on with the activities important to you.

These include:

- personal care – getting dressed, cleaning your teeth, shopping, washing and bathing
- paid or unpaid work, and housework
- leisure – sports, hobbies and social life

The help they give you and your family may include:

- giving you advice on the way Parkinson's can affect your everyday life
- helping you to make your home and workplace easier to get around and use. This could involve moving furniture or adding things like grab rails, walk-in showers and stair lifts
- working with you and your family to plan the best daily or weekly

routines that will let you carry out important activities

- teaching you and your family new ways to cope with the physical and psychological problems that may affect your life
- telling you what equipment to use at home or work to help you to carry out your everyday activities
- giving you advice, information and support to help you to use transport and community and leisure opportunities to the full
- helping you with a support plan to keep and improve your social life

Occupational therapists work in hospitals and in the community. They carry out a lot of home visits to do assessments and give advice. Your GP, specialist or Parkinson's nurse can refer you, or in some areas you can refer yourself by getting in touch with your local social services department, or your local social work department if you live in Scotland or Northern Ireland.

Some occupational therapists work privately. If you choose to see an occupational therapist privately, for a fee, make sure that they are properly trained. To be sure of this,

they will have the letters SROT (State Registered Occupational Therapist) after their name. Also, make sure they have worked with people with Parkinson's. To find a private occupational therapist, contact Occupational Therapists in Independent Practice. See page 128 for contact details.

### Find out more

- See our information sheet Occupational therapy and Parkinson's.
- For more information on the work of occupational therapists, contact the British Association of Occupational Therapists.

### What equipment might I need?

There is a wide range of aids and equipment available to help with particular problems. You may not need any, but if you do, what you have depends on your situation.

Equipment and aids aren't always the answer and they can be very expensive. Before you buy anything, a therapist should assess your needs and make suggestions. They might give you exercises, ways to do things that make them easier, or treatment. They'll only suggest equipment if they think it will help you. They can give you

advice on where to get it, and any help you can get with paying for it. If you don't get an assessment, you could spend a lot of money on equipment that is not right or you could have got cheaper elsewhere.

What kind of therapist you see depends on what activity you need help with. There is some overlap between each type of therapy, but they often work together as a team.

In general:

- an occupational therapist gives advice on daily living, including washing, bathing, dressing, eating, reading and leisure
- a physiotherapist advises on movement problems at home and elsewhere, but an occupational therapist can also help you with equipment for this

Who you see depends on how the services are arranged in your area. Your GP, specialist or Parkinson's nurse can give you more information about this.

Who pays for the equipment depends on different things. This includes the type of equipment, your personal situation (eg whether you are receiving benefits) and the funding available. If it's thought to be essential, it should be given free

of charge. Your therapist, GP, specialist or Parkinson's nurse should be able to let you know what help you can get.

### Find out more

- Our Mali Jenkins Fund provides one-off grants to people with Parkinson's. The aim of the fund is to give financial assistance towards equipment, adaptations and respite breaks that will improve quality of life. Contact our helpline on **0808 800 0303** or visit **[parkinsons.org.uk/malijenkinsfund](http://parkinsons.org.uk/malijenkinsfund)** for more information.

- The Disabled Living Foundation is a registered charity that provides practical advice and information on equipment to help disabled people be more independent. It has a helpline for general information, a range of information sheets on equipment and centres where you can get advice from therapists and try things out before you buy. Its information sheet, Sources of Funding and Obtaining Equipment for Disabled and Older People, can be downloaded from its website or ordered by post.



- AbilityNet is a voluntary organisation that aims to make computer technology accessible to people with disabilities. They have a free advice and information service, a website ([www.abilitynet.org.uk](http://www.abilitynet.org.uk)) and links with centres across the UK.
- Disability Action (Northern Ireland) has a range of assistive technology products that people can try and in some cases loan (for a short period) before they go ahead and buy the product. See page 125 for contact details.
- See our information sheets Equipment and disability aids and Computers, the internet and useful websites.

## Will I need to make changes to my home?

Some people need to adapt their home to make living with Parkinson's easier. You could improve access to your front door with a ramp, refit a bathroom that's easier to manage or put in a stair lift. Before you do this, get advice from an occupational therapist who can look at the problems you're having and suggest ways to fix them.

Care and Repair is a charity that aims to improve the housing and

living conditions of older people and disabled people in England, Scotland and Wales, allowing them to live independently in their homes. It provides another source of information and advice. Its useful guide, In Good Repair, has advice on repairs, adaptations, funding and finding a good builder or tradesman. See page 123 for contact details.

## How can social services help me manage at home?

Your local social services or social work department, or department of health and social services should arrange support if you need help to live independently because of your age, health condition or disability.

If you fit into any of these categories they must assess you to see what services you need. A care manager or social worker will carry out a needs or care assessment. This will usually take place in your home and will take into account your personal needs and your social and cultural background. It covers the following:

### Care needs

A care manager or social worker should explore with you the support and services you may need, and what's available in your area. From this they will develop a care plan with you and give you

a copy of it. This might be provided by your local social services or social work department, or department of health and social services, or by private agencies and voluntary organisations. Different local authorities have different ways of deciding who gets access to which services.

If you are not happy with your assessment, or its outcome:

- tell social services, and ask for another assessment if necessary
- ask your Parkinson's UK information and support worker or call our helpline on **0808 800 0303**

- if still not resolved informally, ask for details of the local authority's complaints procedure and make a formal complaint
- go along to your local politician's surgery and ask them to raise the matter at a higher level

### Carers' needs

Your carer can ask for their needs to be included in your assessment, too. This means their needs are taken into account when your services are planned, if they are receiving services or if they need more help. They can also have an assessment in their own right. This can happen even if the person they care for doesn't want to be assessed.



It gives the carer the chance to talk about what help they need for their wellbeing.

The types of services available will change according to where you live, but might include help in your home with caring tasks, or housework, day care, equipment or changes to your home, or chances for leisure and meeting people.

### Who pays for care?

This assessment is free of charge.

Who pays for any services that social services recommend depends on your finances and whether you qualify to receive the services where you live.

This is usually decided after a care manager or social worker has assessed your finances. This might happen during the needs or carer's assessment. If you don't give this information, social services may assume you can pay for everything.

Your local authority may offer you financial support if you need it, as long as you meet their requirements. They should also be able to tell you about other financial help that's available.

In Scotland, personal care is available without charge for everyone in the country aged 65

and over who have been assessed by the local authority as needing it. Free nursing care is available for people of any age.

### How can I make sure my home is safe?

There are two areas where safety in the home may be important to you:

- preventing falls or other injuries and managing day-to-day activities safely
- reducing your vulnerability, especially to bogus callers

A physiotherapist can help you with ways to prevent and manage falls. An occupational therapist can advise you on safety in and around your home.

They may suggest:

- using non-slip mats in the bath or shower
- rearranging furniture to make moving around your house safer
- checking that electrical leads don't cross walkways
- fixing loose carpets and floorboards
- installing grab rails alongside stairways and in places that you find hard to move around



- using equipment or disability aids to make some activities easier and safer

### Community alarm schemes

If you live alone or spend a lot of your day on your own, you could register with a community alarm system. These are run by many local authorities, as well as by voluntary organisations such as Age UK. They're not just for older people – there may be times when you feel vulnerable, and these schemes are for anyone who wants to feel safer in their own home.

If you have an accident, you can push a button on your telephone or a device you wear around your wrist or neck to get help from a 24-hour response centre. Most of these schemes involve a charge, but you might be exempt if you're on a low income.

### Bobby Van Scheme

Some local police services offer the Bobby Van Scheme, a free home security service, available for elderly or vulnerable residents. They can carry out a security survey of your home and fit items such as window and door locks, door chains and viewers so you can see who is calling. Although the Bobby Van Scheme isn't UK-wide, there are similar schemes offered

by local crime prevention officers in different areas. Contact your local police station to see if this service is offered where you live.

### Age Northern Ireland First Connect Service

This service offers emotional and practical support to people in later life, including support to increase the safety and security of your home.

### Find out more

- See our information sheets Equipment and disability aids and Falls and Parkinson's.
- Your local social services department can tell you about community alarm schemes in your area.

### Sometimes I don't want to go out and see people because I'm worried how I'll cope. Have you got any tips?

It's common to feel like this, but you should try and live as active and normal a life as you can. For some activities you may need to make more effort, or you may need to change some things to make them easier. But if you plan ahead, you'll overcome most problems. If you're embarrassed, talking to and sharing tips and ideas with other people with Parkinson's at your local Parkinson's UK group will help.

Here are some questions to ask yourself to help you plan ahead:

### People

- If you're going out with other people, how much do they know about your Parkinson's?
- Do they need to know you have Parkinson's?
- Will they know how to help you if you need it?
- How much help do they need from you?

### Venue

- Have you been there before?
- Do you need to know if it's easy to access?

### Transport

- Have you made plans to go home at a certain time?
- What if the people you go out with want to go home early, but you want to stay later? What if this is the other way round?
- Do you know how you are getting home?

## Going out essentials

### Medication

Depending on where you're going and for how long, take an extra

supply of medication, just in case. Also, keep an up-to-date list of the Parkinson's drugs you are taking in your wallet or purse, in case of an emergency.

### Mobile phone

Make sure that your phone battery is charged and that you have an ICE (in case of emergency) number stored in your phone book. This is the number of the person that you have chosen for the emergency services to call if they need to.

### Large crowds

If you have problems getting through large crowds, ask someone to walk right in front of you to make space.

### Theatres or cinemas

Book seats at, or near, the end of a row. You'll have more room to move your legs. You can get up and down without getting in anyone's way and can leave quickly if you need to.

# My life with Parkinson's

By Colleen, diagnosed in 2005 at the age of 42

I have never been the type of person who does 'groups'. The whole concept of being in a large group for meetings just doesn't work for me. So here I am on a Saturday in a group, and one full of people who are ill, including me. This sets a precedent – the first group meeting I have attended voluntarily.

So why do I suddenly need a group? I need contact. I need to find specific people who, like me, are young and have Parkinson's. Why do I need this contact? At first it was a reassurance thing – you suddenly get dumped with this condition and you need to benchmark it. The easiest way is to seek out others with the same objective.

Then you need to share. If I told my step-daughter, Kat, who has come with me, 'I can't sleep', she would have some level of understanding. But if I tell a fellow person with Parkinson's, they would know that it's not about the occasional restless night, but a whole new sleep pattern that one needs to adapt to. Shared experience becomes specific.

If being involved and meeting with others means that my small contribution helps another person with Parkinson's, then count me in.



# DIET AND EXERCISE

## Should I eat a special diet?

Eating a healthy diet is important for everyone with Parkinson's, no matter how long you've had the condition. For most people, no special diet is required, but you should eat a well-balanced diet with plenty of fibre, vegetables and fruit.

But there are some practical problems you might have with eating and drinking. These include:

- medication issues – a small number of people taking levodopa may find that a large meal makes the drug work more slowly
- swallowing problems – not being able to take in food can make you lose weight and stop you getting the nutrients you need
- weight gain – especially if you can't move around or don't exercise

- movement problems – this can stop you being able to cook or use cutlery

There are a number of people who can help if you're having any of these problems. In the first instance, speak to your GP, specialist or Parkinson's nurse.

You might want to talk to a dietitian about different food and drink choices, as well as ways to prepare and present things to make your mealtimes as easy as possible.

Your GP, specialist or Parkinson's nurse might refer you to an occupational therapist about equipment and ways of making eating and drinking easier, especially if you have problems with swallowing.

Swallowing problems affect some people with Parkinson's, in particular people who have had the condition for several years. If you're having problems, you may be

referred to a speech and language therapist. They can help you to make changes to your posture, improve your breathing technique or make your face and tongue muscles stronger.

## What can I do about constipation?

Constipation is a common problem for people with Parkinson's. It is caused by:

- muscle rigidity and slowness of movement – Parkinson's symptoms that can stop the bowel from working properly
- lack of fibre in the diet, because of the problems some people have with chewing and swallowing food
- some Parkinson's medication

You can also help to ease constipation by drinking more fluids and eating fibre-rich foods, but avoid eating too much fibre as this can cause problems. Doing exercise can help. And remember not to avoid drinking fluids, even if you're worried about bladder control.

If you have any problems with your bowel or bladder, talk to your GP, specialist or Parkinson's nurse, who might refer you to a dietitian for

more advice. Also, don't use laxatives without speaking to one of these professionals.

**Find out more:** see our booklets [Diet and Parkinson's](#) and [Looking after your bladder and bowels when you have Parkinson's](#), and the information sheet [Eating, swallowing and saliva control in Parkinson's](#).

## Why does protein affect my medication?

Some people find that protein (which is found mainly in meat, fish, eggs, cheese, yoghurt, nuts, beans and pulses) stops their levodopa medication from working as well as it should. If this affects you, your GP, specialist or Parkinson's nurse may advise you to take your levodopa 30 minutes before you eat. It can be taken with a carbohydrate food like a cracker or a biscuit.

You shouldn't reduce the amount of protein you eat as it's important for helping your body renew itself, to fight infection and to maintain your body weight, but you might talk with a healthcare professional about a diet where you eat your required daily amount of protein in the evening.

**Find out more:** see our booklets [Drug treatments for Parkinson's](#) and [Diet and Parkinson's](#).

## Can I drink alcohol?

If you've always enjoyed a drink now and again, there's no reason why you can't still do so. Taken in small amounts, alcohol won't affect your Parkinson's medication. But you should avoid drinking a lot.

Also, if you've just started a new drug regime, you should drink less alcohol until your body is used to the medication. You can talk about this with your GP, specialist or Parkinson's nurse.

## Can vitamin supplements help Parkinson's?

There is no proof that taking extra vitamins, minerals or antioxidants will help your Parkinson's symptoms or slow down the progress of the condition. There is not enough evidence to judge the benefits and safety of various herbal medicines and more research is needed.

A healthy, well-balanced diet should give you all of the nutrients you need. Talk about this with your GP, specialist or Parkinson's nurse if you are worried.

You should also speak to them before trying any supplements or

herbal medicines, as some can cause bad side effects if you taken them in large doses. They can also affect your Parkinson's medication. Some vitamins, including antioxidants, have been looked at in Parkinson's research, but results haven't been clear.

**Find out more:** see our booklets [Diet and Parkinson's](#) and [Complementary therapies and Parkinson's](#).

## What exercise should I do?

Whatever your age and whether you have Parkinson's or not, you need to exercise and keep moving regularly. If you have Parkinson's, your muscle tone can change and your muscles may feel stiff, so it's even more important to keep them moving. But muscle stiffness can make it harder to move your joints and this can lead to injury and pain.

Because you need extra effort to move, you'll feel more tired, so you may not feel like doing much. This may form a vicious circle, leading to you losing mobility.

Movement problems are one of the main Parkinson's symptoms, so you should try to stop this happening for as long as you can by staying active. Just a short walk can help.

Some research even suggests that exercise can slow the progress of Parkinson's.

Different types of exercise can help your body in different ways: to keep your heart, muscles and bones strong, to keep you flexible, to keep your balance and stop you falling, and to help you relax. Doing something that takes in all of these is best, but any exercise will give you physical and mental benefits. Exercise can also help to relieve depression.

## Can I still play sports?

Yes. Many people with Parkinson's take part in active sports like tennis, badminton or squash, bowling, sailing, skiing, swimming and dancing. There are also a number of 'low-key' exercise options to keep you flexible and active, such as yoga, t'ai chi, walking, gardening, golf and daily stretches. Joining an exercise group or taking part in a sporting activity helps you meet other people. This can help to ease the depression that some people feel.



There's no reason you shouldn't enjoy these activities as your Parkinson's progresses. But if you're having some trouble, speak to a physiotherapist. There are also many sporting associations that help and advise people with disabilities.

Here are some ways to keep motivated and maintain your fitness level:

- Look for an activity you enjoy – if something is fun, you're more likely to stick to it.
- Try to find something local so you don't have to travel far.
- Make it a chance to meet people by joining a group.
- Try to find a time of day that's best for you, such as when you're less tired or when you have company.
- Remember that age and illness don't mean you can't improve your fitness. Speak to your GP first if you're worried about anything.
- Don't let it get to you if there are days when you can't do as well as usual. Keep going and you'll see things get better.

**Find out more:** our Keeping Moving exercise DVD and booklet can be done at home. The exercises were put together by two physiotherapists, especially for people with Parkinson's.

## **Parkinson's makes me feel very tired. Why is this?**

Many people with Parkinson's feel very tired and experience a lack of energy. People with Parkinson's may also experience feelings of fatigue.

The feeling of fatigue has been described as an overwhelming sense of tiredness, a lack of energy and a feeling of exhaustion. Fatigue can affect someone physically, mentally and socially.

This strong feeling can affect your ability to move, think or show emotions. For some people, this is the first Parkinson's symptom they get, but it can affect people at all stages of the condition. It's normal for your Parkinson's symptoms to change from day to day, even hour to hour. So you might feel active one day, but too tired the next. You'll find that things you did easily before your diagnosis take more effort now and leave you tired.

Other causes of tiredness include:

- tremor and rigidity – these symptoms put stress on muscles. They have to work harder and sometimes against each other to start or continue movement. This can make them very tired
- stress – this can make your symptoms worse and make you feel more tired
- low energy levels – your energy may go up and down during the day depending on when you take your medication and the dose you take. You might feel more energetic and able to do certain things at different times of the day
- sleep and night-time problems
- depression
- not taking a break from tasks – many people find it difficult to focus for a long time without taking a break
- other medical problems – you may have other conditions such as anaemia or blood pressure problems

If you're tired this can make you less active, which will affect your physical and emotional health. This could lead to depression, boredom and isolation.

Knowing what is making you tired is the first step to take, so talk about this with your GP, specialist or Parkinson's nurse. Changing your medication or adding other drugs may help. You should also talk to them if you need treatment for depression and sleep disorders. You can use self-help, too, such as: improving your sleeping habits, making your diet better and exercising more.

Be aware of how much you can do and what your limits are. Getting a balance between doing things and resting will help you to cope with tiredness. Pace yourself, take regular rests and ask for help when you need it – even if you want to be as independent as possible. Don't try to do too much at once. It's good to plan in advance, too – if you're going to be busy one day, plan a quiet day the next to recover.

A physiotherapist can help you to manage any physical problems that make you tired. An occupational therapist can suggest ways to make your daily activities easier, which will make you less tired.

**Find out more:** see our information sheets [Fatigue and Parkinson's](#), [Sleep and night-time problems in Parkinson's](#) and [Depression and Parkinson's](#).

# My life with Parkinson's

By Sue, diagnosed in 1994 at the age of 43

I will never forget the day when I was diagnosed with Parkinson's. I was 43 at the time, and had a good job that I enjoyed and a happy family life. To start with, I don't think the true impact of all the implications of Parkinson's sunk in.

I did not feel annoyed or bitter, just shocked by what was ahead of me. The one thing I did know was that I was not going to give up without a fight.

My one great lifesaver has always been my local Parkinson's UK group, which gives all of its members great support. Everyone works hard fundraising and organising events to make the members' lives more enjoyable. I've have met some wonderful people and made some great friends.

I am fortunate enough, many years later, to still be quite active. I play golf twice a week, cook, clean, shop, garden and virtually lead a normal life. I never consider that I cannot do something, but work my activities around my Parkinson's. I fit my most energetic activities in during the morning and do other quieter pursuits later in the day. I always try to rest for 30 minutes in the afternoon as I find this really gives me a boost. My theory is that it allows my brain to rest and regenerate itself. I find when I don't play golf or have any physical activity I feel far worse.

I look on my Parkinson's as a great challenge and try to outwit it in every way. I believe that the most important thing is to keep active. Remember, accommodate Parkinson's, but never surrender to it.



# TRAVEL AND LEISURE

## Can I still drive?

Having Parkinson's doesn't always affect your driving licence, but you may have to take a medical or a driving test. Once you've been diagnosed with Parkinson's, it is the law to tell the organisation in charge of driving licences where you live that you have the condition. You will need to contact one of the following:

- UK – Driver and Vehicle Licensing Agency (DVLA)
- Northern Ireland – Driver and Vehicle Agency (DVA)
- Isle of Man – Department of Transport
- Guernsey – Driver and Vehicle Licensing
- Jersey – the parish that issued the licence

The relevant organisation will find out more about how your condition affects your ability to drive and will then inform you about your licence.

Many people with Parkinson's still drive for years after diagnosis, but some people find their medication makes them too drowsy to drive.

You must tell your insurance company you have Parkinson's, and if you have any other health changes that affect how well you can drive. As a driver, you're responsible for making sure you're fit to drive at all times. If you drive when you know you shouldn't for medical reasons, your insurance could be invalid. It's an offence under the Road Traffic Act 1999 to not tell the truth or hold back information to get car insurance.

**Find out more:** see our booklet [Driving and Parkinson's](#).

## Where can I get advice on transport and travel?

Our information sheet Help getting around includes information about transport and travel, including:

- parking – including the Blue Badge scheme
- driving issues
- Motability (a charity that helps people with disabilities use the higher rate mobility part of their Disability Living Allowance or war pensioners' mobility supplement to buy or hire a car).

You can find their contact details at the back of this book

- the National Key Scheme for disabled toilets
- public transport – disabled access and concessionary fare schemes
- wheelchairs
- sources of further advice



## Where can I find out about holidays suitable for people with Parkinson's?

Having Parkinson's shouldn't stop you from enjoying holidays where you can take time out, enjoy leisure activities and see new places. It just may take a bit more planning. You can find out more from:

- Open Britain – a guide to accessible accommodation, attractions and travel in each region of the UK. You can order this from us for £10. See inside back cover for details of how to order resources
- Tourism for All – a voluntary organisation that helps disabled and older people to travel and holiday in the UK and abroad
- Vitalise – a voluntary organisation that provides breaks for disabled adults, children and their carers from around the UK at five easy-to-access centres in England. It also has guides to other UK and European breaks
- our local groups – some run their own holidays, and members may recommend places where they have stayed or give you tips

## Have you got any tips on travelling abroad?

Many people with Parkinson's travel overseas on holiday or for business. There's no reason why the condition should stop you. If you're worried about coming across problems, planning ahead should help. You can also get help from many different places.

These tips can help make your trip as trouble-free as possible:

- Get plenty of information about the country you're going to, including whether you need a visa, local customs, and what you need to know about taking your medication with you (some countries ask for import licences).
- Check what the health service arrangements are in the country you're going to. Find out if they have an agreement with the NHS that means you can use certain medical services if you need to. You can check this on the travel advice section of the Department of Health's website – [www.dh.gov.uk](http://www.dh.gov.uk). Make sure you take the forms you need with you.
- Plan your journey well and get help from tour operators, airlines and travel companies. Most of them are willing to help you, as

long as they know in advance that you have Parkinson's. However, some people with Parkinson's have told us that some airlines have a quota of how many disabled people a plane can carry. You should check in advance.

- Make sure that you have the right insurance for your visit. This should cover any medical treatment you may need, but be sure to give your insurer full details of your condition and the medication you take.
- Take a letter from your GP, specialist or Parkinson's nurse that says you have Parkinson's and lists the medication you are taking, as well as any other important medical information.
- If you're flying, tell the airline if you need to carry syringes or other sharp objects in case you have to take your medication while you're on board.
- Carry your medication in a correctly labelled container – the one that was given to you by your pharmacist. Keep it in your hand luggage and take extra with you just in case. You may not be able to get hold of more of your Parkinson's drugs in the country you're visiting.

- Ask your specialist or Parkinson's nurse for advice on how to take your medication if you travel to a different time zone.
- Take the contact details of any local Parkinson's organisations with you. They might be able to help you with any services that are available to help you in their country.
- Learn how to say, "I have Parkinson's," in the local language, in case you have any problems.

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

## What creative activities can I do?

Many people with Parkinson's enjoy being creative. You might want to try writing, music or art. All of these are enjoyable, fulfilling and can help you to express your emotions. If you join a group, this is also a great way to meet with other people. An occupational therapist can help you with any practical arrangements.

We run a creative competition for people with Parkinson's, called the Mervyn Peake Awards.

The awards are held every year in memory of the famous illustrator, writer and poet who had Parkinson's. There are four categories to enter: art, poetry, photography and digital art. Contact our Events team on **020 7963 9309** or email **mervynpeake@parkinsons.org.uk** to find out more.

**Find out more:** see our booklet [Complementary therapies and Parkinson's](#).

## Could music therapy help me?

Music is important to many people with Parkinson's. Music therapy is the use of music by trained professionals as a treatment for some physical and mental conditions. The music can improve movement and speech and help people to relax or talk about feelings or ideas they have.

It may help you with movements such as walking or moving your arms, any movements you can't control, tremor or speech difficulties.



Music therapists often work to help you with these problems with other professionals. These include physiotherapists and speech and language therapists.

You don't need to know anything about music to enjoy music therapy. You should experience the benefits at each session. Early research has shown that the effects can continue afterwards, too.

Some people also find that listening to a metronome (a machine used by musicians that sounds a regular beat) or music with a strong rhythm makes their walking better and helps them to start moving again when they freeze. Some people find they can still dance, even if it is hard to walk, and some get less tired when they move to music. You'll get the most benefit from music with a regular beat and a familiar tune or one with words or a tune that means something to you.

### **Find out more**

- See our booklet *Complementary therapies and Parkinson's*.
- Your local group may run exercise to music sessions, or they may know about other local activities.

## **How can creative writing help me?**

Writing can help you find out about and explore your thoughts. It's also a chance to be creative. How you write and what you write is up to you. Some people find using a computer easier than writing by hand. You may want to share what you're going through with others in letters, emails or internet blogs, or by creating poems, stories or songs.

You don't have to share it with anyone unless you want to, but many people get inspiration from joining a writing group or taking a writing course. Our online forum has a creative corner, where people can share what they have written.

**Find out more:** see our information sheet *Writing and publishing*.

## **I love gardening but I'm finding some parts hard to manage. Is there help available?**

Gardening has many benefits – it's good exercise, creative, it's out in the fresh air and is an interest you can share with others.

An occupational therapist can help you with techniques and equipment that will make the harder parts easier.

There are also two voluntary organisations that give information and support to gardeners with a long-term illness or disability: Thrive and the Gardening for the Disabled Trust.

### Tips for gardening

- Make the most of tools and equipment that have been designed to help gardeners with long-term illness or disabilities.
- Raised flower beds can help if you have trouble bending down.
- Paths can be widened to give you more room to move around.
- Buy plug plants that are ready to plant out rather than seeds, if you find the fine finger movements needed to sow seeds difficult.
- Gardening is a very popular pastime that brings people together. If you find a particular part of it too hard, friends, neighbours, your Parkinson's UK group, local garden club members or community volunteers may be happy to help you.



### My pet gives me a lot of comfort, but I'm worried what would happen if I went into hospital or couldn't live at home anymore. Who can help?

Some people find that having a pet is a comfort that helps them feel less lonely. It has even been shown that pets can relieve stress and lower blood pressure. Remember though, that a pet can be a big commitment to take care of.

It's natural to worry about what would happen to your pet if you

had to stay away from home, go into hospital or to move to sheltered housing or a care home. The Cinnamon Trust helps people to stay with their pets for as long as possible. With the help of volunteers, they offer services such as pet fostering and dog walking for people with limited mobility. See page 124 for contact details.

The Cinnamon Trust isn't able to help people who are under 60, but there are other animal welfare organisations who can give advice or put you in contact with other local schemes, such as:

- the National Animal Welfare Trust (which has an emergency pet care scheme for members)
- the RSPCA
- the Scottish SPCA
- Cats Protection
- The Blue Cross
- the Pet Fostering Service Scotland (provides an emergency care service for anyone of any age living in Scotland who has to go into hospital or respite care and is temporarily unable to look after their pet)
- the USPCA (Ulster Society for the Prevention of Cruelty to Animals)



There may also be an animal lover at your local Parkinson's UK group who might be able to help.

Canine Partners is a charity that trains assistance dogs that give disabled people more independence. The scheme is open to people with Parkinson's. A 'canine partner' can perform tasks such as loading and unloading a washing machine.

**Find out more:** Age UK has a useful information sheet on pets. See page 122 for contact details of all organisations mentioned here.

# My life with Parkinson's

By Jon, diagnosed in 2007 at the age of 49

I hate flying. Don't get me wrong – I love take off and landing and quite like the bit in between, especially if the movie is good. No, it's all the departure and arrivals stuff I dislike. Even before I was diagnosed, I seemed to have a way of looking guilty. Now that I stumble and shake, it's worse.

On many flights, even your shoes have to be scanned. I have learnt not to wear tight lace-up shoes after taking a fumbling eternity to remove my shoes in front of a queue of grumbling tourists.

US Arrivals is the worst of all. After all, these people carry guns! After a seven-hour flight to Washington, I stood shaking while trying my best nonchalant look as the officer scrutinised my passport – and me. He called his supervisor. There was much whispering before one looked at my flapping arm and asked me, "Are you taking drugs?" The queue behind me suddenly hushed. Well, my medication is certainly a drug so the answer would technically be yes, I thought. Just as I opened my mouth to say so, self-preservation took over. "No sir," I said. They like to be called 'sir'. "I have a medical condition." "Do you have documentation of that?" He questioned. "Yes sir," I said, producing my Parkinson's UK Alert Card. He read it aloud and passed it to his colleague. His colleague read it aloud. They stared unblinking at me for an age it seemed. The silence was broken by a loud thump as he stamped my passport and smiled. "Welcome to the US. You have a nice day, y'hear".



# WORK AND MONEY

## I'm worried about my financial future. Where can I get help?

Many people with Parkinson's and their families have this concern. There is no doubt that disability or illness can have a big effect on your finances. The worries you have and the help available to you will depend on your personal situation and your resources, the stage you're at in your life and how Parkinson's affects you.

If you're younger, your main concerns may be earning a living, paying for your home, raising your family and saving for a pension. If you're older, you may no longer be working, but you may be worried about how you'll cope on your pension.

You may be able to get extra money through welfare benefits if you meet the criteria. Even if you don't need any help right now, it's important to plan for the future. So try to get as much help on the

options or support that might be available to you now and in the future.

### Find out more

- We produce a range of information sheets about different benefits.
- Our helpline (**0808 800 0303**), has a dedicated benefits and employment adviser who can answer questions and provide advice on this subject.
- Our information and support workers can provide one-to-one benefits advice, including help with filling in forms. To find out more, contact our helpline on **0808 800 0303**.
- Organisations that can provide you with expert advice include the Department for Work and Pensions, Citizens Advice, Age UK, Social Security Agency in Northern Ireland and local authority welfare rights offices.

## Will I be able to keep working?

Work is not only important for earning money, but it can also build confidence, self-esteem and personal satisfaction. If you want to stay in work, it's important to talk about suitable treatments with your specialist, to help you do so. If you have practical problems in your workplace, an occupational therapist can carry out an assessment and give you advice on any improvements you can make to your work environment.

If your treatment is carefully managed and you have plenty of support, it could be possible to continue working for many years.

This would usually be with the co-operation of your employers. Although many people with Parkinson's carry on working after their diagnosis, this can depend on the type of job you have and how the condition affects you. Sometimes, changes need to be made to make work easier, or you may change your approach to work, such as reducing your hours, changing career or taking early retirement.

Some jobs are more compatible with Parkinson's than others, so if your job needs a lot of physical effort and quick reactions, you may have to consider an alternative.



Talk about your situation with your current employer and see what support is available from them – many people with Parkinson's have found that their employer is sympathetic and keen to help.

Get as much information and expert advice as possible about your situation, including how you could continue employment and any options available to you. If you belong to a trade union, staff association or professional body, they should be able to provide you with support and advice.

Get advice from the disability services team at your local Jobcentre Plus office. This may include any adaptations or retraining that is available. They can also advise your employer. Financial assistance through the Access to Work scheme may also be available to help you meet the costs of travel to work and to buy equipment that you need to stay in work, retrain or get a new job. Your local Jobcentre Plus office should be listed in the phone directory, or you can search for it on the **www.direct.gov.uk** website.

In Northern Ireland, contact your local Social Security Agency or Jobs and Benefits office. See **www.dsdni.gov.uk** for locations.

## How can my employer help me?

The Equality Act (2010) means that you are under no obligation to tell your employer you have Parkinson's. But in some circumstances, you may feel it is helpful or necessary to do so. This act, along with the Disability Discrimination Acts 1995 and 2005, protects you from discrimination at work. In Northern Ireland, employment legislation is different, but the terms of the Disability Discrimination Act still apply.

Your employer has a statutory duty to give 'reasonable' support and to make reasonable changes to your employment where necessary.

This can include:

- making changes to the place you work
- giving some of your work to someone else
- moving you to another post or place of work
- being flexible about your hours
- giving you training
- giving you modified equipment
- making instructions and manuals easier to use

- using a reader or interpreter
- increasing supervision

If your prospective employer is made aware of your disability, changes should begin at the recruitment stage.

You do not have to pay for any part of a reasonable adjustment. Your employer can get support from the government Access to Work scheme. In England, Scotland and Wales, contact JobCentre Plus. In Northern Ireland, contact your local Jobs and Benefit Office or JobCentre.

### Find out more

- Speak to our Advisory Officer (Benefits and Employment) on **0808 800 0303**.
- Contact the Department for Work and Pensions, the Equality and Human Rights Commission, the Equality Commission for Northern Ireland or The Department of Employment and Learning in Northern Ireland for more information.
- Seek advice from your trade union, staff association or professional body.

## What if I decide to leave work?

Before you make a decision:

- think carefully about how it will affect you emotionally, practically and financially
- don't rush into a decision – give your treatment time to settle down
- speak to your employers and professional or trade organisations to make sure you're leaving on the right terms at the best time. Some companies encourage their employees to go to courses on preparing for retirement
- call our helpline on **0808 800 0303** or speak to your local Citizens Advice Bureau or welfare benefits service

# My life with Parkinson's

By Alun, diagnosed in 1999 at the age of 49

I was a teacher for 27 years, the last two with the knowledge that I had Parkinson's. When I worked (as Head of Information and Communication Technology) with Parkinson's, I found it increasingly difficult to control my mouse, get round the classroom, and write neatly. The only positive statement I can make about my Parkinson's and school is I was unable to write school reports – joy of joys.

I stopped working in 2001. I am lucky because I have my teacher's pension, which is half of my final salary. A year before diagnosis, I took out a critical illness policy, which gives me a monthly income until I am 60. I also receive Incapacity Benefit and Disability Living Allowance, part of which pays for my mobility car.

I am now heavily involved with Parkinson's UK, yet make time for my monkey puzzle trees, being silly, taking photographs and designing websites, including one for a tiny book publisher.

I now realise that your family and your friends keep you positive, look after you and make you forget that you have Parkinson's. Talking to people living with Parkinson's helps you put it into perspective and laughing at Parkinson's is the best medicine. I know crying doesn't get you anywhere, but a joke, a smile and a smirk help me.



# INFORMATION FOR CARERS

## How can I help my friend or relative who has Parkinson's?

The kind of help they will need depends on how the condition affects them, what daily tasks they find hard and what resources are available to help them. Many people with Parkinson's stay independent for many years after diagnosis, even if some activities need to be changed to make them easier.

Your attitude will be very important to your friend or relative and it can make a big difference to how they cope with living with Parkinson's. Remember to:

- encourage them to lead as active and normal life as possible
- allow them to do things for themselves, even if it takes longer
- recognise that Parkinson's changes a lot and the amount of help they need will vary – not

just day to day, but hour to hour – at one time they may be able to do everything, then the next they'll need more help or rest

- ask what help they want from you
- not worry if you sometimes get it wrong
- make sure you have the support you need to help you cope

## Where can I get advice and support to help me as a carer?

It's important to think about your own needs as a carer, as well as those of the person you care for. You can get help from:

- talking to other carers or family members at your local Parkinson's UK group. They can also give information on local services and opportunities to meet others in a similar position

- speaking to your Parkinson's nurse, who can support you as well as the person you care for
- speaking to your local Parkinson's UK information and support worker
- speaking to an adviser on our helpline (on **0808 800 0303**)
- reading the books on caring listed in the More information and support section
- speaking to one of the two main carers' organisations in the UK – Carers UK and Princess Royal Trust for Carers. They can give invaluable support. Their contact details are at the back of this booklet
- carers' services if they are offered by your local primary care or hospital trust, health and social care trust or your local council



## Find out more

If you live in England, visit the NHS Choices website at [www.nhs.uk/carersdirect](http://www.nhs.uk/carersdirect) or the 'caring for someone' section on the UK government website at [www.direct.gov.uk/en/caringforsomeone](http://www.direct.gov.uk/en/caringforsomeone)

If you live in Northern Ireland, visit the 'caring for someone' section on the nidirect website at [www.nidirect.gov.uk](http://www.nidirect.gov.uk)

For information for carers in Wales, visit [www.wales.nhs.uk/carers](http://www.wales.nhs.uk/carers)

Care Information Scotland ([www.careinfoscotland.co.uk](http://www.careinfoscotland.co.uk)) is a telephone and website service providing information about care services for older people living in Scotland.

## Are there any courses that will help me to learn more about what being a carer involves?

The Expert Patients' Programme, explained on p43, is developing courses for carers in some areas. This includes 'Looking after me', which is for people who care for someone living with a long-term health condition or disability. The course aims to help carers look after themselves, take more control

of their situation and make a difference to their lives. All of the tutors have experience of caring for a relative.

**Find out more:** call **0800 988 5550** or visit the website [www.expertpatients.co.uk](http://www.expertpatients.co.uk)

The Expert Patients' Programme only operates in England, but similar programmes are available in Northern Ireland, Scotland and Wales. Contact your Parkinson's UK country team to find out more about these.

The Open University also offers a range of appropriate qualifications. See page 128 for contact details.

Health and social care professionals sometimes run courses on relevant issues. For example, physiotherapists or occupational therapists sometimes run courses on manual handling to help you avoid injury. They can also advise carers at home or in rehabilitation or day centre or hospital settings on relevant aspects of caring. Many carers' centres run courses for carers and also help them with employment and education opportunities.

**Find out more:** see our booklet [The carer's guide](#).

# My life with Parkinson's

By Carole, diagnosed in 2005 at the age of 67

I was diagnosed five years ago and the medication I have is doing a great job. I am a great believer in mind over matter and rarely get depressed about my condition. I would stress the importance of understanding this condition and not worrying when you read about other people's symptoms, as these differ enormously.

For me, it is the small, annoying symptoms that have the greatest effect on my life. Individually these do not present a problem, but together they make life uncomfortable. I try to develop strategies to help overcome these symptoms – with varying degrees of success! In my case, the worst of these symptoms are constipation, sleep problems and restless legs, cramp, nausea and dry eyes.

My husband (my carer) and I have had great help from my specialist. Not only in prescribing medication, but also for the support he has given us in more practical matters. He also suggested a physiotherapist specialising in Parkinson's. I was given exercises that I can do at home using a physio ball, and I do regular sessions, which keep me mobile. I enjoy walking and am able to walk eight to 10 miles quite comfortably.

Early after diagnosis, I visited a nutritionist who understands the problems of Parkinson's. They planned a diet for me that I still follow.

I keep a diary noting any changes in my condition and find there are many more positive days than negative. Keeping mobile has meant my lifestyle is little changed since the first shock of diagnosis. My motto is, 'One life – live it!'

# DOES PARKINSON'S RESEARCH OFFER HOPE FOR THE FUTURE?

More progress has been made in Parkinson's research in the last 10 years than ever before, and this gives us plenty of hope for the future.

So far, we've invested more than £50million on groundbreaking research.

We are committed to funding groundbreaking research to improve life for everyone affected by Parkinson's and to understand more about the condition. Our overall aim is to overcome the symptoms of Parkinson's and find a cure.

We support research related to:

## Drug treatment

Current research is looking at:

- different ways of giving medication, such as nasal sprays, gels and patches
- treatments based on other systems and substances in the

brain that may be involved in Parkinson's, other than dopamine

- medications that enhance the effects of levodopa or reduce its side effects

## Surgery

There is also the potential for new surgical treatments for some people with advanced Parkinson's. In time, this might include stem cell therapy.

## Gene therapy

Some scientists are also looking into using genes as drugs as a possible treatment.

## Non-motor symptoms

These are the Parkinson's symptoms that are not related to movement. They can be caused by the condition or the medication used to treat it. Healthcare professionals are now more aware that these other symptoms are a big part of the condition. This means they have better ways to assess the problems, more research

into treatments and better ways to manage or ease them.

You can read more about our research priorities in our research strategy – Our plan to cure Parkinson’s: The Parkinson’s research strategy 2010-2014.

To find out more about research into Parkinson’s, contact our research department on **020 7931 8080** or visit **[parkinsons.org.uk/research](http://parkinsons.org.uk/research)**



# FINDING OUT MORE ABOUT PARKINSON'S

## How do I find information to help me?

Finding the right information to meet your specific needs will help you to cope with Parkinson's. This may include resources on:

- the nature of Parkinson's, its treatment and management
- the services available to help
- self-help options
- useful organisations
- family support
- research
- personal stories from other people with the condition

The right information for you will depend on your particular needs, which will probably change over time. Having too much information all at once, especially when you are first diagnosed, can be overwhelming. But knowing where to get information you can trust when you want it is

very important. Parkinson's UK is an obvious place to start. We have a wealth of information materials – booklets, information sheets, audio versions, DVDs and more – on many aspects of Parkinson's.

You can also speak to an adviser on our helpline (on **0808 800 0303**) or your local information and support worker, who will be happy to talk about your questions and worries. They can also point you to useful organisations and resources.

If you want to know more about services where you live, your Parkinson's UK information and support worker or local group can help.

There are also many books, websites and useful organisations that other people with Parkinson's have found helpful, which are listed in the More information and support section at the end of this booklet.

## NHS Direct and NHS24

The NHS has a 24-hour, nurse-led telephone information line that can help with health services and conditions. In England and Wales this is NHS Direct on **0845 4647**, and in Scotland, NHS24 on **08454 242424**. In Northern Ireland, you can find health information and contact details for out-of-hours medical services at **www.nidirect.gov.uk**

You can also find out more about health services and conditions on these websites:

- England **www.nhsdirect.nhs.uk**
- Wales **www.nhsdirect.wales.nhs.uk**
- Scotland **www.nhs24.co.uk**
- Northern Ireland **www.n-i.nhs.uk**

To find out more about how the NHS works, visit:

- England **www.nhs.uk**
- Northern Ireland **www.n-i.nhs.uk**
- Scotland **www.show.scot.nhs.uk**
- Wales **www.wales.nhs.uk**
- Isle of Man **www.gov.im/dhss/health**

- Guernsey **www.gov.gg/ccm/navigation/health---social-services**
- Jersey **www.gov.je/health**

You can contact the body responsible for patient liaison in your area. See page 20 for more information.

Also, get in touch with your local social services or social work department or health and social care trust for information about the help that is available from them in your local area. The telephone number should be in your local directory or available from your GP surgery or Citizens Advice Bureau.

## How can I know that information about Parkinson's is reliable?

Articles about health and science in newspapers, on the internet, TV and radio are very popular. It's great to have so much information available, but while there are many excellent resources, there is also material that is questionable or makes dubious, but persuasive claims – especially about alternative therapies.

Ask the following:

## Who produced the information and why?

If you're looking at a website, does it state its aims and objectives? Does it tell you who produced the information, with details of their qualifications and why they're an expert? Does it give a charity number (where relevant) and contact details? Does it subscribe to any codes of practice? These include HON ([www.hon.ch](http://www.hon.ch)) or DISCERN ([www.discern.org.uk](http://www.discern.org.uk))

You should also look out for the Information Standard kitemark. We have been awarded this for the quality of the publications and resources we produce for people affected by Parkinson's. Created by the Department of Health, The Information Standard was developed to help the public identify trustworthy health and social care information easily.

To achieve the Standard, organisations must produce information that is accurate, impartial, balanced, evidence-based, accessible and well-written. Find out more at [www.theinformationstandard.org](http://www.theinformationstandard.org)

## How current is the information?

Does the information include the date it was written, so you can make sure it's up to date?

## What sort of language is used?

Is the information balanced and unbiased or is it sensational and emotional?

## What is the purpose of the information?

Does it just give you information, or is it trying to make you buy a product or a service? Is the website sponsored by certain businesses? If so, does it encourage you to buy their products?

## What evidence is it based on and does it clearly state this?

If you are reading medical information or recommendations, check that it is based on scientific evidence. The type of evidence quoted is also very important. The gold standard of scientific trials is a 'double-blinded randomised controlled trial'. This is a scientific experiment where some people receive treatment and others, who are a 'control' group, receive a fake or 'placebo' version. Who receives the treatment is decided at random and to make it more reliable, neither the researchers or the people involved in the study know who is receiving the real treatment. They should also be published in peer-reviewed journals. This means that the quality of the research has been approved before it is included.

## What about personal experiences?

Reading about the personal experiences of other people with Parkinson's can be very useful, and can give you the chance to talk about different ideas and give mutual support. But you shouldn't use it as proof that something, such a product or service, works. It's important that websites make it clear when information is only based on this. Medical conditions, especially Parkinson's, affect everyone differently, so your experience may be very different from someone else's.

## Is the information from the UK or abroad?

Information from other countries can be very interesting, but may not be relevant to the UK. Also, drug names may be different.

Check anything you're worried about with your GP, specialist or Parkinson's nurse. If you want to try a complementary therapy, check with them that it can be used with your current treatment.

## Find out more

- Visit our website for accurate and up-to-date information about Parkinson's.
- See Health Information: Finding



Reliable Sources on the Internet, a fact sheet published by the British Medical Association (BMA).

- The BMA's Best Health website aims to provide evidence-based information to lay people – see **besthealth.bmj.com** (you need to pay a subscription).
- See I don't know what to believe ... making sense of science stories produced by independent charitable trust Sense About Science. It promotes good science and evidence in public debates. See **www.senseaboutscience.org**
- Patient UK, an evidence-based website, provides a wealth of information on health conditions, maintaining a healthy lifestyle and contact details for many voluntary organisations. See **www.patient.co.uk**

# My life with Parkinson's

By Pat, diagnosed in 2007 at the age of 62

I was not surprised when I found out I had Parkinson's – both my parents had the condition, and my younger brother was diagnosed the previous year. It was not as earthmoving a shock as the diagnosis of breast cancer 12 years earlier. My father was one of the first people with Parkinson's to receive levodopa in the UK.

I told everyone I had Parkinson's straight away, and was given lots of support and hugs. I see no reason to hide it, it is nothing to be ashamed of, after all. In fact, the experience has been very positive. There is no point in struggling on pretending that there is nothing wrong, when help and support is available. Why not access it sooner rather than later, and at the same time make plans for the future?

I have been very lucky with my specialist, whose research into familial Parkinson's is funded by Parkinson's UK. Currently the drugs do work, and most people cannot believe I have Parkinson's. I am careful not to overdo things, however.

I paint, draw and make prints, adapting my techniques to take account of my lack of dexterity. I teach the Expert Patients Programme, and this has been a revelation: I meet so many people with much more severe conditions coping with such courage and sense of humour. It is humbling.

I was given a chicken coop and run, with a cockerel and three laying hens. If I feel down or need to get out of the house, I go and watch the chickens. Their soothing clucking and silly antics soon cheer me up. If I'm reluctant to get up in the morning, the cockerel will soon tell me he needs me to visit him with his morning corn – irresistible!



# MORE INFORMATION AND SUPPORT

## Support and information from Parkinson's UK

We have a range of information resources that are available to order for free (see the inside back cover for details) or to download from our website at [parkinsons.org.uk/publications](http://parkinsons.org.uk/publications)

## Information and support workers

Our information and support workers can also provide details and links to local services. They provide support for anyone affected by Parkinson's.

For details of the local information and support worker in your area, contact our helpline on **0808 800 0303** or email [hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk). You can also find out more on our website at [parkinsons.org.uk/isw](http://parkinsons.org.uk/isw)

## Our helpline

Contact 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](mailto:hello@parkinsons.org.uk)

## Local groups

Support is available through Parkinson's UK local groups. Visit [parkinsons.org.uk/localgroups](http://parkinsons.org.uk/localgroups) or call our helpline for details of your nearest meeting.

## Online forum

Speak to others in a similar situation through our online discussion forum at [parkinsons.org.uk/forum](http://parkinsons.org.uk/forum)

## Other resources

### Books

Look on the internet or visit your local bookshop to order these titles:

### 100 questions and answers about Parkinson's disease

Dr Abraham Lieberman with  
Marcia McCall (2008)  
ISBN 07637 62504

### Living with a long-term illness: the facts

Frankie Campling and Michael  
Sharpe (2006) ISBN 0 19 852882 5

### Living with Parkinson's disease

Bridget McCall (2006)  
ISBN 0 85969 957 9

### Parkinson's at your fingertips (4th edition)

Bridget McCall (2010)  
ISBN 1 85959 222 8

### Parkinson's disease: a guide to treatments, therapies and controlling symptoms

David A Grimes (2004)  
ISBN 1 84119914 1

### The new Parkinson's disease handbook

Dr Harvey Sagar (2002)  
ISBN 0 09 1883873

### Parkinson's disease: a guide for patient and family

Drs Jacob Sage and Roger  
C Duvoisin (2001)  
ISBN 0 7817 29777

### Understanding Parkinson's disease

Tony Schapira (2008) Family  
Doctor Publications Ltd  
ISBN 1 903474256

### Personal accounts

#### Always looking up: the adventures of an incurable optimist

Michael J Fox (2010) Ebury Press,  
ISBN 0091 922 674

#### Voices from the parking lot: Parkinson's insights and perspectives

Edited by Dennis Greene, Joan  
Blessington Snyder and Craig  
L Kendall (2000) Available from  
The Parkinson's Alliance

**[www.parkinsonalliance.net](http://www.parkinsonalliance.net)**

ISBN B000AV07Q6

#### Health is between your ears: living with a chronic illness

Svend Andersen (2002)  
ISBN 87 88130 49 5

#### Living well with Parkinson's

Glenna Wotton Atwood (2005)  
ISBN 0471 282 235

#### Lucky man: a memoir

Michael J Fox (2003)  
ISBN 0 091885671

#### When Parkinson's strikes early: voices, choices, resources and treatment

Barbara Blake-Krebs and  
Linda Herman (2002)  
ISBN 0 89793 340 0

## For carers

### The comfort of home for Parkinson's disease: a guide for caregivers

Maria M Meyer, Paula Derr and Susan C Imke (2007)  
Care Trust Publications LLC  
ISBN 0966476774

### The complete carer's guide

Bridget McCall (2007) Sheldon Press, ISBN 0859699951

### The essential carer's guide

Mary Jordan (2006) Hammersmith Press Ltd, ISBN 1 905140 07 X

### Carers' handbook: what to do and who to turn to

Marina Lewycka (2004) Age Concern Books, ISBN 086242366X

### The selfish pig's guide to caring

Hugh Marriott (2009) Polperro Heritage Press, ISBN 0749929863

## Children

### I'll hold your hand so you won't fall down

Rasheda Ali (2005) Merit Publishing International  
ISBN 187 341 3130

## Other useful guides

### The patient's internet handbook

Robert Kiley and Elizabeth Graham, Royal Society of Medicine (2001)  
ISBN 978 1853154980

### How to read a paper: the basics of evidence-based medicine

(4th revised edition)  
Trisha Greenhalgh, Blackwell Publishing (2010)  
ISBN 1444334360

## Websites

[Patient UK](http://www.patient.co.uk) is a useful online resource produced by two GPs. This evidence-based website provides a wealth of information on health conditions, maintaining and a healthy lifestyle, and contact details for many voluntary organisations.

**[www.patient.co.uk](http://www.patient.co.uk)**

[Bandolier](http://www.medicine.ox.ac.uk/bandolier) is an independent journal and website about evidence-based healthcare, written by Oxford scientists.

**[www.medicine.ox.ac.uk/bandolier](http://www.medicine.ox.ac.uk/bandolier)**

[Quackwatch](http://www.quackwatch.org) is a non-profit organisation, run by Stephen Barrett who is a retired doctor. Based in the USA, it has an international focus and attempts to "combat health-related frauds, myths, fads, and fallacies".

**[www.quackwatch.org](http://www.quackwatch.org)**

## Useful contacts

### AbilityNet

A charity helping disabled adults and children to use computers and the internet by adapting and adjusting their technology. It has links to centres across the country.

**0800 269545**

**enquiries@abilitynet.org.uk**

**www.abilitynet.org.uk**

### Action on Depression (Scotland)

**0808 802 2020**

**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 7582 0400**

**info@afiya-trust.org**

**www.afiyatrust.org.uk**

### Age UK

**0800 169 6565**

**www.ageuk.org.uk**

### Age Cymru

**0800 169 6565**

**www.ageuk.org.uk/cymru**

### Age NI

**0808 808 7575**

**www.ageuk.org.uk/  
northern-ireland**

### Age Scotland

**0845 125 9732**

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

### Alzheimer's Northern Ireland

**028 9066 4100**

**nir@alzheimers.org.uk**

**www.alzheimers.org.uk**

### Alzheimer's Society

**0845 300 0336**

**enquiries@alzheimers.org.uk**

**www.alzheimers.org.uk**

### Alzheimer Scotland

**0808 808 3000**

**alzheimer@alzscot.org**

**www.alzscot.org**

### Anxiety UK

**08444 775 774**

**info@anxietyuk.org.uk**

**www.anxietyuk.org.uk**

### Asian Health Agency

Provides services including counselling, advocacy and respite care for Asian elders, disabled people and carers in England.

**020 8811 1501**

**www.taha.org.uk**

### Benefit Enquiry Line (Department for Work and Pensions)

A confidential telephone service for people with disabilities and their carers providing information and leaflets on benefits.

**0800 882200**  
Textphone **0800 243355**  
**BEL-Customer-Services@**  
**dwp.gsi.gov.uk**  
**www.direct.gov.uk/**  
**disability-money**

**The Blue Cross**  
**0300 777 1897**  
**info@bluecross.org.uk**  
**www.bluecross.org.uk**

**British Association for Counselling**  
**and Psychotherapy**  
**01455 883300**  
Minicom **01455 550307**  
Text **01455 560606**  
**enquiries@bacp.co.uk**  
**www.bacp.co.uk**

**British Association/College of**  
**Occupational Therapists**  
**020 7357 6480**  
**www.cot.org.uk**

**British Medical Association**  
**020 7387 4499**  
**www.bma.org.uk**

**Canine Partners**  
A charity that trains assistance  
dogs for disabled people.  
**0845 658 0480**  
**www.caninepartners.co.uk**

**Care and Repair**  
A charity set up to improve the  
housing and living conditions of  
older people and disabled people.

**Cymru**  
**029 2057 6286**  
**www.careandrepair.org.uk**

**England**  
**0115 950 6500**  
**www.careandrepair-england.org.uk**

**Care and Repair Forum Scotland**  
**0141 221 9879**  
**www.careandrepairsotland.co.uk**

**Care Information Scotland**  
**08456 001 001**  
**www.careinfoscotland.co.uk**

**Carers UK**  
CarersLine **0808 808 7777**  
(Wednesdays and Thursdays only,  
10am–12pm, 2pm–4pm)  
**www.carersuk.org**

**Cynhalwyr Cymru**  
**02920 811 370**  
**www.carersuk.org/wales**

**Carers Northern Ireland**  
**02890 439 843**  
**www.carersuk.org/northernireland**

**Carers Scotland**  
**0141 445 3070**  
**www.carersuk.org/scotland**

Cats Protection  
03000 121212  
helpline@cats.org.uk  
www.cats.org.uk

Cause mental health  
(Northern Ireland)  
0845 603 0291  
www.cause.org.uk

Chartered Society of Physiotherapy  
020 7306 6666  
www.csp.org.uk

Chinese National Healthy  
Living Centre  
Advice on health issues including  
caring help for the Chinese  
community.  
020 7287 0904 or  
020 7534 6546  
general@cnhlc.org.uk  
www.cnhlc.org.uk

The Cinnamon Trust  
This organisation helps people  
aged over 60 years or terminally  
ill people to stay with their pets for  
as long as possible.  
01736 757 900  
admin@cinnamon.org.uk  
www.cinnamon.org.uk

Citizens Advice  
  
England  
0844 411 1444  
www.citizensadvice.org.uk

Wales  
0844 477 2020

Northern Ireland  
www.citizensadvice.co.uk

Scotland  
www.cas.org.uk

Online advice guide:  
www.adviceguide.org.uk

Community Health Council (CHC)  
– Wales  
0845 644 7814  
enquiries@waleschc.org.uk  
www.patienthelp.wales.nhs.uk

The Consumer Health  
information Centre  
www.chic.org.uk

Crossroads Care (England  
and Wales)  
A major charity providing practical  
support to carers in the home. It  
has more than 200 schemes across  
England and Wales, with partner  
organisations in Northern Ireland  
and Scotland.  
0845 450 0350  
www.crossroads.org.uk

Crossroads Caring for Carers  
Northern Ireland  
028 9181 4455  
www.crossroadscare.co.uk

**Crossroads Caring Scotland**  
**0141 226 3793**  
**www.crossroads-scotland.co.uk**

### Depression Alliance

Charity supporting anyone with depression in England and Wales, and their families.

**0845 123 2320**  
**information@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**  
**www.disabilityaction.org**

### Disability Alliance

Provides people with disabilities with information on their rights and benefits, including its Disability Rights Handbook.

**020 7247 8776**  
**www.disabilityalliance.org**

### Disabled Living Foundation

Helpline **0845 130 9177**  
(Monday–Friday 10am–4pm)

**helpline@dlf.org.uk**  
**www.dlf.org.uk**

**Disabled Parents Network**  
**0300 3300 639**  
**www.disabledparentsnetwork.org.uk**

**Disability Pregnancy and Parenthood International**  
**0800 018 4730**  
Textphone **0800 018 9949**  
**info@dppi.org.uk**  
**www.dppi.org.uk**

**Driver and Vehicle Agency (DVA) – Northern Ireland**  
**0845 402 4000**  
**www.dvani.gov.uk**

**Driver and Vehicle Licensing Agency (DVLA) – UK**  
General Medical Line  
(car and motorcycle)  
**0300 790 6806**  
**www.dft.gov.uk/dvla**

**The Equality and Human Rights Commission**  
**www.equalityhumanrights.com**

**England**  
**0845 604 6610**  
Textphone **0845 604 6620**  
**englandhelpline@equalityhumanrights.com**

**Scotland**  
**0845 604 5510**  
Textphone **0845 604 5520**  
**scotlandhelpline@equalityhumanrights.com**

## Wales

**0845 604 8810**

Textphone **0845 604 8820**

**waleshelpline@**

**equalityhumanrights.com**

## Equality Commission for

### Northern Ireland

**028 9089 0890**

Textphone **028 9050 0589**

**information@equalityni.org**

**www.equalityni.org**

## The Expert Patients Programme

**0800 988 5550**

**get.info@eppcic.co.uk**

**www.expertpatients.co.uk**

## Friends, Families and Travellers

Supports Gypsy and Traveller communities in a range of ways, including access to health and social care services.

**01273 234 777**

**fft@gypsy-traveller.org**

**www.gypsy-traveller.org**

## Gardening for the Disabled Trust

**www.gardeningfordisabledtrust.org.uk**

## Gingerbread

**0808 802 0925**

**www.gingerbread.org.uk**

## Gingerbread Northern Ireland

**0808 808 8090**

**advice@gingerbreadni.org**

**www.gingerbreadni.org**

## Health Rights Information Scotland

**0141 226 5261**

**hris@consumerfocus.org.uk**

**www.hris.org.uk**

## In Control Support Centre

**01564 821 650**

**info@in-control.org.uk**

**www.in-control.org.uk**

## Independent Advice and Support Service (IASS – Scotland)

**www.cas.org.uk**

## Jobcentre Plus

**www.direct.gov.uk**

## Learndirect

**0800 101 901**

**www.learndirect.co.uk**

## Learndirect Scotland

**0808 100 9000**

**www.learndirectscotland.com**

## The Lesbian and Gay Foundation

**0845 330 3030**

**info@lgf.org.uk**

**www.lgf.org.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](http://www.nhs.uk)

Northern Ireland  
[www.hscni.net](http://www.hscni.net)

Scotland  
[www.show.scot.nhs.uk](http://www.show.scot.nhs.uk)

Wales  
[www.wales.nhs.uk](http://www.wales.nhs.uk)

Local Involvement Networks  
(LINKs, England only)  
Contact your local council for details.

Lone Parent Helpline England  
and Wales  
**0808 802 0925**  
[www.loneparenthelpline.org](http://www.loneparenthelpline.org)

Lone Parent Helpline Scotland  
**0808 801 0323**  
[www.loneparenthelpline.org](http://www.loneparenthelpline.org)

MedicAlert  
This charity produces alert  
bracelets and other identification  
items, for people with medical  
conditions.  
**0800 581420**  
[info@medicalert.org.uk](mailto:info@medicalert.org.uk)  
[www.medicalert.org.uk](http://www.medicalert.org.uk)

Mind  
**0300 123 3393**  
[info@mind.org.uk](mailto:info@mind.org.uk)  
[www.mind.org.uk](http://www.mind.org.uk)

Motability Car Scheme  
**0845 456 4566**  
[www.motability.co.uk](http://www.motability.co.uk)

The Multiple System Atrophy Trust  
**020 7940 4666**  
[office@msatrust.org.uk](mailto:office@msatrust.org.uk)  
[www.msatrust.org.uk](http://www.msatrust.org.uk)

National Animal Welfare Trust  
**020 8950 0177**  
[www.nawt.org.uk](http://www.nawt.org.uk)

NHS Direct (England)  
**0845 4647**  
Textphone **0845 606 4647**  
[www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)

NHS Direct (Wales)  
**0845 4647**  
[www.nhsdirect.wales.nhs.uk](http://www.nhsdirect.wales.nhs.uk)

NHS24 (Scotland)  
**08454 242424**  
[www.nhs24.com](http://www.nhs24.com)

Northern Ireland Association  
for Mental Health  
**028 9032 8474**  
[www.niamh.co.uk](http://www.niamh.co.uk)

Northern Ireland out-of-hours  
medical service  
Local details can be found at  
[www.nidirect.gov.uk](http://www.nidirect.gov.uk)

### No Panic

A charity that helps people to overcome anxiety disorders.

**0808 808 0545**

**[www.nopanic.org.uk](http://www.nopanic.org.uk)**

### Occupational Therapists in Independent Practice

**0845 129 7699**

**[www.otip.co.uk](http://www.otip.co.uk)**

### One Parent Families Scotland

**0131 556 3899**

**[info@opfs.org.uk](mailto:info@opfs.org.uk)**

**[www.opfs.org.uk](http://www.opfs.org.uk)**

### Open University

**0845 300 6090**

**[www.open.ac.uk](http://www.open.ac.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.

**020 7354 8291**

**[info@outsiders.org.uk](mailto:info@outsiders.org.uk)**

**[www.outsiders.org.uk](http://www.outsiders.org.uk)**

### Sex and Disability Helpline

**0707 499 3527** (higher phone rate)

**[sexdis@outsiders.org.uk](mailto:sexdis@outsiders.org.uk)**

**[www.outsiders.org.uk](http://www.outsiders.org.uk)**

### Patient Advice and Liaison Services (PALS – England)

Contact your local primary care trust or visit the website

**[www.pals.nhs.uk](http://www.pals.nhs.uk)**

### Patient and Client Council (Northern Ireland)

**0800 917 0222**

**[Info.pcc@hscni.net](mailto:Info.pcc@hscni.net)**

**[www.patientclientcouncil.hscni.net](http://www.patientclientcouncil.hscni.net)**

### Patient's Association

**0845 608 4455**

**[helpline@patients-association.com](mailto:helpline@patients-association.com)**

**[www.patients-association.org.uk](http://www.patients-association.org.uk)**

### The Pet Fostering Service, Scotland

**0844 811 9909**

**[www.pfss.org.uk](http://www.pfss.org.uk)**

### Pets as Therapy

**01844 345 445**

**[www.petsastherapy.org](http://www.petsastherapy.org)**

### The Princess Royal Trust for Carers

A national charity that provides information, support and practical help to carers.

**0844 800 4361**

**[www.carers.org](http://www.carers.org)**

### Glasgow office

**0141 221 5066**

### PSP (Europe) Association

**01327 322410**

**[psp@pspeur.org](mailto:psp@pspeur.org)**

**[www.pspeur.org](http://www.pspeur.org)**

### RADAR

**020 7250 3222**

Textphone **020 7250 4119**

**radar@radar.org.uk**

**www.radar.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**

**www.relationships-scotland.org.uk**

### Royal College of Psychiatrists

**020 7235 2351**

**www.rcpsych.ac.uk**

### RSPCA

**0300 1234 999**

**www.rspca.org.uk**

### Scottish Association for Mental Health

**0141 530 1000**

**enquire@samh.org.uk**

**www.samh.org.uk**

### Scottish SPCA

**03000 999 999**

**www.scottishspca.org**

### Talisman Ltd (SOS Talisman)

Produces jewellery that contains information about the wearer, in case of accident or illness.

**020 8554 5579**

**sostalisman@btinternet.com**

**www.sostalisman.co.uk**

### Thrive

A national charity that uses gardening to change the lives of disabled people.

**0118 988 5688**

**www.thrive.org.uk**

### USPCA (Ulster Society for the Prevention of Cruelty to Animals)

**028 3025 1000**

**www.uspca.co.uk**

### Vitalise

A charity that offers respite care for disabled people and carers.

**0845 345 1972**

**info@vitalise.org.uk**

**www.vitalise.org.uk**

# NOTES

# GLOSSARY

## Bradykinesia

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

## Dyskinesia

Involuntary movements, often a side effect of taking levodopa for a long period of time.

## Dystonia

A symptom of Parkinson's. It is a sustained, involuntary muscle contraction that can affect different parts of the body.

## Freezing

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

## Occupational therapist

A healthcare professional who gives advice on daily living, including washing, bathing, dressing, eating, reading and leisure activities.

## Physiotherapist

A healthcare professional who advises on movement problems at home and elsewhere (an occupational therapist can also help you with equipment for this).

## 'Wearing off'

This is where a Parkinson's drug becomes less effective before it is time for your next dose. You may go 'off' – this is when your symptoms are less under control and it is harder to move. You may switch 'on' again soon after taking your next dose of medication.

## Speech and language therapist

A healthcare professional who gives advice on anything to do with communication. They can also help with swallowing problems.

## 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

## Living with Parkinson's

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:

### Information Resources

Parkinson's UK

215 Vauxhall Bridge Road

London SW1V 1EJ

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

### Please tick...

- I have Parkinson's. When were you diagnosed? .....
- 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

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, please complete the details below and we'll be in touch.

Membership

Information review group

(People affected by Parkinson's who give us feedback on new and updated resources)

Name .....

.....

Address .....

.....

Telephone .....

Email .....



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

**Anette Schrag, Reader and Consultant Neurologist, Institute of Neurology, University College London**

**Stella Gay, Parkinson's Disease Nurse Specialist, Guy's and St Thomas' NHS Foundation Trust**

**Vicky Riddle, Information and Support Worker, Parkinson's UK**

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

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](https://parkinsons.org.uk/publications)**

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

**01473 212115**

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

**[parkinsons.org.uk/publications](https://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](https://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–8pm, Saturday 10am–2pm. Interpreting available.

Text Relay **18001 0808 800 0303**

(for textphone users only)

**hello@parkinsons.org.uk**

**parkinsons.org.uk**

\*calls are free from UK landlines and most mobile networks.

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