

LIVING WITH PARKINSON'S

PARKINSON'S^{UK} 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, self-management, work and travel.

Everyone's experience of Parkinson's is different, and how the condition may affect your day-to-day life can vary. By providing practical information about life with Parkinson's, we hope this guide will answer some of your questions and help you to take control.

Through the voices of others with the condition, we hope it will provide 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 words and their meanings can be found at the back of this booklet.

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TYPES OF 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 *Types of Parkinson's*. We offer support to everyone 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 also contact the PSP (Europe) Association. See the 'Useful contacts' section on page 118.

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 of the nerve cells in their brain that make it have died. Without dopamine, people can find their movements become slower, so it takes longer to do things.

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 *Types of Parkinson's*.

How many people have Parkinson's?

About one person in every 500 has Parkinson's. That's about 127,000 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 the condition takes to progress and how it is treated may be different for you than for other people with the condition. Many people also find that how the condition affects them can change from day to day, and even from hour to hour.

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, you will be able to notice it more easily when your affected body part is resting, or if you are angry or excited. This is known as a resting tremor. 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 *Wearing off and involuntary movements (dyskinesia)*.

What are the other symptoms of Parkinson's?

For a long time, Parkinson's was seen as a condition that mainly affected 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 all of these symptoms. The speed at which the condition develops and how strongly you experience any symptoms also changes from person to person. Some other symptoms you may experience include the following.

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 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.

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 out more: see our information sheet *Dental health and Parkinson's*.

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: see page 36 and read our information sheet *Depression 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 and problems with eating food and taking medication.

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, which can be due to muscle spasms, or a range of other causes (dystonias – see glossary on page 127).

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*.

If you experience sleep and night-time problems, speak to your GP or specialist. You can also speak to your Parkinson's nurse, if you have one. A Parkinson's nurse is a qualified registered general nurse with specialist experience, knowledge and skills in Parkinson's. They play a vital role in the care of people with Parkinson's. You can read more about them on page 18.

We have a non-motor symptoms questionnaire available to help you talk about these symptoms with your healthcare professional. 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

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 may just 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 may 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*, *Mild*

memory problems 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. Your GP should be able to refer you.

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 multiple system atrophy, progressive supranuclear palsy or Wilson's disease.

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

How does Parkinson's progress?

Parkinson's gets worse over time, but every 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 and lots of things you can do to help manage your symptoms.

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. Or you can call our free helpline on **0808 800 0303** for information and support. You can also speak to a Parkinson's local adviser.

Details can be found at parkinsons.org.uk/localadvisers

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.

'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 – 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. This guide looks at tips for managing all these areas.

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 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 33 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.

Other rare conditions have similar symptoms to juvenile Parkinson's, including Wilson's disease, dopa-responsive dystonia (Segawa's syndrome) or an unusual form of Huntington's disease.

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 get Parkinson's than women, 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.

One explanation could be because of the activity of oestrogen (the

female sex hormone), but further research is needed.

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.



My life with Parkinson's

by Michael, diagnosed in 2007 at the age of 57

I was diagnosed after being referred by my doctor to a neurologist. A year earlier I had looked on the internet to see why I had a few symptoms which I could not explain. My right-hand ring finger was trembling, which was something I had noticed for many years.

Also, my wife had noticed I had a tendency not to swing an arm while walking, which had also been happening for many years.

The website I looked at suggested that these were symptoms of Parkinson's, so I made an appointment with my GP.

The doctor said he did not think I had Parkinson's but told me to keep an eye on it and then come back at a future date.

Well, the symptoms were not affecting me in the slightest work-wise, but I did notice that I didn't have as much energy as usual and got quite tired. I also noticed that I had lost my sense of smell.

When I went back to the doctor about six months later he referred me to a neurologist. I was investigated by the neurologist and the conclusion was that I had Parkinson's.

Thankfully, I was prepared for that diagnosis and so I wasn't taken aback too much.

HEALTHCARE PROFESSIONALS

Which healthcare professionals can help me?

Your GP

If you think you have Parkinson's, the first person you should see is your GP. The average GP only has a small number of patients with Parkinson's. 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, health advice and help to access the services you need. They should work closely with your specialist.

Your GP will work with a team that includes 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 wish to be involved in making decisions about your treatment.

The multidisciplinary 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

You can ask your Parkinson's local adviser (see page 117 for details) to find out what is available in your area.

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 helping 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 then approach another practice in your area.

You can get advice from your local Patient Advice and Liaison Service (PALS) in England, which is based in your hospital; 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 sheet *Monitoring your symptoms* 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**

- **www.embarrassingproblems.com** is a website that has information and advice on health problems that you might find hard to talk about.

What does a Parkinson's nurse do?

Parkinson's nurses provide expert advice and support to people with Parkinson's, and those who care for them, to manage symptoms. They can also act as a liaison between other health and social care professionals to make sure your needs are met.

The role of the Parkinson's nurse varies across the UK. Each will offer different services, aiming to meet local needs. Some nurses are based in the community, whereas others are based in hospitals. Many Parkinson's nurses are independent prescribers. This means they can prescribe and make adjustments to medication, so someone with Parkinson's doesn't always need to see a specialist for changes to, or queries about, their Parkinson's drugs.

Parkinson's nurses may not be available in every area, but your GP or specialist can give you more details on local services. Find out more at **parkinsons.org.uk/nurses**

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 local adviser (see page 117 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 recommended by the SIGN guidelines.

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 on 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 therapy 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. Here's what to do if you want to complain about your NHS services.

- Contact your local Patient Advice and Liaison Service (PALS) if you live in England. In England, you can also get involved in Healthwatch. This is an independent consumer organisation that aims to make sure that the views and experiences of people who use health and social care services are heard and taken seriously – both locally and nationally. Your local Healthwatch can help
- Contact 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 121 for details.
- Contact 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
- 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 125 for more details.

with complaints you have about services, including those related to your Parkinson's. To find your local Healthwatch, visit www.healthwatch.co.uk, or call **03000 683 000**.

- You can also get help to make a complaint from your local Citizens Advice Bureau. See page 121 for contact details.

Find out more

Call our helpline on **0808 800 0303** for information and support. They can also let you know how to contact your Parkinson's local adviser, 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/niceguidelines.

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. Visit 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. I was an occupational therapist and 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 their most recent dose wears off before their 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 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 your symptoms and enjoy a better quality of life. These include drugs, surgery, physiotherapy, speech and language therapy, and occupational therapy.

If you have mild symptoms and have just been diagnosed, you might not start taking Parkinson's drugs until your symptoms get in the way of your 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.

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

Parkinson's drugs

What drug treatments are there?

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.

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 the companies who market them have given them.

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

Generic name	Brand name
<p>Levodopa</p> <p>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.</p>	
Co-beneldopa (benserazide plus levodopa)	Madopar Madopar CR
Co-careldopa (carbidopa plus levodopa, available in generic form)	Caramet CR Duodopa Sinemet Sinemet CR Sinemet Plus Half Sinemet CR
Co-careldopa plus entacapone (see below)	Stalevo
<p>Dopamine agonists</p> <p>These drugs may be given on their own or prescribed alongside levodopa or other drugs.</p>	
Bromocriptine (available in generic form)	Parlodel
Cabergoline (available in generic form)	Cabaser
Pergolide (available in generic form)	Celance
Pramipexole	Mirapexin Mirapexin prolonged release
Ropinirole (available in generic form)	Adartrel Ralnea XL Requip Requip XL Spiroco XL
Rotigotine	Neupro

Generic name	Brand name
<p>Apomorphine (available in generic form) Unlike other dopamine agonists, apomorphine is usually reserved for advanced Parkinson's, when symptoms are severe and levodopa is not working well all the time.</p>	<p>APO-go PEN APO-go PFS</p>
<p>Monoamine oxidase type B (MAO-B) inhibitors These drugs are sometimes used alone in early Parkinson's or with levodopa and sometimes other drugs in advanced Parkinson's.</p>	
Rasagiline	Azilect
<p>Selegiline (available in generic form)</p>	<p>Eldepryl Zelapar</p>
<p>Catechol-O-methyltransferase (COMT) inhibitors In advanced Parkinson's, COMT inhibitors are used alongside levodopa to help it work more smoothly.</p>	
Entacapone	Comtess
Tolcapone	Tasmar
<p>Glutamate antagonist This is mostly used with other Parkinson's medication and has an effect on tremor and stiff muscles.</p>	
Amantadine	No branded version available
<p>Anticholinergics These drugs are not used very often for Parkinson's but sometimes they are used for reducing tremor and stiff muscles.</p>	
<p>Orphenadrine (available in generic form)</p>	<p>Biorphen Disipal</p>
<p>Procyclidine (available in generic form)</p>	<p>Arpicolin Kemadrin</p>
<p>Trihexyphenidyl (benzhexol) (available in generic form)</p>	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 their own 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 find a pill timer useful. 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 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 you may start to experience side effects from your Parkinson's drugs.

Some people's side effects will have a big impact on their lives and have to be managed along with the symptoms. Speak to your GP, specialist or Parkinson's nurse, as changing or adding to your medication might help.

Some of the older dopamine agonists increase the risk of heart problems. As a group, these are known as the 'ergot' types and they include: bromocriptine, pergolide and cabergoline. Because of this risk, these Parkinson's drugs are only used when other dopamine agonists do not work well.

All newer dopamine agonists are non-ergot in type. These are apomorphine, pramipexole, ropinirole and rotigotine. They have not been associated with an increased risk of heart damage. Doctors prefer to use these if possible.

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 people take dopamine agonist medication, but it can affect those 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.

Some people may also experience hypersexuality. This 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 the 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 (you may not realise you have these side effects).

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 119 for details).

Find out more: see our information sheet *Impulsive and compulsive behaviour in Parkinson's*.

Dopamine agonist withdrawal syndrome

This can happen when someone very suddenly stops taking dopamine agonists, perhaps because they are experiencing impulsive and compulsive behaviour. It can lead to symptoms that include depression, anxiety or pain.



It is very important any withdrawal from Parkinson's drugs is done gradually, 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 can be a common problem and one that Parkinson's UK continues to campaign on through our Get It On Time campaign. We want to make sure that people with Parkinson's get their medication on time – every time.

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 parkinsons.org.uk/getitontime and our booklet *Going into hospital*.
- 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 booklet *Going into hospital*. On this you can list your drugs and your needs, and anything else, such as pets 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 or by the telephone.

There are some other items you may find useful:

'The bottle in the fridge scheme'

This is a free scheme designed to help alert emergency services to your

condition if they need to enter your property in an emergency situation.

As part of the scheme you record basic medical details and emergency contact numbers on a standard form and keep it in the fridge. You then put a green sticker on your fridge door, and another on the inside of your front door, so emergency services know you are part of the scheme. Speak to your pharmacist or GP about getting a kit.

Parkinson's UK medication card

You can 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. The contact details for MedicAlert can be found on page 124.



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.

Surgery for Parkinson's is mainly used to treat people whose symptoms can't be controlled by drugs. It may also be used if you are experiencing strong involuntary movements (dyskinesias).

Surgery may not be an option if you have uncontrolled high blood pressure, heart and lung disease, severe depression, confusion, dementia or psychosis. It can, however, be an option if psychiatric symptoms have got worse when taking Parkinson's medication.

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.

As with any operation, each form of surgery for Parkinson's carries its own risks. Any outcomes of surgery,

whether good or bad, will have an effect on the quality of life of someone with Parkinson's and those around them. If you have any questions or concerns about whether surgery could be an option for you, speak to your specialist or Parkinson's nurse.

What is deep brain stimulation?

Deep brain stimulation involves inserting very fine wires, with electrodes at their tips, into targeted parts of the brain.

This is often done under local anaesthetic so the patient is awake and the site for stimulation can be correctly found. When the site 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 anaesthetic.

Talk to your Parkinson's specialist to find out if 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 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 49.

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 process your thoughts or worries. 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 to better manage 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.

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 Parkinson's local adviser.

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 (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.

Parkinson's UK also offers a peer support service, where you can speak to trained volunteers who have a similar experience of the condition as you. You can find out more at parkinsons.org.uk/peersupport or by calling our helpline.

You may also meet someone at your local Parkinson's UK group who you can speak to about living with the condition. See page 117 for more details. You may also find it useful to attend the Parkinson's UK self-management programme, which focuses on the emotional impact of living with Parkinson's. You can find out more at parkinsons.org.uk/selfmanagement or see page 43.

There are also online forums where you can talk to other people, including ours at parkinsons.org.uk/forum

Find out more: the mental health charity Mind has a guide, *Making sense of talking treatments*. 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. See page 124 for Mind's contact details.

Do people with Parkinson's get depression and why?

Depression affects some people with Parkinson's. Depression is usually diagnosed when someone has feelings of extreme sadness for a long time. Depression 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.

Some people may 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 for some people.

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. Learning more about depression, taking exercise and finding ways to relax may also help.

Find out more

- See our information sheet *Depression and Parkinson's*.
- Our Parkinson's local advisers 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 125 for contact details of all organisations.

Are panic attacks common in Parkinson's?

Panicking is the body's natural reaction to fear or danger. The chemical adrenaline is released

and 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 not working so 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.

Activities 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 information on their website **www.mind.org.uk** about anxiety and panic attacks,
- or they have booklets to order for a small charge. See page 124 for contact details.
- Other organisations that can help you include No Panic and Anxiety UK. See pages 119 and 124 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 more than 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 McCabe, 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.

HELPING YOURSELF

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 take control of life with the condition as medical treatments and health and social care. Below are some strategies that people with Parkinson's have told us work for them.

Having a positive attitude

Although it won't always 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.

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 on *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 above.

Some local Parkinson's UK groups offer regular creative sessions such as art and singing groups. Find your local group at parkinsons.org.uk/localgroups. You can also enter your visual artwork 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 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.

“ I have been going to tai chi classes for about four years and find them helpful for balance and co-ordination as well as the companionship. ”

Caroline, diagnosed in 2003

Meet 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 to find one in your area.

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 Parkinson's UK regional fundraiser by calling **0808 800 0303** or visiting parkinsons.org.uk/localtoyou

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](https://www.nhs.uk)
www.nhs.uk

Northern Ireland:
www.nidirect.gov.uk

Scotland:
www.nhs24.com

Wales: [Health in Wales](https://www.wales.nhs.uk)
www.wales.nhs.uk

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.

What is self-management?

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

“ 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

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

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

- what self-management is

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

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

For more information on dates and locations in your area or to book

a place please visit **parkinsons.org.uk/selfmanagement** email **selfmanagement@parkinsons.org.uk**, or call our helpline.

Personal budgets and individual budgets

Across the UK, there are new initiatives to 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 intended to become the main way of delivering and funding social care services in the future. In Scotland, everyone needing social care must be offered self-directed support, which can include payments among other options. In Northern Ireland 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 those 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 Parkinson's local adviser, or our helpline on **0808 800 0303** for more information.
- In England and Wales, visit **www.gov.uk** to find out more about direct payments.
- The Department of Health in England has produced an information guide to direct payments. This easy-read version can be downloaded from

www.dh.gov.uk/publications
or you can call **0300 123 1002**
(Textphone **0300 123 1003**)
to order a copy.

on the publications section
of the Scottish Government
Health Directorates website
at www.sehd.scot.nhs.uk

- In Northern Ireland, find out more
at 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

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), conductive education, herbal medicine, homeopathy, osteopathy, Pilates, 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 scientific 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. You may find relaxation therapies 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. Although there has been very little research into the effect of cannabis on people with Parkinson's, the way it affects mood means that it's likely to have a negative effect on everyday life.

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 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.

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.

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 your partner, family, friends and colleagues can change. This can happen at any stage of the condition. You may adapt to these changes and fit them into your life, or you may find them difficult. Your relationship with your family may be the most affected.

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

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 from 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 and 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 affectionate 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 towards 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.

- Work together to solve problems so that everyone is happy. This may mean having to be flexible and coming to a compromise.

- 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.
- 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 Parkinson's local advisers, our Parkinson's local advisers (on **0808 800 0303**), counsellors and psychologists may be able to offer you support.
- You may also find it useful to attend the Parkinson's UK self-management programme which focuses on emotions and their impact on relationships. You can find out more on page 43.
- 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.
- You might want to 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

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.

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.

A side effect of some Parkinson's drugs is an increased interest in sex. This is called hypersexuality (see page 29). This can have a big

effect on personal and professional relationships. You should speak to your GP, specialist or Parkinson's nurse if you are worried about this. See page 29 for more about impulsive and compulsive behaviours.

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. You might have a different attitude to sex, but Parkinson's shouldn't stop you enjoying it.
- 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.

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.

At some point you'll need to decide whether or not to tell a new partner about your condition, and how and when you'll have the conversation.

Opening up to someone else about Parkinson's is a personal decision. Some people may see it as an issue but others may be anxious about it. Remember that not everyone needs to know, and not everyone needs to know straight away, so wait until you're ready.

You can't decide for someone else if they want a relationship with you, so be yourself and see what happens.

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 dreamed 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 son – 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.

by 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 page 58 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 they'll get Parkinson's.
- Call our helpline on **0808 800 0303**, speak to your Parkinson's local adviser, 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're coping with the news.
- Speak to other 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 may 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. These are called *My mum has Parkinson's*, *My dad has Parkinson's*, *My gran has Parkinson's* and *My grandad has Parkinson's*. We also produce an online guide for teenagers at parkinsons.org.uk/teenagers.

Will I be able to father children?

There are many 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 may 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 anti-sickness drugs 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 enough 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.

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.

You could try speaking to people through your local Parkinson's UK group or on our online forum. You can also contact an organisation that supports lone parents, such as Gingerbread, Gingerbread Northern Ireland or One Parent Families Scotland. See the 'Useful contacts' section on page 118 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.

by 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. This support would be normally part of a larger care package, but may be offered as individual support depending on your local authority.

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

Physical problems

These can make you less independent and make it harder to manage 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**

These tips might also 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 local adviser 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.

- 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 Bernard, diagnosed in 2012 at the age of 81

I had experienced some of the symptoms (slowness of walking, tremor of my jaw, drooling, problems with tying laces and fastening buttons) for years before my diagnosis but had regarded them as signs of ageing. My GP carried out tests which I later recognised as tests for Parkinson's and referred me immediately to a consultant neurologist, whom I saw two weeks later, and who diagnosed early Parkinson's.

I joined Parkinson's UK and have found their information services very helpful, especially the information sheet Living alone with Parkinson's as my wife died of cancer five years ago. The local branch of Parkinson's UK and the specialist Parkinson's nurse have both been supportive.

The DVLA has allowed me to keep my driving licence. This makes it easier for me to visit many relatives and friends, to give lifts to friends who cannot drive, and to pursue some leisure activities that would otherwise be closed to me. I should emphasise, however, that I am a regular user of my county's Older Drivers' Skills Appraisal Scheme and I am ready to stop driving as soon as I am unsafe on the roads.

My leisure activities include teaching and playing bridge, being steward at the town's museum, belonging to a reading group and U5A Groups and meeting with my children and grandchildren.

I will try to continue pursuing as many of my leisure activities for as long as I can and, as a naturally impatient person, to accept gracefully the longer time it takes me to do everyday tasks.



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?

- Speak to your GP, specialist or Parkinson's nurse about changes to your medication.
- Ask your GP or specialist to refer you to a speech and language therapist, who can advise on speech and non-verbal problems.
- Visit an occupational therapist, who 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, computers and tablets 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 in Parkinson's*, 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 with 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 or tablet 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 may also 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 123 for contact details.

Find out more: see our [information sheet *Using computers and the internet*](#).



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 120 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:

- 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
- advising 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. 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 124 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 which may help with particular problems. 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 have an assessment, you could spend a lot of money on



equipment that is not right or you could have got cheaper elsewhere.

The type of therapist you see will depend on the 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 (for example 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** 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) 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 121 for contact details.
- See our information on *Daily living equipment for people with Parkinson's* and *Using computers and the internet*.

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 to make it 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.

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
- speak to 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. If necessary, 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 well being.

The types of services available will change according to where you live, but might include help in your home with caring tasks, 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 has 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 time 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 only for older people – there can be times when everyone feels 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 on *Daily living equipment for people with Parkinson's* 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're 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 easily if you need to.

My life with Parkinson's

by Doug, diagnosed in 2011

I was diagnosed in 2011 and so far, with the help of medication, I am leading a relatively normal life. I have been lucky because I do not suffer any side effects from the drugs.

I started out with a tremor in my right hand and arm and severe cramps in my lower right foot and leg. My handwriting was terrible, I had trouble swallowing and later had problems with excessive saliva. My GP referred me to a neurologist. My first neurologist said that I should stay off drugs until absolutely necessary. But the second neurologist I saw has the philosophy that you should get the best out of life while you are young – so take the drugs. I went with the second neurologist's advice. All symptoms have gone now and only reappear when I forget to take my drugs.

I remain optimistic about my future and I think that your outlook is very important to managing the condition. So, get some good drugs that work for you, exercise at least four times a week, and keep your chin up and believe there will be significant breakthroughs in the coming years.

DIET AND EXERCISE

Should I eat a special diet?

Eating a healthy diet is important for everyone. For most people, no special diet is required, but it's recommended 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 can refer you.

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 by your Parkinson's nurse or specialist 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 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, fight infection and maintain your body weight, but you can 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.

Can vitamin supplements or herbal medicine 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 also 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 take 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, it's important 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 may 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-impact' 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 having a long-term condition 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 about the benefits of exercise and the different types to focus on at parkinsons.org.uk/exercise

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

Many people with Parkinson's feel very tired and experience a lack of energy.

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 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 can also get a £1,000 fine. 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 a criminal offence 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 the Armed Forces Independence Payment or War Pensioners' Mobility Supplement to buy or hire a car). You can find their contact details at the back of this book. Anyone not receiving Disability Living Allowance, will need to be awarded the Enhanced Mobility Component of Personal Independence Payment to access a Motability vehicle
- the National Key Scheme for disabled toilets
- public transport – disabled access and concessionary fare schemes
- wheelchairs
- Customised Parkinson's alert cards in 25 different languages can be downloaded from the European Parkinson's Disease Association website, to carry while abroad. Find out more at **www.epda.eu.com**

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:

- Tourism for All – a voluntary organisation that helps disabled and older people to travel and holiday in the UK and abroad (**www.tourismforall.org.uk**)
- 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 has guides to other UK and European breaks (**www.vitalise.org.uk**)
- 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.

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

- Get plenty of information about the country you're going to, including 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. 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. 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 us on **020 7963 9378** or visit **parkinsons.org.uk/mervynpeake** to find out more.

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

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.

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.

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.
- If you find the fine finger movements needed to sow seeds difficult buy plug plants that are ready to plant out rather than seeds.

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 any more. 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 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 121 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 (Royal Society for Prevention of Cruelty to Animals)
- 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 119 for contact details of all organisations mentioned here.



My life with Parkinson's

by Joanne, diagnosed in 2006

There are a raft of symptoms but not everybody will necessarily experience all of them and, of those symptoms that are experienced, their severity may fluctuate quite widely. Only the person with the condition can truly know, day to day, moment by moment, what it is they are experiencing. Nurses and carers just have to accept that how the person reports they are feeling/coping is how it is, however contradictory it may seem.

Most people seem to think that Parkinson's is only about tremor – they don't know the difference between tremor, dystonia or drug-induced dyskinesias. The non-motor symptoms of Parkinson's are more invisible but are those that impact day-to-day living.

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 Parkinson's local advisers 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 Bureau, 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, 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 employer and see what support is available from them – many people with Parkinson's have found that

their employer is supportive 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 at **www.gov.uk**

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, unless:

- you think your Parkinson's may cause a health and safety risk either to you or someone else
- you need your employer to make changes to the way you work, ie reasonable adjustments (see below)

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 where 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

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



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

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

It's important to think about your own needs, 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 Parkinson's local adviser or an adviser on our helpline (**0808 800 0303**)
- speaking to one of the two main carers' organisations in the UK – Carers UK and the Carers Trust. 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

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 a 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

Find out more

If you live in England, visit the NHS Choices website at **www.nhs.uk/carersdirect** or the 'caring for someone' section on the UK government website at **www.gov.uk/browse/disabilities/carers**

If you live in Northern Ireland, visit the 'caring for someone' section on the nidirect website at **www.nidirect.gov.uk**

For information for carers in Wales, visit **www.wales.nhs.uk/carers**

Care Information Scotland (**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 Parkinson's UK self-management programme brings eight to 12 carers, partners and people with Parkinson's into self-management groups for six weeks (two and a half hours per week) to talk about shared experiences and learn from one another.

The groups are an opportunity for carers to reflect on living with the condition, identify their needs and think about the future. To find out if there is a group near you visit **parkinsons.org.uk/selfmanagement** or call our helpline.

The Open University also offers a range of qualifications you may find interesting, such as health and wellbeing. See page 124 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. This depends on the area you live in, so speak to your Parkinson's local adviser to find out whether there are any in your area.

Physiotherapists or occupational therapists can also advise carers at home or in rehabilitation/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

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 £60million in ground-breaking research.

We are committed to funding 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.

As well as our research towards finding a cure, we also fund research to improve life for people living with Parkinson's. This includes:

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, there is more research into treatments and there are better ways to manage or ease these symptoms.

To find out more about research into Parkinson's, contact our research department on **020 7931 8080** or visit **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 a good place to start. We have a wealth of information materials – booklets, information sheets (audio and translated versions), DVDs and more – on many aspects of Parkinson's.

You can also speak to an adviser on our helpline (**0808 800 0303**) or your Parkinson's local adviser, 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 local to you, your Parkinson's local adviser and local groups 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 111 information telephone services

The NHS has a 24-hour telephone information line that can help with health services and conditions. In England this is NHS111, and this can be used by dialling **111**.

In Scotland, the information line is NHS24 on **08454 242424**. In Wales you can contact NHS Direct on **0845 4647**. And 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.nhs.uk

Wales
www.nhsdirect.wales.nhs.uk
or **www.wales.nhs.uk**

Scotland
www.nhs24.com or **www.show.scot.nhs.uk**

Northern Ireland
www.n-i.nhs.uk or **www.hscni.net**

To find out more about how the NHS works in other parts of the UK, visit:

Isle of Man
www.gov.im /health

Guernsey
www.gov.gg/healthandwellbeing

Jersey
www.gov.je/health

You can contact the body responsible for patient liaison (providing information and support about health services) in your area.

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 and 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 such as HON (www.hon.ch) or DISCERN (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. Supported by NHS England, 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

If you're still unsure if the information you're looking at is credible, you may want to ask yourself the following questions:

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 nor 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 – **parkinsons.org.uk**
- Visit **www.nhs.uk** for more information about finding reliable and accurate health information online.
- The BMA's Best Treatments website aims to provide evidence-based information to lay people – see **www.besttreatments.co.uk** (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 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

Parkinson's local advisers

Our Parkinson's local advisers can provide details of, and links, to local services. They provide support for anyone affected by Parkinson's.

For details of the Parkinson's local adviser in your area, contact our helpline on **0808 800 0303** or email hello@parkinsons.org.uk. You can also find out more on our website at parkinsons.org.uk/supportnetworks

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

Our helpline also provides an interpreting service for people in the UK whose first language is not English. The service covers over 170 languages.

Self-management programme

Parkinson's UK has developed a self-management programme for people with Parkinson's, partners and carers. It is an opportunity to reflect on life with the condition, learn about self-management and think about the future. To find out if there is a group near you visit parkinsons.org.uk/selfmanagement

Local groups

Support is available through Parkinson's UK local groups. They offer support and friendship, and the chance to meet other people affected by Parkinson's. The groups come in all shapes and sizes, and there are some specifically for younger people with Parkinson's. As well as friendship and support, many groups offer a range of activities, such as exercise classes and dancing, day trips and talks

about various topics to do with Parkinson's. Visit **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**

Other resources

Books

There are plenty of books written by medical professionals and people affected by Parkinson's on all aspects of living with the condition. Browse the internet or local bookshop for titles that you may be interested in.

Websites

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

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

Quackwatch 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

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 Afiya Trust

This voluntary organisation aims to remove the disadvantage in health care services experienced by black and Asian groups and other minority communities in England.
020 7803 1180
info@afiya-trust.org
www.afiya-trust.org.uk

Age UK

0800 169 6565
www.ageuk.org.uk

Age Cymru

0800 223 444
www.ageuk.org.uk/cymru

Age NI

0808 808 7575
www.ageuk.org.uk/northern-ireland

Age Scotland

0800 470 8090
www.ageuk.org.uk/scotland

Alzheimer's Northern Ireland

028 9066 4100
enquiries@alzheimers.org.uk
www.alzheimers.org.uk

Alzheimer's Society

0300 222 1122
enquiries@alzheimers.org.uk
www.alzheimers.org.uk

Alzheimer Scotland

0808 808 3000
info@alzscot.org
www.alzscot.org

Anxiety UK

08444 775 774
info@anxietyuk.org.uk
www.anxietyuk.org.uk

Asian Health Agency

Provides a range of services including counselling, advocacy and respite care for Asian elders, disabled people and carers in England.
020 8811 1501
www.taha.org.uk

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
bacp@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 2067 4830

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

The Carers Trust

A national charity that exists to make it easier for carers to cope by providing information, support and practical help.

0844 800 4361

info@carers.org

www.carers.org

Scotland office

0300 123 2008

Wales office

0292 009 0087

Carers UK

CarersLine **0808 808 7777**

(Monday to Friday, 10am–4pm)

www.carersuk.org

Cynhalwyr Cymru

0808 808 7777

www.carersuk.org/wales

Carers Northern Ireland

02890 439 843

www.carersuk.org/northernireland

Carers Scotland

0808 808 7777

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 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 or

02920 233 558

enquiries@waleschc.org.uk

www.patienthelp.wales.nhs.uk

The Consumer Health

Information Centre

www.chic.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 benefits helpline

0845 712 3456

dcpu.customer-services@dwp.

gsi.gov.uk

Disability Rights UK

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

020 7250 3222

enquiries@disabilityrightsuk.org

www.disabilityrightsuk.org

Disabled Living Foundation

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

helpline@dlf.org.uk

www.dlf.org.uk

Disabled Parents Network

07817 300 103

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

0300 790 6806

www.direct.gov.uk/emaildvla

www.direct.gov.uk/driverhealth

The Equality and Human Rights Commission

www.equalityhumanrights.com

0808 800 0082

Textphone: **0808 800 0084**

www.equalityadvisoryservice.com

Equality Commission for Northern Ireland

028 9050 0600

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

This project 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
(HRIS – Scotland)
0800 22 44 88
nhs.inform@nhs24.scot.nhs.uk
www.hris.org.uk

Healthwatch
03000 68 3000
rights@healthwatch.co.uk
www.healthwatch.co.uk

In Control Support Centre
01564 821 650
admin@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/contract-
jobcentre-plus

Learndirect
0800 101 901
www.learndirect.com

Learndirect Scotland (now called
My World of Work)
0800 917 8000
www.myworldofwork.co.uk

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

Northern Ireland
www.hscni.net

Scotland
www.show.scot.nhs.uk

Wales
www.wales.nhs.uk

Lone Parent Helpline England
and Wales
0808 802 0925
www.loneparenthelpline.org.uk

Lone Parent Helpline Scotland
0808 801 0323
www.loneparenthelpline.org.uk

MedicAlert

This charity produces alert bracelets and other identification items, for people with medical conditions.

01908 951045

info@medicalert.org.uk

www.medicalert.org.uk

Mind

0300 123 3393

info@mind.org.uk

www.mind.org.uk

Motability Car Scheme

0845 456 4566

www.motability.co.uk

The Multiple System Atrophy Trust

020 7940 4666

www.msatrust.org.uk

National Animal Welfare Trust

020 8950 0177

www.nawt.org.uk

NHS Choices

www.nhs.uk

NHS Direct (Wales)

0845 4647

www.nhsdirect.wales.nhs.uk

NHS24 (Scotland)

08454 242424

www.nhs24.com

Northern Ireland Association for Mental Health

028 9032 8474

www.niamh.co.uk

Northern Ireland out-of-hours medical service

Local details can be found at

www.nidirect.gov.uk

No Panic

A charity that helps people to overcome anxiety disorders.

0800 138 8889

admin@nopanic.org.uk

www.nopanic.org.uk

Occupational Therapists in Independent Practice

0845 129 7699

www.cotss-ip.org.uk/

One Parent Families Scotland

0800 801 0323

helpline@opfs.org.uk

www.opfs.org.uk

Open University

0845 300 6090

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.

0707 499 0808

info@outsiders.org.uk

www.outsiders.org.uk

Sex and Disability Helpline

0707 499 3527 (higher phone rate)

sexdis@outsiders.org.uk

www.outsiders.org.uk

Patient and Client Council (Northern Ireland)

0800 917 0222

Info.pcc@hscni.net

www.patientclientcouncil.hscni.net

Patient's Association

0845 608 4455

helpline@patients-association.com

www.patients-association.org.uk

The Pet Fostering Service, Scotland

0844 811 9909

www.pfss.org.uk

Pets as Therapy

01844 345 445

www.petsastherapy.org

The Princess Royal Trust for Carers

A national charity that exists to make it easier for carers to cope by providing information, support and practical help.

0844 800 4361

www.carers.org

Glasgow office

0141 221 5066

The PSP Association

0300 0110 112

helpline@pspassociation.org.uk

www.pspassociation.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

sotalisman@btinternet.com

www.sotalisman.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)

www.uspca.co.uk

Vitalise

A charity that offers respite care
for disabled people and carers.

0303 303 0145/0147

info@vitalise.org.uk

www.vitalise.org.uk

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).

Speech and language therapist

A healthcare professional who gives advice on anything to do with communication. They can also help with swallowing problems.

'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.

My contacts	
GP	
Specialist	
Parkinson's nurse	
Parkinson's local adviser	
Physiotherapist	
Occupational therapist	
Speech and language therapist	
Parkinson's UK local group contacts	
Local authority	
Other	
In an emergency please contact	

Our information

All of our most up-to-date information is available at

parkinsons.org.uk/information-support

If you'd prefer to read one of our printed leaflets or booklets, find out how to place an order at **parkinsons.org.uk/ordering-resources** or by calling **0300 123 3689**.

We make every effort to ensure that our services provide current, unbiased and accurate information. We hope that this will add to any professional advice you receive and 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.

If you'd like to find out more about how we put our information together, including references and the sources of evidence we use, please contact us at **publications@parkinsons.org.uk**

Can you help?

At Parkinson's UK, we are totally dependent on donations from individuals and organisations to fund the work that we do. There are many ways that you can help us to support people with Parkinson's.

If you would like to get involved, please contact our Supporter Services team on **020 7932 1303** or visit our website at **parkinsons.org.uk/support**. Thank you.

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Living with Parkinson's (B077/2014)

Do you have any feedback about this information? Your comments will help us ensure our resources are as useful and easy to understand as possible. Please return to [Information Content team, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ](#), or email publications@parkinsons.org.uk. Thank you!

1. Please choose the option that best fits you.

- I have Parkinson's and was diagnosed in
 - I care for someone with Parkinson's
 - I have a friend or family member with Parkinson's
 - I'm a professional working with people with Parkinson's
 - Other (please specify)
-
-

2. Where did you get this information from?

- GP
 - Specialist
 - Parkinson's nurse
 - Parkinson's UK local group
 - Parkinson's UK local adviser
 - Ordered directly from us
 - Call to the helpline
 - Other (please specify)
-
-

3. Has it answered all your questions?

- Yes, completely
- Not sure
- Yes, mostly
- Not at all
- Partly

4. How easy was it to understand?

- Very easy
- Quite difficult
- Easy
- Very difficult
- Not sure



5. Has it helped you manage your condition better, or make choices that have improved your life in some way?

- | | |
|---------------------------------------------|-----------------------------------------------|
| <input type="checkbox"/> It helped a lot | <input type="checkbox"/> It didn't help |
| <input type="checkbox"/> It helped a little | <input type="checkbox"/> It made things worse |
| <input type="checkbox"/> No change | |

6. What is your ethnic background?*

- | | |
|-------------------------------------------------|----------------------------------------|
| <input type="checkbox"/> Asian or Asian British | <input type="checkbox"/> Mixed |
| <input type="checkbox"/> Black or Black British | <input type="checkbox"/> White British |
| <input type="checkbox"/> Chinese | <input type="checkbox"/> White other |
| <input type="checkbox"/> Other (please specify) | |
-

*We ask about your ethnicity to ensure our information is reaching a broad range of people. However, this question is optional.

Want to hear more from us?

- I would like a response to my feedback
- I would like to be a member of Parkinson's UK
- I'm interested in joining the Information review group, to offer feedback on Parkinson's UK information

If you've answered yes to any of these options, please complete your details below.

Name

Address

Email

Telephone

How would you prefer us to contact you?

- Email Post Phone

We will not pass on your details to any other organisation or third party. To find out more, read our privacy policy at parkinsons.org.uk/termsandconditions



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

Annette Hand, Parkinson's nurse, Jubilee Day Hospital, North Tyneside General Hospital, North Shields

Sharon Holland, Parkinson's local adviser, North West England

Stella Gay, Parkinson's nurse, Guys and St Thomas' Hospital, London

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

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

Every hour, two people in the UK are told they have Parkinson's – a brain condition that turns lives upside down, leaving a future full of uncertainty.

Parkinson's UK is here to make sure people have whatever they need to take back control – from information to inspiration.

We want everyone to get the best health and social care. So we bring professionals together to drive improvements that enable people to live life to the full.

Ultimately, we want to end Parkinson's. That's why we inspire and support the international research community to develop life-changing treatments, faster. And we won't stop until we find a cure.

**Together we can bring forward the day
when no one fears Parkinson's.**

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

Free confidential helpline **0808 800 0303**
(Monday to Friday 9am–7pm, Saturday 10am–2pm).

Interpreting available.

NGT Relay **18001 0808 800 0303** (for use with smart phones, tablets, PCs and other devices). For more information see **www.ngts.org.uk**

hello@parkinsons.org.uk
parkinsons.org.uk

Order code: PKB077

Last updated November 2014. We review our information within three years. Please check our website for the most up-to-date versions of all our information.

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