



**Parkinson's**  
Disease Society



# **Parkinson's and** **you**



**An introduction to**  
**Parkinson's**  
**disease**



## About the Parkinson's Disease Society

The Parkinson's Disease Society (PDS) works with people with Parkinson's, their carers, families and friends, and health and social care professionals to provide support, information and advice. We are committed to investing in research, education and campaigning to improve the lives of people affected by the condition. The PDS has over 30,000 members, and more than 330 branches, support groups and special interest groups throughout the UK.

For more details on the friendly support, relevant information and expert advice that becoming a member can provide, including details of our membership magazine, *The Parkinson*, please call 020 7932 1344 or email [membership@parkinsons.org.uk](mailto:membership@parkinsons.org.uk)

Parkinson's Disease Society

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Calls are free from UK landlines and some mobile networks.)

Text Relay: 18001 0808 800 0303

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# Contents

<b>Introduction to Parkinson's</b>	<b>5</b>
What is Parkinson's disease? What causes it?	5
What are the symptoms?	5
How many people have Parkinson's?	7
At what age do people get Parkinson's?	7
How is Parkinson's diagnosed?	8
How will my condition progress? Will I need care and treatment?	8
Is there a cure?	10
Will I die from Parkinson's?	10
Is Parkinson's infectious?	10
Will my children or grandchildren inherit Parkinson's?	10
<b>Treating Parkinson's</b>	<b>12</b>
What medicines are available?	12
Which medical professionals can help me?	13
Which therapists can help?	15
Do complementary therapies have any benefit?	16
What surgical options are there?	17
<b>Living with Parkinson's</b>	<b>19</b>
Will I be able to carry on working?	19
Am I entitled to any benefits?	20
Will I be able to continue driving?	20
How can I improve my mobility?	21
What sort of equipment might I need?	22
Should I change my diet and exercise routine?	22
Is it normal to feel anxious, stressed, depressed and/or frustrated because I've got Parkinson's?	24
What can I do to keep positive?	26

If I live alone, how can I get help?	28
Will my family be affected? What should they do?	29
Will my intimate relationships be affected?	30
Tips for friends, family and carers	31

## **Parkinson's Disease Society** **32**

Introduction to the Parkinson's Disease Society	32
What do we do and how can we help?	32
Getting involved	33

## **Useful contacts** **35**

My contacts	38
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## **Thank you**

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# Introduction to Parkinson's

## What is Parkinson's disease? What causes it?

Parkinson's is a progressive and fluctuating neurological condition affecting movements such as walking, swallowing and writing.

It occurs when cells are lost from the part of the brain that controls movement (substantia nigra). These lost cells are those that produce dopamine, a chemical messenger that enables us to perform smooth, co-ordinated movements by transmitting messages between nerve cells and muscles. When around 80% of the dopamine has been lost the symptoms of Parkinson's appear.

The cause of the depletion of dopamine-producing cells is currently unknown. Most researchers believe that multiple factors play a contributory role in causing Parkinson's. Research into the cause is currently focussed on genetics and environmental factors and how they may interact to cause the condition.

Parkinson's disease is named after Dr James Parkinson (1755–1824), a London doctor who first identified Parkinson's disease as a specific condition. Parkinson's disease is the most common form of 'parkinsonism' – an umbrella term that describes conditions with symptoms of tremor, rigidity and slowness of movement. Other conditions include Multiple System Atrophy and Progressive Supranuclear Palsy.

## What are the symptoms?

Parkinson's has three main symptoms:

**Tremor.** Shaking usually begins in one hand or arm and is more likely to occur when the affected part of the body is at rest. Tremor will usually

decrease or subside when the affected part is being used, and often becomes more noticeable when a person with Parkinson's is anxious or excited. Around 70% of people with Parkinson's have a tremor and it is slightly less common in younger people with Parkinson's.

**Muscular rigidity or stiffness.** This is a common early sign in untreated people with Parkinson's. People may experience problems turning round, getting out of a chair, turning over in bed or making fine finger movements such as touch typing or fastening a button. Some people find their posture becomes stooped or that their face becomes stiff, making facial expressions more difficult. Stiffness can affect many everyday tasks and can sometimes be painful.

**Slowness of movement (bradykinesia).**

People with Parkinson's often find that initiating movements becomes more difficult or that it takes longer to perform movements. Lack of co-ordination when making movements can also be difficult.



"In my experience, the condition affects people in different ways. My symptoms seem to be different to other people I've met with Parkinson's."

In addition to these three main symptoms, you may experience a range of other symptoms, such as difficulties with handwriting and other forms of communication such as speech and facial expression. You may also experience symptoms such as tiredness, depression, a loss of confidence, swallowing problems, and issues with balance.

The symptoms of Parkinson's and their nature vary for each person. The severity of symptoms also fluctuate, so many people with Parkinson's find that they have good days and bad days.

## How many people have Parkinson's?

It is estimated that four million people worldwide have Parkinson's. In the UK, one in 500 people have the condition (currently around 120,000 individuals), and each year approximately 10,000 UK people are diagnosed with Parkinson's. Statistically, slightly more men than women have the disease.

"One of the first things was that I seemed to lose control of my handwriting. It had always been a large and clear hand, but it began to get small and crabby and I couldn't seem to correct it."

Also affected are half a million family members and carers who live with people with Parkinson's.

## At what age do people get Parkinson's?

The risk of developing Parkinson's increases with age, and symptoms often appear after the age of 50. Some people may not be diagnosed until they are in their 70s or 80s. However,



in some cases Parkinson's is diagnosed before the age of 40 – this is known as young-onset Parkinson's disease. In newly diagnosed people, one in twenty will be aged under 40 years.

Younger people with Parkinson's often have different issues and needs. This is why the PDS has a special interest group that provides support and encouragement to younger people with Parkinson's (for contact details, please see page 35). There is also a publication for younger people with Parkinson's called *Living with Parkinson's: a guide for people of working age affected by the condition*.

## How is Parkinson's diagnosed?

Parkinson's tends to develop gradually and it can be a number of months or even years before the symptoms become obvious enough for a person to consult a doctor. It is not easy to diagnose Parkinson's, so a specialist usually looks for the presence of two or more of the main symptoms of tremor, rigidity or bradykinesia (slowness of movement). He or she will also consider the person's medical history and carry out a clinical examination before making a diagnosis. The symptoms of Parkinson's can have other causes and you may be referred for hospital tests and scans to rule these out.

## How will my condition progress? Will I need care and treatment?

The symptoms of Parkinson's usually begin slowly. It is important to remember that everyone with Parkinson's is different and will have a unique collection of symptoms and responses to treatment. The nature and severity of symptoms and the rate at which the condition progresses will also be individual.


The question "how will I be in five or ten years time?" is often asked. This is difficult to answer. The condition may take years to progress to a point where it can cause you major problems, and if this happens, many of these symptoms can be treated.



As Parkinson's progresses, an increased amount of care and support may be required, although some people maintain a good quality of life with limited care or treatment.

Drugs are the main treatment to help control the symptoms of Parkinson's. There are many different drugs prescribed for Parkinson's, depending on the symptoms. None of them are perfect, but research into treatments is improving the options all the time.

In most newly diagnosed people considerable improvements can be achieved by careful introduction of one or more antiparkinsonian drug. Drugs are reviewed over time to ensure each person receives the best combination for them as the condition progresses. It is important to know that you may need to be careful if you take medication for other reasons – your specialist will be able to advise on this.



“My feeling is that many people are optimistic – I certainly am, and I hope others are too. It is important that everyone gets the help they need.”

For more information, please see page 12 of this booklet, as well as the PDS *Drug Treatment of Parkinson's Disease* booklet.

Surgery is also sometimes used in Parkinson's. For more information, please see page 17.

Therapies such as physiotherapy, speech and language therapy, and occupational therapy can also play an important role in the management of Parkinson's. Referral to these therapies is usually through your GP or by self-referral. For more information, please see page 15 of this booklet, as well as the information sheets *Speech and Language Therapy*, *Physiotherapy*, and *Occupational Therapy*.

There are also many tips and self-help ideas people with Parkinson's can use to relieve their symptoms. The PDS membership magazine, *The Parkinson*, often features hints and tips which you may find useful.

## Is there a cure?

At present there is no cure for Parkinson's, but researchers and scientists are steadily making advances in understanding the condition, its causes and how best to treat it.



## Will I die from Parkinson's?

With the treatment that is now available, life expectancy for someone with Parkinson's is average and, if used correctly, none of the drugs that are prescribed for Parkinson's have side effects that could cause death. However, occasionally the general physical and mental health of people who have become seriously disabled (usually those who have had Parkinson's for many years), can either cause or exacerbate other illnesses and so contribute to the final cause of death.

## Is Parkinson's infectious?

No, Parkinson's disease cannot be caught like flu or measles. No one knows what causes it, but experts agree that it is not infectious.

## Will my children or grandchildren inherit Parkinson's?

In the vast majority of cases, Parkinson's is not hereditary. It is rare to find more than one person in a family who has Parkinson's, although occasionally it does seem to run in particular families. In most cases, the development is random.

Some researchers think that some people may have a genetic susceptibility to developing the condition. Those with this genetic

susceptibility may be more likely to develop Parkinson's when exposed to other factors such as environmental toxins. The role that genetics may play in the development of Parkinson's disease is currently the subject of much research.

For more information on the current research funded by the Society, please contact the PDS Research Team on 020 7963 9316 or email [research@parkinsons.org.uk](mailto:research@parkinsons.org.uk).

# Treating Parkinson's

## What medicines are available?

The drug treatment of Parkinson's varies from person to person, and is usually the main treatment for the condition. If you are newly diagnosed with Parkinson's, the initial and careful introduction of medication can often make a considerable improvement to your symptoms. If your symptoms are mild, you may not need to take medication at all.

Research continues to expand the medication options for people with Parkinson's all the time. However, as yet there are no perfect drugs that can provide a long-term treatment and you may need to take several different drugs at once, or change the dosage and type of medication as your symptoms change.



There are several types of drugs used to help people with Parkinson's, and they act in different ways to relieve symptoms. As explained in the first section, Parkinson's occurs when the level of dopamine-producing cells in the brain drops significantly. Some drugs aim to increase the level of dopamine that reaches the brain, some stimulate the parts of the brain where dopamine should work (in effect replacing the dopamine), and others block the action of chemicals or enzymes that affect dopamine. For more information on specific drugs, please read the *Drug Treatment of Parkinson's* booklet or talk to your Parkinson's nurse (if you have one) or your specialist.

## Which medical professionals can help me?

**General Practitioners (GPs)** are a gateway to many health services, from hospital consultants to therapists, and psychologists to home care. Many of these services are only available with a GP referral. The great advantage of GPs for people with Parkinson's is that they often know their patients well and so can provide the kind of "whole person" approach which most people want. However, they are most unlikely to know as much about Parkinson's as specialists do. The average GP generally only has 3-4 patients with Parkinson's and while often very caring, their knowledge of the latest diagnostic and treatment options available may be relatively limited. The PDS therefore encourages people to seek specialist advice.



**Parkinson's specialists** are hospital doctors, usually neurologists or specialists in care of the elderly (geriatricians) with a particular interest in Parkinson's. Referral to a specialist is essential because Parkinson's is a complex condition which is difficult to diagnose, and can require complex drug treatment which may need to be adjusted as the condition progresses. Not all neurologists specialise in Parkinson's, so try to ensure that you are referred to one who does. You may find that access to other professionals such as Parkinson's Disease Nurse Specialists, therapists and dieticians may be easier through a specialist as they often work in multi-disciplinary teams.

**Parkinson's Disease Nurse Specialists (PDNS)** are experienced Registered General Nurses who have also undertaken a special course in Parkinson's. They can make a very significant contribution to the good management of the condition and to the support of carers.

They offer help and advice, and act as a link between the professionals involved in your care. The PDS believes it is important that all people with Parkinson's have access to specialist nursing care and is actively campaigning to try and help make this happen. To find out if there is a PDNS in your area, contact your GP or specialist.

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

**Dietitians** can help if you have problems with your diet, for example if you are under or overweight, or have digestive problems such as constipation. Your doctor can refer you to a dietician, and in some areas you can refer yourself.

**Social workers** provide a wide range of non-medical care that may include advice on home support, claiming benefits and respite care. They are also responsible for your community care assessment and for carers' assessments. Contact your local Social Services Department (or Social Work Department if you live in Scotland) for access to a social worker.

**Pharmacists** play a very important role in the support of people living with Parkinson's. Their specialist understanding of the makeup and interactions of the chemicals in the drugs you are prescribed enables them to give very precise advice.

Many people with Parkinson's have other illnesses or conditions requiring medication, and sometimes the combination of drugs does not work well together. Your pharmacist may offer alternatives or timing options to assist and can advise on the best type of formulation. For example, should it be capsules, liquids or pills? When is the best time to take your medication? Should you take it with food? They will also advise on

dispensing aids such as pill timers, or be able to offer advice if you find opening bottles difficult.

**Psychologists** and **counsellors** give assistance and support to people with depression or other mental health issues. Low mood is common in people with Parkinson's and you may experience a degree of depression at some time. Your GP can refer you to a psychologist or counsellor if this becomes serious.

### Which therapists can help?

**Physiotherapists** are trained health professionals who use physical treatments, including exercise, to help manage any stiffness in joints and to restore muscle strength and mobility. They can also advise or train your carer (if you have one) in safe and appropriate ways to help you with mobility concerns, and suggest ways to prevent falls.

People with Parkinson's and their carers can derive significant benefits from short-term or occasional contact with physiotherapists and early referral to a physiotherapist is strongly recommended. Referral to a physiotherapist is made through your GP.

**Speech and language therapists** are health professionals who specialise in all aspects of communication, from facial expression and body language to speech and specialised communication aids. They are also experts in swallowing problems. Speech and language therapists can be extremely helpful to people with Parkinson's who experience communication difficulties, and early access to their advice is strongly recommended.

Your family and friends can assist by encouraging you to continue with exercises, and by learning for themselves how to support and maintain your communication skills.

In most areas, self-referral to a speech and language therapist is possible through the speech and language therapy department at your local hospital. Referrals can also be made through your GP or specialist.

**Occupational therapists** are health professionals who help people with disabilities to achieve maximum function and independence. They also assess an individual's ability to carry out the activities of daily living and advise on ways of making homes and workplaces safer or more manageable. Sometimes this involves advice about appropriate adaptations, aids or equipment. Occasionally, particularly in the case of movement problems, it may involve carefully selected tasks and activities. Occupational therapists are also skilled in advising on and encouraging leisure activities which promote physical and mental wellbeing. They can be contacted directly in some areas or a referral can be made via your GP, consultant, community health service or Social Services/Social Work Department.

### **Do complementary therapies have any benefit?**

The PDS receives many enquires about the role of complementary therapies in the management of Parkinson's. Many people find complementary therapies beneficial for postural control, fitness, relaxation, social interaction and personal development. Relaxation therapies have been found to be particularly helpful as stress can make the symptoms of Parkinson's worse. Techniques used include acupuncture, Alexander Technique, aromatherapy, art therapy, hydrotherapy, massage, music therapy, reflexology, tai chi and yoga.



For more information resources on complementary therapies, please contact Sharward Services, the PDS Distribution House (please see page 35 for contact details).

The PDS recommends that people interested in trying complementary therapies should consult their doctor to ensure that the therapy is suitable for people with Parkinson's. This is particularly true of herbal medicines or any therapy involving the taking of vitamins, as some substances may interfere with Parkinson's medication. It is also important to use a qualified complementary therapist. GP surgeries can often provide a list of local practitioners.

## What surgical options are there?

Surgical options are available for some people with Parkinson's, depending on their symptoms. We recommend taking advice from your specialist. The options are:

**Stereotactic surgery**, which involves inserting a fine needle into the brain and causing selective damage to certain cells in either the thalamus (thalamotomy) or the globus pallidus (pallidotomy). This is known to have a beneficial effect on people with Parkinson's.

**Deep brain stimulation**, which involves the implantation of a wire with four electrodes at its tip into one of three target sites in the brain: the thalamus, the globus pallidus or the subthalamic nucleus. This wire is connected to a small unit called an implantable pulse generator (IPG) which is implanted under the skin in the chest rather like a pacemaker. When switched on, the IPG produces electrical signals which are sent to the brain to stop or reduce Parkinson's symptoms.

In the future, other surgery-related treatments may be shown to be safe and beneficial and could be introduced. These are some way off but might include:

- Brain implants using brain tissue to replace the dead and dying dopamine-producing cells. This treatment is still at an early experimental stage and is likely to remain so for several years.
- The infusion of chemicals into the basal ganglia. This is also at an early stage of research.

For more information please see the booklet *Surgery and Parkinson's Disease* as well as the information sheet *Deep Brain Stimulation* .

# Living with Parkinson's

## Will I be able to carry on working?

For people in full or part-time work the diagnosis of Parkinson's will raise many questions. Work is not only an important source of income, but can also build confidence, self-esteem and personal satisfaction.

If you need or wish to remain in work, it is vitally important to establish satisfactory drug or other treatment with your specialist. With careful



management, some people can continue to work for many years. If the work situation creates practical problems, an occupational therapist can be asked to carry out an assessment and advise on practical solutions. Inevitably, some jobs are more compatible with Parkinson's than others so, for example, those in jobs requiring high levels of physical stamina and fast reactions may need to consider alternatives.

If you decide to stop working, it is important to carefully consider the emotional, practical and financial considerations involved. Our advice is not to rush into a decision – give the treatment time to settle down. Even when people are happy with their decision to retire early, it is worth talking to employers, professional or trade organisations to establish the most favourable terms and timing.

Some firms encourage their employees to attend courses on preparing for retirement, and courses are run by some local Further Education colleges. When considering retirement it is important to think of ways to remain healthy and active.

For information on employment issues, please contact the PDS Helpline on 0808 800 0303. Other sources of information and advice are your local Citizens Advice and your local welfare benefits service.

## **Am I entitled to any benefits?**

Adequate finance is essential and you may be eligible for one or more statutory benefits. The rules about eligibility for benefits are complex and can change. For more information and guidance contact:

- the PDS Helpline (0808 800 0303)
- an Information and Support Worker from your local branch of the PDS
- the local Social Services/Social Work Department
- your local Citizens Advice Bureau
- your local benefits office (found in the telephone directory under 'Government')
- benefits advice agencies
- disability rights officers from your Social Services/ Social Work Department.

For more information, please read the PDS Rights and Benefits Information Sheets.

## **Will I be able to continue driving?**

Having Parkinson's does not necessarily mean your driving licence will be affected, although you may be required to have a medical or take a driving test. Some people find their medication can make them drowsy and therefore unable to drive.

You have a legal obligation to inform the Driver & Vehicle Licensing Agency (DVLA) of your diagnosis, but it is a good idea to discuss driving with your GP or consultant before approaching the DVLA. Once informed,

the Agency may contact your doctor to confirm your fitness to drive and, if positive, you may be issued with a 1, 2 or 3-year renewable licence. It is reassuring to note that many people with Parkinson's continue to drive for years after diagnosis, if supported by their doctor.

All drivers have a responsibility to ensure that they are medically fit to drive at all times. Any person who knowingly drives while unfit may invalidate their insurance cover. It is therefore essential to inform your insurance company of any change in your health that may affect your ability to drive. It is an offence under the Road Traffic Act (1999) to make a false statement or withhold information for the purposes of obtaining a certificate of motor insurance.

For more information on driving, please see the booklet *Parkinson's and Driving*.

## **How can I improve my mobility?**

As you will already know, Parkinson's is a condition which affects movement. Slowness and stiffness are the two main causes of movement or mobility problems and both are treated by carefully adjusted medication and by keeping as active as possible.

Physiotherapists and occupational therapists can advise on exercises and special techniques or 'tricks' to help with mobility. The most important thing is to keep as active as possible, and allow plenty of time to initiate and complete activities as independently as you can, even if it takes longer than expected.

Depending on your symptoms, there is a wide range of equipment available to improve your mobility. Although it can be difficult to accept the need to start using aids, many people find specialist equipment, for example, grab rails on stairs and in the bathroom, or walking sticks and

frames, can help increase independence. Your physiotherapist or occupational therapist can advise on what is available to suit your needs. Talk to your GP about referrals to these services.

## **What sort of equipment might I need?**

There are all kinds of aids and equipment available today to help people who have difficulties carrying out daily living activities. These might include smaller aids to help with washing, bathing, reaching, eating and drinking, or larger adaptations such as stair lifts and wheelchairs.

If you are considering buying services or equipment to help your day-to-day living, the PDS strongly advises that you request an assessment from the relevant therapist first. The therapist will assess your needs and make recommendations accordingly. These recommendations may involve equipment, but may also involve exercises, a change to the way you do something, or other kinds of treatment. If the therapist suggests equipment, he or she should be able to advise you on suppliers and any funding that may be available.



## **Should I change my diet and exercise routine?**

Maintaining a healthy lifestyle is important for everyone, not only people with Parkinson's. A balanced and nutritious diet including three meals a day (or four smaller meals) is recommended. You should aim to eat a mix of starchy foods (such as bread, rice, potatoes, noodles, cereal, crackers, oats, yams), fruit and vegetables, dairy products, and proteins (meat, fish, eggs, beans or pulses). Fatty or sugary foods should be eaten in moderation.

A small number of people taking levodopa medication may find a large protein meal slows the effectiveness of the medication. In these relatively few cases, we recommend discussing the matter with your specialist or PDNS.

It is also important to drink plenty of fluids. Unless your doctor has advised you otherwise, alcoholic drinks in small amounts are not harmful, and may be beneficial if this helps you maintain your normal social life.

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

If you are overweight, you may need a diet with reduced fat and carbohydrates. This can improve mobility by easing strain on your joints. If, as occasionally happens, you lose excessive amounts of weight, you may need special dietary supervision and dietary supplements. The PDS advises that you talk to a doctor or dietician before considering any changes to your diet.

For more information on diet and Parkinson's, please see the *Parkinson's and Diet* booklet.

Exercise is good for everyone and is especially important for people with Parkinson's as the condition can cause muscles and joints to get stiff and rigid. Exercise can also help relieve depression. Joining an exercise group or participating in a sporting activity can also offer social opportunities. Many people with Parkinson's are involved in active sports and activities such as racquet sports, bowling, sailing, skiing, swimming and dancing. If you are having difficulty finding suitable local facilities or groups.

There are also a number of 'low-key' exercise options to keep you flexible and active, such as yoga, tai chi, walking, gardening, golf and daily stretches. We have a booklet and DVD called *Keeping Moving*, which outlines a set of exercises that can be done at home.

If you are unsure about the suitability or safety of any exercise you would like to do, you should discuss this further with your doctor or ask for a referral to a physiotherapist.



The main thing is to try to stay active, but to do things at your own pace.

### **Is it normal to feel anxious, stressed, depressed and/or frustrated because I have Parkinson's?**

Yes it is, particularly when you are first diagnosed. Some people feel relief at knowing the cause of their symptoms, but others find it hard to accept that they have Parkinson's and can feel anxious, stressed, angry and depressed. As time goes on, these feelings may subside, but they can also reappear periodically as Parkinson's progresses.

Many people feel anxious or stressed at times. This can often be addressed with the help of relevant information or advice, and through discussions with your family and with health or support professionals.

Learning to relax, perhaps through yoga, meditation, or listening to music are ways of tackling anxiety. Anxiety or stress can be a concern to people with Parkinson's because it is likely to make symptoms more apparent. It can also interfere with sleep, affecting

how people manage the fatigue which can increase in people with Parkinson's. If anxiety or stress are severe and seriously interfering with life and normal activity, then it is important to seek advice from your doctor.

Depression is common in Parkinson's and can occur at any stage of the condition. Doctors generally believe that depression in Parkinson's is caused by the chemical changes in the brain which cause the condition. Depression in Parkinson's can also occur as a reaction to the effect that having the condition may have on a person's lifestyle. For most people with Parkinson's, both biological and psychological factors are likely to play a role. Symptoms of depression may include low moods or self esteem, lack of interest in or pleasure from usual activities or interests, tiredness and difficulty sleeping.

Your doctor may prescribe antidepressants which can be very effective in treating depression in Parkinson's, as long as they are compatible with any medication you are taking for Parkinson's. Counselling and cognitive therapy can also be beneficial. Exercise and some complementary therapies such as aromatherapy, yoga, music and art therapy, and reflexology may help you if you are depressed by encouraging relaxation and improving your sense of wellbeing.

It can be extremely hard for carers when the person they are caring for has serious depression. Being aware of the symptoms and where to find help is very important, and can make the situation easier to manage. This is especially important when there have been episodes of depression prior to the diagnosis of Parkinson's.

It is easy to see why someone with Parkinson's can become frustrated by slowness and the extra effort that may be required to do everyday things. Although it is difficult to avoid frustration altogether,

finding the best possible treatment and support, keeping active and learning how to organise your day can be beneficial.

Many people ask, “why me?”

Unfortunately there is no answer to this question. However, learning to accept the situation has been found to help people start to get on with their lives again.



Families and carers can become frustrated too, even when they understand the effects of Parkinson's. It is important for the health and welfare of carers that they regularly make time for themselves. More information can be found in the *PDS Carers' Guide*.

Frustration may be eased by talking to someone who understands, such as a close friend, a PDS branch member, someone else with Parkinson's or a support worker. People with Parkinson's and carers can also telephone the PDS Helpline for medical advice or someone to talk to. This confidential service is available on 0808 800 0303 (calls are free from UK landlines and some mobile networks from Monday to Friday between 9am and 8pm (except bank holidays), Saturday 10am to 2pm). Text Relay: 18001 0808 800 0303 (for textphone users only).

## **What can I do to keep positive?**

Parkinson's is a medical condition for which most people need medical intervention in the form of drugs and/or physical therapies. The outcome can, however, be greatly influenced by your attitude to the condition. Being positive, thinking about what can be done rather than what can't, and viewing problems as challenges rather than as something insurmountable can all help.

“When I was first diagnosed, I made the mistake of becoming the illness and stopping being me. But now I’ve learnt to adapt to Parkinson’s and to get on with my life.”

However, even the most optimistic and energetic person may find it difficult to be positive immediately after diagnosis. Others who are prone to worry might always find it hard, but it is certainly worth trying the positive approach. If you find particular difficulties in being positive, you should talk to your GP about the possibility of counselling.

Many people with Parkinson’s lead active and fulfilling lives, not by pretending that nothing is wrong, but by understanding how their Parkinson’s affects them and then working around it. This is what American writer, Sidney Dorros, meant by his strategy of “accommodation without surrender” when writing about Parkinson’s.

Spending time socialising also helps keep many people positive and active, and the attitude of family and friends can influence this. They need to encourage the person with Parkinson’s to lead as normal and active a life as possible. This means encouraging them to do things for themselves – even if it takes longer. Relatives and friends also need to recognise

“I would say to people, try very hard to remain positive about yourself, and keep living life as fully as you can.”

the variability of Parkinson’s and to learn when to allow their friend or relative to rest or to accept help. These are not easy judgements to make, so do not be too discouraged if you sometimes get it wrong. Talking to other relatives at a local branch of the PDS can be beneficial.

Finding satisfying and enjoyable leisure activities is essential for leading a healthy life. This is true whether you have Parkinson’s or care for someone with Parkinson’s. Leisure opportunities could

include playing sports or going to a gym, spending time on hobbies such as art classes, taking part in drama groups or choirs, or educational opportunities such as crafts, languages, martial arts through to university degrees. Libraries are a good source of information about local clubs and activities, and some operate travelling libraries for those not able to travel easily. For people with impaired eyesight, listening books, National Talking Newspapers and Magazines (see page 36 for contact details), dvds, CDs, large print books and books on tape are all good leisure resources. Occupational Therapists also give advice on leisure activities.



There are more than 330 branches and support groups of the PDS based around the UK. These meet regularly to offer people with Parkinson's a chance to find out information, attend social events, participate in fundraising, and hear visiting speakers. Further details of branches are available from the PDS national office or from the Society's website: [www.parkinsons.org.uk](http://www.parkinsons.org.uk)

### **If I live alone, how can I get help?**

Many people with Parkinson's live on their own and manage very well. But for others, the diagnosis may bring extra concerns because they live alone. One common concern is the fear of falling and not being able to summon help. It is important to know that support and constructive advice are available if needed.

For more tips and practical information on this subject, as well as useful organisations you can contact, please see the information sheet *Living Alone with Parkinson's*.

## Will my family be affected? What should they do?

Parkinson's does not just affect the person with the condition. Partners, family members, and friends also live with Parkinson's, and their individual circumstances will determine how they are affected. Roles within families may gradually change as the condition progresses, and this may be hard on the individuals concerned. Discussing these changes openly within the family will help make things easier, as will keeping a sense of humour. Talking to a professional may also help.

It is helpful for the person with Parkinson's to make clear what they are willing or unwilling to do, and at what times they need help or would rather be independent. Family members need to be careful not to take over (even though this may be well intentioned) but should try to be there to offer support when it is needed. It is also important to try not to



let Parkinson's dominate everything, and to keep doing the things you have always enjoyed as a family or as individuals.

Sometimes children and young people who live with their parents are involved in supporting a parent with Parkinson's. Although they may not be directly involved in providing help, the effect of having a parent with Parkinson's may mean that they need support. It is important for young people to have someone to talk to and ask questions about Parkinson's such as a doctor or specialist nurse, and also try to ensure they have easy access to appropriate information.

## Will my intimate relationships be affected?

At whatever age a person is diagnosed with Parkinson's, they still have an interest in continuing with normal life and for many this includes intimate and sexual relationships.

There are many reasons, quite unconnected to Parkinson's, why people have problems with intimate, personal relationships, but there is no doubt that the addition of a physical disability can create extra difficulties. Parkinson's interferes with freedom and fluidity of movement and can make gestures less spontaneous. Showing affection may sometimes be harder for a person with Parkinson's as they may not always be steady enough to give a hug or lean over to give a kiss. And for the carer, if he or she is the spouse or sexual partner, it can also be difficult to make the transition from the nursing side of being a carer to being an intimate sexual partner.



Communication is essential, and many people report that keeping a sense of humour has helped. It is also important to talk with your doctor, the PDS Helpline or with a counsellor at an organisation like Relate (see page 36 for contact details). Often this can reduce the anxiety and stress which are a major cause of sexual problems. If something more is required, your doctor or counsellor will know where further help can be sought. We have a booklet called *Intimate Relationships* which has more information.

## Tips for friends, family and carers

If you provide support to someone who has Parkinson's you are sometimes considered to be their 'carer'. Not everyone likes this term, and it can mean many things. You may provide emotional support, practical help, or personal care for someone for a varying amount of time each week. It is important that carers consider their own needs as well as those of the person they care for.



Here are some tips:

- Acknowledge your feelings and try to talk about them with the person you care for.
- Be clear about what you are able or willing to do as a carer so there are no unrealistic expectations.
- Seek help for the tasks you are not able or willing to do before any difficulties arise.
- Look after yourself, particularly your health, and keep some time for your own social life, hobbies or pastimes.
- Try to carry on doing the things you both enjoy together.
- Retaining your sense of humour helps to keep things in perspective.
- As a carer, you may be entitled to financial support – contact the PDS Helpline on 0808 800 0303 (Monday to Friday, 9am to 8pm, (except bank holidays) Saturday, 10am to 2pm).  
Text Relay: 18001 0808 800 0303 (for textphone users only) or Carers UK Advice Line (0808 808 7777) for more information.

Find more tips for carers in our booklet *The Carers' Guide*.

# Parkinson's Disease Society

## Introduction to the Parkinson's Disease Society

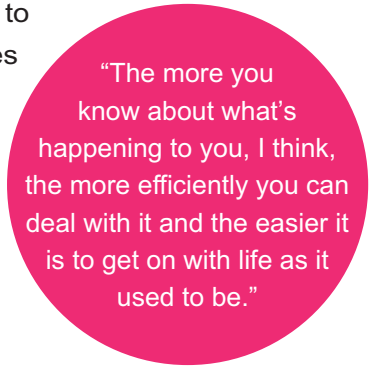
The Parkinson's Disease Society (PDS) has more than 30,000 members, 35,000 supporters and more than 330 branches and support groups throughout the UK, and is a registered charity. The Society was founded in 1969 by Mali Jenkins, whose sister had Parkinson's.

## What do we do and how can we help?

We provide support, advice and information to people with Parkinson's, their carers, families and friends, and to health and social services professionals involved in Parkinson's management and care.

The Society has invested millions of pounds in funding research into the cause, cure and prevention of Parkinson's, and improvements in available treatments. The Society also develops models of good practice in service provision, such as Parkinson's Disease Nurse Specialists, and campaigns for changes to improve the lives of people affected by Parkinson's.

The Society has a wide range of information booklets, leaflets and videos available for people with Parkinson's, their carers, families and friends. There is also a range of publications written for professionals working with people with Parkinson's. Many of these resources are available free either from [www.parkinsons.org.uk](http://www.parkinsons.org.uk) or by calling our distribution house, Sharward Services (see page 35).



"The more you know about what's happening to you, I think, the more efficiently you can deal with it and the easier it is to get on with life as it used to be."

We have two specialist groups – one for younger people with Parkinson's (Younger Parkinson's Network) and one for people with an interest in medical research (SPRING). Contact details are listed on page 35.

As well as a National Office based in London, the PDS has a large number of field staff who work closely with people with Parkinson's in their local area, including Information and Support Workers.

PDS branches exist across the UK and offer people with Parkinson's, their carers, families and friends support and information. To find your nearest PDS branch please call PDS Helpline 0808 800 0303 or visit our website [www.parkinsons.org.uk](http://www.parkinsons.org.uk).

If you would like further information on Parkinson's, please do not hesitate to contact us:

Parkinson's Disease Society

215 Vauxhall Bridge Road

London SW1V 1EJ

Tel: 020 7931 8080 Fax: 020 7233 9908

Email: [enquiries@parkinsons.org.uk](mailto:enquiries@parkinsons.org.uk)

Website: [www.parkinsons.org.uk](http://www.parkinsons.org.uk)

Helpline: 0808 800 0303 (Monday to Friday 9am to 8pm,  
(except bank holidays), Saturday 10am to 2pm)

Text Relay: 18001 0808 800 0303

(for textphone users only)

## Getting involved

If you would like to become a member please contact the membership team on 020 7932 1344 (cost £4 annually for UK residents; overseas membership is available for £15).

Members receive the quarterly membership magazine, *The Parkinson*.

The more members we have, the louder our voice in our campaigns for a better quality of life for those with Parkinson's.

As a charity, the PDS relies entirely on voluntary donations to deliver its services. With your donation, we can reach out to more people with Parkinson's, their carers and families, and support research that may one day lead to an effective cure. If you would like to make a donation, please visit our website ([www.parkinsons.org.uk](http://www.parkinsons.org.uk)) or call 020 7932 1303.



# Useful contacts

## PDS distribution house

Sharward Services Ltd  
Westerfield Business Centre  
Main Road, Westerfield  
Ipswich, Suffolk IP6 9AB  
Tel: 01473 212115  
Fax: 01473 212114  
Email: [pds@sharward.co.uk](mailto:pds@sharward.co.uk)

## PDS special interest groups

SPRING (Special Parkinson's  
Research Interest Group)  
PO Box 440, Horsham  
West Sussex RH13 0YE  
Tel/Fax: 01403 730163  
Email:  
[secretary@spring.parkinsons.org.uk](mailto:secretary@spring.parkinsons.org.uk)  
Website:  
<http://spring.parkinsons.org.uk>

**YPN** (Younger Parkinson's Network)  
PO Box 33209  
London SW1V 1WH  
Tel: 0808 800 0303 Monday to  
Friday, 9am to 8pm, Saturday,  
10am to 2pm (except Bank  
Holidays)  
Email: [YPN@parkinsons.org.uk](mailto:YPN@parkinsons.org.uk)  
Website: [www.parkinsons.org.uk/ypn](http://www.parkinsons.org.uk/ypn)

## General contacts

### Age UK

Website: [www.ageuk.org](http://www.ageuk.org)

### England

York House  
207-221 Pentonville Road  
London N1 9UZ  
Tel: 0800 107 8977

### Astral House

1268 London Road  
London SW16 4ER  
Phone: 020 8765 7200  
Email: [contact@ageuk.org.uk](mailto:contact@ageuk.org.uk)  
Website: [www.ageuk.org.uk](http://www.ageuk.org.uk)

### Scotland

Causewayside House  
160 Causewayside  
Edinburgh EH9 1PR  
Tel: 0845 125 9732  
Email:  
[enquiries@ageconcernand  
helptheagedscotland.org.uk](mailto:enquiries@ageconcernandhelptheagedscotland.org.uk)

### Wales

Ty John Pathy, 13/14 Neptune  
Court, Vanguard Way, Cardiff  
CF24 5PJ

Tel: 0800 169 6565  
Email: [enquiries@accymru.org.uk](mailto:enquiries@accymru.org.uk)

### **Northern Ireland**

3 Lower Crescent  
Belfast BT7 1NR

Tel: 0808 808 7575

Email:  
[info@ageconcernhelptheagedni.org](mailto:info@ageconcernhelptheagedni.org)

### **Carers UK**

20 Great Dover Street  
London SE1 4LX

Tel: 020 7378 4999

Email: [info@carersuk.org](mailto:info@carersuk.org)

Advice Line: 0808 808 7777

(Wednesday to Thursday,  
10am to 12pm, 2 to 4pm)

Email: [adviceline-at-carersuk.org](mailto:adviceline-at-carersuk.org)

Website: [www.carersuk.org](http://www.carersuk.org)

### **Disabled Living Foundation**

380-384 Harrow Road  
London W9 2HU

Tel: 020 7289 6111

Helpline: 0845 130 9177

(Monday to Friday, 10am to 4pm)

Email: [info@dlf.org.uk](mailto:info@dlf.org.uk)

Website: [www.dlf.org.uk](http://www.dlf.org.uk)

### **DVLA**

DVLA Drivers Medical Group  
Swansea SA99 1TU

Tel: 0300 790 6806 (Monday to  
Friday, 8am to 5.30pm, Saturday,  
8am to 1pm)

Email: [eftd@dvla.gsi.gov.uk](mailto:eftd@dvla.gsi.gov.uk)

Website: [www.dvla.gov.uk](http://www.dvla.gov.uk)

### **Princess Royal Trust for Carers**

Unit 14, Bourne Court

Southend Road

Woodford Green

Essex IG8 8HD

Tel: 0844 800 4361

Email: [info@carers.org](mailto:info@carers.org)

Website: [www.carers.org](http://www.carers.org)

### **RELATE**

Premier House, Carolina Court,  
Lakeside, Doncaster, DN4 5RA

Tel: 0300 100 1234

Email: [enquiries@relate.org.uk](mailto:enquiries@relate.org.uk)

Website: [www.relate.org.uk](http://www.relate.org.uk)

### **National Talking Newspapers and Magazines**

National Recording Centre

Heathfield

East Sussex TN21 8DB

Tel: 01435 866102

Fax: 01435 865422

Email: [info@tnauk.org.uk](mailto:info@tnauk.org.uk)

Website: [www.tnauk.org.uk](http://www.tnauk.org.uk)



# My contacts

Specialist doctor: .....

Parkinson's Disease Nurse Specialist: .....

GP: .....

Support worker: .....

Physiotherapist: .....

Occupational Therapist: .....

Speech and Language Therapist: .....

My PDS branch contact(s): .....

.....

Other: .....

In an emergency please contact: .....

## How you can help us

We are totally dependent on voluntary donations so if you would like to make a contribution, it would be gratefully received. Any money received will help us support others affected by Parkinson's through information, care and research. To make a donation, please call 020 7932 1303, visit [www.parkinsons.org.uk/donate](http://www.parkinsons.org.uk/donate) or write to Parkinson's Disease Society, 215 Vauxhall Bridge Road, London SW1V 1EJ. Thank you.



**Parkinson's**  
Disease Society

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Registered Office: 215 Vauxhall Bridge Road,  
London SW1V 1EJ

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