

PARKINSON'S: THE CARER'S GUIDE

Find out more about
getting support if you're
a family member, friend
or carer



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

A carer is someone who looks after a family member, partner or friend who is in need of care and support, and who is usually not paid for the care they provide.

If you care for someone with Parkinson's, this booklet looks at issues that may affect you.

Whether you provide care and support for someone who has recently been diagnosed, or who has been living with Parkinson's for a while, it offers practical tips and information organised in seven sections:

- About Parkinson's
- Help from health and social care professionals
- Carers' needs and rights
- Looking after yourself: your feelings
- Looking after yourself: your health
- Taking a break
- Work, money and benefits
- Planning for the future
- Having a voice
- More information and support, including ways to get in touch with other carers

CONTENTS

About Parkinson's	5
What is Parkinson's?	5
Caring for someone with Parkinson's	6
Practical tips	6
Parkinson's medication	7
Help from health and social care professionals	10
Who can help?	11
Training	13
Carers' needs and rights	15
Support for you	15
How can I get this support?	16
Carer's assessments	16
Care following a hospital stay	22
Personal budgets and direct payments	22
NHS continuing healthcare (CHC)	24
Finding out more about carers' rights	25
Young carers	25
Carers with learning disabilities	27
Social and cultural needs	28

CONTENTS (CONTINUED)

Looking after yourself: your feelings	29
In the early stages of Parkinson's	29
Your feelings and support as Parkinson's progresses	31
Emergency support	34
Health services	35
Looking after yourself: your health	37
How do I get the most from health services?	37
Taking care of yourself	39
Taking a break	42
Respite care	42
Preparing for your break	45
Money, work and benefits	46
Employment while caring	46
Thinking about money	50
Planning for the future	52
More information and support	54
My contacts	57

ABOUT PARKINSON'S

Parkinson's is the fastest growing neurological condition in the world. You are not alone. This is a general introduction to Parkinson's. You can read more about the condition in our other booklets and on our website.

In this section:

- What is Parkinson's?
- Caring for someone with Parkinson's
- Practical tips
- Parkinson's medication

What is Parkinson's?

Parkinson's is a progressive neurological condition. People with Parkinson's don't have enough of a chemical called dopamine because some of the nerve cells in the brain that produce it have died.

Without dopamine, people can find that their movements become slower, so it takes longer to do things. Symptoms often associated with Parkinson's are tremor and stiffness, but the condition doesn't just affect movement and there is a range of other symptoms.

Caring for someone with Parkinson's

Not everyone with Parkinson's has the same symptoms and they don't appear in a particular order, progress at the same speed or in the same way. Many people find that how the condition affects them can change from day to day, and even from hour to hour.

Because of this, comparing the progression of Parkinson's in the person you care for with others may not be helpful.

Someone newly diagnosed with Parkinson's may not need any practical help, but it can be important for them to have someone to talk to for emotional support.

As time goes by and Parkinson's symptoms develop, the person you care for may rely on you more for support. Because of this, it's important to know how to get the support you need with your caring role (see the More information and support section).

Practical tips

An **occupational therapist** may be able to offer advice on making everyday tasks easier and leisure activities more accessible as your needs change.

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

You can also get practical tips for coping with a range of Parkinson's symptoms from our other free information resources. For example:

- For practical suggestions on communicating with someone with Parkinson's, see our information sheet *Communication and Parkinson's*.

- Have a look at our information sheet *Freezing in Parkinson's* for ways to deal with this symptom.
- For advice on dementia, see our information sheets *Parkinson's dementia* and *Dementia with Lewy bodies*.
- Find useful dietary information in our booklet *Diet and Parkinson's*.

Parkinson's medication

Parkinson's medication can be one of the biggest concerns of day-to-day life with Parkinson's. Someone with Parkinson's may have a complicated medication regimen, taking a number of different tablets each day at specific times. So, being responsible for medication may feel quite daunting, especially as the condition progresses.

Ask for support from your GP, specialist, Parkinson's nurse (if you have one) or pharmacist to get a good understanding of the type and timing of medication – a chart or diary may be useful to help you record this. Having this information written down will help you to discuss this with the relevant healthcare professional.

Having this information means you can plan the regimen around what you are doing, allowing you to maintain a good standard of living and to continue doing the things you enjoy. It can also help when you have to plan for special occasions, such as holidays.

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

Impulsive and compulsive behaviour

This is a side effect of some Parkinson's drugs. Although only a relatively small number of people experience this behaviour, it can have a big impact on the person affected and those around them. Types of impulsive and compulsive behaviour include addictive gambling, eating and shopping, or an increase in sexual thoughts and feelings.

It's important that all people with Parkinson's are assessed for risk factors of impulsive and compulsive behaviour before they start taking their medication.

Sometimes, people who experience this behaviour may not realise they have a problem, or not realise the effects their behaviour will have.

It's important to monitor the behaviour of the person you care for. Someone with impulsive and compulsive behaviour may be quite secretive about what they're doing, but if you notice anything unusual, it's important you discuss it with a healthcare professional as soon as possible.

Signs to look out for include:

- Have they recently put on weight? There may be a number of reasons for this, but you might want to look for the signs of binge eating.
- Are they being more private than usual about their finances?
- Have they started collecting or organising certain objects?
- Have you noticed any repetitive behaviour?
- If the person with Parkinson's is your partner, have you noticed an increase in their sex drive or a change in their sexual behaviour?

- Are they going shopping more often than usual?
- Are they spending more time than usual on their computer (perhaps on shopping or gambling websites)?
- Are they taking more of their Parkinson's medication than they should?
- Do they have aggressive outbursts?
- Is there a family history of gambling or alcoholism, or any of the behaviour above?

Find out more: see our booklet *Drug treatments for Parkinson's* and our information sheet *Impulsive and compulsive behaviour in Parkinson's*. This information sheet includes a checklist that can help you discuss this issue with your specialist or Parkinson's nurse.

HELP FROM HEALTH AND SOCIAL CARE PROFESSIONALS

There are many professionals who can make a big difference to the quality of life of someone with Parkinson's. Many also provide support directly to carers.

In this section:

- Who can help?
- Training

The more support the person you're caring for gets from professionals, the more you will be able to sustain your role as a source of support for that person. It's important to know about the different people who can help the person you care for.

These experts, from different areas of health and social care, make up the 'multidisciplinary team'. As a carer, you're an important part of the multidisciplinary team, and sharing your experience and skills with the professionals you come across will help them to do their best for the person you care for. It may help others with Parkinson's, too.

Your GP, specialist or other health and social care professionals can identify people who can help you and the person you are caring for. You may also be able to self-refer.

Who can help?

Professionals or organisations that can help:

Specialists, consultants or GPs directly influence your healthcare and the healthcare of the person you care for, and these professionals can refer you towards other services.

Parkinson's nurses provide help and information with all aspects of Parkinson's and its effects. They can identify services to help you and the person you care for. Ask your specialist, GP or Parkinson's local adviser whether there is one in your area, or call our helpline on **0808 800 0303**.

District or community nurses help with healthcare, medication and referral to experts in particular areas, such as physiotherapists. District nurses or community teams will not be able to adjust Parkinson's medication, but they may discuss this with your specialist or Parkinson's nurse for you.

Occupational therapists help people to maintain their independence. They advise on activities of daily living, such as dressing, bathing, cooking, leisure activities and relaxation. You can usually contact an occupational therapist through your GP, your social services or social work department or health and social care trust.

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

Physiotherapists use physical treatments, including exercise, to help manage any stiffness in joints and to restore muscle strength and mobility. They can also advise you as a carer on safe ways to help the person you care for if they have problems moving, and can suggest ways to prevent falls.

Your GP or Parkinson's nurse may refer you or the person you care for to a physiotherapist, but in some places you can refer yourself by calling the physiotherapy department in your local hospital. Some Parkinson's UK local groups organise physiotherapy and exercise classes, often at a reduced cost. Visit [parkinsons.org.uk/localgroups](https://www.parkinsons.org.uk/localgroups) or call our helpline on **0808 800 0303** for details of your nearest meeting.

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

Speech and language therapists treat problems associated with communication (speaking, poor facial expression, etc) and swallowing. They can help people to improve speech quality and minimise problems such as low volume or lack of clarity.

A speech and language therapist can also work with you as a carer, to help improve how you communicate with the person you care for. You can usually refer yourself to the speech and language therapy department at your local hospital, if there is one. In some areas, speech and language therapy is based in community services. Speak to your GP, specialist or Parkinson's nurse about what is available where you live.

Find out more: see our information sheet *Speech and language therapy and Parkinson's*.

Dietitians can advise on all issues around food, drink, eating, diet and weight changes. Your GP can help you access a dietitian.

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

Social workers may be a central point of contact between you and your local authority. They may have links with your Parkinson's local adviser.

Our **Parkinson's advisers** can offer emotional and practical support for family, friends and carers. Call **0808 800 0303** or email hello@parkinsons.org.uk to get in touch.

Other Parkinson's UK local staff and groups can help with information and support on all aspects of living with Parkinson's. Visit [parkinsons.org.uk/localtoyou](https://www.parkinsons.org.uk/localtoyou) or call our helpline on **0808 800 0303** for details of your nearest meeting and your regional team.

Disability and mobility organisations help with equipment for daily living, and provide information and advocacy on issues facing people with disabilities and their carers. Motability operates a scheme that allows disabled people to exchange certain benefits for a car, wheelchair or scooter. See the More information and support section on page 65 for contact details.

Carers' organisations help with information, training, support groups and advocacy for carers in your area.

Training

As the person you're caring for's Parkinson's progresses, you may get more involved in practical care, helping with medication or physical tasks. Training will help you to take care of your own health (especially your back – see Looking after yourself: your health on page 42 for more on this),

give you confidence to do these tasks and improve the quality of life for the person you care for.

You can find details of training programmes for carers by contacting your local carers centre or carers organisation. See the More information and support section on page 74 for details of carers' organisations.

CARERS' NEEDS AND RIGHTS

You might not think of yourself as a 'carer', seeing what you do as part of life as a partner, son, daughter, friend or relative. But recognising your role as a carer may mean you can claim benefits and access services that can help you.

In this section:

- Support for you
- How can I get this support?
- Carer's assessments
- Care following a hospital stay
- Personal budgets and direct payments
- NHS continuing healthcare (CHC)
- Finding out more about carers' rights
- Young carers
- Carers with learning disabilities
- Social and cultural needs

Support for you

Making your own informed choices, finding help, and accepting services and entitlements will help you care for yourself and the person you support.

The services most likely to affect you are those that will give you a break from caring (see more in the Taking a break section on page 48).

Other services include:

- support – such as local carers' groups or projects
- advice and information – for example, on benefits
- equipment and aids – to help make caring tasks easier
- training – for example, in lifting and handling
- counselling

How can I get this support?

Your local authority, usually through its social services or social work department, or your local health and social care trust, arranges and provides support services for local people.

The services are not just for older people or those with disabilities, they are also for carers.

The person you care for is entitled to an assessment to find out what services they need. If you regularly provide a substantial amount of care, you can also have your needs recognised in a 'carer's assessment'. It doesn't cost anything to be assessed.

Carer's assessments

As a carer, it is your right to have an assessment of your needs if:

- you provide regular and substantial care to someone (they do not have to be related to you)
- the person you care for is being discharged from hospital
- you are a parent carer of a disabled child under 18

You do not have to live with the person you care for.

The assessment will consider your needs separately from the needs of the person you care for.

An assessment is important because it considers whether you are able to provide care, how much help you give and if you want/are able to continue to do so.

It takes into account the pressures on you created by your caring role.

It will help social services, social work or the health and social care trust to provide the right services to support you in your caring role.

It also gives you a chance to talk about your own health and any impact your caring role has on this.

An assessment offers:

- recognition of your role as a carer
- a point of contact if your situation changes
- the support you need to be able to care for someone else

An assessment won't:

- judge how you care for someone
- give you standard solutions that may not help you
- always provide the services you want

An assessment will consider:

- how long you've been caring
- how many hours a week you provide care – this can include time spent with the person, as well as the time spent managing medication, taking them to appointments and providing emotional support

- how much help you get now
- how appropriate your caring role is in terms of your relationship with the person
- how many 'roles' you have (for example, if you're also an employee or a parent)
- how the caring is affecting you and your family, both physically and emotionally

An assessment may result in:

- help for the person with Parkinson's, which in turn will be helpful for you
- equipment to make caring and support easier
- breaks for you from caring
- information about services or groups that can support you

Ask for one if you think you need support. You can have your needs assessed even if the person you're caring for doesn't want to be assessed themselves. You should not feel forced to take on responsibility that you don't think you can cope with.

You can also look at how to balance other aspects of your life, such as work, family and hobbies. The Carers (Equal Opportunities) Act (England and Wales) and Community Care and Health Act (Scotland) require that a carer's assessment has to consider whether you want to work, as well as your education, training and leisure activities.

Preparing for a carer's assessment

- Prepare well to give yourself the best chance of getting the services you need. Your assessor may not know much about Parkinson's.
- What services would really help you? This may include information, help with looking after medication, equipment and aids, a meal delivery service, someone to help with personal tasks, such as dressing or shopping, someone to talk to or counselling, or time for yourself, which is a must.
- Be ready to show the assessor a diary of all the tasks you currently do to help the person you care for. If you can, expand your entries to include the daily time that caring takes, any night-time problems you have and time taken to give medication. Talk about your feelings, and give details of the impact that caring has on your life. This is to provide a fair, accurate account of your situation.
- If you want to, ask someone else to come along, such as a friend or Parkinson's local adviser.
- Tell the assessor how you feel about the care you give. Are you stressed or overloaded?
- Tell the assessor about any particular cultural or religious needs you have, such as specific diets.
- Talk to other carers via our local groups or carers' organisations.

Separate assessments

You can ask for the assessment to be completed alone or with the person you care for.

Your assessor will look at the whole situation and arrange services to suit you and the person you are caring for.

Your assessment is your chance to really explain how caring affects you, and what help you need to do it. It is important to have your own time and to be able to speak freely. If you want to, you are entitled to ask for your assessment to take place at a separate time (and place) than that of the person you support.

You are most likely to be assessed by a care manager or social worker, but it could also be a health professional, such as an occupational therapist or nurse. After your assessment, you should be told, in writing, its outcome and what services will be provided.

If you think your circumstances have changed, you can have a reassessment.

During your assessment

Your assessment may take place in your own home or somewhere away from there if you choose. It's likely the assessment will be completed over the phone. Make sure the time is convenient for you and you have the opportunity to consider your answers.

Be honest about the amount of caring you do and the effect this has on you (and your family). Caring for someone can be rewarding at times, but at other times it can be very demanding. A carer's assessment is your time to talk about your own needs and concerns about the care you are providing. The focus of the interview will be on you, not the person you are caring for.

You may be sent a pre-assessment checklist, but see page 84 for some prompts to help you think about your caring role and the impact of this during your assessment. It's also designed to help you identify any help that would make a difference to you as a carer.

After your assessment

Following a carer's assessment, if your local authority agrees you have needs, they will arrange services to help you. Having an assessment doesn't mean you have to take a service if you don't want to.

The range of services available varies across the UK and the level of help available will vary by area. In some areas, services are only offered to those thought to be in critical need.

Some social services and social work departments have had to limit the support they can offer because they're getting less government funding. In some cases, an assessment can mean taking services away.

To find out more, you'll find the contact details for your local authority in your local phone book, or speak to your Parkinson's local adviser or GP. You can also call our helpline on **0808 800 0303**.

Paying for services

When help is offered as a result of an assessment, your ability to pay for that help may also be assessed. Depending on the results of this assessment, you may have to pay for some or all of the services offered. Charges depend on your circumstances and local criteria.

You don't have to have a financial assessment if you don't want to, but this will mean you have to pay for services yourself (but not for continuing care – see page 26 for details).

Care following a hospital stay

If you will be providing regular and substantial care for someone being discharged from hospital, you have the right to ask for an assessment.

An assessment of you and the person you care for will usually be carried out before they are discharged from hospital. If you are already caring and have had a carer's assessment in the last 12 months, your needs must be reassessed before the person leaves hospital to see whether you need further support.

If the hospital believes the person you support will need community care services when they leave hospital, they must contact the relevant body to carry out an assessment. But they have to speak to both of you first.

Personal budgets and direct payments

Direct payments are cash payments made by the local social services department or health and social care trust straight to the person who has been assessed as needing social care services. The money is for them to use if they'd like to arrange and pay for their own care and support to meet any needs they've been assessed as having.

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.

Direct payments are available in England, Wales and Northern Ireland.

Councils in England may also offer personal budgets to people.

This is an 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.

In Scotland, the Social Care (Self-Directed Support) Act 2013 requires councils to offer people eligible for social care support the option of a direct payment, an individual budget managed by the council, a service commissioned by the council or a mixture of any of the three.

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.

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 the financial position of the person who is assessed. Part of the assessment will determine how much they will need to contribute towards their personal budget.

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

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.

NHS continuing healthcare (CHC)

NHS continuing healthcare (CHC) is a package of care arranged and funded by the NHS in England and Wales. If the person you care for has advanced Parkinson's with a high level of healthcare needs, it may be worth looking at whether CHC is available to you.

This care is free, without a means-test and can cover care in a nursing home or in your own home. It can enable people with Parkinson's and their family to finance the full package of care needed.

NHS continuing healthcare is not available in Northern Ireland and Scotland.

Who can get NHS continuing healthcare funding?

To be eligible, someone's care needs must be primarily 'complex healthcare needs' (and the responsibility of the NHS) and beyond the scope of local authority social care services. Just having a diagnosis of Parkinson's does not guarantee CHC funding.

The CHC assessment process

There is no application form – instead, professionals, such as a social worker, occupational therapist, Parkinson's nurse or nursing home staff, carry out an assessment of the care needs. If you can't get someone to do an assessment, you can ask the integrated care board (or local health board in Wales) to appoint someone who can.

This is firstly through the NHS continuing healthcare checklist. Then a team gather evidence before making a recommendation to the integrated care board or local health board who finally decide.

The knowledge and evidence of family and carers can be vital. If funding is not recommended, you can ask for a copy of the papers, and seek a review or appeal.

The integrated care board or local health board review the funding after 3 months, and then annually, as it's not permanent funding.

To find out more about NHS continuing healthcare, please contact our helpline on **0808 800 0303** to speak to one of our advisers.

Finding out more about carers' rights

You can find out more about your rights and entitlements as a carer by getting in touch with Carers UK. See the More information and support section on page 66 for details of how to contact them.

Young carers

If you're under 18 and help to support a parent or grandparent with Parkinson's, either on your own or with other family members, you're a young carer. Although you might not help your relative directly, you may still need extra support, such as:

- someone to talk to. This could be another younger person or someone you trust, such as a voluntary mentor, a doctor, teacher or a family friend
- appropriate information, including where to go for advice and support

You may not feel like you want to talk about what you're going through, but it's important to find someone to share your worries with. Being a young carer may have an effect on your school work and social life.

No one (young person or adult) has to be a carer if they don't want to be. Support is available from social services for your family member. Accepting this help gives you a better chance of looking after your own health and development.

You, or your parent or guardian, should tell your GP that you are a young carer. They can help you access any support you may need.

Ask for a carer's assessment

See page 17 for more detail on carer's assessments. This is available to you whatever your age. You can speak to your local social services for advice, or ask a family member or someone at your school or college to help you do this.

You, the person you care for, or anyone else helping you with this can speak to your Parkinson's local adviser.

Help with education

Ask your school or college whether they can arrange flexible courses or tuition. Your GP, or the Parkinson's nurse of the person you care for may be able to help you with this, or may let you know about others who can help. You can also speak to a Parkinson's local adviser (see page 32).

Young carers' groups

Around the UK, there are many young carers' projects and groups that can help you get support from and help other young carers.

Some have websites where you can get in touch with each other. Carers Trust has a forum where you can speak to other young carers. Visit www.youngcarers.net

The children's charity Barnardo's runs projects across the UK to support young carers. There is also more information on its website at www.barnardos.org.uk

Carers UK and The Children's Society are good sources of advice. At www.youngcarer.com you can search for your local young carers' project, with services included across England, Northern Ireland, Scotland and Wales.

If you live in England, you can also visit www.gov.uk to find out what your local authority has in place for young carers.

Other places to get support include a Parkinson's nurse (if you have one), your Parkinson's local adviser (see page 62 for more information about what they do) and our helpline on **0808 800 0303**. You can also visit parkinsons.org.uk to find out how we can help.

The following free booklets may also be useful. Call **0845 121 2354** or email resources@parkinsons.org.uk for your copies, or download them from our website at parkinsons.org.uk/publications

Parkinson's in your life: a guide for teenagers – for young people aged between 11 and 17 to help them understand Parkinson's.

My Mum has Parkinson's, My Dad has Parkinson's, My Grandad has Parkinson's and My Gran has Parkinson's – illustrated books for children aged between three and seven who have a parent or grandparent with Parkinson's.

Carers with learning disabilities

The Foundation for People with Learning Disabilities campaigns to help people with learning disabilities, their families and carers.

It also has a range of publications for people with learning disabilities who may be caring for a family member. The charity doesn't have a helpline, but you can access publications on its website at www.learningdisabilities.org.uk

Mencap supports people with learning disabilities and operates an advice helpline. Call **0808 808 1111** or visit www.mencap.org.uk

Social and cultural needs

Most services and support for carers will take into account any specialist services or cultural and language needs you have. As a carer, you are entitled to expect this and to ask for interpreters to be present at your meetings, or to have any information translated. Contact your local social service or social work department, health authority, health board or health and social care trust to find out how they can support your needs.

LOOKING AFTER YOURSELF: YOUR FEELINGS

If you're busy caring for someone with Parkinson's, while perhaps working or raising a family, often you don't have time to think about yourself. But it's important to acknowledge your feelings.

In this section:

- In the early stages of Parkinson's
- Your feelings and support as Parkinson's progresses
- Emergency support
- Health services

In the early stages of Parkinson's

It may take time and support from others to:

- understand and come to terms with Parkinson's
- manage the stress Parkinson's may create
- live with the changes it might bring to your personal relationships, relationships with others and your working life
- prevent Parkinson's from taking over your life
- know that you are doing a good job of caring

How you feel will depend on your relationship with the person with Parkinson's, and how they are managing their symptoms. The health and social care professionals listed earlier in this booklet can support you both.

It is quite normal for a carer to feel many of the same feelings as the person with Parkinson's. Before, and even after, a diagnosis is made you may experience one or more of these:

- denial, where you find it hard to accept the situation – you may notice the symptoms, and then try to ignore them
- sadness or depression
- fear about the future
- anxiety
- fatigue – excessive tiredness
- confusion about the changes in your role in your relationship
- relief to have a reason for the symptoms
- anger – you may be questioning why this is happening to you, or you might be looking for something or somebody to blame
- guilt – perhaps feeling you should do more for the person you care for, or worrying that you're more concerned about the effect on your own life
- frustration – wondering whether you could be doing more for the person with Parkinson's
- worries about money and finances

It can also be difficult if you and the person with Parkinson's are at different stages in coming to terms with the diagnosis. One of you may wish to face it and gather the information you need to get on, while the other could be in denial.

Finding out about Parkinson's

Once you've accepted the diagnosis, you may want to know more. We and other carers' organisations have lots of information for when you're ready.

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

Your feelings and support as Parkinson's progresses

Looking after your relationships

As Parkinson's progresses, the condition can affect the life of a carer as much as it does the person with Parkinson's. There may be a point where you realise your role has changed from being a partner, family member or friend to being a carer.

- Communication problems (reduced facial expression or quietened speech) can affect relationships, as they can often be mistaken for low mood or depression. A speech and language therapist may be able to help.

Find out more: see our information sheets *Communication and Parkinson's* and *Speech and language therapy and Parkinson's*.

- Depression can affect people with Parkinson's and their carers. Don't ignore it – speak to your doctor about treatment, which may include medication or counselling. See page 46 for a list of the signs and symptoms to look out for.

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

Some people with Parkinson's can be anxious about going out. Encourage them to remain sociable.

Call our helpline on **0808 800 0303** for details of your local Parkinson's UK group, or for details of your Parkinson's local adviser, who may be able to suggest other groups and support in your area.

If caring for a partner:

- You may have to get used to different roles within the relationship than you previously had.
- If your sleep is disrupted it may mean you have to sleep separately, but it is very important that you get enough rest.
- Parkinson's can sometimes affect sexual relationships.

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

Managing stress and strain

It's important to look after your physical and mental health. Back pain and stress-related illness are two common complaints for carers.

Whatever care you provide, even if you feel you're coping, there is support available for you.

Here is some advice from other carers of people with Parkinson's:

- Plan ahead where you can, to help reduce uncertainty.
- Accept your feelings and talk about what you are doing and how you are feeling to the person you care for, family, friends or other people in a similar situation.

- Tell friends, colleagues (and your children's school if relevant) how caring fits with the rest of your life and how they can help you.
- Some friends and family may have trouble dealing with the symptoms and their feelings about someone close having Parkinson's, but this may improve with time.
- Make it clear what you are and are not willing to do – this prevents unrealistic expectations and resentment building up.
- Encourage independence – it is important to let the person you care for be as independent as possible, even if tasks take much longer. Resist the temptation to take over, and offer support rather than inundating the person you're caring for with advice and practical help.
- Look after yourself and keep time aside for you – make sure you don't neglect your own health and quality of life, and accept support from others. You may need to make arrangements for someone to look after the person you care for, but try to keep your social life as normal as possible and do things you enjoy.
- Make changes to how you divide your roles and responsibilities – these can still be shared, so that neither person carries all the responsibility.
- Get support before problems reach crisis point (see the Emergency support section on page 38). Your GP, Parkinson's local adviser or a social worker can assist you – ask them what help they can give you, so you're prepared, even if you don't think you need help right now.

- Try to keep your sense of humour – many people say that having a sense of humour helps to keep things in perspective, even if caring becomes demanding, lonely and frustrating at times.
- Plan things together – try not to let Parkinson's dominate everything. Do things you enjoy doing together, even if this means doing them differently.

Find out more: see our information booklets *Parkinson's and you* and *Intimate relationships and Parkinson's*.

Emergency support

You may worry what will happen to the person you care for, if you were suddenly taken ill, or another relative or friend needed your support. Emergencies like this could affect the care you can provide, so it's a good idea to find out what support is on offer if you need it in the future.

- Ask your local authority whether they provide emergency respite care for carers.
- Set up systems for managing crises before they happen.
- Keep key telephone numbers, such as your employer, in an easy-to-find place.
- Use a community care alarm service if you need to – ask your local social services, social work department or health and social care trust.
- Use pagers or mobiles.
- Make sure your carer's assessment takes into account what support you will need in an emergency.

- Speak to your relatives or neighbours about any support they can give you in an emergency.
- Consider installing a key safe, and give the code to a trusted neighbour or nurse, so they can access your home in an emergency.

What if I need urgent help?

In a medical emergency, always call **999**.

Health services

NHS 111 (England)

Nurses can help you assess whether urgent treatment is required.

111

Textphone **18001 111**

www.nhs.uk

The NHS in England also operates walk-in centres, often in a local hospital, where you can get non-emergency help out of hours.

NHS Direct (Wales)

0845 4647

www.nhsdirect.wales.nhs.uk

NHS 24 (Scotland)

08454 242424

www.nhs24.com

Northern Ireland out-of-hours medical service

You can find details of your local out-of-hours service at

www.gpoutofhours.hscni.net

This service is for people who need urgent medical treatment that they would normally receive from their GP, but who can't wait until the practice is open the next day.

Social care

Call a directory enquiries service or look in your local phone book to get in contact with your local social services department, social work department in Scotland or health and social care trust in Northern Ireland. A duty officer will be on call to give advice.

Emotional

Samaritans

24-hour confidential emotional support

0845 790 9090

jo@samaritans.org

www.samaritans.org.uk

LOOKING AFTER YOURSELF: YOUR HEALTH

If you have a good quality of life, this will benefit you and the person you care for.

In this section:

- How do I get the most from health services?
- Taking care of yourself

Letting your own health suffer or allowing your stress levels to rise will not help you to care well. Parkinson's can be unpredictable, which might make it hard to care for your own physical and emotional health.

Recognising your needs will help you to balance caring with the rest of your life.

Our local groups and Parkinson's local advisers, family, friends, community or faith networks can provide the support you need to care, or can direct you to helpful resources and services.

How do I get the most from health services?

Your GP may not be an expert in Parkinson's, but they can direct you to other health and social care services. Along with your Parkinson's specialist and district or Parkinson's nurse, they will be a crucial part of your support team.

Register as a carer with your GP surgery

Some GP surgeries have a carers' register or database. If you're on this, you will be given special consideration because of the pressures and responsibilities of your role.

Many GP surgeries use this register to:

- make all practice staff aware of your role
- give you access to appointments quickly if you need them and help to get the services you need at the right time, without you having to tell everyone, every time, about your caring responsibilities
- point you towards other useful services
- give you up-to-date information about events for carers
- offer appointments for more appropriate times
- ensure outpatient appointments and admission letters state that you are a carer
- offer free flu vaccinations

If your GP surgery doesn't have a carers' register, explain to them how operating one will help them to consider your and other carers' needs.

How do I make the most of appointments about my own health?

- As soon as you notice an issue, book an appointment. This helps make sure any problems are managed as effectively as possible.
- Prepare for your appointment – keep a diary of how you (and the person you care for) have been, your feelings and any issues that have arisen.

- Make a list of things that you want to talk about, but keep the list short and put things in order of importance.

Taking care of yourself

- Speak to your Parkinson's nurse, GP, your local social services department, social work department in Scotland or health and social care trust in Northern Ireland, about the services you need. You can also ask your Parkinson's local adviser (see page 74 for details).
- Try to make time for friends and hobbies.
- Talk to people in similar circumstances. You could visit your local Parkinson's UK group, speak to others on our online forum at parkinsons.org.uk/forum, or attend a local carers' group.
- Keep up with work, training or volunteering.
- Eat well and healthily.
- It's important to sleep well, though it's not always easy to do so. Talk about this with your GP and try some relaxation techniques. Also ask your GP for advice on helping the person you care for at night. Some night-time care may be available – be sure to raise any night-time care issues at your carer's assessment.

Find out more: see our information sheet *Sleep and night-time problems in Parkinson's*.

- Look after your back, especially if you have to lift the person you care for. An occupational therapist can give you advice on how to do this safely.

- Try to take a break when you need it – see the next section for information about respite care and holidays.

The Carers UK website has free useful information on looking after yourself, including how to look after your back. Go to www.carersuk.org to find out more.

Helping yourself to relax

Recognise the signs of stress and find techniques to help with relaxation. Meditation, yoga or massage are just some ways to relax, but find what suits you best – activities that absorb your concentration, such as gardening or reading can be therapeutic.

If you don't have the opportunity to take time away from home to relax, spend a few minutes listening to relaxing music or borrow a meditation or yoga DVD from your local library.

Exercise as regularly as you can – even a walk may help. Exercise referral schemes are available at some leisure centres. They're open to people who have been prescribed exercise by their GP, nurse or another health professional. The scheme may consist of exercise classes such as dance, yoga and t'ai chi. Ask your GP, nurse or other health professional for more information.

Recognising the signs of depression

Depression may come on slowly and the symptoms of depression can be complex, so it may take time for you to recognise the early signs. It may take someone else to suggest that there is something wrong.

Depression may interfere with your work, social and family life. The NHS describes symptoms including:

- continuous low mood or sadness, feelings of hopelessness, helplessness and guilt
- low self-esteem
- tearfulness
- feeling irritable and intolerant of others
- lack of motivation and little interest in things you used to enjoy
- suicidal thoughts or thoughts of harming yourself or the person you care for
- slowed movement or speech
- disturbed sleep patterns
- taking part in fewer social activities and avoiding contact with friends

If you think you might be depressed, speak to your GP who can refer you to further help if necessary. You may also wish to contact our helpline on **0808 800 0303** for information and support. For details of other organisations you can speak to, see the More information and support section on page 65.

TAKING A BREAK

A break from daily routines and responsibilities is important, especially if you care full-time because you are retired or don't work and are with the person you care for 24 hours a day.

In this section:

- Respite care
- Preparing for your break

Your local authority has a responsibility for arranging services that help you to take a break from caring. A carer's assessment by your local social services, social work department or health and social care trust (see the Carers' needs and rights section) will demonstrate your need for a break. Support to take time out varies from area to area.

Services may be provided by social services, social work or voluntary organisations. Care can also be funded in different ways: by yourself, your local authority, or charities.

Respite care

Breaks from caring are often called 'respite care'. They can help to increase your patience and confidence and help you to return refreshed. This care can vary from a few hours' break to a longer holiday. You may want to go away alone, or there may be the chance to go with the person you care for on a holiday where care is provided.

Everyone needs time to relax – don't feel guilty about respite or day care.

Respite can be given in a variety of ways, including:

Care for the person with Parkinson's in your home

Someone visiting your home regularly, giving you time to do your own thing at home or elsewhere. It can be a short period, just two to three hours a day, or overnight, and can be occasional or frequent. This might be a social services care worker, or someone from a charity such as Carers Trust – see the More information and support section for details.

Day care for the person with Parkinson's outside of the home

The person with Parkinson's spends some time at a day centre, providing you with time to do whatever you need to do. Some respite options, such as day centres, offer therapy or sports sessions, classes, and other recreational activities.

Care away from home for the person with Parkinson's

The person you care for could have short, perhaps regular, stays in a care or nursing home.

Trips and holidays together with the person you care for

This may be to a centre or hotel where there are care services supplied.

This gives both parties a rest and change of scene. Try to remember that respite care is recognised as a 'break' for you, rather than time for you to catch up on caring-related tasks. It's your time to recharge your batteries and enjoy doing something for yourself.

Why is respite care important?

Respite care can help both you and the person with Parkinson's. It allows both of you to have a break, and perhaps to socialise with other people.

Do I have to pay for respite care?

Depending on the outcome of your carer's assessment, respite care may be funded by your local authority, a charity or yourself.

What organisations run respite care breaks?

Aside from some local authorities, the following organisations offer respite care.

- Revitalise is a charity providing short breaks (respite care) and other services for disabled people, visually impaired people, and carers. The scheme is open to everyone in the UK, but they only have centres in England.
- A small number of the Carers' Centres that work in partnership with Carers Trust directly provide respite care. If they do not provide this service in your area they can give you information and support about what is available locally.
- Carers Trust, Crossroads Caring for Carers Northern Ireland, Crossroads Caring Scotland and The Princess Royal Trust for Carers in Scotland offer support for carers and short-term respite care.

See the More information and support section for contact details.

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

For information about taking a break from caring see Carers UK's leaflet, Taking a Break. See the More information and support section for contact details.

Preparing for your break

- If you are going away for a break, confirm that the venue will definitely meet all your needs (access, mobility, diet, religious requirements, arrangements for children, pets etc).
- Prepare, so you can make the most of your time away.
- Check that the people providing services for the person you care for know what to do – routinely and in the case of an emergency.

If you're taking a break on your own

If you are spending time away from the person you care for, you may enjoy a break more if you know that they can call for help if they need to. Social services and carers' groups may loan or help you buy such items as:

- telephone alarm units, making calling for help quicker and easier
- pendant alarms, providing a close-to-hand call for help
- mobile phones, ensuring a telephone is to hand at all times
- pagers, so that you can be alerted, wherever you are

If you're going to be away, tell people, such as neighbours, close friends, relatives, your care provider and the call centre for your panic alarm (if you have one) how you can be reached. Some charities, such as Carers UK (see the More information and support section for details), have emergency 'contact cards' you could use. Emergency contact cards are also available from some local authorities, but this depends on your location.

MONEY, WORK AND BENEFITS

You can claim benefits to help with the extra costs you may face if you have Parkinson's, or if you care for someone with the condition.

In this section:

- Employment while caring
- Thinking about money

Employment while caring

You may be working as well as caring for someone with Parkinson's. Paid work can provide financial independence and money to help with caring, a break from caring, social networks and friendships, self-esteem and a better pension, but combining your responsibilities has its own challenges.

Your employment needs should be taken into account in any assessment from your local authority (see the Carers' needs and rights section).

The Equality Act 2010

This Act states that people can't be directly discriminated against or harassed because they care for someone. This means that carers can't be treated less favourably or not allowed the flexibility they are legally entitled to.

Should I tell my employer that I'm a carer?

You might make this decision depending on whether your employer has a policy to support carers, or whether they'd be open to exploring ways to support you. Find out what's available before you approach your manager.

As a working carer, you are likely to need a range of support – such as access to a telephone to check on the person you care for.

An understanding employer can make all the difference to whether or not you feel you can seek support.

Possible support options include:

- flexible working – a carer has the right to request flexible working. The employer must meet the employee for a discussion. If the employer refuses the request, the employee is entitled to have an appeal meeting to try to encourage the employer to change the decision
- leave arrangements (paid or unpaid at your employer's discretion, to cover intensive periods of care)
- an employee assistance programme, if your workplace has one. This is a workplace-focused programme designed to resolve any personal or work-related problems you have that may affect your ability to do your job
- access to advice and information, for example on a staff website or carers' network

Support

If you are a member of a trade union, ask them for help. A local, or regional, union representative may be able to negotiate with your employer on your behalf and attend meetings with you.

If you are not in a union, there is a right to have a colleague attend certain types of meeting with you.

Should I tell other colleagues?

Colleagues can be very supportive, and it may help to talk with someone you can trust at work. You may find that other colleagues are also carers. Together, you may be able to talk to your employer about ways you could be supported in juggling your job and caring.

Can I get time off in an emergency?

You have the right to take a 'reasonable' amount of time off work to deal with an emergency involving someone you care for.

You should not be victimised or dismissed by your employer for using this right. It is at the employer's discretion whether the leave is paid or unpaid. Situations where leave might be taken include:

- an acute emergency, such as a fall, that results in an ambulance visit
- a disruption or breakdown in care arrangements
- if the person you care for falls ill
- to make longer-term arrangements for a dependant

You should also find out how unpaid time off might affect your work rights, pension and working tax credit eligibility.

Leaving work

If you are thinking of leaving work altogether, think about whether it's right for you:

- Do you really want to leave, or is there an alternative?

- Could you manage with less money (and any effect on an occupational pension)?
- How do you feel about the potential loss of independence, social contact and valuable skills?

Employers are keen to keep skilled, experienced and committed staff, so they may be keen to consider solutions. These could include:

- part-time working or job sharing
- working from home
- paid or unpaid leave that allows you to think about long-term options

If you decide you have to leave work, think about options other than resigning, such as:

- a career break
- voluntary redundancy
- early retirement

It may take some time to get used to the new situation and it's important to have some 'me time'. But there should be benefits, such as more leisure time together.

Find out more: see our *Work and Parkinson's* booklet, which has more information for carers too, or visit parkinsons.org.uk/carers

Employers for Carers

This is a website set up by employers for employers, which provides practical advice on supporting carers within their workforce. Visit www.employersforcarers.org

Thinking about money

When you're caring for someone with a long-term condition like Parkinson's, you may worry about your finances. Here are some tips to think about.

Do:

- talk with the person you care for (and other family members if you need to) about your financial needs and arrangements
- talk to a professional adviser
- claim all the benefits you are entitled to

Don't:

- ignore any concerns about money worries
- make decisions with long-term consequences without taking time to think things through
- think that claiming benefits or accepting grants is not for you – resources are there for people in your situation

How can I access benefits and allowances?

You can speak to your Parkinson's local adviser or the advisory officer for benefits and employment on our helpline (**0808 800 0303**).

It's very important to find out what you are entitled to, and claim it. Remember, not all benefits are means tested or taxed.

Carer's Allowance

Carer's Allowance is a taxable benefit to help people who look after someone who is disabled. You do not have to be related to, or live with, the person that you care for.

There are certain requirements you and the person you care for have to meet.

Find out more: see our information on Carer's Allowance.

Finances checklist

- Make time to consider your financial needs.
- Review your needs at least once a year and always when your circumstances change.
- Use an impartial, professional adviser.
- Find out what benefits and allowances you are entitled to, and claim them.
- Some benefits kick-start others – some exclude others.
- Some benefits also mean reduced charges for services.
- Carers' eligibility for benefits reflects different factors – these can change if the person you care for goes into hospital.
- A Carer's Premium increases some benefits – always ask a qualified adviser to work out the best ways for you to get the most money you're entitled to.

Making a Will and Power of Attorney

The person you care for may wish to consider the following points and think about their wishes in case a time comes when they are unable to make decisions themselves.

PLANNING FOR THE FUTURE

It may be that you don't want to think far ahead, and choose instead to enjoy life and deal with the future when it happens. However, you might want to plan where you can.

- It's a good idea to discuss this in advance, so you are aware of their wishes about how they would like to be cared for and who should look after their affairs.
- Making a Will may be an important part of this, so the person you care for can express what they'd like to happen to their possessions.
- At the same time, they may wish to appoint someone to act on their behalf when they can't make decisions.
- More than one person can be appointed an attorney using a Power of Attorney.
- In England, there are two types of Power of Attorney: one for Property and Financial Affairs, and one for Personal Welfare or Health and Welfare.
- In Northern Ireland, you are able to make an Enduring Power of Attorney, for someone to deal with financial matters.
- In Scotland, you can make a Continuing Power of Attorney, which deals with financial affairs, or a Welfare Power of Attorney, which deals with social and healthcare needs.

- If you are the person's primary carer, it is important that you know about any arrangements that are made.

Find out more: see our information on legal rights and options at [parkinsons.org.uk](https://www.parkinsons.org.uk)

MORE INFORMATION AND SUPPORT

Carers UK

Carers UK provides information and support to people who are caring at home. The charity has support groups, branches and local offices throughout the UK.

0808 808 7777
advice@carersuk.org
www.carersuk.org

Carers Trust

This charity provides support, information and centres for carers throughout the UK and most centres run carers' groups.

0300 772 9600 (England)
0300 772 7701 (Scotland)
0300 772 9702 (Wales)
info@carers.org
www.carers.org

Mind

Mind provides support and advice on all kinds of mental health problems for people living in England and Wales. It has a range of publications and local support groups.

0300 123 3393
info@mind.org.uk
www.mind.co.uk
www.mind.org.uk/about-us/mind-cymru

Motability

Motability helps disabled people with their personal mobility.

0300 456 4566
Textphone 0300 037 0100
www.motability.co.uk

Parkinson's nurses

Parkinson's nurses have specialist experience and knowledge of Parkinson's

They can:

- support people coming to terms with their Parkinson's diagnosis
- help people to manage their medication, so they get the best results and fewer side effects
- make referrals to other professionals such as speech and language therapists and physiotherapists

Some nurses are based in the community, such as your GP surgery. Others are based in hospital settings and clinics.

Talk to your GP or specialist for more details on speaking to a Parkinson's nurse.

Parkinson's UK information and support

You can read our most up-to-date information at **parkinsons.org.uk**. You can order printed information by calling **0330 124 3250** or visiting **parkinsons.org.uk/orderingresources**

If you'd like to speak to someone, our specialist adviser team can provide information about any aspect of living with Parkinson's.

They can talk to you about managing symptoms and medication, social care, employment rights, benefits, how you're feeling, and much more.

Call our team on: **0808 800 0303** or email **hello@parkinsons.org.uk**

We'll provide expert information over phone or email or put you in touch with an adviser locally.

If you'd like to meet other people living with Parkinson's in your local area, you can find friendship and support through our network of volunteers and local groups. Go to **parkinsons.org.uk/localgroups** or call our helpline to find out more.

Our forum is also a very active space to share and chat with others who really understand, at a time that suits you. Visit parkinsons.org.uk/forum

Thank you

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

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

Feedback

If you have any comments or feedback about our information, please call **0800 138 6593**, email feedback@parkinsons.org.uk, or write to us at

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

If you'd like to find out more about how we put our information together, please contact us at healthcontent@parkinsons.org.uk or visit our website.

Can you help?

At Parkinson's UK, we are totally dependent on donations from individuals and organisations to fund the work that we do.

There are many ways that you can help us to support people with Parkinson's. If you would like to get involved, please contact our Supporter Care team on **0800 138 6593** or visit our website at parkinsons.org.uk/donate

Thank you.

My contacts

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

These pages have been left intentionally blank.

These pages have been left intentionally blank.

We are Parkinson's UK.
Powered by people.
Funded by you.
Improving life for everyone
affected by Parkinson's.
Together we'll find a cure.

PARKINSON'S^{UK}

Free confidential helpline **0808 800 0303**
Monday to Friday 9am–6pm, Saturday 10am–2pm
(interpreting available)
NGT relay **18001 0808 800 0303**
(for textphone users only)
hello@parkinsons.org.uk
parkinsons.org.uk

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



This is a revised version of the original Carer's Guide published by Parkinson's UK in 2013. We're currently producing a new booklet. In the meantime you can find lots of information on our website at parkinsons.org.uk

Parkinson's UK is the operating name of the Parkinson's Disease Society of the United Kingdom. A charity registered in England and Wales (258197) and in Scotland (SC037554). © Parkinson's UK 05/23 (CS3750)

