

THE CARER'S GUIDE

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 help and advice in seven sections:

- about Parkinson's
- help from health and social care professionals
- carers' needs and rights
- looking after yourself
- work, money and benefits
- having a voice
- more information and support

An audio version of this booklet is also available. See inside back cover for details of how to order.

If you want to speak to people going through similar experiences, you can visit your local Parkinson's UK group. Call our helpline on **0808 800 0303** or visit **parkinsons.org.uk/localgroups** to find your nearest group.

You can get in touch with others through our online forum at **parkinsons.org.uk/forum**, where you can chat to other carers, find support and share information.

You can also join our Facebook group at **www.facebook.com/parkinsonsuk** or follow us on Twitter at **www.twitter.com/parkinsonsuk**

Contents

About Parkinson's	5
What is Parkinson's?	5
Caring for someone with Parkinson's	5
Parkinson's medication	7
Help from health and social care professionals	11
Who can help?	11
Training	13
Carers' needs and rights	15
Support for you	15
How can I get this support?	15
Carer's assessments	16
Care following a hospital stay	19
Personal budgets and direct payments	22
Continuing care	23
Young carers	25
Carers with learning disabilities	29
Lesbian, gay, bisexual and transgender carers	29
Social and cultural needs	29
Transient communities	29
Looking after yourself: your feelings	31
In the early stages of Parkinson's	31
Your feelings and support as Parkinson's progresses	33
Looking after your relationships	33
Managing stress and strain	34
Emergency support	36

Looking after yourself: your health	39
How do I get the most from health services?	39
Taking care of yourself	41
Taking a break	45
Respite care	45
Preparing for your break	48
Work, money and benefits	51
Employment while caring	51
Thinking about money	54
Planning for the future	58
Having a voice	61
How can I get involved?	61
More information and support	63
My contacts	72

ABOUT PARKINSON'S

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. The symptoms most often associated with Parkinson's are tremor, stiffness and slowness of movement, but there is a range of other symptoms, too.

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 on page 63).

Find out more: we have a range of information resources for people with Parkinson's and their carers. For a general overview of living with Parkinson's, see our booklets *Parkinson's and you* (for people newly diagnosed with Parkinson's) and *Living with Parkinson's*.



See the inside back cover for details of how to order.

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.

You can also get practical tips for coping with a range of Parkinson's symptoms from our 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 advice in our booklet *Diet and Parkinson's*.

This is just a selection of the publications we have available. See the inside back cover for details of how to get hold of our resources.

“Both myself and my husband can get very frustrated, because simple tasks seem to take forever. Plans often have to be changed as well, because days can be so unpredictable. It is important to have practical ways to deal with everyday problems.”

A carer of someone with 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 regime, 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. Talking it through will help to ease any worry.

Having this information means you can plan the regime 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*, our Parkinson's medication card and Parkinson's medication record.



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.

Sometimes, people who experience this behaviour may not realise they have a problem, so 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 protective 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*.

My life as a carer

By Sue, whose husband Charlie had Parkinson's

My husband Charlie had Parkinson's for 35 years. As his disability increased, we still wanted him to feel he was making a contribution to the daily running of the house. We found that sharing activities together was wonderful. We enjoyed working together.

When it comes to communication, it can sometimes take time for a person with Parkinson's to respond to a question. And this can take time to get used to. Try not to ask multiple questions and pre-empt with a reply. My children were always saying 'let dad answer'.

When people first started calling me a carer, I didn't like it, because I am his partner. However, it was important for me to recognise that when more of my time, support and assistance were needed, I was his carer as well as his partner.

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.

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 'multi-disciplinary team'. As a carer, you're an important part of the multi-disciplinary 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.

Support for the person you care for is crucial for both of you.

Who can help?

Professionals or organisations that can help include:

Specialists, consultants or GPs directly influence your healthcare, and these professionals can refer you towards other services.

District or community nurses help with healthcare, medication and referral to experts in particular areas, such as physiotherapists.

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 local Parkinson's UK information and support worker whether there is one in your area, or call our helpline on **0808 800 0303**.

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 and massage, 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 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 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.

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 local Parkinson's UK information and support worker.

Parkinson's UK information and support workers provide information and support to all people with Parkinson's. They also view carers of people with Parkinson's as clients in their own right. They will see a carer separately and/or away from home if this is what the carer wants. Find out about your local information and support worker by contacting our helpline on **0808 800 0303** or visiting **parkinsons.org.uk/isw**

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** 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 page 67 for contact details.

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

Training

As Parkinson's progresses in the person you're caring for, 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 page 41 for more information 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, organised by a range of providers, on the courses section of our website at **parkinsons.org.uk/localtoyou**



CARERS' NEEDS AND RIGHTS

You might not think of yourself as a 'carer', seeing what you do as part of life as a partner, husband, wife, 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.

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 Taking a break on page 45). 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

“ I don't like labels. I don't think of myself as a carer. But if we are to get any help, I realise unity is strength and we must be recognised as a group. ”

A carer of someone with Parkinson's

- 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. 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.

After your assessment, if your local authority agrees you have needs, they will arrange services to help you. The range of services available varies across the UK. Having an assessment doesn't mean you have to take a service if you don't want to.

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 UK information and support worker or GP. You can also call our helpline on **0808 800 0303**.



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 much help you get now
- how appropriate your caring role is in terms of your relationship with the person
- how many 'roles' you have (ie 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

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. See page 21 for advice on what to do if you are not happy with your assessment, or its outcome.

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.

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 23 for details).

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, aids, someone to help with personal tasks, such as dressing or shopping, someone to talk to, 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 UK information and support worker.
- 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' associations.

Separate assessments

Your assessor will look at the whole situation and arrange services to suit you and the person you are caring for. If you want, you can have the assessment at the same time as the person you care for, but you don't have to.

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.

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.

Community Care Act 2003 (England and Wales)

This states that if someone has continuing needs:

- an assessment should take place and a care plan drawn up before discharge from hospital
- carers should be assessed immediately and services put in place promptly
- if needed, equipment or services for intermediate care must be provided promptly and free of charge to people who are eligible, including carers

These duties are incorporated into the Social Work Act (Scotland).

Carers Strategies (Wales) Measure 2010

This law sets a legal duty on each health board in Wales to develop a carers strategy by October 2012. The strategy will include providing appropriate information and advice, and involving carers at all stages of care. You can find out more on

the Welsh Assembly Government website at www.wales.gov.uk

Social Care Charges (Wales) Measure 2010

This law means that people in Wales who receive homecare and other non-residential social services will pay a maximum charge of £50 a week for these services. They may pay less than this or nothing, depending on local authority charging policies and individual circumstances.

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

- tell the relevant authority responsible for care services where you are, and ask for another assessment if necessary
- ask your Parkinson's UK information and support worker, call our helpline on **0808 800 0303** or speak to your local carers' organisation or advocacy service for further advice
- if things can't be resolved this way informally, ask for details of the local authority's complaints procedure and make a formal complaint
- contact your local politician and ask them to raise the matter at a higher level

Personal budgets and direct payments

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

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

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

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

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

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

The aim of this scheme is to give people greater choice and control over their lives, and will help them to make their own decisions about how their care and support is delivered and paid for. Payments could go towards respite care or caring support. The amount of the direct payment will depend on 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 information and support worker, or our helpline on **0808 800 0303** for more information.

In England, the Department of Health has produced an information guide, *A guide to getting direct payments from your local council*. An easy-read version is also available.

Both can be downloaded from **www.dh.gov.uk/publications**. You can also call **0300 123 1002** (Textphone **0300 123 1003**) to order. If you order the easy-read version on the telephone, you can request a pack that includes a CD-ROM and an audio tape.

In Scotland, you can find out more about direct payments on the publications section of the Scottish Government Health Directorates website at **www.sehd.scot.nhs.uk**

Continuing care

This is a package of professional care funded by the NHS, which is given to meet the physical or mental health needs of a person with a disability, injury or illness, over an extended period of time.

An assessment by a multi-disciplinary team will determine which elements of care are required for each individual.

While this is a further source of support for you and the person you care for, being assessed and found eligible for this is not easy, so for advice, speak to your Parkinson's UK information and support worker, GP or Parkinson's nurse. There may be an advocate for continuing care in your area, but not every area will have someone in this role.

Carers of people receiving continuing care are still eligible for a carer's assessment.

My life as a carer

By Jim, whose wife Gill has Parkinson's

As the chairman of my local Parkinson's UK group, I arranged for us to have a talk from the local authority about benefits and entitlements. The lady who came to speak mentioned direct payments for carers. I wanted to find out more for my branch members. I thought if I could understand what was involved and go through the process myself I could help others. I didn't expect to be eligible, but I was pleased when, after my assessment, I was offered four hours a week support to help me to have some time to attend to my own needs.

As we have many good friends, we decided to approach three of them to see whether they would be happy to support us by coming to the house when I go out. They make sure Gill is safe, which gives me peace of mind. Although our friends were reluctant to receive payment, they were keen to be involved.

At the start, sorting out the supporting paperwork took time to get right. I ended up writing a programme on my computer that calculates the hours spent, what is owed and how much tax and holiday entitlement is owed. Once the processes are set up it is not complicated, but time needs to be taken at the start.

Knowing that someone Gill likes is with her allows me to switch off, relax and concentrate on what I need to do. The time allows me to go to local group meetings and events. I also manage to play the odd game of golf, which I enjoy.

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, 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 16 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.

Help with education

Ask your school or college whether they can arrange flexible courses or tuition. Your GP may be able to help you with this, or may let you know about others who can help.

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. The Princess Royal Trust for Carers 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. See page 63 for other contact details.

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 shown across England, Northern Ireland, Scotland and Wales.

If you live in England, you can also visit **www.direct.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 local Parkinson's UK information and support worker (see page 63 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 booklets may also be useful:

Parkinson's: the facts – for young people aged between 11 and 17 to help them understand Parkinson's.

Our Mum has Parkinson's – an illustrated book for eight to 11-year-olds who have a parent with 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.

See the inside back cover for details of how to order.

You may also be interested in *I'll hold your hand so you won't fall*, a book written for children by Muhammed Ali's daughter, Rasheda.

My life as a carer

By Jenny, whose dad has Parkinson's

My dad, Ken, was diagnosed with Parkinson's in 2001, when I was 17. I knew almost nothing about the condition and it was a complete shock. At the time, I was a typical teenager, preoccupied with my own world. Looking back, I can remember him freezing, and that he had tremor in his left arm and leg. Dad has since been diagnosed with dementia.

My mum, Linda, is dad's full time carer, but as his condition has progressed, my sister, Catherine, and I have helped with caring for him more and more. We both moved out a few years ago, but I've come back temporarily.

We do things like help him if he falls over, move him when he's frozen, cook for him, and help him remember his tablets. We also try and help out generally around the house. Catherine and I feel guilty about not being able to do more. We both work full time, but between us try to look after dad a few days each month, so mum can have a break and see her friends and family. We are also on call if she needs anything.

I worry about mum – caring can be both physically and mentally demanding. Caring for anyone inevitably changes your relationship with someone as you become their world. Although it has been tough for all of us as a family, we are very close.

I'd advise anyone to ask for help if you need it – this can come from healthcare professionals and your own support network.

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 **0300 333 1111** or visit www.mencap.org.uk

Lesbian, gay, bisexual and transgender carers

Age UK has a booklet, *Lesbian, gay or bisexual: planning for later life*, which has a section on being a carer, as well as information about benefits and housing options. The Lesbian and Gay Foundation has an online forum for carers at www.lgf.org.uk where you can talk about your experiences with others.

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. See the More information and support section on page 63 for other organisations who can help.

Transient communities

The project Friends, Families and Travellers supports Gypsy and Traveller communities in a range of ways, including access to health and social care services. Almost half of the staff team are travellers. See page 65 for contact details.

My life as a carer

By Jennifer, whose dad has Parkinson's

My dad, now 66, was diagnosed with Parkinson's in 2006 and has since developed dementia. Dad has gone from a fit, healthy, sociable man to someone who needs constant care. It's hard to find activities that might interest my dad and keep him awake and stimulated.

My mum is his main carer and she makes sure he gets out most days, even just for a short walk. An occupational therapist has helped by organising a respite centre for dad to go to one day a week, which has given mum some time to do her own things. Another morning, a support worker comes to take him out, maybe to tenpin bowling or for a coffee. Dad has always enjoyed music and was a great singer, so he enjoys it when we put on the old songs he used to sing.

Our advice to others is to take all the help you can get. Emotionally it is very hard – having to repeat everything for dad and remind him where he is, but reassurance helps him.

Occasionally we see a glimmer of the funny, sociable person he used to be and we are reminded he is still there.

LOOKING AFTER YOURSELF: YOUR FEELINGS

In the early stages of Parkinson's

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.

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 on page 11 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 booklets *Parkinson's and you* and *Living with Parkinson's*.



Your feelings and support as Parkinson's progresses

Looking after your relationships

As Parkinson's develops, it can have an effect on relationships. The symptoms themselves may cause problems:

- 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 42 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.

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* and contact details for relevant organisations at the back of this booklet.

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 Emergency support on page 36). Your GP, information and support worker 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*.



See the Carers UK booklet, *Balancing Life and Caring*. Contact details for Carers UK can be found on page 63.

The Carers Direct section of the NHS Choices website **www.nhs.uk/carersdirect** has information about types of support available in England.

The carers’ section on the Health in Wales website **www.wales.nhs.uk/carers** has information on support in Wales.

The ‘Caring for someone’ section on the nidirect website **www.nidirect.gov.uk** has information for carers in Northern Ireland.

You can also talk to others at your local Parkinson’s UK group, or on our online forum – **parkinsons.org.uk/forum**.

Your local council and **www.carersuk.org** should have details of local carers’ projects where you may be able to get emotional support or information.

Crossroads Care (for England and Wales), Crossroads Caring for Carers Northern Ireland and Crossroads Caring Scotland offer support for carers, including short-term respite care. See page 64 for contact details.

Visit our online forum at **parkinsons.org.uk/forum**, where you can chat to other carers in confidence, find support and share information and concerns.

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

NHS Direct (England and Wales)

Nurses can help you assess whether urgent treatment is required.

0845 4647

Textphone **0845 606 4647**

www.nhsdirect.nhs.uk

www.nhsdirect.wales.nhs.uk

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

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 on the nidirect website **www.nidirect.gov.uk**.

This service is for people who need urgent medical treatment that they would normally receive from their

GP, but who cannot 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. 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 information and support workers, 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.

“It's important that carers can get support from others in the same position as them, as well as the opportunity for respite from their duties as a carer. It's very easy to get lost as an individual when you're caring for someone else.”

Sue, whose husband has Parkinson's

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 your 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.
- If the person you care for is happy for you to be there, accompany them in their appointments with healthcare professionals. Also, invite them along if you are happy for them to attend your own appointments.
- Be honest about your needs, your feelings and what you think would help.
- If you're not feeling confident, take a friend or advocate with you. Having someone else in the meeting can help you to remember what is said, and taking brief notes might help, too.
- 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*.

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.
- 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.

See the Princess Royal Trust's guide, *Improving Health Services for Carers*.

The National Back Pain Association also produces a booklet, *A Carer's Guide to Safer Moving and Handling of People*.

Contact details for these organisations can be found in the More information and support section on page 63.

For information on how to manage stress, see the Consumer Health Information Centre's website: www.chic.org.uk

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. NHS Choices 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 pages 68 and 69.





PISCES

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.

Taking a break is also important if you have children and you want to be able to take them on holiday.

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 page 16) 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 (eg a social services care worker, or someone from a charity such as Crossroads Care – see page 64 for details) 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.

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

The person with Parkinson's spending 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.



Funding from Parkinson's UK

Our Mali Jenkins fund provides one-off grants to people with Parkinson's. The aim of the fund is to give financial help towards equipment, adaptations and respite breaks that will improve quality of life.

If you meet the eligibility criteria, you can apply for up to £1,000 towards respite breaks for you and your carer. Call our helpline on **0808 800 0303** for more information.

What organisations run respite care breaks?

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

Vitalise 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 The Princess Royal Trust for Carers 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.

“ I have a lot on my shoulders, not just because of my husband's Parkinson's, but family issues, too. I treat myself to a massage sometimes, just for 'me time'. ”

A carer whose husband has Parkinson's

Crossroads Care, Crossroads Caring for Carers Northern Ireland and Crossroads Caring Scotland offer support for carers and short-term respite care.

See the More information and support section on page 63 for contact details for these organisations.

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

You can also order *OpenBritain 2011*, produced jointly by RADAR and Tourism for All UK with the support of VisitBritain, from our distributor for £10 including postage. For information about taking a break from caring see Carers UK's leaflet, *Taking a Break*, or visit their website www.carersuk.org

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 page 63 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.

My life as a carer

By John, whose wife has Parkinson's

Although I don't call myself a carer, and I don't see myself as one, I have an important role to play in caring for my wife.

She was diagnosed seven years ago and fortunately is still quite capable and independent. Despite this, she has lost a great deal of her self-confidence, she is much slower at everything she does and gets tired quickly. She doesn't drive any longer, so I am now her chauffeur.

Although she often struggles greatly to get up from her chair or move in or get out of bed, she insists that I continue with my hobby one day a week and also take a two-week break with my friends, again to follow my hobby.

We have always done some things separately, and will continue this as long as it is safe and enjoyable. She now helps one day a week at a warden-controlled home, helping the elderly residents play bingo, and on occasions calls the bingo.

We believe that remaining as positive as you can is important for both of us. Life goes on despite Parkinson's, but a lot of how much you enjoy life depends very largely on your attitude.



WORK, MONEY AND BENEFITS

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 Carers' needs and rights on page 15).

The Equality Act 2010

Carers have gained new rights under the Equality Act, published in October 2010. The Act means 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.

Call our helpline adviser (employment and benefits) on **0808 800 0303** to discuss your employment rights.



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 managing both 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.

“ I think you should tell your employer that you're caring for someone with Parkinson's, as you may need time off for things such as specialist appointments. I found that my colleagues were very supportive, but I think it's important to try not to make every conversation about caring. ”

David, whose wife has Parkinson's

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.

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 local Parkinson's UK information and support worker or the advisory officer for benefits and employment on our helpline (**0808 800 0303**).

We also have a range of rights and benefits information sheets available to order for free. See the inside back cover for details of how to order.

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

This 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. You can find out more about Carer's Allowance at **www.direct.gov.uk** or by calling **0845 608 4321**. You can request a claim form on this number or you can claim online at **www.dwp.gov.uk/carersallowance**

Residents of Northern Ireland should visit **www.nidirect.gov.uk**



How do I access one-off grants?

Charitable benevolent funds and trusts offer grants and can support daily costs for individuals in need. Some provide regular help, advice and practical support.

Your local Citizens Advice Bureau may hold a record of these. Occupational charities, for those who work or have worked in particular industries, and those for ex-service people can be particularly helpful.

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.



Pensions

Consider:

- When will you and/or the person you care for receive a pension?
- What will your pension(s) be worth?
- As a carer you may qualify for National Insurance credits, which help to maintain your National Insurance record and protect your entitlement to the basic State Pension and some other state benefits, even if you're not in paid employment. Check whether you qualify.
- Can you arrange a personal pension to suit your likely needs?

Further information

Ask your local information and support worker for advice, speak to our dedicated benefits and employment advisor on our helpline (**0808 800 0303**), or speak to an independent financial adviser.

To find an adviser, ask people you know whether they can recommend anyone, or alternatively, you should be able to find one in local listings. Contact the Financial Services Authority to check they are registered. Call **0845 606 1234** or search the register at **www.fsa.gov.uk**

You can also contact:

- CarersLine **0808 808 7777** or **www.carersuk.org**
- local Citizens Advice offices
- welfare rights units
- disability organisations
- Age UK branches
- carers' projects
- Carers Direct **www.nhsuk/carersdirect**
- the Social Security Agency in Northern Ireland **www.dsdni.gov.uk**
- the 'Caring for someone' section on the nidirect website **www.nidirect.gov.uk**
- the carers' section on the Health in Wales website **www.wales.nhs.uk/carers**

Find out more: see our wide range of rights and benefits information sheets, including *Carer's Allowance*.

Carers UK's Carers Online information service is a useful source of information. See **www.carersuk.org**.

The charity produces the guide *Benefits: What's Available and How to Get Them*, and information

leaflets including *Carers and employment, Carers Allowance and the Carer Premium and Carers and Learning*.

The *Disability Rights Handbook* is available to order from Disability Alliance for a charge.

Age UK produces a number of useful fact sheets, including *Dealing with debt*.

Also, see the Help the Hospices booklet, *Flexible Working for people caring for a relative or friend*.

Contact details for these organisations can be found in the More information and support section on page 63.

Planning for the future

Should I start thinking ahead?

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. Think about things like finances, employment, housing and leisure, so you can be ready for important decisions, as and when you need to make them.

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.

- 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 booklets *Preparing for end of life: a practical guide* and *Preparing for end of life: an emotional guide*.





Parkinson's
MOVEMENT

LONDON

...ing about aut
...out autist

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

PARKINSON'S
CHANGE IT!
FIND A CURE!
JOIN US!

HAVING A VOICE

In learning to live with Parkinson's, you'll know a lot about the challenges of getting the services you need. Many people use their experiences to make changes, by making comments or complaints, responding to consultations, joining carers' groups and writing to local politicians and other decision makers.

How can I get involved?

Join our Campaigns Network

We are actively involved, locally and nationally, in campaigning and influencing services to improve the lives of people affected by Parkinson's. If you'd like to get involved in our campaigns locally or directed at UK governments, you can join our National Campaigns Network. Visit parkinsons.org.uk/campaignsnetwork, email campaigns@parkinsons.org.uk or call **020 7963 9332** to find out more.

To help influence services locally, you can contact your regional or country team via our helpline on **0808 800 0303**.

Contact a carers' organisation

Carers' organisations help carers to get the support they need. Many campaign to increase the recognition of carers' roles, and represent carers' views to those supplying social and healthcare services. Contact details can be found in the More information and support section on page 63.

Help to shape health and social care

You can get involved and help shape health and social care in all areas of the UK. Contact your local council, health board or health and social care trust for more information.

In England, each local authority has a Local Involvement Network (LINK), which monitors and reviews local NHS and social care services.

They ensure that people's views about these services are fed back to NHS and other care providers. The government has announced plans for local involvement networks to change, but there will still be a way to become involved in shaping services in your area. (LINKs) will become part of a body that will operate locally and nationally, called Healthwatch.

Find out more: If you experience any problems that concern Parkinson's medication, either in a hospital or a care setting, see our leaflets, *Helping you complain about medicines management*. There are versions for England, Northern Ireland, Scotland and Wales.



MORE INFORMATION AND SUPPORT

Support and information from Parkinson's UK

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

Parkinson's UK information and support workers

We provide information and advice to carers through our UK-wide team of information and support workers. For details of the local information and support worker in your area, contact our helpline on **0808 800 0303** or email **hello@parkinsons.org.uk**. You can also find out more on our website at **parkinsons.org.uk/isw**

Our helpline

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

Local groups

Support is available through Parkinson's UK local groups. Visit **parkinsons.org.uk/localgroups** or call our helpline for details of your nearest meeting.

Online forum

Speak to others in a similar situation through our online discussion forum at **parkinsons.org.uk/forum**

Organisations for carers, friends or family members

Carers UK

Carers UK provides information and advice to anyone who is looking after a sick, disabled or older frail friend or relative at home. They can also put carers in touch with one another and bring issues to the attention of the government and media.

The charity has a range of publications including a carers' rights guide – one each for England, Northern Ireland, Scotland and Wales.

Carersline **0808 808 7777**
(Wednesdays and Thursdays only,
10am–12pm, 2pm–4pm)
info@carersuk.org
www.carersuk.org

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

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

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

Caring for Someone
UK government website that aims
to provide details of all services and
benefits affecting carers.
**www.direct.gov.uk/en/
caringforsomeone**

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

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

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

**The Princess Royal Trust
for Carers**
A national charity that exists to
make it easier for carers to cope
by providing information, support
and practical help.

It has 133 independently-managed
Carers' Centres across the UK and
lots of web-based information,
including a section for young carers.
0844 800 4361
info@carers.org
www.carers.org
www.youngcarers.net

Glasgow office
0141 221 5666
Wales office
02920 221 788

Services near to you

If you live in England, find addresses, telephone numbers and websites for services for carers near where you live on the Carers Direct website. Visit **www.nhs.uk/carersdirect** for advice and information about money and legal issues, your wellbeing, younger carers and much more. Although some of the information is only relevant if you live in England, much of the information is transferable.

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

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

Carers from black, Asian and other minority ethnic communities

The Afya Trust

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

020 7582 0400

www.afyatrust.org.uk

Asian Health Agency

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

020 8811 1501

www.taha.org.uk

Chinese National Healthy Living Centre

Advice on health issues including caring help for the Chinese community.

020 7287 0904 or

020 7534 6546

general@cnhlc.org.uk

www.cnhlc.org.uk

Friends, Families and Travellers

This project supports Gypsy and Traveller communities in a range of ways, including access to health and social care services. Almost half of the staff team are travellers.

01273 234777

fft@gypsy-traveller.org

www.gypsy-traveller.org

Older people

Age UK (formerly Age Concern and Help the Aged)

Advice, information, resources and campaigning work for older people's issues.

Age UK – England

0800 169 6565

contact@ageuk.org.uk

www.ageuk.org.uk

Age NI

0808 808 7575

info@ageni.org

www.ageuk.org.uk/

northern-ireland

Age Scotland

0845 125 9732

enquiries@ageconcernandhelp

theagedscotland.org.uk

www.ageuk.org.uk/scotland

Age Cymru

0800 169 6565

enquiries@agecymru.org.uk

www.ageuk.org.uk/cymru

Care Directions

Website providing detailed advice and information on a range of health and care issues for older people.

www.caredirections.co.uk

Organisations for disabled people

Disability Alliance

Provides people with disabilities with information on their rights and benefits, including its *Disability Rights Handbook*. There is a charge for this publication, but this is reduced for people claiming benefit.

020 7247 8776

www.disabilityalliance.org



Disabled Living Foundation

Provides information and advice on disability equipment, aiding daily living and independence for disabled and older people.

0845 130 9177

helpline@dlf.org.uk

www.dlf.org.uk

Foundation for People with Learning Disabilities

This charity 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

Learning disability charity.

0300 333 1111

help@mencap.org.uk

www.mencap.org.uk

Northern Ireland

mencapni@mencap.org.uk

Wales

helpline.wales@mencap.org.uk

Motability

0845 456 4566

Textphone **0845 675 0009**

www.motability.co.uk

The Royal Association for Deaf people

As part of a project called Reaching out to deaf carers, this charity is developing materials for deaf carers whose first language is British Sign Language.

0845 688 2525

Minicom **0845 688 2527**

info@royaldeaf.org.uk

www.royaldeaf.org.uk

Health

The Consumer Health Information Centre

www.chic.org.uk

Local Involvement Networks (LINKs, England only)

Contact your local council for more details.

The National Back Pain Association

0845 130 2704

info@backcare.org.uk

www.backcare.org.uk

NHS Direct (England and Wales)

0845 4647 (24-hour service)

Textphone **0845 606 4647**

www.nhsdirect.nhs.uk

www.nhsdirect.wales.nhs.uk

NHS24 (Scotland)

08454 242424

(24-hour service)

www.nhs24.com

Northern Ireland out-of-hours medical service

Local details can be found at www.nidirect.gov.uk

Living arrangements

Counsel and Care

A national charity that works with older people, their families and carers to help them get the best care and support. It also produces publications, such as *The Complete Care Home Guide*.

0845 300 7585

advice@counselandcare.org.uk

www.counselandcare.org.uk

Help the Hospices

020 7520 8200

info@helpthehospices.org.uk

www.helpthehospices.org.uk

Relatives and Residents Association

Provides information and advice on care homes (fees, standards, complaints, etc), as well as a 'listening ear' for those with emotional concerns.

020 7359 8148

Advice Line **020 7359 8136**

info@relres.org

www.relres.org

Relationships

The Lesbian and Gay Foundation

0845 330 3030

www.lgf.org.uk

The Outsiders

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

020 7354 8291

info@outsiders.org.uk

Sex and Disability Helpline

0707 499 3527

(higher phone rate)

sexdis@outsiders.org.uk

www.outsiders.org.uk

Relate

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

0300 100 1234

www.relate.org.uk

Mental health

British Association for Counselling and Psychotherapy

List of accredited therapists available.

01455 883300

bacp@bacp.co.uk

www.bacp.co.uk

Depression Alliance

National charity supporting anyone with depression, and their families.

0845 123 2320

information@depressionalliance.org

www.depressionalliance.org

Depression Alliance Scotland

0845 123 2320

info@dascot.org

www.dascot.org

Mind

Mental health charity.

0300 123 3393

info@mind.org.uk

www.mind.org.uk

Niamh – Northern Ireland Association for Mental Health

028 9032 8474

www.niamh.co.uk

Samaritans

Local branch numbers are in phone books under 'S'. Confidential, emotional support, 24 hours a day.

0845 790 9090 (local rate)

jo@samaritans.org.uk

www.samaritans.org

Scottish Association for Mental Health

0141 530 1000

info@samh.org.uk

www.samh.org.uk

Respite care

Vitalise

Provides breaks for disabled adults, children and carers, including the visually impaired. Day care services for disabled people available in Derby and Cornwall.

0845 345 1970

info@vitalise.org.uk

www.vitalise.org.uk

Work, money and benefits

Citizens Advice

England and Wales

0844 477 2020

info@nacab.org.uk

www.nacab.org.uk

Northern Ireland

www.citizensadvice.co.uk

Scotland

www.cas.org.uk

Website for online advice:

www.adviceguide.org.uk

Benefit Enquiry Line

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

0800 882200

Textphone **0800 243355**

BEL-Customer-Services@

dwp.gsi.gov.uk

www.direct.gov.uk/disability-money

Directgov

Website of the UK government, with information on public services
www.direct.gov.uk

Employers for Carers

A website set up by employers for employers, which provides practical advice on supporting carers within their workforce.

020 7378 4956

employers@carersuk.org

www.employersforcarers.org

Young Carers Initiative

Provides support and information for young carers, their families and those who work to support them.

www.youngcarer.com

Young carers

Barnado's

Children's charity that offers support to young carers

020 8550 8822

info@barnardos.org.uk

www.barnardos.org.uk

Barnado's Cymru

029 2049 3387

Barnado's Northern Ireland

028 9067 2366

Barnado's Scotland

0131 334 9893

The Children's Society

0845 300 1128

www.childrensociety.org.uk

NOTES

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

The carer's guide

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

Information Resources

Parkinson's UK

215 Vauxhall Bridge Road

London SW1V 1EJ

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

Please tick...

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

Where did you get this booklet from?

Please tick...

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

How useful have you found this booklet?

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

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



Continued over the page

What aspects did you find most helpful?

.....

.....

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

.....

.....

Do you have any other comments?

.....

.....

If you would like to become a member of Parkinson's UK, or are interested in joining our Information Review Group, please complete the details below and we'll be in touch.

Membership

Information review group

(People affected by Parkinson's who give us feedback on new and updated resources)

Name

.....

Address

.....

Telephone

Email



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

Sarah Buchanan and Elaine Willis, the original authors of The carer's guide, from which this version has been adapted.

Lee Kieft, Parkinson's Disease Nurse Specialist, The Queen Elizabeth Hospital, Woolwich, London

Jill Strickland, Information and Support Manager for the North West, Parkinson's UK

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

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

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

How to order our resources

01473 212115

resources@parkinsons.org.uk

parkinsons.org.uk/publications

Can you help?

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

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

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

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

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

Parkinson's UK

Free* confidential helpline **0808 800 0303**

Monday to Friday 9am–8pm, Saturday 10am–2pm. Interpreting available.

Text Relay **18001 0808 800 0303**

(for textphone users only)

hello@parkinsons.org.uk

parkinsons.org.uk

*calls are free from UK landlines and most mobile networks.

Last updated June 2011. Next update available June 2013.
B071

© Parkinson's UK, June 2011. 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).

