

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

PREPARING FOR END OF LIFE

A practical and emotional guide

This booklet looks at the practical and emotional issues relating to Parkinson's and the later stages of life. This includes decisions you may need to make, the care you would like to have, and how to put your affairs in order. There is also information about the help and support that is available.

For the majority of people, Parkinson's will not significantly affect their life expectancy, but it can lead to poor health in later life. Thinking about the future now, and discussing your wishes and preferences with the people in your life, may help you feel more in control and confident about what lies ahead. It also takes away the burden from family or friends of having to make decisions on your behalf, should you become too ill to make decisions for yourself.

Talking to someone you know and trust about future decisions can also be helpful. This might be a person with an understanding of Parkinson's, such as your GP, specialist, Parkinson's nurse (if you have one), or one of our helpline advisers or Parkinson's local advisers. You can also talk

to a palliative care consultant or nurse at your local hospital or hospice. For financial and legal matters you may wish to talk to a solicitor or an advisor at the Citizens Advice (see page 31 for contact details).

This booklet also contains advice and information for carers, close family and friends, including how to arrange a funeral and finding bereavement support.

Contents

How will my condition progress?	5
Could I die from Parkinson's?	5
How might my symptoms progress?	5
Why should I think about end-of-life issues?	6
Arranging the right care	8
What is palliative care?	8
Who provides palliative care?	8
Involving my family	8
When should I start thinking about palliative care?	9
Preparing for end of life	10
Talking to people close to you	10
Talking to children	10
Making your wishes known	10
Looking after your affairs	11
Making a Will	12
Power of Attorney	14
Losing the capacity to make decisions	16
Making an Advance Decision	18
Brain donation for Parkinson's research	21
Where to get emotional support	22
Counselling	22
Where is counselling available?	22
Information and support centres	22
Parkinson's UK local groups	23
Religious and spiritual support	24
Online support	24

What to do when someone dies: information for family and friends	25
How to register a death.....	25
Who do I need to inform?.....	26
How do I arrange a funeral?.....	27
How do I cope with bereavement?.....	27
More information and support	29
Support and information from Parkinson’s UK	29
Parkinson’s UK Brain Bank	30
Useful contacts.....	30
Checklist for important documents and information	37

HOW WILL MY CONDITION PROGRESS?

Could I die from Parkinson's?

For the majority of people, Parkinson's will not significantly affect their life expectancy. However, some of the more advanced symptoms can lead to increased disability and poor health, which can make someone more vulnerable to infection.

How might my symptoms progress?

Parkinson's is a progressive condition. This means it will get worse over time. It's difficult to predict at what speed your Parkinson's will progress or what symptoms you may get, because the condition is different for everyone.

Most of the current treatments involve managing the main movement symptoms of Parkinson's, which are tremor, rigidity and slowness of movement. Over time, these can affect everyday activities, such as walking, talking, swallowing and eating.

“My suggestion to others would be to use this booklet to plan ahead. Do it now and then enjoy life as much as possible.”

Peter, who enjoys sports, exercise and outdoor pursuits

As well as problems with movement, you may experience symptoms such as tiredness, pain, depression and constipation. These symptoms can also often be managed with treatments and therapies.

Some people also find they experience changes in how their mind works. This may be a side effect of some Parkinson's medication and can include difficulties with memory, concentration, hallucinations, delusions, anxiety and depression.

Your GP, Parkinson's nurse or specialist should be able to advise on treatments to help with this, too.

If you feel your condition is changing, or if you have concerns about the future, speak with your Parkinson's nurse or specialist. Such a conversation can often put your mind at rest.

In the advanced stages of Parkinson's, your care needs may be more complex and require planning by you, your family and the health and social care professionals involved.

Why should I think about end-of-life issues?

Although you may be recently diagnosed, or have few problematic symptoms of Parkinson's, it is important to know what decisions you may have to face in the future. Having the opportunity to plan your treatment and care for the later stages of your condition, however far off, can give you, your friends and family peace of mind.

One approach that can be helpful is to think of the end of life in terms of having a 'good death'. This can mean:

- you're physically comfortable and free from pain
- you're at peace with yourself and loved ones
- you feel you are ready to say goodbye
- you have made your wishes clear and they are respected
- you're treated with dignity and care

Planning your future care now means that difficult decisions can be considered. It makes sure that everyone is clear about your wishes.



ARRANGING THE RIGHT CARE

What is palliative care?

Palliative care is about improving the quality of life for you, your family and loved ones, through managing symptoms, relieving pain and dealing with any other distressing aspects of the condition. Palliative care acts as an extra layer of support and can be given whatever age you are or stage of your condition. It can play an important part of care when you are approaching the end of your life.

Palliative care is a holistic, or 'whole person', approach that supports the personal, social, psychological and spiritual needs of you and your family. It gives you some control and choice over areas such as treatment options and where you will be cared for, as well as providing advice and support to all the people involved in your care.

Who provides palliative care?

Palliative care can be given whether you're at home, living in a care home or in hospital. It may be provided by a Parkinson's nurse

who works with a multidisciplinary team for both day-to-day and specialist care.

In some areas, the local hospice or your GP can refer you to specialist palliative care teams. They can help with the management of complex symptoms.

Physiotherapists, occupational therapists, speech and language therapists and dietitians all have important roles to play in the advanced stages of Parkinson's.

A GP or Parkinson's nurse will usually be involved in arranging palliative care.

Involving my family

Including your family in the early stages of your decision making will help you all feel more comfortable about the future. It also relieves them of the burden of second-guessing your wishes should you become unable to make decisions for yourself.

If your family have provided you with care and support, they should be considered as a key part of the multidisciplinary team involved in your palliative care.

When should I start thinking about palliative care?

It may be difficult to start thinking about palliative care, especially

if you are young or only recently diagnosed. But it is important that you consider your options as early as you can. This will help make sure your needs are met in the future and give you and your family peace of mind now. You can always review your options, as and when your condition changes.



PREPARING FOR END OF LIFE

Talking to people close to you

It's not easy to know when to talk to people close to you about the end of life, and these conversations may take place over a period of time. If you have family in another country, or want to be buried abroad, you will need to plan ahead. Although discussing your care and affairs can be difficult, it is important and will help everybody cope better with the future.

If you're a parent of dependent children, making plans for them and knowing they will be cared for will give you some peace of mind. You may need to get agreement from your chosen guardian(s) and write your wishes into your Will (see page 12).

Talking to children

Talking to children – young and adult – about dying is a sensitive issue. Many people worry that young children will become too upset if they know someone they love is dying. However, if they are

not involved they may just worry alone or feel that somehow they are to blame for what is happening. Children may also feel annoyed or even angry that they have not been told what is going on.

Children also need time to prepare themselves and may have things they want to do or say, or worries they need to express.

Find out more: see our information sheet *Talking to children about Parkinson's* and our online information *Parkinson's in your life: a guide for teenagers*.

Making your wishes known

This booklet looks at various documents that will help people involved in your care know about your wishes. It's a good idea to decide in advance what you would like to happen towards the end of your life, or when you become unable to make decisions for yourself. This is particularly important if communication becomes a problem in the future.

Of course, your views may change over time so it is useful to have regular discussions and update the relevant documents if necessary.

Personal issues to think about:

- where you would like to be cared for at the later stages of life (at home, in a hospital, nursing home, or hospice)
- whether you would want to know about the effects of any treatment you may be offered
- who should talk to children or close family about your impending death if you are unable to
- what you want your final days to be like
- whether you want family members living abroad to be present in your final days
- whether you have any specific cultural or religious wishes
- whether you want your brain or organs donated
- who should look after your pets
- whether you want to become a brain donor (see page 30)

“ I think that if you don't make the right preparations, it can cause severe problems for the loved ones left behind. ”

David, who is an avid reader

Looking after your affairs

On the more practical side of things, keeping important documents in a safe place and letting your loved ones know where to find them can make things easier.

Make sure your family know where to find:

- details of your bank, building society, credit cards, pension, tax, savings and investments, and any other financial contacts, including telephone numbers and addresses your passport, house deeds, life insurance and other policies, mortgage and hire purchase agreements
- birth and marriage certificates
- car and house keys

- usernames and passwords for any online accounts
- how to access important financial and other records on your computer
- divorce papers
- make a list of regular payments that will need to be cancelled, for example subscriptions you may have to societies or clubs, magazines, mobile phones or donations to charities

At the back of this booklet (page 37) there is a comprehensive checklist you can use.

Making a Will

Anyone over the age of 18 (or age 12 in Scotland) can make a Will. This means you can decide what happens to your property and possessions after your death. If you don't make one, it may cause problems for relatives in the future.

Making a Will is important because otherwise your assets – savings, investments or property – will be divided according to legal rules rather than your wishes. This is particularly important in the case of step-children, who would be left out if there was no Will.

Although you can write a Will yourself, it's best to speak to a



solicitor. This will also help to reduce the possibility of any misunderstandings at a later date.

Things to remember:

- ask how much the service will cost and how much time it will take
- it's a solicitor's responsibility to keep you informed of costs and to give you a clear bill that shows the work done and the amount charged

If needed, ask whether your solicitor will make home or hospital visits. If you are seriously or terminally ill, the solicitor may ask that your doctor be present at the same time to give an opinion on your capacity to make a Will. Or the solicitor may ask for a report of your physical and mental health, to prove that you are able to make decisions about your assets. Alternatively, your solicitor may recommend your doctor acts as a witness to the Will.

If these steps are not taken, your wishes may be contested at a later time.

In your Will you can choose your executors. These are the people who will sort out your finances after your death. You can decide who will receive your money or

a particular item, such a piece of jewellery. It is also helpful to include your funeral instructions.

It is also a good idea to consider signing a Power of Attorney (see page 14) at the same time as making a Will. This is in case you are unable to make decisions at any time in the future. Your solicitor will be able to advise you on both.

For information on legal and financial matters contact:

[Citizens Advice](#)

This charity offers free, independent and confidential advice online, by phone or face to face.

www.citizensadvice.org.uk
08444 11 14 44 (England)
08444 77 20 20 (Wales)

To find a solicitor near you:

[The Law Society](#)

This organisation represents solicitors in England and Wales.

020 7320 5650
www.lawsociety.org.uk

[STEP \(the Society of Trust and Estate Practitioners\)](#)

This is the umbrella body for those dealing with Trusts and Estates. Visit the website to search for a solicitor in your area.

020 7340 0500
www.step.org

England and Wales
Solicitors Regulation Authority
0870 606 2555
www.sra.org.uk

Guernsey
The Guernsey Bar
01481 812812
www.guernseybar.com

Isle of Man
Isle of Man Law Society
01624 662910
www.iomlawsociety.co.im

Jersey
The Law Society of Jersey
01534 613920
www.jerseylawsociety.je

Northern Ireland
Law Society – Northern Ireland
028 9023 1614
www.lawsoc-ni.org

Scotland
Law Society of Scotland
0131 226 7411
www.lawscot.org.uk

Will Aid

Every November some solicitors take part in Will Aid, this means that they will write your will without

charging the normal fee. Instead you are invited to make a voluntary donation which goes to nine charities. For further details go to **www.willaid.org.uk**. You can find your local participating solicitor by calling **0300 0309 558**.

Power of Attorney

A Power of Attorney is a written legal document giving someone else authority to take actions and decisions on your behalf. The person you appoint is known as an Attorney.

How to choose an Attorney

You can appoint more than one person to act for you. Before you choose someone, think about how well you know them, and whether you can trust them to look after your money and make decisions in your best interests. You cannot choose someone who is bankrupt to be your Attorney.

If you choose more than one person, decide whether they should act only jointly (both must agree before acting) or jointly and separately (just one of them can make a decision if necessary).

It may be a good idea to talk to a solicitor about preparing a Power of Attorney and the costs involved.

England and Wales

There are two types of Lasting Power of Attorney (LPA) that can be used in England and Wales. Both types of LPA must be registered with the Office of the Public Guardian before they can be used. You can choose to make one type or both. It is always best to complete Lasting Power of Attorney forms before they are needed.

Finance and Property Lasting Power of Attorney

This type of Power of Attorney allows your Attorney to deal with financial matters such as paying bills, how to spend your money, collecting pensions and dealing with bank or building society accounts. It can also include selling your home if necessary. Your Attorney can sign cheques on your behalf and any other paperwork if you are physically unable to do so, but still able to make your own decisions.

Health and Welfare (previously called Personal Welfare) Lasting Power of Attorney

This type of Power of Attorney allows your Attorney to make health and social care decisions on your behalf when you can't do so because of mental incapacity. This can include when to accept or refuse medical care, life-sustaining treatment, your care arrangements, where you should live and who has



access to confidential information, such as your health records.

The Enduring Power of Attorney was replaced by the Finance and Property Lasting Power of Attorney on 1 October 2007.

If you made an Enduring Power of Attorney that was signed and witnessed before October 2007 you can either continue to use it or cancel it and set up a Finance and Property Lasting Power of Attorney. You can also make a Health and Welfare Lasting Power of Attorney.

It may be a good idea to get advice from a solicitor about preparing these documents. You can also get advice and forms you will need from

the Office of the Public Guardian, part of the Ministry of Justice, and the government website. Call **0300 456 0300**, visit **www.justice.gov.uk**, or visit the Gov.uk website at **www.gov.uk**

Northern Ireland

In Northern Ireland you are able to make an Enduring Power of Attorney dealing with financial matters. There is currently no way of appointing a Health and Welfare Attorney.

If a person has not already appointed an Enduring Power of Attorney, and becomes mentally incapacitated, the High Court may appoint a 'controller' to deal with the day-to-day management of that person's affairs.

All matters regarding Enduring Power of Attorney and Controllership are handled by the High Court (Office of Care and Protection) based in Belfast. Call **028 9072 4733** or visit **www.courtsni.gov.uk** for details.

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. You can also make a Power of

Attorney that deals with both financial and welfare/care matters. These types of Power of Attorney must be registered with the Office of the Public Guardian (Scotland).

A Continuing Power of Attorney, which deals with money or financial matters, can be used as soon as it has been registered or you can state that it is only to be used at a later date, such as when a doctor says you are no longer able to make any decisions. A Welfare Power of Attorney can only be used once you are no longer able to make any decisions about your care.

For more information visit **www.scotland.gov.uk/Topics/Justice/law/awi**, or the Office of the Public Guardian (Scotland) website at **www.publicguardian-scotland.gov.uk**. You can also call **01324 678 300**.

Losing the capacity to make decisions

The Mental Capacity Act 2005 (England and Wales)

Mental capacity means being able to make your own decisions. This Act concerns people in England and Wales who have lost that ability some or all of the time. The aim of the Act is to ensure that every effort is made to include the

individual in decision making, and take into account their wishes, feelings, values and beliefs, including religious and cultural traditions.

If the individual has lost capacity, and if they have not made a Health and Welfare Lasting Power of Attorney, then the healthcare professionals will be able to make decisions on behalf of the incapacitated person acting in that person's 'best interests'.

The Act includes a code of practice for Attorneys, healthcare workers and other people who support those who have lost the capacity to make their own decisions.

The Office of the Public Guardian and Gov.uk can provide information and advice about The Mental Capacity Act. Call **0300 4560 300** or visit **www.justice.gov.uk** or **www.gov.uk**

[Mental Health \(Northern Ireland\) Order 1986](#)

The High Court is responsible for the management of the property and affairs of people in Northern Ireland, who are incapable of managing their own financial affairs, under the provisions of Part VIII of the Mental Health (Northern Ireland) Order 1986.

Further information can be found through the Office of Care and



Protection in Belfast.
Call **028 9072 4733** or visit
www.nidirect.gov.uk/the-mental-health-act

Adults with Incapacity (Scotland) Act 2000

If an individual who has not made a Power of Attorney becomes incapable of making decisions, an application may be made (usually by a friend or family member or solicitor) to the local Sheriff Court for a Guardianship Order or intervention order.

The Court will grant powers that might otherwise be granted under a Welfare or Continuing Power of Attorney. You may need a solicitor to help you with the court order and to inform you about the costs involved.

People appointed under such orders have a duty to act for the benefit of the person the order relates to, and to provide a management plan and an annual account of their actions to the Public Guardian.

The Office of the Public Guardian (Scotland) also provides a useful Code of Conduct for people appointed by the court.

Further information and sample forms may be obtained from the Office of the Public Guardian

(Scotland). Call **01324 678300** or visit **www.publicguardian-scotland.gov.uk**. You can also find out more at the website of the Mental Welfare Commission for Scotland: **www.mwscot.org.uk**

Making an Advance Decision

Medical treatments require consent (this means a person needs to agree with them). But in case you're unable to make decisions about your healthcare in the future, it is possible to make an Advance Decision (also known as an Advance Decision to Refuse Treatment, formerly Living Will, and an Advance Directive in Scotland).

There is currently no legislation in Northern Ireland covering the use of Advance Decisions.

An Advance Decision can be made if you're aged 18 or over, to specify which medical treatments you would accept or refuse under certain circumstances, even if this will cause an earlier death. These can be specific or general and could include the following:

- the use of antibiotics in the case of severe bacterial infection
- whether you want to be put on a drip if swallowing becomes too difficult

- whether you want to be fed artificially
- what happens if your heart or breathing stops
- whether your care should concentrate on providing comfort and peace
- whether you would like to be told by doctors how serious your condition is, or if you would rather not know
- you understand that you cannot insist on receiving any particular treatment that your doctors consider inappropriate
- you are not pressurised or influenced by anyone else
- the Advance Decision is the most recent expression of your wishes
- you become incapable of making any decisions because you are either unconscious or mentally incapable of making your own decisions.

It is important to make an Advance Decision when you are mentally competent. It will be legally binding in England and Wales if:

- you are an adult over the age of 18
- you are mentally able and not experiencing mental distress when you make the Advance Decision
- you understand what may happen by refusing or opting for a particular treatment
- you specify the treatment to be refused and specify the circumstances in which this refusal would apply. If this is not clear, your doctors may not act

You may already have raised these issues with your doctors or Parkinson's nurse and had the opportunity to discuss it with them.

In some cases the medical team may even outline your wishes in a letter, so everyone has a copy of your decisions. This is helpful if you have problems with writing or speaking, if English is not your first language, or if you have learning difficulties or disabilities such as sight difficulties.

If your Advance Decision includes refusing life-sustaining treatment, there are some special requirements. It must be in writing and signed and dated by you and a witness. It must also contain a clear written statement saying the Advance

Decision is to apply to the specific treatment, even if your life is at risk.

Advance Decisions should never be confused with voluntary euthanasia or assisted suicide.

Not every situation can be planned for in an Advance Decision and it will need to be checked by the healthcare provider when treatment is needed, to make sure it applies to the particular situation.

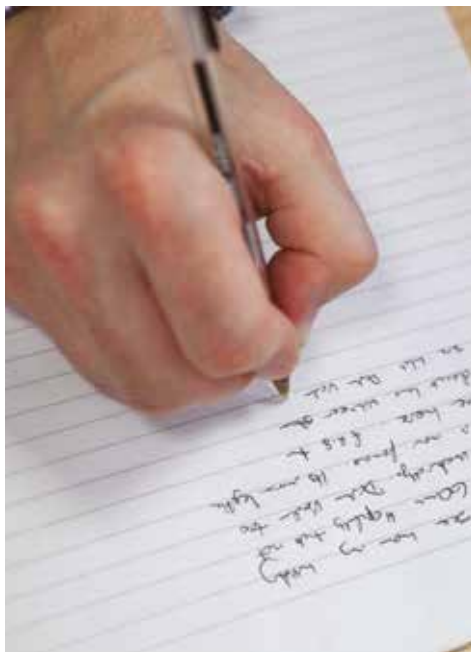
You should keep your Advance Decision under review and amend it if circumstances change, or if new treatments become available.

It is a good idea to check your Advance Decision and re-sign it and date it every few years, to confirm that it still reflects your wishes.

It's important to keep an up-to-date copy of your Advance Decision with your GP, or healthcare professional, your family and your solicitor. You may also want to carry a note of your wishes with you.

If you have made a Health and Welfare Lasting Power of Attorney you should take care that this and the Advance Decision don't conflict with each other.

There are other ways you can document your wishes for your



future care. An Advance Statement (also called a Statement of Wishes) is a general statement of what you want and what is important to you. It is written down but is not legally binding like the Advanced Decision.

Scotland

In Scotland you can express your wishes about how you would like to be treated in a social, medical and care situation when you are no longer able to make a decision.

You can include your wishes in a Welfare Power of Attorney or an Advance Medical Directive. It is important to know that in Scotland your wishes are not legally binding.

It is possible that doctors could override your wishes if they felt that was for your benefit.

But, according to the law your past and present wishes should be taken into account, so it is important that you discuss your advance care treatment with your family, GP and people responsible for your care. Your solicitor will advise you on the best way to record your wishes.

For more information on Advance Decisions visit the NHS Choices website at **www.nhs.uk**

You can also contact Age UK on **0800 169 6565** or visit **www.ageuk.org.uk**

Compassion in Dying provides free forms that meet all of the criteria to be legally binding. Contact them on **0800 999 2434** or visit **www.compassionindying.org.uk**

Brain donation for Parkinson's research

The Parkinson's UK Brain Bank provides human brain tissue to researchers around the world who are working towards a cure for Parkinson's.

Research using donated tissue has already led to important medical breakthroughs in treating Parkinson's.

“ I was never prouder than at my husband Geoff's funeral last year when our rector told the congregation about Geoff's decision to donate to the Brain Bank. ”

Pam, a registered donor

Anyone can become a potential donor – including people without Parkinson's. This enables researchers to compare what happens in a brain affected by Parkinson's, with one that is not.

If this is a decision you are considering, it is important to discuss it with those closest to you to make sure they are aware of your plans.

For more information visit **parkinsons.org.uk/brainbank** – see page 30 for contact details.

WHERE TO GET EMOTIONAL SUPPORT

Whether you're someone with Parkinson's, a family member or friend of someone with the condition, you may need support to help you deal with and think through end-of-life issues.

Counselling

Counsellors are trained to help support people through difficult situations. They can help you understand your own feelings and talk about them. Talking to someone other than your family and friends can give you the opportunity to have frank and confidential conversations, and this may help you cope better.

Where is counselling available?

Your GP can refer you to a counsellor but availability can depend on local authority funding, and waiting lists can be long.

Counselling is also offered through hospices, and you don't have to be a patient at one. Some local and national charities also offer low cost or free counselling.

Other sources of counselling include private therapists, but this will involve a fee. Telephone counselling is also an option. This might be a good choice for anyone who is not mobile.

More information on all types of counselling and therapists is available from the British Association for Counselling and Psychotherapy on **01455 883 316** or visit **www.bacp.co.uk**

Your Parkinson's nurse or Parkinson's local adviser will know what is available in your local area.

For details of the Parkinson's local adviser in your area, please call the Parkinson's UK helpline on **0808 800 0303** or visit **parkinsons.org.uk/support**

Information and support centres

Information and support centres, such as the Citizens Advice Bureau, community centres and carers centres, are useful if you want to ask questions and talk to specialist staff

and trained volunteers. The centres have booklets and leaflets and some organise complementary therapies.

Your GP or Parkinson's local adviser will be able to help direct you.

Parkinson's UK local groups

Parkinson's UK has local groups throughout the UK. These are run by volunteers who usually have experience of Parkinson's and are supported by Parkinson's UK staff.

The groups welcome family members and carers, and some involve health or social care professionals. Some areas have groups for people with Parkinson's who are of working age.

Local groups offer a chance to talk to others in similar situations. Many of them also offer a range of social events and activities, such as exercise classes or complementary therapies.

Hospitals and clinics may also run their own Parkinson's support groups, often set up by health or social care professionals. Ask your local hospital or clinic for more information.

To find out if there is a Parkinson's UK local group in your area, visit the Parkinson's UK website **[parkinsons.org.uk/supportforyou](https://www.parkinsons.org.uk/supportforyou)**, or call the helpline on **0808 800 0303**.



Religious and spiritual support

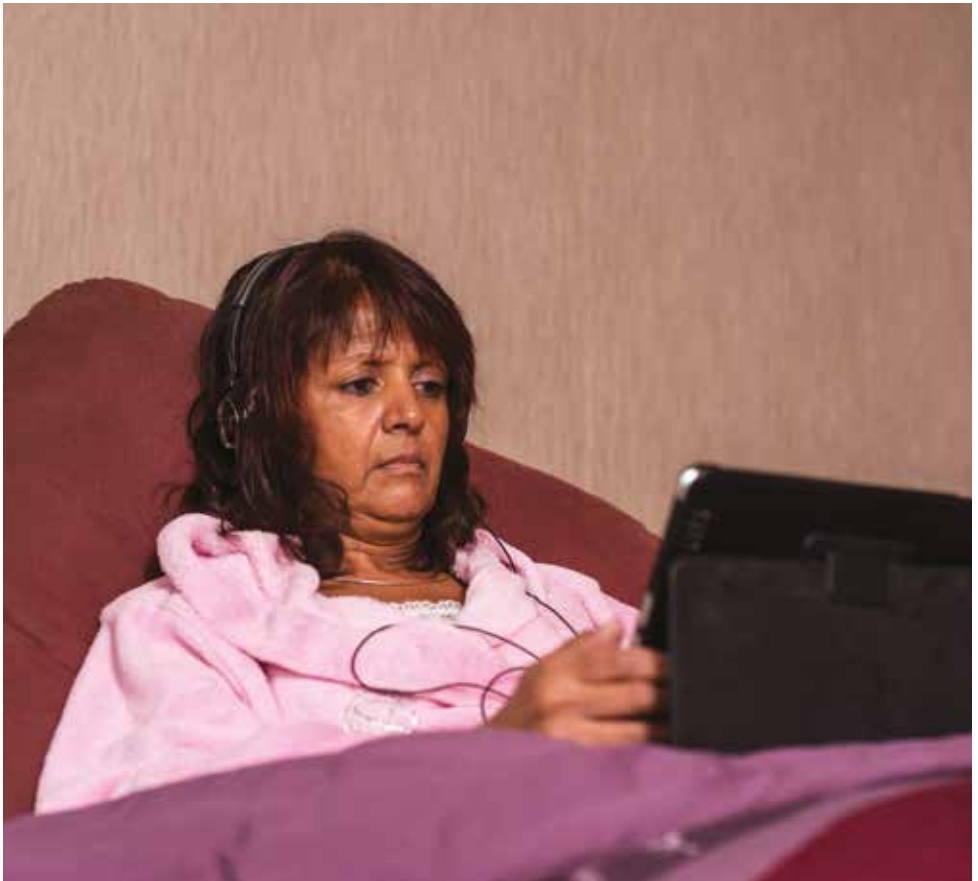
Some people find their religious faith or spiritual beliefs give them strength. You might like to talk to your faith leader about your worries and fears. They will be used to talking to people who have been through similar experiences to you.

Your faith community may also be a good source of practical and emotional support.

A hospital chaplain will be willing to help people of any religion and those who don't have a faith. You can ask to talk to the chaplain at any time.

Online support

Our forum is another way to share your experiences of Parkinson's and chat to others affected by the condition online. You can join the Parkinson's UK online forum at parkinsons.org.uk/forum



WHAT TO DO WHEN SOMEONE DIES: INFORMATION FOR FAMILY AND FRIENDS

If someone dies in a hospital, hospice or care home, the staff will contact the person named as next of kin and will guide them through the next steps.

If the death is expected and at home, you will need to contact the deceased's GP, or nearest doctor as soon as possible. You cannot register a death without a death certificate signed by a GP.

The person may have registered to be a brain donor. If so, you should contact the Parkinson's UK Brain Bank on the 24-hour emergency contact number as soon as possible after death. For more information, see page 30.

They may also be registered to donate other organs to the NHS. If this is the case then the NHS will have record of their donation registration and will proceed to carry out this request.

“ I would have appreciated this information when my Dad, who had Parkinson's, died 11 years ago. ”

Josie, who likes to cycle

How to register a death

England and Wales

A death in England and Wales must be registered with the Registrar of Births and Deaths. You can go to any register office in the country, but if you use the one in the area where the person died then you will be given the documents that you need on that day. The registration must take place within five days. A death that takes place in England can only be registered in English but deaths in Wales may be registered bilingually in English and Welsh.

You will find contact details in the phone book under 'Registration of Births, Deaths and Marriages', or visit **www.gov.uk** and use the search tool.

For more information visit **www.gov.uk/en/governmentcitizensandrights**

Tell Us Once is a service that informs other government departments about a death on your behalf. Speak to the Registrar when you register the death and see if this service is available in your area. Visit **www.gov.uk/tell-us-once**

Northern Ireland

You must register a death within five days with any District Registration Office in Northern Ireland. The address for registration will be in the telephone directory under 'Registration of births, deaths and marriages'.

For more information visit **www.nidirect.gov.uk/registering-a-death**

Scotland

Any death that happens in Scotland must be registered within eight days by the Registrar of Births, Deaths and Marriages. The law allows a death to be registered in any registration district in Scotland. The registrar will

need a death certificate, which will be given to you by the doctor. You will need two doctor's certificates for a cremation, or one for a burial.

You will also need an extract of the death certificate to show banks, and so on. This is supplied by the registrar for a small charge.

You can find the address of the local registrar via the undertaker, hospital, doctor, telephone book or online. For more information visit **www.gro-scotland.gov.uk**

You may also be able to sign up to the Tell Us Once service. Speak to the Registrar when you register the death and see if this service is available in your area.

Who do I need to inform?

There are several people and organisations to inform when someone dies, including:

- social security – if the person who has died received a state pension and benefits, contact the DWP Bereavement Service. They will tell each service and cancel all claims, tell you if you can claim any money towards funeral and bereavement benefits and help you apply over the phone. They will also tell you if you can use your late spouse

or civil partner's National Insurance contributions to increase your own state pension.

- banks and building societies
- creditors (a person or company that money is owed to)
- GP
- solicitor
- employer
- house, car and contents insurers

You may also need to ensure that official documents are returned such as:

- passport
- driving licence
- season tickets or club membership cards
- National Insurance papers
- library books

How do I arrange a funeral?

You may have already discussed the type of funeral arrangements wanted. There may also be instructions in the person's Will, so it is important to check this.

Your funeral director will support and guide you through this process. The person who has died may have taken out a pre-paid funeral plan. If so, check what services it covers. If there is no plan, check with the undertaker about arrangements for payment of the funeral account.

You may also be entitled to help with costs from the Department for Work and Pensions, depending on the financial status of the person arranging the funeral (not of the person who's died). Contact your local Social Security Office for questions about financial help. Your undertaker may also be able to help with social security forms.

For more information visit:

England and Wales
www.gov.uk

Northern Ireland
www.nidirect.gov.uk

Scotland
www.scotland.gov.uk

How do I cope with bereavement?

Bereavement is about coming to terms with loss. When a loved one dies you may feel a range of different emotions, including sadness, anger, anxiety or grief or,

especially in the early stages of loss, nothing at all.

You may want to talk to a trusted friend or family member, or have contact with a spiritual or faith leader. Alternatively, you may like to consider contacting your Parkinson's nurse or GP, who will be able to put you in touch with a local organisation that can offer you support.

If you have been caring for a loved one, it may be difficult to come to terms with the loss of your caring role. When you're ready, it may help you to think about what to do next.

Volunteering, learning something new, or returning to work are some of the ways in which you can focus your mind on something new, use existing skills or socialise.

“ All I can say to others is try to carry on and don't isolate yourself. A huge part of your life is lost, but don't forget that there is still life to live. ”

Alan, who enjoys a wide social life with friends

Carers UK has a lot of information available about what you can do when caring ends.

For contact details and for more sources of bereavement support, please see page 34.



MORE INFORMATION AND SUPPORT

Parkinson's nurses

Parkinson's nurses provide expert advice and support to people with Parkinson's and those who care for them. They can also make contact with other health and social care professionals to make sure your needs are met.

The role of the Parkinson's nurse varies. Each will offer different services, aiming to meet local needs. Some nurses are based in the community, whereas others are based in hospital settings.

Many Parkinson's nurses are independent prescribers. This means they can prescribe and make adjustments to medication, so someone with Parkinson's doesn't always need to see their specialist for changes to or queries about their Parkinson's drugs.

Parkinson's nurses may not be available in every area, but your GP or specialist can give you more details on local services.

You can find out more at parkinsons.org.uk/nurses

Support and information from Parkinson's UK

We have a range of free information resources that are available to read online at parkinsons.org.uk/information-support or order (see the back cover for details).

Parkinson's local advisers

Our Parkinson's local advisers can provide confidential, one-to-one information about Parkinson's and local services.

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

Our helpline

Contact our free confidential helpline for general support and information. Call **0808 800 0303** or email **hello@parkinsons.org.uk**

A Path through Parkinson's

A Path through Parkinson's is a self-management programme designed to help you think about and plan how you want to navigate your life with Parkinson's. The programme brings a small group of people with Parkinson's, partners and carers together locally for six sessions of discussion, activity and self-reflection. The aim is to share experiences, discuss the practical and emotional impact of Parkinson's and talk through some of the bigger questions about life with the condition. Each group is led by trained facilitators with first-hand experience of Parkinson's. Visit **parkinsons.org.uk/selfmanagement** for more information.

Local groups

Support is available through Parkinson's UK local groups. They offer support and friendship, and the chance to meet other people affected by Parkinson's. The groups come in all shapes and sizes, and there are some specifically for younger people with Parkinson's. As well as friendship and support,

many groups offer a range of activities, such as exercise classes and dancing, day trips and talks about various topics to do with Parkinson's. Visit **parkinsons.org.uk/localgroups** or call our helpline for details of your nearest meeting.

Online forum

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

Parkinson's UK Brain Bank

Contact the Brain Bank as soon as possible in the event of the death of a registered donor.

Emergency contact number:
07659 104 537.

Anyone can become a potential donor – including people without Parkinson's. To receive an information pack, please contact the Brain Bank.

020 7594 9732
brainbank@imperial.ac.uk
parkinsons.org.uk/brainbank

Useful contacts

Advance Decision to Refuse Treatment (ADRT)

An NHS training website with a section for patients that explores options in advance care planning.
www.adrt.nhs.uk

Age UK

Age UK's information sheets Planning for a funeral and When someone Dies, Bereavement, and Dealing with an Estate are aimed at next-of-kin and executors and are available free, or can be downloaded from the website.

0800 169 6565

www.ageuk.org.uk

0808 808 7575

www.ageuk.org.uk/northern-ireland

0845 125 9732

www.ageuk.org.uk/scotland

0800 169 6565

www.ageuk.org.uk/cymru

British Association for Counselling and Psychotherapy (BACP)

For lists of qualified psychotherapists and counsellors.

01455 883 316

www.bacp.co.uk

Cinnamon Trust

A network of volunteers who provide dog-walking and fostering for pets while owners are in hospital.

01736 757 900

www.cinnamon.org.uk

Citizens Advice

A national network offering free and confidential advice. To find your nearest centre call:

020 7833 2181

www.citizensadvice.org.uk

Wales

0844 477 2020

Scotland

www.cas.org.uk

Compassion in Dying

A UK charity working to inform and empower people to exercise their rights and choices around end of life care. They provide telephone and advocacy support on Advanced Decisions and Lasting Power of Attorney.

0800 999 2434

info@compassionindying.org.uk

www.compassionindying.org.uk

Dying Matters

A website led by the National Council for Palliative Care. Includes practical and emotional advice, templates for Advanced Decisions, plus a community forum.

www.dyingmatters.org

Government online

These websites provide a wide range of public service information and services online. The caring sections on the sites include information about employment, health, money matters, and carers' rights.

England

www.gov.uk

Northern Ireland

www.nidirect.gov.uk

Scotland

www.scotland.gov.uk

Wales

www.assemblywales.org
or www.cynulliadcymru.org

Hospice at Home

Hospice at Home aims to enable people with advanced illness to be cared for at home, and to die at home if that is their wish.

www.hospiceathome.org.uk

Hospice Information and Help the Hospices

An enquiry service for hospice and palliative care.

020 7520 8200

www.helpthehospices.org.uk

Making Decisions

A guide to The Mental Capacity Act 2005, including what happens when you are unable to make decisions, Lasting and Enduring Powers of Attorney, and advance decisions.

023 8087 8038

www.gov.uk/make-decisions-for-someone

National Council for Palliative Care

An umbrella charity for all those involved with end-of-life care, including patients, carers and professionals. Includes a booklet to download on planning future care.

020 7697 1520

www.ncpc.org.uk

Natural Death Centre

Support for those dying at home, and help with family-organised and environmentally-friendly funerals. It also publishes The Natural Death Handbook.

01962 712 690

www.naturaldeath.org.uk

NHS24

For advice and information on any health concern for people in Scotland.

111 (24 hours)

www.nhs24.com

NHS 111

NHS111 is a 24-hour telephone information line that has replaced NHS Direct in England and Wales, and can be used by dialling **111**.

Office of the Public Guardian

For information on Powers of Attorney.

www.gov.uk/government/organisations/office-of-the-public-guardian

England and Wales

0300 456 0300

www.justice.gov.uk

Scotland

01324 678 300

www.publicguardian-scotland.gov.uk

Northern Ireland

(Office of Care and Protection)

028 9072 4733

www.courtsni.gov.uk

PACE

PACE promotes the mental health and emotional wellbeing of the lesbian, gay, bisexual and transgender community. It provides a telephone and email support service throughout the UK.

020 7700 1323

www.pacehealth.org.uk

Patient Advice and Liaison Service (PALS)

Available in most hospitals in England. It provides help and advice to patients, their relatives, carers and friends. Particularly deals with problems associated with patient care in the hospital.

www.pals.nhs.uk

Relate

Relate provides relationship therapy to individuals, married or cohabiting couples.

0300 100 1234

www.relate.org.uk

Samaritans

For anyone with feelings of distress or despair, or who feels suicidal. Provides a 24-hour telephone service, seven days a week.

0845 790 9090

www.samaritans.org.uk

The Silverline

A free confidential helpline providing information, friendship and advice to older people.

0800 470 8090

www.thesilverline.org.uk

Solicitors for the Elderly

This is a national organisation of lawyers who are committed to providing and promoting independent legal advice for older and vulnerable people, their family and carers.

0844 567 6173

admin@solicitorsfortheelderly.com

www.solicitorsfortheelderly.com

UK Transplant

How to register to become an organ donor.

0300 123 2323

www.organdonation.nhs.uk

Help with bereavement

Age UK

Provides a free, step-by-step booklet called *When Someone Dies*.

0800 169 6565

www.ageuk.org.uk

Befriending Network

Offers supportive, reliable relationships through volunteer befrienders to anyone who is socially isolated.

0131 225 6156

info@befriending.co.uk

www.befriending.co.uk

The Bereavement Register

To stop unwanted mail for the deceased.

01732 467 940

0800 082 1230 (24-hour automated service)

help@thebereavementregister.org.uk

www.the-bereavement-register.org.uk

www.the-bereavement-register.org.uk

Carers UK

Carers UK website has information on coping when caring ends.

www.carersuk.org

020 7378 4999

Carers NI

02890 439 843

Carers Scotland

0141 445 3070

Carers Wales

02920 811 370

Care for the Family

Helps those facing family difficulties, including bereavement.

029 2081 0800

www.careforthefamily.org.uk

Child Bereavement Network

Support for bereaved children and young people, their parents and carers.

020 7843 6309

www.childhoodbereavementnetwork.org.uk

Cruse Bereavement Network

Offers help to people bereaved by death, whatever their age, nationality or belief. Also offers free counselling services.

0844 477 9400

www.cruse.org.uk

England

0844 477 9400

helpline@cruse.org.uk

www.crusebereavementcare.org.uk

Northern Ireland

02890 792 419

northern.ireland@cruse.org.uk

Scotland

0845 600 2227

info@crusescotland.org.uk

www.crusescotland.org.uk

Wales

02920 886 913

wales.cymru@cruse.org.uk

RD4U – Cruse Youth Bereavement Service

Designed for young people by young people, to offer support after the death of a loved one.

0808 808 1677

info@rd4u.org.uk

www.rd4u.org.uk

London Friend LGBT Bereavement Helpline

Offers support across the UK to the lesbian, gay, bisexual and transgendered community.

020 7837 3337

www.londonfriend.org.uk/get-support/helpline

National Association of Funeral Directors

Can provide advice on organising funerals and monitors the standards of funeral directors.

0845 230 1343

www.nafd.org.uk

National Association of Widows

Offers a friendly helping hand to widows.

02476634848

www.widows.uk.net

Natural Death Centre

Provides information on 'alternative' funerals, including family-organised, environmentally friendly funerals.

01962 712 690

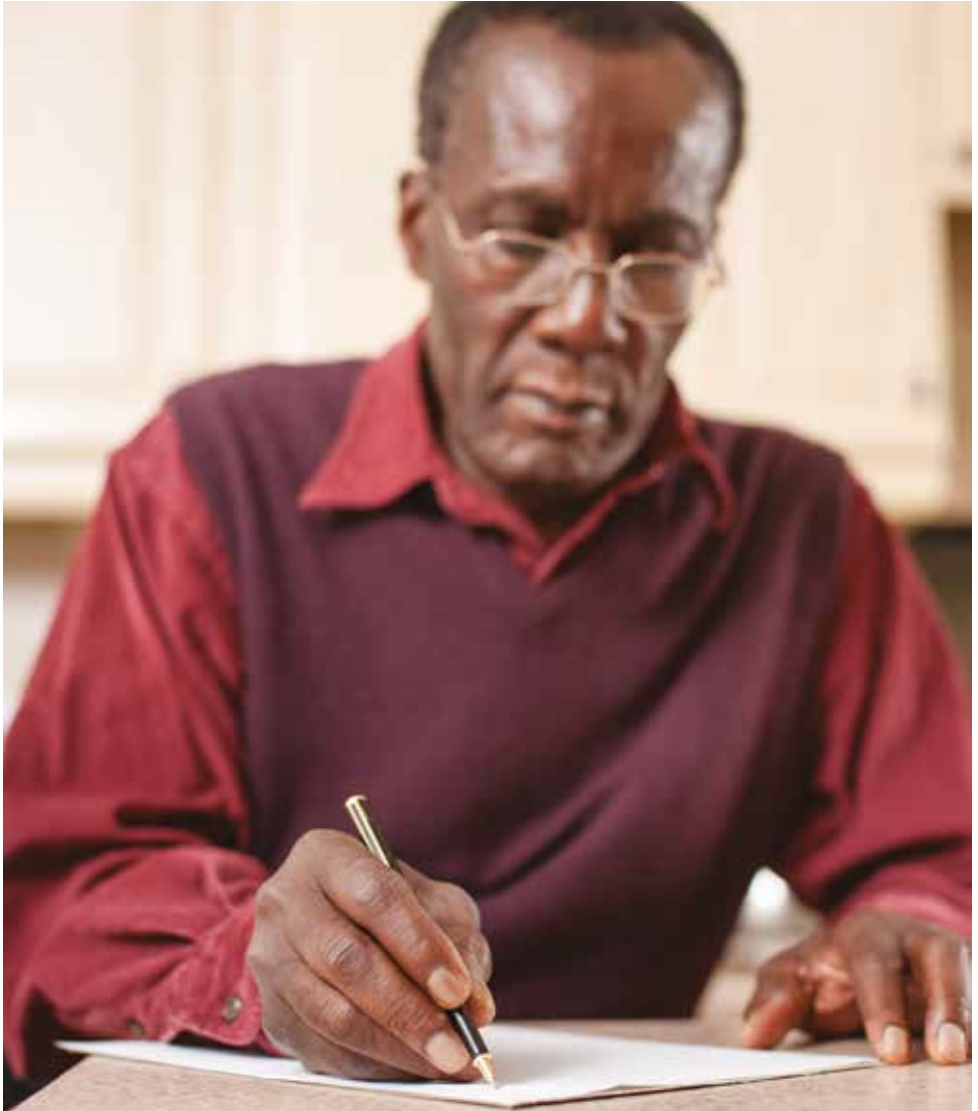
www.naturaldeath.org.uk

Winston's Wish

A child bereavement charity that helps young people readjust to life after the death of a parent or sibling.

0845 203 0405

www.winstonswish.org.uk



CHECKLIST FOR IMPORTANT DOCUMENTS AND INFORMATION

Fill in this checklist as soon as you can. Make sure you keep it in a secure place, for example, with your solicitor, and remember to keep it up to date.

Assets

Current account details (bank name, address, account number)
.....
.....

Savings and investments (account numbers and share certificates)
.....
.....

Online bank and savings accounts, including usernames and passwords
.....
.....

Car(s)
.....
.....

Contents of house, eg, furniture and personal effects
.....
.....

House (or other owned property)
.....
.....

National savings and premium bonds
.....
.....

Pensions: state and private

.....
.....
.....

Insurances

.....
.....
.....

Business

.....
.....
.....

Debts/liabilities

Credit card providers' details and account numbers

.....
.....
.....

Direct debits, standing orders and other monthly payments

.....
.....
.....

Hire purchase/loan agreement details

.....
.....
.....

Mobile phone provider and account details

.....
.....
.....

Mortgage provider's details and account number

.....
.....
.....

Rental agreements and statements

.....
.....
.....

Utility providers (gas, electricity, water) and council tax

.....
.....
.....

Other information

Tax office details and National Insurance number

.....
.....
.....

NHS or Health Service number

.....
.....
.....

Safety deposit box

.....
.....

Social media (Facebook, eBay, Twitter, weblogs) accounts and passwords

.....
.....
.....

Employer and trade union details

.....
.....
.....

Where to find important documents

- House deeds
.....
- Birth and marriage certificates
.....
- Divorce decree
.....
- Will and Power of Attorney
.....
- Advance decision
.....
- Passport and driving licence
.....
- Vehicle registration document
.....
- Insurance policies
.....
- Bank statements
.....
- Share certificates
.....
- Address book listing friends and family
.....
- Travel cards and membership cards (eg, for library, sports club)
.....
- Parkinson's UK brain donor card / other donor cards
.....
- Keys for property and car(s)
.....
- General paperwork
.....

Preparing for end of life (B092/2016)

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

1. Please choose the option that best fits you.

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

2. Where did you get this information from?

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

3. Has it answered all your questions?

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

4. How easy was it to understand?

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

Continued over the page



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

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

6. What is your ethnic background?*

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

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

Want to hear more from us?

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

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

Name

Address

Email

Telephone

How would you prefer us to contact you?

- Email Post Phone

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



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

Alexandra Heaton, Parkinson's local adviser, Parkinson's UK

Peter Jeffreys, STEP, CLA, Wilsons Law

Alice Rose, Parkinson's nurse, County Durham and Darlington Foundation Trust

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

Our information

All of our most up-to-date information is available at **parkinsons.org.uk/information-support**

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

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

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

Can you help?

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

If you would like to get involved, please contact our Supporter Services team on **0800 138 6593** or visit our website at **parkinsons.org.uk/donate**. Thank you.

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

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

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

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

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

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

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

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

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

Order code: B092

Last updated March 2016. We review our information within three years. Please check our website for the most up-to-date versions of all our information.

© Parkinson's 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).

