

# DEEP BRAIN STIMULATION FOR PARKINSON'S

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The main treatment for Parkinson's is medication. But if the best available drug treatments no longer control your symptoms, you may be suitable for deep brain stimulation (DBS).

This booklet gives you an overview of deep brain stimulation and will help you weigh up the advantages and disadvantages of having this procedure. It also provides advice for family, friends and carers.

You can use this information to help you make an informed decision with your specialist about whether deep brain stimulation is right for you.

# Contents

<b>Considering deep brain stimulation</b> .....	5
What is deep brain stimulation? .....	5
How successful is deep brain stimulation? .....	5
Personal experiences of deep brain stimulation .....	6
What are the potential benefits of deep brain stimulation? .....	7
What are the disadvantages of deep brain stimulation? .....	7
Who can have deep brain stimulation? .....	8
Is deep brain stimulation right for me? .....	8
How are people assessed for deep brain stimulation? .....	9
Where is deep brain stimulation carried out? .....	10
How can I find out more about deep brain stimulation? .....	10
<b>Having deep brain stimulation</b> .....	13
What devices are used in deep brain stimulation? .....	14
Recovery .....	14
Programming of the pulse generator .....	14
What are the side effects of programming your pulse generator? ..	15
After surgery .....	16
<b>For family, friends and carers</b> .....	17
A loved one is considering deep brain stimulation, what do I need to know? .....	17
What will happen after the procedure? .....	17
What side effects should I look out for? .....	18
Looking after yourself .....	18

## Key messages

- Deep brain stimulation for Parkinson's may be an option for people whose symptoms are no longer controlled well by the best available medication for their condition.
- It is not a cure and does not stop Parkinson's from progressing. But in many cases it has given people with the condition better control of their motor (movement) symptoms including tremor, speed of movements and involuntary movements (dyskinesia).
- Like all types of surgery, there are risks involved with deep brain stimulation. Make sure you have spoken to your specialist and understand what complications there could be before going ahead. Ask them to write anything down that you are unsure about. You may also find useful questions to ask your health professional in our section on 'How can I find out more about deep brain stimulation?'

# CONSIDERING DEEP BRAIN STIMULATION

## What is deep brain stimulation?

Deep brain stimulation is the main type of surgery used to treat Parkinson's. Usually, it is most effective at improving motor (movement) symptoms.

A pulse generator (a device like a heart pacemaker) is placed under the skin around the chest or stomach area. It is connected to one or two fine wires that are inserted into specific areas of your brain.

When the pulse generator is switched on, the electrodes deliver high frequency stimulation to the targeted area. This stimulation changes some of the electrical signals in the brain that cause the symptoms of Parkinson's.

## How successful is deep brain stimulation?

People with Parkinson's often find that deep brain stimulation works well in controlling many of their symptoms. But remember that deep brain stimulation won't stop

Parkinson's from progressing and it isn't a cure. Although many people benefit from the procedure, it isn't a suitable treatment for everyone with the condition. Find out more in our section on 'How are people assessed for deep brain stimulation'.

It's important to remember that not everyone with Parkinson's will see an improvement in their condition after deep brain stimulation and in some cases symptoms can actually be made worse. You can find out more about this in the section on 'Disadvantages of deep brain stimulation.'

You may find our online forum helpful as many people will have shared their experiences of the procedure and you could ask them questions. This could help you weight up the pros and cons. Find out more at [parkinsons.org.uk/forum](https://parkinsons.org.uk/forum)

## Personal experiences of deep brain stimulation

“ In November 2011 I was assessed as being suitable for DBS, and five months later I was ‘switched on’ at Frenchay Hospital, Bristol. I was 48 at the time. Once everything had settled down, my life improved hugely, and years of uncontrollable shaking finally ceased. ”

**Mark**

“ The vast majority of people with Parkinson’s who have DBS operations have their lives transformed for the better. In Stephen’s case, it has had a major side effect that neither he, nor the hospital staff, could have predicted. He has Blespharospasm (rare contraction of the eyelids). The benefit is that his tremor continues to be significantly less than before he had DBS. However, knowing what he now knows of the possible side effects, Stephen is not sure whether he preferred life with tremor before DBS, or the difficulties of living with sight loss he has now. ”

**Fiona, Stephen’s husband**

“ I just couldn’t tolerate the medication anymore. I’d tried so many different drugs, from levodopa to apomorphine, but the side effects were ruining my life. After DBS my tremor – which at times could be violently strong, to the point where I couldn’t text or write my name – instantly improved. My posture was better too. ”

**Christian**

Read more from Christian at [parkinsons.org.uk/dbs/story](https://parkinsons.org.uk/dbs/story)

## What are the potential benefits of deep brain stimulation?

Deep brain stimulation isn't suitable for everyone, but if it is right for you, you may experience a number of benefits.

- It may help control your movement symptoms for a longer period of time than medication alone. The motor symptoms that responded well to medication before surgery are the most likely to improve with deep brain stimulation.
- In particular, deep brain stimulation can be an effective treatment for severe Parkinson's tremor, even if the tremor does not respond well to medication.
- It may significantly improve motor fluctuations – where your mobility varies throughout the day. This can increase the number of hours you spend in an 'on' state each day, when your symptoms are well controlled.
- It should mean your Parkinson's medication can be significantly reduced. This will reduce the risk of medication side effects, such as involuntary movements (dyskinesia).

- It may give you some relief from non-motor symptoms, such as sleep disturbance and pain.
- It may improve your ability to perform day-to-day activities, such as feeding and dressing yourself, getting up out of a chair and walking. This will improve your independence.
- It may improve your overall quality of life and that of the people around you.

It's important to remember that deep brain stimulation is not a cure. As with all treatments currently available for Parkinson's, deep brain stimulation will simply help to manage your symptoms.

## What are the disadvantages of deep brain stimulation?

Many people who have deep brain stimulation experience an improvement in the way their condition affects them, but there are some disadvantages.

- Deep brain stimulation is unlikely to improve any movement symptoms that levodopa does not improve. (Tremor is an exception – see our section 'What are the benefits of deep brain stimulation?')

- Some people with Parkinson's have balance problems and speech problems that do not respond to medication. These types of issues are referred to as 'treatment resistant symptoms' and deep brain stimulation can actually make them worse. Specialists will check carefully for these problems before considering surgery.
- Some people with Parkinson's have memory problems and other cognitive problems related to the condition. These type of issues might also get worse after deep brain stimulation, so it is important to exclude these problems before considering surgery.
- The risks of the surgery itself include bleeding or stroke during the surgery as well as anaesthetic complications. However, surgical complications are rare.
- You may also experience side effects from the stimulation that targets a specific area of your brain. Find out more in our section on 'Side effects from programming your pulse generator.'
- If you've had deep brain stimulation, it's important to know that some pieces of

exercise equipment, including certain bikes, cross trainers and rowing machines, can interfere with or turn off the device. This is because of some of the strong magnetic fields the machines use.

## Who can have deep brain stimulation?

Current guidelines from The International Parkinson and Movement Disorder Society state that deep brain stimulation should only be offered to people after they have been diagnosed with Parkinson's for more than five years. The most important reason for this is that it takes five years until a clinician can be clearer about whether you have Parkinson's. Before this, you may have another condition that is similar to Parkinson's, but which would respond poorly to deep brain stimulation.

In rare cases deep brain stimulation can be considered for people who have had Parkinson's for less than five years, but only after very careful assessment.

## Is deep brain stimulation right for me?

Once you have considered the benefits and disadvantages of deep brain stimulation you will need to get full information on the procedure from your specialist. Together

you can decide whether deep brain stimulation is the best option for you.

If it is, you will be referred to a consultant neurologist or surgeon at a hospital that performs the surgery. Then, if there is a possibility that you are suitable for deep brain stimulation, you will be fully assessed as either an outpatient or an inpatient.

## How are people assessed for deep brain stimulation?

Everyone being considered for deep brain stimulation needs to go through a careful selection process. This will usually involve assessments of:

- memory and other cognitive functions
- psychiatric problems
- impulsive and compulsive behaviour
- mobility problems and their response to levodopa

The whole assessment process usually takes a few months and it is important to realise that it is not an 'exam'. It is simply an assessment of all your symptoms to determine whether they are likely to be improved with deep brain stimulation. It also makes sure you don't have problems which might be made worse by the procedure.

The assessment will usually be in two parts:

### Part one

The first part of the assessment looks at how well your symptoms respond to Parkinson's medication.

To do this, you will be asked not to take your Parkinson's medication for a period of time before the assessment. This is important as it means specialists can get an accurate picture of your symptoms when you are in an 'off' state and how much your symptoms improve when you are 'on'.

Being 'on' describes when a person's symptoms are controlled and they are feeling at their most capable. Being 'off' is when Parkinson's symptoms come back and are at their worst.

You will first be assessed when you are in your 'off' state. You will then be given Parkinson's medication and will be monitored again after this.

Some parts of the assessment may be filmed, if you are happy for this to happen. A film of your assessment gives specialists a record of your progress before and after surgery.

## Part two

The second part of the process involves an assessment of your attention, memory, mood and behaviour. Problems with attention and memory affect many people with Parkinson's, but they affect different people in different ways.

Studies have shown that deep brain stimulation works best for people who have no, or very mild, memory and thinking problems.

You will be asked to complete cognitive tests to give the surgical team an idea of any thinking difficulties you have and to find out what your cognitive abilities are before surgery. These require concentration and can be tiring, but you will have short breaks throughout.

### Results of the assessment

The process can also involve having an MRI scan of the brain. An MRI scan can help the specialist plan your operation by identifying the area of the brain they will target. A scan can also make sure there is no existing damage, such as lesions, or changes in the brain that could make the operation more difficult or risky.

The specialist will discuss the results of the assessment with you. They will explain whether deep brain stimulation could help you, and if so,

in what way. They will also discuss the surgical procedure and follow-up care with you. If surgery is an option for you, this will help you make an informed decision about whether you want to have it.

It is particularly important to talk through your assessment results as deep brain stimulation doesn't always work for everyone. Knowing how the procedure is likely to affect you will mean you can come to an informed decision with your specialist.

### Where is deep brain stimulation surgery carried out?

Currently, deep brain stimulation is carried out at only 17 centres in the UK. But you have the right to be referred to any of these centres, even if they are not near where you live.

Deep brain stimulation is available in England. You will have to travel to England for surgery if you live in Wales, Northern Ireland and east of Scotland.

You can have deep brain stimulation if you live in the west of Scotland.

If you do have to travel for surgery, the arrangements for covering your travel and accommodation costs for you and a carer vary depending

on where you live. You should speak to your specialist about this.

## How can I find out more about deep brain stimulation?

Your main source of information should come from members of the specialist team at your surgical centre, including the neurosurgeon, your specialist and Parkinson's nurse.

You will have your own questions and concerns about deep brain stimulation. It's important that you fully understand the procedure involved, the possible benefits and potential risks.

Write down any questions you have and take these to your appointment with the specialist.

Here are some general questions you may also want to ask:

- Am I suitable for deep brain stimulation?
- What could be the potential benefits of deep brain stimulation for me?
- What are the risks of deep brain stimulation and how often have your patients had complications in the past?
- How is the surgery performed? (For example, will I be under general anaesthetic during the procedure or will I be awake for part of it?)
- How long will I have to wait for surgery?
- How long will I be in hospital?
- How long does it take to recover from surgery?
- How will the surgery affect my condition?
- How will my medication regime change after the operation?
- How often will I need to come back for treatment after surgery?
- How often will my deep brain stimulation battery need replacing?

“Once they told me that I could have it, I started to panic! But the staff were brilliant. They talked me through the procedure and what the risks were, and I had an MRI scan to map out my brain.”

**Christian**



# HAVING DEEP BRAIN STIMULATION

## The procedure

During your surgery, a frame will be positioned around your head to help avoid movement during the procedure. Two thin, insulated wires (each with electrodes known as 'contacts') are inserted into the brain. Rarely, when the symptoms mainly affect one side of the body, these leads are only inserted on one side of the brain. The lead implanted in the left side of the brain controls symptoms affecting the right side of the body and the lead implanted in the right side of the brain controls symptoms on the left side of the body.

Your surgeon will implant the leads into a specific area of the brain that is suitable for your Parkinson's – the position will not be the same for everyone. After surgery you might have a detailed scan of your brain (CT scan) to make sure that the leads are in the correct place.

Surgery is performed in a different way at each surgical centre. It will either take place under general anaesthetic (with the person asleep)

or with the person awake for part of the procedure. If you have general anaesthesia and you are asleep during surgery, you may be briefly woken up to check for improvements in your symptoms. When you speak to staff at the surgical centre, ask them how they carry out the operation.

Depending on the technique used, the procedure is either completed during one operation or during two separate operations. This might happen so that the device can be implanted a few days after the leads.

There are other variations in technique between surgical centres, including:

- choosing the right target site in your brain for placing the leads
- whether or not your hair is shaved
- when the stimulator is switched on and programmed

The team at your surgical centre can give you more information about how they do each of these things.

## What devices are used in deep brain stimulation?

There are several deep brain stimulation devices available that transmit the electrical current needed. These are called pulse generators or neurostimulators. Different manufacturers make different devices and the team at your surgical centre will explain which are available and the advantages of each one.

There are a few differences between each device, but the main difference is that there are rechargeable and non-rechargeable devices.

### Non-rechargeable pulse generator

On average, the battery lasts between three and five years depending on the settings required. Some batteries for non-rechargeable devices may last longer than chargeable ones before a replacement is needed.

### Rechargeable pulse generator

If you have a rechargeable unit implanted, you will be taught how to use it. The pulse generator will need recharging regularly and you will need to take your recharging unit with you if you are going to be away from home for more than a few days. The battery will last around 15 years before it has to be replaced.

There are precautions that need to be taken with each device but these will vary depending on the manufacturer and model. The team at your surgical centre will be able to give you information specific to your device so make sure you ask them any questions you have.

## Recovery

You will usually need to stay in hospital for a couple of days after you have had surgery. Before you are discharged, healthcare staff should assess what support you may need when you leave hospital.

If you or your healthcare professionals identify any support needs, these should be recorded in a written care plan. You should not be discharged until the support you need has been put in place.

If you're concerned about arrangements for going home after your hospital stay, you should speak to a hospital social worker.

**Find out more:** see our [information on going into hospital when you have Parkinson's](#).

## Programming your pulse generator

The deep brain stimulation system is not switched on immediately.

A few days or weeks after surgery (depending on your centre), the system is switched on. This allows an electric current to pass into the brain in order to improve mobility symptoms. Your specialist or Parkinson's nurse will programme the generator using a small portable computer. They will try out various settings to determine which ones work best and which ones cause side effects for you.

Then over a few weeks the settings will slowly be increased, and at the same time medication adjustments can be made as needed. This means it will probably take a few weeks after your surgery before your stimulator setting and medication doses are optimised and you notice the full benefit. Some people find that their symptoms actually get worse before they get better during these weeks. If this happens you may experience issues such as increased dyskinesia and 'off' time until your stimulator settings and medication doses are right for you.

You may also be given the option to make some changes to the settings.

It may take several months to fully programme the stimulator and adjust your Parkinson's medication to get the most benefit from your treatment.

## What are the side effects from programming your pulse generator?

You may also experience side effects from the stimulation that targets a specific area of your brain. These side effects can usually be managed by altering the programming of your deep brain stimulation device.

They include:

- tingling or a sensation of pins and needles
- changes in speech or language, such as problems articulating words, a soft voice or difficulty finding words
- dizziness or light-headedness
- involuntary muscle contractions (dystonia or dyskinesia)
- problems with balance and falls
- movement problems or reduced co-ordination
- closure of the eyelids (although this is rare)
- jolting or shocking sensations
- problems associated with the pulse generator and leads, including wound breakdown and infection. These can usually be treated with antibiotics but occasionally the whole system needs to be removed.

- These side effects can be uncomfortable but are not dangerous. Usually they can be minimised by changing the settings on your device.

## After surgery

- If you go into hospital in the future, it's important to make staff aware that you have had deep brain stimulation surgery. You should also tell any other healthcare professionals you see that you have a deep brain stimulation system implanted. This includes dentists, surgeons and physiotherapists.
- Diathermy (the use of a high frequency electronic current to produce heat, often used for muscle relaxation) should not be used if you have had deep brain stimulation surgery.
- If you require any surgery in the future, the surgeon and anaesthetist should be told you have a deep brain stimulator as there are certain precautions they need to take during surgery.
- MRI scans can only be used under very strict conditions.

Antibiotics have to be prescribed when there is a risk of germs getting in to the blood stream, for example during dental procedures or other

surgery. Your specialist or Parkinson's nurse can advise healthcare professionals on this before antibiotics are prescribed.

Most everyday activities are safe, but there are some that could damage the system. You should talk to your specialist about these.

You can travel by plane, but you should inform airport security and carry a card with you that explains you have had deep brain stimulation. Ask your healthcare professional if they can provide one for you. You should also carry the hand-held programmer with you when travelling, in case the stimulator is accidentally switched off.

“As far as the programming is concerned, this is really easy. Every time something is changed, it is recorded in great detail by the specialist nurse. This means that any changes can be made in line with the current programme.”

**Mark**

# FOR FAMILY, FRIENDS AND CARERS

## **A loved one is considering deep brain stimulation.**

### **What do I need to know?**

A specialist will carefully consider whether surgery is suitable for each individual person – it is important to remember it's not suitable for everyone.

Making the decision to have surgery for Parkinson's is often not an easy one to make, with a number of factors to consider. If you are close to the person with Parkinson's, you should be involved in conversations as any outcomes of the surgery may have an impact on you too.

As everyone with Parkinson's is different, each person with the condition will react differently to surgery.

Talk about what might happen before, during and after the procedure with the specialist or Parkinson's nurse, to make sure all your concerns are answered.

It can be helpful to write down your questions and take them with you to the appointment (You can find some example questions in the section on 'How can I find out more about deep brain stimulation?').

### **What will happen after the procedure?**

After deep brain stimulation surgery, there will be an initial period of healing where the person with Parkinson's may need extra care and attention.

After this period, there will be a visit back to the surgical centre, where the stimulator will be turned on. It will be adjusted until the best possible symptom control is achieved. This may take some time and may involve a few visits.

Once this has happened, there should be an improvement in the person's Parkinson's symptoms and they should find it easier to perform some day-to-day activities. If you help someone with everyday tasks, you may find they need less help at this point.

Many people will be able to significantly reduce the amount of medication they take. This will mean their medication regime may become less complicated. However, it's important to remember that the condition will continue to progress.

## What side effects should I look out for?

The results of the procedure will be monitored over time, and you can play an important part in this by keeping track of any changes in symptoms. Keeping a diary may help with this.

You can find out more about the potential side effects of deep brain stimulation in the section on 'What are the disadvantages of deep brain stimulation?' and 'What are the side effects of programming your pulse generator?'

## Looking after yourself

If you're a carer, it's important to look after yourself while the person you care for is preparing for deep brain stimulation, during their stay in hospital and once they are discharged. This will help you stay healthy and avoid stress.

Breaks from caring are often called 'respite care'. This care can vary from a few hours' break to a longer holiday. Your local authority has a responsibility for arranging services that can help you to take a break from caring.

**Find out more:** see our [information on caring for someone with Parkinson's](#).



# 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 act as a liaison between other health and social care professionals to make sure your needs are met.

Parkinson's nurses may not be available in every area, but your GP or specialist can tell you about local services.

You can find out more at [parkinsons.org.uk/nurses](https://parkinsons.org.uk/nurses)

## Information and support from Parkinson's UK

You can call our free confidential helpline for general support and information. Call **0808 800 0303** (calls are free from UK landlines and most mobile networks) or email [hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk)

Our helpline can also put you in touch with one of our local advisers, who provide one-to-one information and support to anyone

affected by Parkinson's. They can also provide links to local groups and services.

Our website has information about your local support team and how to contact them at [parkinsons.org.uk/localtoyou](https://parkinsons.org.uk/localtoyou)

You can find details of our local groups and your nearest meeting at [parkinsons.org.uk/localgroups](https://parkinsons.org.uk/localgroups)

You can also visit [parkinsons.org.uk/forum](https://parkinsons.org.uk/forum) to chat to other people with similar experiences on our online discussion forum.

## Deep brain stimulation (PKB123/2019)

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](mailto:publications@parkinsons.org.uk). Thank you!

### 1. Please choose the option that best fits you.

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

### 2. Where did you get this information from?

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

### 3. Has it answered all your questions?

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

### 4. How easy was it to understand?

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



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

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

## 6. What is your ethnic background?\*

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

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

## Want to hear more from us?

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

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

Name

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Address

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Email

---

Telephone

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## 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](https://parkinsons.org.uk/termsandconditions)



## Thank you

Thank you to everyone who contributed to or reviewed this information, including experts and people affected by Parkinson's.

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

## 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](https://parkinsons.org.uk/donate)**. Thank you.

## Our information

All of our most up-to-date information is available at **[parkinsons.org.uk/information-support](https://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](https://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](mailto:publications@parkinsons.org.uk)**

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](http://www.ngts.org.uk)**

**[hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk)**  
**[parkinsons.org.uk](http://parkinsons.org.uk)**

Order code: **PKB123**

Last updated November 2019. We review our information within three years. Please check our website for the most up-to-date versions of all our information.

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