

SURGERY FOR PARKINSON'S

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



Although the main treatment for Parkinson's is medication, there are some types of surgery available to treat the symptoms.

This booklet gives you an overview of the different types of surgery and the advantages and disadvantages of having a procedure. It also provides helpful advice for carers, loved ones and friends.

For some people, the idea of surgery may be daunting, but this information can help you talk to your specialist or Parkinson's nurse (if you have one) and make an informed decision about whether surgery is right for you.

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KEY MESSAGES

- Surgery for Parkinson's is mainly used to treat people whose symptoms can't be controlled by drugs.
- Surgery may not be a suitable option for everyone with Parkinson's.
- It is not a cure and does not stop Parkinson's from progressing, but may give some people better control of their physical symptoms.
- There are different types of surgery to treat Parkinson's. This booklet focuses on deep brain stimulation, as this is the main type of surgery used to treat the condition. Lesioning surgery is also referred to, but this is only used rarely.
- Like all types of surgery, there are risks involved. Make sure you have spoken to your specialist and understand what the potential complications are before going ahead.

“ My tremor was so bad I'd had enough. I chose to have the operation. They woke me up part-way through the operation to monitor my tremor, but I didn't feel anything. I just heard someone calling my name and holding my hand up so they could watch how the tremor was. Surgery isn't a cure and it didn't make me 100% better, but I take less than half the amount of medication I used to. ”

From our online forum

DEEP BRAIN STIMULATION

This is the main type of surgery used to treat the physical symptoms of Parkinson's. It involves implanting very fine wires with electrodes at their tips into the brain.

These are connected to extensions that are tunnelled under the skin behind the ear and down the neck. They are connected to a pulse generator (a device like a pacemaker), which is placed under the skin around the chest or stomach area.

When the device 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.

Deep brain stimulation is a 'non-destructive' type of surgery. This means that it doesn't destroy any part of the brain.

It's also reversible in many cases, if no damage occurs during surgery.

So, if it isn't successful, the system can be switched off, or removed if necessary. This is different to lesioning surgery, which does cause permanent damage to cells in a target area of the brain (see page 23 for more information).

Deep brain stimulation can work well to control your symptoms, but it won't stop Parkinson's from progressing and it isn't a cure.

Although many people benefit from deep brain stimulation, it isn't a suitable treatment for everyone with the condition.

Is deep brain stimulation right for me?

If you want to find out whether deep brain stimulation is suitable for you, speak to your specialist or Parkinson's nurse.

You may be referred to a consultant neurologist or surgeon at a hospital that performs the surgery. Once you have seen the specialist and 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?

A detailed assessment will find out whether you would benefit from deep brain stimulation. The specialist will decide this by looking at your specific symptoms and looking at any additional risks of surgery. You can read more about the risks of deep brain stimulation on page 14.

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 so 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 recur and are at their most debilitating.

You will first be assessed when you are in your 'off' state. You will then



be asked to follow your normal medication regimen and will be assessed again when you feel at your best.

The assessments will include some timed tests of your ability to perform certain tasks and movements. 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.

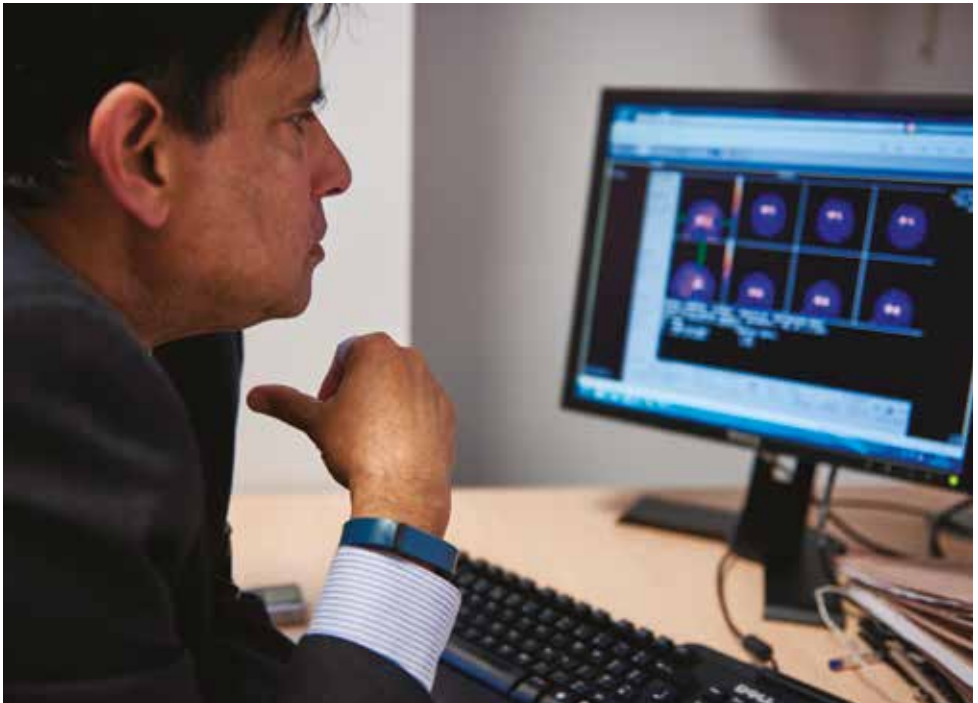
Part two

The second part of the process involves an assessment of your attention, memory, mood and

behaviour. Problems with attention and memory (cognitive function) 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 tests require concentration and can



be tiring, but you will have short breaks during the assessment.

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 or not 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 a fully informed decision about whether you want to go ahead.

Where is deep brain stimulation surgery carried out?

Deep brain stimulation is only carried out at certain centres in the UK.

You have the right to be referred to any of these centres, even if they are not near your home.

“ I had two lengthy meetings with my surgeon and his comments to me went a long way with my decision to have the operation. I would say that a conversation with your surgeon is a must as they should know the answers to all your questions above anyone else.”

Sue, diagnosed in 1995

Currently, people living in Wales or Northern Ireland have to travel to England for surgery. You will also need to travel to England if you live in the east of Scotland. If you live in the west of the country, you will be able to have the surgery in 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, of course, have your own questions and concerns about deep brain stimulation. It is 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 wish 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? (eg will I be unconscious 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 regimen 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?

There is a lot of information about deep brain stimulation available on the internet and in publications. But the differences in the surgical techniques and approaches used in each surgical centre mean that some information will also be different.



ADVANTAGES AND DISADVANTAGES

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.
- It may significantly 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 may improve your independence.
- It may improve your quality of life and that of those around you.

It is 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.

This means that you will almost definitely still need to take some medication, and while deep brain stimulation should help control movement symptoms, it will not stop the condition from progressing.

It is unlikely to improve any movement symptoms that levodopa does not improve.

“ When I was assessed as suitable for surgery I was warned of the risks. But I had no quality of life, so I had nothing to lose. Everyone has a different idea of quality of life – mine was to be able to dance.

I had the operation in November 2010. They put the implant in place and connected all the wires. I then waited four weeks to let it settle in before they switched it on.

I was warned that at first I would feel great. But the next 12 months would be rough, as my brain got used to the stimulation.

No matter how much they tried to prepare me, I didn't realise how the operation would impact on every area of my life. My marriage, family, everything. I got so frustrated and angry. I had been on so much medication and I found it difficult to adjust to the lower doses. It tested every part of me. But when it settled down, wow – I got my life back.

Don't get me wrong, I have bad days like everyone else. Some days I struggle, but that's fine. I'll do it tomorrow.

Everyone with Parkinson's is different. Although deep brain stimulation has improved my life, it may not be right for someone else. I'd advise anyone considering surgery to really think about it and do the research. You need a lot of support and patience.”

Koki, diagnosed in 2006

How effective is deep brain stimulation?

Evidence has shown that deep brain stimulation can significantly improve quality of life for some people with Parkinson's, more than medication alone.

Research has shown that surgery improves quality of life in people with advanced Parkinson's whose symptoms are no longer controlled by medication, or are not controlled as well as they were before.

It can also help people who experience lots of side effects from the medication they take.

Surgery is normally performed in the later stages of Parkinson's, but recent studies have found that some people may benefit from deep brain stimulation earlier.

Research into the most effective time to have surgery is ongoing. Researchers are also looking at the long-term effects of surgery, including if it is more cost effective than medical therapy alone.

What are the risks of deep brain stimulation?

Like any surgery, there are some potential risks with deep brain stimulation.

“So has it all been worthwhile? I can move easily, the tremor in my hands and arms has gone and I'm much more flexible. Best of all is the feeling I'm in control.”

David, diagnosed in 1996

Although the chance of complications is small, your specialist should discuss all of them with you before you agree to go ahead with surgery.

Risks include:

- stroke
- speech problems
- wound infection
- seizures
- confusion or disorientation after your operations
- haemorrhage (excessive bleeding)
- death

- medical complications from general anaesthetic, such as chest infection, deep vein thrombosis (a clot in the leg), pulmonary embolism (a clot that can lodge in the lungs)

What are the potential complications of deep brain stimulation?

Short-term side effects of the stimulator being switched on

There are some side effects that are caused by the stimulation current spreading to areas other than the planned target area.

These may 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

- jolting or shocking sensations

These side effects should disappear completely when the electric current is reduced or stopped.

Long-term issues after surgery

Over time, the following problems might happen:

- loss of battery strength. The battery generally lasts between three and five years in a non-rechargeable neurostimulator



and nine or 10 years in a rechargeable neurostimulator (see page 20). The neurostimulator can be replaced using relatively simple surgery and it is unlikely you will need any more brain surgery

- electrodes or extension leads break or current leaks
- the neurostimulator switches off. This will lead to symptoms being uncontrolled. But you can easily switch it back on if you have a hand-held programmer
- experience of depression and apathy. This may be a symptom of Parkinson's or a side effect of reducing medication after surgery or stimulation

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

- weight gain. A dietitian will be able to offer advice and information

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

Impulsive and compulsive behaviour

Although it is more often considered a side effect of some Parkinson's medication, some people who have had deep brain stimulation may experience impulsive and compulsive behaviour.

Impulsive behaviour is when a person can't resist the temptation to carry out activities that could lead them to harm themselves or others. This includes a strong urge to gamble, shop or binge-eat.

Some people with Parkinson's experience hypersexuality, where they become so preoccupied with sex that it can cause problems with their work or personal life. In many cases, this behaviour is out of character.

Compulsive behaviour is when a person has an overwhelming drive or urge to act in a certain way, often repetitively, to reduce the worry or tension that they get from that urge. This can include collecting, sorting and organising objects.

These behaviours can have a devastating impact on the person with Parkinson's and those around them if they are not managed.

It is important that everyone with Parkinson's is assessed by a healthcare professional for any potential risk of impulsive and compulsive behaviour before they are treated.

There are certain factors that may mean you are more likely to experience this behaviour. These include a family history of gambling or alcohol abuse, a personal history of addictive behaviour, being male, being a younger person with Parkinson's, being a smoker, being single and living alone.

Even if a person with Parkinson's doesn't fit any of these categories, their behaviour should be monitored over time.

Sometimes people who experience impulsive and compulsive behaviour may not realise they have a problem. So if you are a carer or a family member and you notice any unusual behaviour, talk to the person with Parkinson's and seek support from your healthcare professional.

Find out more: see our [information sheet *Impulsive and compulsive behaviour*](#).



THE PROCEDURE

During surgery, 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.

The wires can be inserted into particular parts of the brain depending on a person's individual symptoms.

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

- how the target site is located for placing the lead in the brain
- 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 these issues.

What devices are used in deep brain stimulation?

There are a number of deep brain stimulation devices available, which are made by different manufacturers. The team at your surgical centre will explain which devices are available and the advantages of each one.

“

I have to admit I enjoyed every minute of the operation. I had no side effects, not even a headache, although I had two incisions in my head, which had been tightly stitched. My surgeon had been very lighthearted, joking with me on several occasions and explained what he was doing as he went along.

When it came to placing the electrodes, my surgeon did his bit and then the electrodes were attached to a monitor by the Parkinson's nurse, who from her readings told him that he could 'fine tune' the positioning further. The neurologist's job was to say if he thought this was the best position for me. I held out my hand and watched in disbelief as the tremor went from being severe to nothing. I couldn't believe this was happening, it was truly amazing.

Having finished the operation, the team proclaimed all was satisfactory. I thanked them for giving me this opportunity and promptly burst into tears! ”

David, diagnosed in 1996

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

Non-rechargeable neurostimulator

The non-rechargeable battery for this device is stored within the neurostimulator. On average, the battery lasts between three and five years depending on the stimulator settings required. Some may last longer before a replacement is needed.

Rechargeable neurostimulator

The rechargeable battery is stored within the neurostimulator. If you have a rechargeable neurostimulator

implanted, you will be given and taught how to use a recharging unit.

The neurostimulator 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.

Depending on the device, the battery will last at least nine years before it has to be replaced.

There are precautions that need to be taken with each device (like with a pacemaker) 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.



Programming

Your specialist or Parkinson's nurse will programme the stimulator using a small portable computer.

During a programming session, an antenna attached to the computer is held over the area where the neurostimulator is, to communicate with it. The nurse or specialist will assess how your symptoms change on various settings, and programme the stimulator to the setting that controls your symptoms the best. This information is then stored within your implanted neurostimulator.

The stimulator may continue to be adjusted and your medication reviewed. You will be given instructions on how to use your own programmer. This will allow you to adjust the stimulation and check the battery life.

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.

You will usually need to stay in hospital for at least a week 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 professional 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 are concerned about arrangements for going home after your hospital stay, you should speak to a hospital social worker.

Find out more: see our booklet *Going into hospital when you have Parkinson's*.

After surgery

If you go into hospital in the future, it is 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 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.

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 this.

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.



LESIONING SURGERY

This procedure involves making a lesion to cells in a target area of the brain. The target site is found using a brain scan. An electrode is then inserted into the site and an electric current is passed through the tip.

The current is used to target some of the cells that control movement, and the lesion may reduce movement symptoms, such as tremor or involuntary movements (dyskinesia).

The lesion made is permanent and cannot be reversed. This is different to deep brain stimulation, which is a 'non-destructive' type of surgery, so doesn't destroy any part of the brain. It's also reversible in many cases, if no damage occurs during surgery. See page 6 for more information.

The main types of lesioning surgery are:

Thalamotomy

This involves making a lesion in part of the brain called the thalamus. This technique is now only used in rare cases. The procedure is usually done on one side only, because bilateral (both sides) thalamotomy is thought to be much more risky.

Pallidotomy

This involves making a lesion in part of the brain called the globus pallidus. The main benefit of this type of surgery is that it may reduce involuntary movements (dyskinesia), which can be a side effect of Parkinson's medication. But it can also help with other motor and non-motor symptoms.

Subthalamotomy

This involves making a lesion in part of the brain called the subthalamic nucleus. This technique has been performed by some neurosurgeons, mostly in countries where deep brain stimulation is not available.

It is not certain what its long-term effects are.

Lesioning surgery can be an effective treatment, but it isn't a recommended choice for most people, because lesioning may cause permanent side effects.



FOR CARERS, LOVED ONES AND FRIENDS

A loved one is considering having surgery for Parkinson's. 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, it is likely that you will be involved in this process. 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 your loved one's specialist or Parkinson's nurse, to make sure all of your concerns

are answered. It can be helpful to write down your questions and take them with you to the appointment (see page 10 for some example questions).

What will happen next?

After deep brain stimulation surgery, there will be an initial period of healing, where, like anyone who has had surgery, a person with Parkinson's may need additional 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 day-to-day tasks, you may find they need less help at this point.



BLACK SABBATH

U.S. TOUR '78

Many people will be able to significantly reduce the amount of medication taken, and therefore their medication regimen may become less complicated. It is important to remember, however, 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. Speak to your specialist or Parkinson's nurse to discuss any concerns you have.

Find out more: see our [information sheet, *Keeping a diary: for carers*](#).

See page 15 for information about the potential side effects of deep brain stimulation. Some side effects are less obvious than others, and you may find the section on page 16 about impulsive and compulsive behaviour helpful.

Looking after yourself

If you are a carer, it is important to look after yourself while the person you care for is preparing for

“It was not an easy decision for Paul to have the operation. I felt terrible fear, as it's not without risk. As a family, we've always believed a risk is worth taking, and we decided together it was the right option for us. The results have made everything worthwhile.”

A carer whose husband had deep brain stimulation

surgery, during their stay in hospital and once they are discharged – letting your own health suffer or allowing your stress levels to rise will not be helpful.

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 [booklet *The carer's guide*](#).

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

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

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

You can find details of our local groups and your nearest meeting at parkinsons.org.uk/localgroups

You can also visit parkinsons.org.uk/forum to chat to other people with similar experiences on our online discussion forum.



GLOSSARY

Basal ganglia

This is the part of the brain involved in the co-ordination of movement. It is located deep in the lower region of the brain, and is where dopamine-producing nerve cells are found. It is made up of different parts, including the substantia nigra, which produces dopamine, the striatum, where dopamine is released, and the subthalamic nucleus.

Dopamine

This is a chemical made by cells in the substantia nigra, which is found in the basal ganglia in the brain. Dopamine plays a big part in movement, cognition and mood. People with Parkinson's don't have enough dopamine because the nerve cells that make it have died.

Dyskinesia

These are involuntary movements, often a side effect of taking levodopa for a long period of time.

Dystonia

A movement disorder, but also a symptom of Parkinson's. It is a sustained, involuntary muscle contraction that can affect different parts of the body.

Freezing

A symptom of Parkinson's where someone will stop suddenly while walking or when starting a movement. It can also affect repetitive movements, such as brushing your teeth or talking.

Implantable pulse generator

This is a small unit used in deep brain stimulation. It is implanted (under general anaesthetic) under the skin of the chest, like a pacemaker. It contains a battery and electronics to generate the electrical signals for the stimulation. It is programmed by a professional using a computer, but on a day-to-day basis the stimulation can be adjusted by the person with Parkinson's using a hand-held programmer or a magnet.

Levodopa

This is a natural amino acid that the brain converts into dopamine. Drugs containing levodopa are often used to treat Parkinson's.

Magnetic Resonance Imaging (MRI)

This is a scan used to look at the structure of the brain or other parts of the body in detail.

'On/off'

This describes the quick changes to mobility that can affect some people with Parkinson's. Someone may go 'off' – this is when their symptoms are less under control and it is harder to move. They may switch 'on' again soon after taking their next dose of medication.

Thalamotomy

This is a surgical treatment that may, in rare cases, be used in people who experience strong tremor as a symptom of Parkinson's. It involves making a lesion in the part of the brain called the thalamus.

'Wearing off'

This is where a Parkinson's drug becomes less effective before it is time for your next dose. This may cause you to go 'off'.

Surgery for Parkinson's (B123/2015)

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:

Mr Alex Green, Consultant Neurosurgeon, Oxford University Hospitals NHS Trust

Patsy Cotton, Advanced Nurse Practitioner for Parkinson's Disease and Movement Disorders, Greater Manchester Neurosciences Centre

Lucy Partington, Movement Disorders Nurse Specialist, Salford Royal Hospital, Greater Manchester

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

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.

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**

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: PKB123

Last updated July 2015. 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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