

DEEP BRAIN STIMULATION

Treatments, therapies and side effects

Find out more about deep brain stimulation (DBS) and how the treatment can help people with Parkinson's



PARKINSON'S^{UK}
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The main treatment for Parkinson's is usually 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 DBS and will help you weigh up the advantages and disadvantages of having this procedure. It also provides advice for family, friends and anyone caring for a person with Parkinson's.

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



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KEY POINTS

DBS isn't a cure and doesn't stop Parkinson's from progressing. But in many cases, it's 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 DBS. Make sure you've spoken to your specialist and understand what complications there could be before going ahead.
- You may also find useful questions to ask your health professional in our section on 'How can I find out more about DBS?'
- If you're considering DBS, you'll first need to undergo a series of tests to see if you're suitable for this type of surgery. These tests will be carried out by a specialist team, including a neurologist and DBS nurse.
- DBS isn't just a surgery but an on-going treatment. As your condition progresses, the settings on your DBS device will need to be adjusted every few months, based on your symptoms.

CONSIDERING DBS

Deep brain stimulation (DBS) is a type of surgery used to treat Parkinson's. It may be an option for when your symptoms are no longer controlled well by medication.

In this section:

- What is DBS?
- How successful is DBS?
- Potential benefits of DBS
- Disadvantages of DBS
- Who can have DBS?
- Is DBS right for me?
- How are people assessed for DBS?
- Where is DBS surgery carried out?
- How can I find out more about DBS?

What is DBS?

DBS is the main type of surgery used to treat Parkinson's. Usually, it's most effective at improving motor (movement) symptoms, such as tremor, slowness of movement, rigidity and dyskinesia.

A pulse generator (a device like a heart pacemaker) is placed under the skin around the chest or stomach area. It's 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.

Throughout the procedure, you'll be supported by a team of healthcare professionals, including a neurologist, neurosurgeon, Parkinson's nurse and DBS nurse.

The DBS nurse will play a key role in supporting you during all stages of the procedure, from the assessment period through to surgery. They will also provide support and advice to your family and anyone who's caring for you.

Once the surgery is over, the DBS nurse will support you during the recovery period. They will also help you with managing any long-term care needs resulting from your surgery. This includes checking the settings on your DBS device, and suggesting changes to your medication based on your symptoms.

How successful is DBS?

People with Parkinson's often find that DBS works well in controlling many of their symptoms. But remember that DBS 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.

It's important to remember that not everyone with Parkinson's will see an improvement in their condition after DBS. In some cases symptoms can actually be made worse.

You can find out more about this in the section on 'Disadvantages of DBS.'

You may find our online forum helpful as many people will have shared their experiences of the procedure. This could help you weigh up the pros and cons. Find out more at

parkinsons.org.uk/forum

We also have some real life stories about DBS in our online magazine, which you can find at **parkinsons.org.uk/your-magazine**

You might like to watch our 'Parkinson's, DBS and Me' video series. It follows Jo as she navigates appointments with consultants, NHS waiting times and the surgery itself.

You can watch the 'Parkinson's, DBS and Me' series at **parkinsons.org.uk/DBSandme**

Potential benefits of DBS

DBS isn't suitable for everyone. But if it's 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 DBS.
- DBS can be an effective treatment for severe Parkinson's tremor, even if the tremor doesn't 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 lower the risk of medication side effects, such as involuntary movements (dyskinesia).
- It may give you some relief from non-motor symptoms of Parkinson's, such as sleep disturbance and pain.
- It may improve your ability to perform day-to-day activities, such as eating, getting dressed, getting up out of a chair and walking. This will help to increase your independence.
- It may increase your overall quality of life and for people who support or care for you.
- It's important to remember that DBS isn't a cure. But as with all treatments currently available for Parkinson's, it can help to manage your symptoms.

Find out more: see our information on wearing off and involuntary movements (dyskinesia).

Disadvantages of DBS

Many people who have DBS see an improvement in the way their Parkinson's symptoms affect them. But there are some disadvantages.

- DBS is unlikely to improve any movement symptoms that levodopa doesn't improve. (Tremor is an exception – see our section 'Potential benefits of DBS')

- Some people with Parkinson's have balance problems and speech issues that don't respond to medication. This includes freezing caused by being in crowded areas or walking in narrow spaces rather than by 'wearing off'. These types of issues are known as 'treatment resistant symptoms' and DBS can make them worse. Specialists will check carefully for these problems before considering surgery.
- Many people with Parkinson's have memory problems and other cognitive issues due to the condition. These might also get worse after DBS, so it's important to rule out these problems before considering surgery. Again, specialists will check carefully for these problems before considering surgery.
- There are potential risks in the surgery itself. These include bleeding or stroke during the procedure. There are also complications linked to having an anaesthetic, although these 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.'
- Some types of electronic devices can interfere with or turn off the DBS device, including airport body scanners and shop theft detectors. This is because of the strong magnetic fields the machines use.

Who can have DBS?

There are no official guidelines for who can have DBS. But research shows that having the treatment in the early stages of Parkinson's may help to slow the progress of symptoms.

DBS for Parkinson's is recommended if:

- your movement symptoms are seriously impacting your quality of life and ability to perform daily activities
- your movement symptoms respond well to medication (such as levodopa), but it's become less effective and you have bad 'off' periods
- you're not experiencing serious issues with memory and thinking, hallucinations, dementia or severe depression

Waiting time for DBS surgery (including the assessment process) will vary from centre to centre.

Is DBS right for me?

Once you've considered the benefits and disadvantages of DBS, you'll need to discuss it with your specialist. Together you can decide whether this treatment 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. There, you will be assessed as either an outpatient or an inpatient.

How are people assessed for DBS?

Everyone being considered for DBS needs to go through a careful selection process. This will usually involve looking at:

- your memory and other cognitive functions

- if you have any psychiatric problems, such as severe depression or hallucinations
- if you experience impulsive and compulsive behaviour
- any mobility problems you may have and how these respond to levodopa

The assessment process usually takes a few months and looks at all of your symptoms to determine whether they are likely to improve after having DBS. 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. This is sometimes known as the 'levodopa challenge test'.

You'll be asked not to take your Parkinson's medication for a period of time before the assessment. This allows specialists to get an accurate picture of your symptoms when you're in an 'off' state, and how much your symptoms improve when you're 'on'.

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

You'll first be assessed when you're in your 'off' state. You'll then be given Parkinson's medication and will be monitored again after this. For some people, this can be difficult, as they have to experience their symptoms when they aren't under control. You might find this upsetting and challenging.

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

Find out more: see our information on wearing off and involuntary movements (dyskinesia).

Part two

The second part of the process assesses your attention, memory, mood and behaviour.

Problems with attention and memory affect many people with Parkinson's, but they affect people in different ways. Studies have shown that DBS works best for people who have no, or very mild, memory and thinking problems.

You'll be asked to complete cognitive tests. This helps the surgical team see 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'll have short breaks throughout.

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. It can also make sure there's no existing damage, such as lesions, or changes in the brain that could make the operation more difficult or risky.

Results of the assessment

Your specialist will discuss the results of the assessment with you. They will explain whether DBS could help you, and if so, in what way.

They will also discuss the surgical procedure and follow-up care with you.

It's particularly important to talk through your assessment results as DBS 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 DBS surgery carried out?

DBS is currently carried out at 17 centres in the UK.

You have the right to be referred to any of these centres, even if they're not near where you live.

DBS is available at several centres in England. If you live in Northern Ireland or Wales, you'll have to travel to England for surgery. If you live in Scotland, you can have DBS at the National Deep Brain Stimulation Service for Movement Disorders in Glasgow.

If you do have to travel for surgery, arrangements for covering your travel and accommodation costs for you and the person who cares for you, vary depending on where you live. You should speak to your specialist about this.

You can find a map of all the current DBS centres in the UK on the DBS Nurse Association website at **www.dbsnurseassociation.org/dbs-centres-in-the-uk**

How can I find out more about DBS?

You should speak to members of the specialist team at your surgical centre, including the neurosurgeon, Parkinson's nurse and DBS nurse.

They'll be able to answer your questions and listen to any concerns you may have about the procedure.

During the initial assessment stage, the DBS nurse will explain what you can expect from the surgery and the recovery period.

It's important that you understand what the procedure involves, the possible benefits and potential risks.

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

You may want to ask:

- Am I suitable for DBS?
- What could be the potential benefits of DBS for me?
- What are the risks of the treatment, 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 for the surgery?
- 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 DBS battery need replacing?
- Will I need to make adjustments to my work routine and daily activities?

HAVING DBS

Surgery is performed in a different way at each surgical centre.

In this section:

- The procedure
- What devices are used in DBS?
- Recovery
- Programming your pulse generator
- What are the side effects from programming your pulse generator?
- After surgery

The procedure

During your surgery, a frame will be positioned around your head to help avoid movement during the procedure. Small holes are then drilled into the skull before two thin, insulated wires (each with electrodes known as 'contacts') are inserted into your brain.

Rarely, when the symptoms mainly affect one side of the body, these leads are only inserted on one side of your 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's best for you – 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 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 (when you're asleep) or you may be awake for part of the procedure. If you have a general anaesthetic and you're asleep during surgery, you may be briefly woken up to check for improvements in your symptoms.

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 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 DBS?

There are several DBS devices available that transmit the electrical current needed. These are called pulse generators or neurostimulators. There are rechargeable and nonrechargeable devices available.

Different manufacturers make different devices and the team at your surgical centre will explain which are available and the advantages of each one.

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'll be taught how to use it.

The pulse generator will need recharging regularly, and you'll need to take your recharging unit with you if you're going to be away from home for more than a few days. The battery will usually last between 15-25 years (depending on the manufacturer) 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'll usually need to stay in hospital for a short while after you've had surgery. Before being discharged, healthcare staff should assess what support you may need once you go home. If you or your health 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.

Find out more: see our information on going into hospital when you have Parkinson's.

Programming your pulse generator

The DBS system is not switched on immediately.

The system is switched on a few days or weeks after your surgery (depending on your centre).

This allows an electric current to pass into your brain in order to improve your movement symptoms.

Your specialist, such as your neurologist or DBS nurse, will programme the generator using a small portable computer. They'll try out various settings to work out which ones are best for you, and which ones cause side effects.

Then over a few weeks, the settings will slowly be increased. At the same time, your medication may be adjusted as needed.

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 up to twelve 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 experience side effects from the stimulation that targets a specific area of your brain. These side effects can usually be managed by changing the programming of your DBS device. They include:

- numbness or a tingling sensation
- changes in speech or language, such as a soft voice, or problems speaking fluently or finding words
- dizziness or light-headedness
- involuntary muscle contractions (dystonia or dyskinesia)
- muscle tightness of the face or arm
- weakness of face or limbs
- problems with balance and falls
- movement problems or reduced coordination
- closure of the eyelids (although this is rare)
- jolting or shocking sensations
- temporary worsening of symptoms

These side effects can be uncomfortable but aren't dangerous. Usually they can be managed 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've had DBS surgery. You should also tell any other health professionals you see that you have a DBS system implanted. This includes dentists, surgeons and physiotherapists.

It can affect your treatment, including:

- Diathermy (the use of a high-frequency electronic current to produce heat, often used for muscle relaxation) should not be used if you've had DBS surgery.
- If you need any surgery in the future, the surgeon and anaesthetist should be told you have a deep brain stimulator. There are certain precautions they will need to take during surgery.
- MRI scans can only be used under very strict conditions.
- Antibiotics have to be prescribed when there's a risk of germs getting into your bloodstream. For example, during dental procedures or other surgery. Your specialist or Parkinson's nurse can advise health 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've had DBS. Ask your health professional if they can provide one for you. You should also carry the handheld programmer with you when travelling, in case the stimulator is accidentally switched off.

FOR FAMILY, FRIENDS AND THOSE CARING FOR PEOPLE WITH PARKINSON'S

If you're close to the person with Parkinson's, it's important to be involved in conversations around DBS, as any outcomes of the surgery may have an impact on you too.

In this section:

- A loved one is considering DBS. What do I need to know?
- What will happen after the procedure?
- What side effects should I look out for?
- Looking after yourself

A loved one is considering DBS. What do I need to know?

The decision to have surgery for Parkinson's is often not an easy one to make, with a number of factors to consider. It's important to remember DBS isn't suitable for everyone.

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

You should talk about what might happen before, during and after the procedure with the specialist or Parkinson's nurse, to make sure all your questions and 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 DBS?').

You might find it helpful to tell the DBS nurse what your expectations are of the surgery. There can sometimes be differences in what the person having DBS expects and what their loved ones expect.

What will happen after the procedure?

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

After this, 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, Parkinson's symptoms should improve and the person with Parkinson's 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 DBS in the sections on 'Disadvantages of DBS?' and 'What are the side effects of programming your pulse generator?'

Looking after yourself

If you're caring for someone with Parkinson's, it's important to look after yourself while the person is preparing for DBS, during their stay in hospital and once they're discharged. This will help you stay healthy and avoid stress.

Find out more: see our information on caring for someone with Parkinson's.

MORE INFORMATION AND SUPPORT

Parkinson's nurses

Parkinson's nurses have specialist experience and knowledge of Parkinson's. They can:

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

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

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

Parkinson's UK information and support

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

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

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

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

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

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

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

Thank you

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

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

Feedback

If you have any comments or feedback about our information, please call **0800 138 6593**, email **feedback@parkinsons.org.uk**, or write to us at Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ.

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

Can you help?

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

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

Thank you.

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Improving life for everyone
affected by Parkinson's.
Together we'll find a cure.

PARKINSON'S^{UK}

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