

Surgery and Parkinson's Disease



About the Parkinson's Disease Society

The Parkinson's Disease Society (PDS) works with people with Parkinson's, their carers, families and friends, and health and social care professionals to provide support, information and advice. We are committed to investing in research, education and campaigning to improve the lives of people affected by the condition. The PDS has over 30,000 members, and more than 330 branches, support groups and special interest groups throughout the UK.

For more details on the friendly support, relevant information and expert advice that becoming a member can provide, including details of our membership magazine, *The Parkinson*, please call 020 7932 1344 or email membership@parkinsons.org.uk

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Introduction

Over the past few years, there has been renewed interest in surgery to treat Parkinson's disease.

Although drug treatment (particularly levodopa) is the main form of treatment for Parkinson's, it can be complicated and have side effects that some people find difficult to manage.

Surgery is generally only used to treat people who have had Parkinson's for some time and whose symptoms are not controlled effectively by medication. It may also be used for people who are experiencing very troublesome dyskinesias.

This booklet explains the different types of surgery available. It features case studies of people who have had surgery, explaining the procedure and the after effects. The case studies show that while surgery can be successful it does not work for everyone. For some people, it is just not suitable. There are risks involved, which are explained in this booklet.

If you are thinking about the possibility of surgery, you must discuss this with your doctor and/or medical team. A list of the most commonly asked questions can be found in the final chapter of this booklet. These have been compiled through talking to medical professionals and people who have had surgery.

There are some potentially exciting research projects into new forms of surgery. However, they are still at early stages and, as with all medical trials, need to be tested for several years before they are considered safe and effective. This booklet outlines some of the new research being conducted and provides further sources of information.

Acknowledgements

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Mr T R K Varma

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Karen O'Sullivan

Parkinson's Disease Nurse Specialist

Lucy Mooney

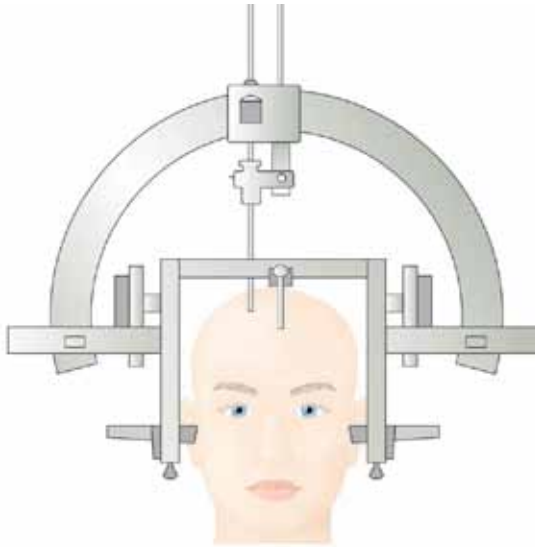
Roseanne McCabe, who has had deep brain stimulation.

Surgery overview

History of surgery

Surgical procedures were once the main treatment for Parkinson's.

In 1947, the neurologists Ernst Spiegel and Henry Wycis were the first to use a 'stereotactic frame' in a human operation. The frame fitted around the head and held it in place. This guiding device, along with atlases of the human brain, allowed surgeons to pinpoint areas of the brain for surgery. Before computer technology, using this map, surgeons would mark out the basal ganglia (the area of the brain affected by Parkinson's) and then make a lesion or cut in it.



The stereotactic frame in place

With the introduction of the drug levodopa in 1967, surgical techniques were largely abandoned because the drug was seen as a more effective treatment. Over the next 10–15 years it became apparent that, although levodopa was often dramatically effective, it was not a perfect treatment. This realisation, together with improved surgical techniques and understanding, led to the

resurgence of interest in surgery as a treatment for Parkinson's, particularly for people who have had the condition for some time.

One of the most common surgical treatments is deep brain stimulation (DBS), which was pioneered in the 1980s by a research team in Grenoble, France, led by Professor Benabid and Professor Pollack. As this type of surgery does not involve lesioning, it does not destroy any part of the brain. It is now performed at many centres around the world, including several in the UK.



Professor Benabid (left) and Professor Pollack

Important advances in scanning equipment have made these treatments possible. Computed Tomography (CT or CAT scan) became available in the late 1970s and the combination of CT and stereotactic technology was possible in the mid to late 1980s. By the 1990s, the use of MRI (magnetic resonance imaging) for functional stereotaxis was routine. With this technology, surgeons are able to scan the brain, homing in on the target area. This has allowed greater accuracy and led to a further increase in surgery for Parkinson's.

What techniques are used to treat Parkinson's?

At present, the main areas of interest in surgery for Parkinson's are:

- deep brain stimulation (thalamic, pallidal and subthalamic stimulation)
- lesioning (pallidotomy, thalamotomy and subthalamotomy)
- gamma knife surgery

What are the risks?

Each form of surgery for Parkinson's carries its own risks and these should be discussed with your consultant. However, some of the general risks associated with these techniques include: increased risk of a stroke leading to paralysis; haemorrhage leading to stroke; swelling in the brain; cognitive changes; mood changes; speech problems; and, very rarely, death.

Who is suitable for surgery?

Surgery is not suitable for everyone. It is generally used to treat people who have had Parkinson's for some time and whose symptoms are not controlled effectively by medication and/or are experiencing very troublesome dyskinesias (involuntary movements associated with some anti-Parkinson's medication). The risks of surgery may be increased in very elderly people and those with other conditions that might cause complications. Most surgeons will not operate on anyone who is experiencing confusion or psychosis, has experienced a stroke or has dementia or severe depression.

Types of surgery

Deep brain stimulation (DBS)

DBS is an exciting development in Parkinson's treatment. However, it is not a suitable treatment for everyone and has some risks and side effects. The best treatment for most people is still drug therapy.

What does DBS involve?

The procedure involves implanting a wire, with four electrodes (conductors that carry electrical signals) at its tip, into one of three parts of the brain:



Image of the electrodes

- The thalamus (the procedure is known as thalamic stimulation)
- The globus pallidus (the procedure is known as pallidal stimulation)
- The subthalamic region (the procedure is known as subthalamic stimulation)

The techniques of surgery varies between treatment centres; some carry out the operation under general anaesthesia and some while the patient is awake. When the procedure is carried out under general anaesthetic, the position of the electrodes is planned using MRI scans.

One of the three parts of the brain is stimulated with a small electric current and the person's response is monitored. For example, if a tremor is reduced, it confirms that the target area has been found.

Like everything, there are advantages and disadvantages to the techniques used – this is often a reflection of the equipment used and the surgical team's preference.

In all cases of DBS, the wire is then connected to a small unit called an Implantable Pulse Generator (IPG), which is implanted (under general anaesthetic) under the skin, generally near the collarbone or sometimes the abdomen. It acts like a pacemaker. The IPG contains the battery and electronics to generate the electrical signals for the stimulation. The IPG is programmed by the clinician using a small programming device; but on a day-to-day basis, the stimulation can be switched 'on' and 'off' by the person with Parkinson's using a hand-held programmer or a magnet. Patients can also use their hand-held programmers to increase or decrease the voltage of the stimulator.



When the stimulator is switched on, electrical signals are sent to the brain to control or reduce the Parkinson's symptoms. When the stimulator is switched off the symptoms return. Stimulation on the left side of the brain affects the symptoms on the right side of the body and vice versa. Bilateral stimulation to control symptoms on both sides of the body is now preferred and requires only one IPG, known as Kinetra.



Image of the Access Controller being placed over the implanted pulse generator (IPG), called the Kinetra, to allow the patient to make the fine adjustments to their stimulation as necessary

Image of the Access Controller being placed over the implanted pulse generator (IPG), called the Kinetra, to allow the patient to make the fine adjustments to their stimulation as necessary

At present, the battery in the IPG usually lasts for about 3–5 years. When the battery needs changing, it is necessary to replace the whole IPG under the skin in the chest but not the wire in the brain. The whole system is often called Activa Therapy.



This picture has been taken some time after surgery

What are the possible benefits of DBS?

DBS is a non-destructive form of surgery. This means that it does not destroy a part of the brain. It is also reversible so that if the procedure is not successful the IPG and the electrode can be removed.

It is important to remember that DBS controls or reduces symptoms but it does not cure the underlying Parkinson's. This means that most people who have DBS continue to need treatment with medication and, while DBS helps control motor symptoms, it does not stop disease progression.

What are the different types of DBS?

Thalamic stimulation

Thalamic stimulation can treat Parkinson's tremor. It is used for people who have disabling tremor that is not controlled effectively by medication. Studies suggest that thalamic stimulation results in either a reduction or a complete suppression of tremor in

about 80% of the people with Parkinson's who undergo the operation. Occasionally, however, the tremor reappears and some people derive no benefit at all.

It is not yet known whether the positive effects of thalamic stimulation are permanent. Some early recipients of the therapy have now been monitored for more than ten years and they have found that the level of control over tremor seems to have been constant.

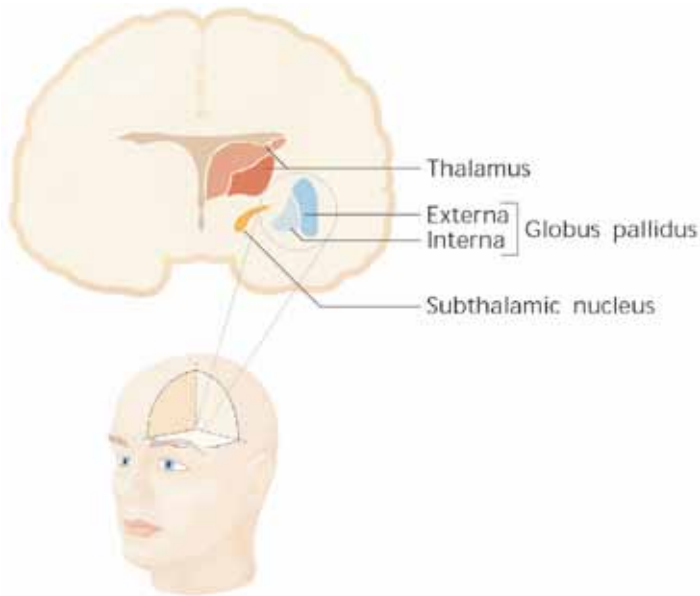
However, Parkinson's is a progressive condition and symptoms such as bradykinesia (slowness of movement) and dyskinesia (involuntary movement associated with some anti-Parkinson's medication) do deteriorate because they are not helped by thalamic stimulation. Most centres have now abandoned thalamic stimulation in favour of pallidal stimulation and subthalamic stimulation, although they continue to use it for essential tremor.

Pallidal stimulation

Pallidal stimulation has been used to treat people with Parkinson's who have disabling levodopa-induced involuntary movements (dyskinesias).

Pallidal stimulation can have a beneficial effect on dyskinesias and it usually helps stiffness (rigidity) and generally improves 'on' time in people who experience the 'on-off' syndrome as a side effect of their medication. See the PDS information sheet, *Motor Fluctuations*, for more information on dyskinesias and the 'on-off' syndrome.

About 70–80% of people who have pallidal stimulation will find some benefit. It may do little for slowness of movement (bradykinesia) and can sometimes make it worse.



Diagrammatic representation of the parts of the brain associated with deep brain stimulation

Subthalamic stimulation

About 70–80% of people who have subthalamic stimulation will derive some benefit from it. In particular, the procedure can have a major effect on tremor, slowness of movement and stiffness. Most people who have had subthalamic stimulation have also been able to significantly reduce their dose of levodopa medication, leading in turn to a reduction in the level of involuntary movements (dyskinesias) experienced. All the aspects of ‘off’ periods caused as a side effect of levodopa drugs respond to subthalamic stimulation.

Some clinicians who have experience of performing both pallidal and subthalamic stimulation have now abandoned pallidal stimulation in favour of the latter, because of its perceived benefits. It has been shown that with subthalamic stimulation, there is a 40–50% reduction in L-dopa medication but with

pallidal, patients tolerate an increase in medication, which is required to obtain the same motor benefits.

The lower stimulation voltage used in subthalamic stimulation also means a greater battery life and fewer replacements.

What are the possible risks/side effects of DBS?

Post-operative side effects of DBS are generally mild, temporary and reversible. The surgeon can also adjust the level of stimulation in order to minimise these effects. The possible side effects of the stimulation include: pain; swelling at the implant site; an allergic reaction to the implant; change of effectiveness over time; tingling in the face or limbs; speech and vision problems; dizziness; reduced co-ordination or movement problems; difficulty in maintaining attention or concentration; jolting or shocking sensation; temporary worsening of the tremor when the stimulation is stopped. It is also possible that the electrode may move from the original implantation site.

There are some risks associated with the surgery itself and these include: bleeding in the brain (which causes damage that can lead to paralysis or, in rare cases, death if the damage is severe); leakage of fluid surrounding the brain (which can predispose to headaches or, in some cases, meningitis); infection and seizures. The risk of one of these serious events is about 5%. The risks of the surgery are increased in elderly people (over 70–75 years of age) and those with other conditions, such as cerebrovascular disease and high blood pressure. Despite best efforts during surgery, it is not always possible to obtain optimal electrode position and sometimes it may be necessary to re-operate to reposition the electrodes.

Can I have diathermy or ‘deep heat’ once I have had DBS?

Diathermy is a treatment that uses radio frequency (RF) energy or sound waves to heat a targeted part of the body. Healthcare professionals may refer to diathermy as ‘deep heat’ or use other similar terms. The goal of this therapy is, typically, to reduce swelling and stiffness of muscles and joints, as well as to promote healing of tissue following surgical procedures or injury. The heat generated by diathermy is thought to accelerate blood flow and metabolism, thus facilitating the process of absorption and tissue repair.

People who have DBS should not have diathermy on any part of their body as it can cause permanent nerve or tissue damage and result in injury or death.

Diathermy is provided by a variety of health professionals, including physiotherapists, nurses, chiropractors, dentists and sports therapists. At least three forms of diathermy are used in the medical community – radio frequency or shortwave diathermy, therapeutic ultrasound diathermy and microwave diathermy. All of these are contraindicated (potentially damaging) for people who have a DBS.

NB: diagnostic ultrasound is different from therapeutic ultrasound diathermy. Diagnostic ultrasound is not contraindicated for people who have DBS.

Surgical diathermy is slightly different. However, monopolar surgical diathermy should not be used during surgery and your surgeon should be made aware of this. Bipolar diathermy to stop bleeding during operations is quite safe if you have an implanted neurostimulator.

Anyone who has had DBS who might be treated with diathermy should discuss this further with their specialist/neurosurgeon.

Can I have an MRI scan once I have had DBS?

MRI (magnetic resonance imaging) scans are a radiology technique that uses magnetism, radio waves and a computer to produce images of the body structures.

Medtronic, the company that make the equipment involved in deep brain stimulation have produced a leaflet called MRI Guidelines for Neurological Products. There is a section in this publication that deals with the effects of MRI on deep brain stimulation systems. Your specialist/neurosurgeon can advise further on whether an MRI is suitable for you or not.

If you have DBS, do you need to take precautions before having certain medical procedures?

If you have DBS and you plan to have dental work, operations involving a general anaesthetic or urinary catheterisation, it would be advisable to take antibiotics. If you have hardware implanted in you, during these procedures, bacteria can land on the hardware and infect it. These antibiotics are given as a preventative measure. Hospitals and surgeons have different antibiotic policies in place for each of the procedures they perform. They should use a similar approach to the one used to prevent infection in a heart valve. Your doctor should be able to advise further.

What is the cost of DBS?

The total cost of DBS varies, but is generally between £25,000 and £30,000. This includes the DBS system and the surgery itself, along with inpatient stay and follow-up assessments. The National Health Service pays for a limited amount of operations each year, and some private health insurance companies may also fund it.

Case studies of people who have had DBS

The following accounts are based on true stories but names have been withheld to protect confidentiality.

Patient A

“I was asked to take part in a large-scale trial of deep brain stimulation. The first operation took seven hours and I was fully conscious throughout. Firstly, they clamped my head so it could not move. I didn't realise how frightening this would be, and the effect of tightening up the bolts to hold the metal work in place echoed through my ears.

“They then gave me an MRI scan and took me to the theatre. They shaved part of my head and drilled two holes in my skull. The drill kept going until there was no resistance and then it automatically stopped (so the brain is not damaged). It took about thirty seconds to drill through my skull. Then they implanted an electrode on either side of my brain. Finding the right place to insert it takes between ten minutes and an hour. While this was going on I was being continually asked my name and address and asked to make various movements with my hands, presumably to show that I was still compos mentis. After this, the electrode was positioned and clicked into place.

The second side took a lot longer and I was beginning to get distressed. I was sweating, my back was aching and my legs felt very stiff. They finally found the right spot, closed up the holes, released the head vice and sent me back to the ward.

“Overnight, I was monitored at four-hourly intervals to check my blood pressure and sugar levels. A nurse put support stockings on me to avoid thrombosis developing. As morning came, I felt much better and managed to struggle to the toilet on my own. The next day I dressed myself and went for a walk with my family in the local park in the afternoon.

“Two days later I was put under a general anaesthetic so that they could implant a very expensive battery in my chest – I am told it costs £10,000. These are linked to the electrodes

by leads. This operation only took 40 minutes. I left hospital three days later.

“After the operation I had to go back to hospital for adjustments, which are done by computer, using a stimulator placed over the battery in my chest. It can take up to six months before the settings are adjusted to the right level.”

Update: Patient A has had a very successful operation; enjoys an improved quality of life, has much less dyskinesia and is currently taking less medication.

Patient B

“The surgeon explained the risks to me – a stroke resulting from excessive bleeding in the brain while the probes were being installed, developing epileptic fits, and the possibility of developing meningitis. He put all these risks at 2%.

“I went to a large hospital which offers this treatment.

They conduct three operations – the first, under anaesthetic, is to bore a hole in the skull and be fitted with a small steel plate. Brain scans check the 3-D measurements, to check where the probes would best be located. The second, which took about six hours and is the most hazardous, installs the probes in their optimum position. In my case, this stage resulted in some internal bleeding, although it was completed successfully a few weeks later, leaving only the third stage – connecting up the wire.

“The early benefit was freedom from the dreaded dyskinesias. These had dogged me for a long time and had resulted in a very sore neck, which in turn had resulted in a trapped nerve affecting my right arm, which was partially paralysed. I was now completely free of the pain and endless bouts of involuntary movement.”

Patient B's wife provides an update: “After the early euphoria of the operation, we now realise that Patient B is in one of the 3–5% of people for whom the operation was not totally successful. He was in hospital for ten weeks instead of three and in that time his speech deteriorated, as did his bladder control. There was an increase in drooling and in the phenomenon of freezing.

“It turns out that he had a stroke during the second part of the operation. He still needs a 24-hour apomorphine pump, Sinemet to start the day, Amantadine later on and sleeping pills at night.

“Twenty months after leaving hospital, he needs someone with him virtually all the time as he cannot do up buttons and sometimes ‘freezes’ or falls. His speech and mobility are poor and he has had to stop driving.

Update from the surgeon: “We have since discovered that dementia has set in. This may be due to Parkinson’s, although he definitely didn’t have it before the operation. Patient B is now very immobilised and goes into respite care every three weeks for about ten days or so. The response to DBS and medication was lost because of Parkinson’s disease progression rather than a direct result of surgery”.

Lesioning

These techniques involve making selective damage (a lesion) to certain cells within specific areas of the brain. The target site is located with the aid of computer technology. An electrode is then inserted with its tip at the optimum point. By passing an electric current through the tip, a small, destructive lesion is then made. These lesions are known to have a beneficial effect on some of the symptoms of Parkinson’s.

Lesioning is unlikely to continue as a treatment option because it is irreversible and cannot be modified without a further operation.

If done bilaterally, the risk would be very high. There is very little lesioning being undertaken in the UK for Parkinson's disease.

The main target areas for lesioning are:

Thalamotomy – which involves making a lesion in a part of the thalamus. This technique is now used mainly to treat drug-resistant tremor. It is usually done on one side only as thalamotomy on both sides is thought to be too risky.

Pallidotomy – which is regaining popularity as a procedure, and is now the most common form of lesioning technique used. The target site is located in the part of the brain known as the globus pallidus. Pallidotomy is most important for its dramatic effect on rigidity and akinesia (lack of movement) and reductions in the sudden, involuntary movements (dyskinesias) that can result from drug therapy. Some bilateral pallidotomies are being performed for optimum symptom control. However, these carry increased surgical risks.

Subthalamotomy – which involves making a destructive lesion in the subthalamic nucleus – rather than implanting an electrode, as is the case with subthalamic stimulation. Subthalamotomy is still experimental and has not gained popularity because of the perceived high risk and the uncertainty about its long-term effects in a progressive condition.

Case study of a stereotactic thalamotomy patient

Patient C

“I was diagnosed with Parkinson's when I was 54. My main symptom was tremor, which badly affected my right hand and arm. I tried all the usual drugs but none seemed to bring about any improvement. My consultant suggested an operation known as stereotactic thalamotomy, noted for relieving tremor.

“At the appointment with the neurosurgeon, I was told that my operation would be on the left side of the brain (the opposite side to the tremor). The operation carried a small risk of my speech being affected, as well as slight weakness or clumsiness of the limbs, which, if it occurs, is usually temporary. The greatest risk was that the procedure might not relieve the tremor.

“I was admitted to hospital 14 months later. The first day was taken up with a thorough medical examination, temperature and blood pressure, weight, heart scan and hundreds of questions. The first part of the operation took place the next day.

“I was given a general anaesthetic and a small hole was made through the bone of my skull, where the electrode was to be inserted the next day. They shaved a patch of hair about 2–3 inches near the top of my head. I had to have about six stitches but a dressing covered them for the first few days.

“Being a Muslim woman, who normally wears Muslim dress (long coat or dress with long sleeves and a headscarf), I had asked to be kept covered up as much as possible. When I came round from the operation, my scarf was neatly folded on my pillow and my Muslim modesty had been taken into account by covering my head with a dressing ‘hat’.

“The next day I was taken to the operating theatre fully conscious, partly so that any adverse reaction to the electrode could be observed and also to observe the tremor, which would be nonexistent under general anaesthetic. Firstly, they took a couple of X-rays, one from the back of my head and one from the front. Information from these X-rays enables the computer to work out where the electrode is to be positioned.

“In order to guide the electrode to the target site in the thalamus, a metal stereotactic frame was attached to my head. I was given four local anaesthetics, two in my forehead and two at the back. After they had taken effect, the surgeon

screwed the frame on firmly. He then told me that I would feel something cold as he threaded the electrode between the stitches and into the hole. Then he sat down at the computer, which I could not see. Fortunately the brain does not feel pain and I was completely unaware of the electrode's passage through my head.

"I was instructed to report any strange sensation and suddenly I felt my nose and mouth twitching like a rabbit! The surgeon remarked that it showed we were on the right track. A few seconds later he announced that he had reached the target and I saw that my hand had stopped shaking. He said that if he now removed the electrode, the tremor would shortly resume.

To prevent this, he needed to heat the electrode gently until it reached the correct temperature and maintain it at that heat for about ninety seconds. After this the procedure was complete, the electrode and metal frame were removed – and it was over!

"I went straight back to the ward, very relieved it was over and with no tremor. I was extremely tired over the next few days.

My legs felt odd – very heavy and clumsy, the right one in particular. I remembered this could be a temporary side effect.

"I left hospital after a week and was referred to a local health centre for physiotherapy. I kept bumping into doors, as my legs did not seem to go where I put them. But gradually things improved as I regained control. I was easily tired and needed frequent rests. Thirty days after the operation my hand was still tremor free, apart from the occasional slow shake, but nothing like as severe as it was. I would say it is an 80% improvement.

I am still working on getting my leg as normal as possible but my arm has regained its swing."

Gamma knife surgery

Gamma knife surgery is a development in the application of lesioning – it doesn't actually involve a knife. It is a form of radiotherapy that focuses one dose of gamma radiation through the skin and skull. The effects of gamma knife surgery may take weeks or months to be seen, and the risks of this type of surgery, relative to other surgical procedures, are not yet known.

The difference between gamma knife surgery and traditional lesioning techniques is that gamma knife surgery is non-invasive and it cannot be monitored during the procedure by testing the person with Parkinson's response to an internal electrode. Therefore, gamma knife surgery is, at present, not a widely-accepted therapy.

Surgery today and tomorrow

What does the future hold for surgery?

There are currently many unanswered questions concerning surgical techniques for Parkinson's and further research is necessary. At the present time, researchers are unsure as to how long beneficial results may last or if any procedures may delay the progression of Parkinson's.

Another possibility is that the best symptom control may be obtained by using a combination of surgical techniques or the insertion of additional electrodes into other regions of the brain. This may result in the surgery being more effective with fewer side effects for some people. The questions need to be addressed in further clinical trials. Future surgical therapeutic options, which currently remain experimental, are aimed at replacing and/or restoring the dying dopamine cells. There have been many exciting developments in surgical treatment for Parkinson's in recent years and the future looks promising.

Although we know that surgery for people with advanced Parkinson's can produce clear, short-term improvements, we do not know when is the best time to perform the surgery. It is important to find out reliably which of these strategies is the best. Also, in a disease with a long time course such as Parkinson's, it is very important to assess the long-term impact of surgery on the daily life of people with Parkinson's (and on their carers).

Is further information available on surgery in general?

The main source of information and advice is your consultant, who can refer you to a neurosurgeon if appropriate. Each person with Parkinson's will have his or her own questions and concerns about surgery. It is important for people who are considering surgery to ensure that they fully understand the procedure involved, the possible benefits and potential risks. It may be helpful to ask how often the neurosurgeon has performed the proposed procedure and what results they have achieved so far.

Questions to ask before surgery

A surgical Parkinson's Disease Nurse Specialist can deal with some of the questions that patients often ask before deciding to have surgery.

The answers may vary according to the hospital, type of treatment and surgical procedure, and the patient themselves.

The following questions are frequently asked:

How will the operation help me?

It is not a miracle cure but, in most cases, it will help to alleviate some of your Parkinson's symptoms, such as slowness of movement, stiffness and tremor. It should give you a better quality of life with more 'on' time and less dyskinesia.

Will I be able to do things that I haven't been able to do for a long time?

Some patients are able to do many things that they haven't been able to do for years, such as turning over in bed, making coffee, doing up buttons, going shopping by themselves and playing cards. Some have reported that their sense of smell has returned.

However, you will still have 'on-off' times, need medication and will still have Parkinson's, which is a progressive disease.

What are the risks/side effects of surgery?

These will vary according to individual patients, so it is important to ask about this.

How long will I be in hospital?

Usually seven to ten days, although this varies from Centre to Centre, according to the technique used.

How long will I have to wait for surgery?

Waiting lists will vary according to each hospital.

Will my hair be shaved?

This will depend on the Centre you go to and there are pros and cons to hair shaving. If it concerns you, raise the matter with the hospital before you are due for surgery.

Will I be able to drive again?

This varies – you may be advised to refrain from driving for six months.

Can I go back to work?

Usually, those employed before having the operation can go back to work once they have made a full recovery from surgery.

How often do the batteries in the Implantable Pulse Generator (IPG) or pacemaker need to be changed?

The batteries have a relatively long life and only need to be changed every three to five years, depending on stimulator settings.

Where does the wire go to connect the IPG from my brain?

It goes from the top of the scalp, underneath the skin, and down the side of the neck to the IPG, generally by the collarbone or sometimes in the abdomen. Sometimes the wire can get tight so it is important to keep moving your neck after the operation.

Can I go through security machines at airports?

No. The IPG will probably activate the security machines so you must inform airline staff and walk around machines. Ask to be provided with documentary evidence that you can present to the security staff.

Can I travel by plane?

Yes.

Can I have an MRI scan?

You should discuss this with the surgical team and see page 17 of this booklet for more information on this.

Will my medication decrease after the operation?

This varies from person to person. However, after successful surgery, doses of levodopa can usually be reduced by about 40–50%.

Can I have diathermy or ‘deep heat’ after DBS?

No. This can cause permanent nerve or tissue damage in people who have had DBS, and can be potentially fatal.

How often do I have to come back for treatment after surgery?

Usually people are asked to come back after six weeks, three months, six months and 12 months. This will vary among hospitals and the type of treatment.

Further sources of information

www.rewiredforlife.org

The Re-Wired for Life Foundation is a US-based non-profit organisation, created to promote the understanding of deep brain stimulation (DBS). This site offers assistance to patients in dealing with their day-to-day condition before, during and after surgery; and offers related educational and information services as they become available.

www.medtronic.co.uk

This site has a section on Parkinson's and provides information about different forms of treatment, particularly deep brain stimulation.

[Parkinson's Disease Society of the United Kingdom](http://www.parkinsons.org.uk)

The Society offers a comprehensive website and freephone Helpline staffed by advisory nurse officers. A range of useful information resources is available, including booklets, information sheets and leaflets.

www.parkinsons.org.uk

Glossary

Akinesia – lack or marked slowness of voluntary movements; the inability to initiate such action.

Amantadine – a drug used to treat Parkinson's.

Apomorphine – a dopamine agonist drug, used to treat Parkinson's, which is administered by subcutaneous (under the skin) injection or infusion pump. Other administration methods include nasal (via the nose), and sublingual (under the tongue).

Basal ganglia – part of the brain that controls movement. It is a collection of associated cell groups that includes the substantia nigra, which produces dopamine, striatum where dopamine is released, caudate nucleus, putamen, globus pallidus and subthalamic nucleus.

Computed Tomography (CT or CAT scan) – a method of analysing brain structure by passing narrow X-ray beams through a person's head from several angles to produce measurements from which a computer can construct an image of the brain.

Dopamine – a neurotransmitter produced by cells in the substantia nigra, within the basal ganglia in the brain.

The function of dopamine is to modulate the messages sent from the brain to other parts of the body, particularly those involved in the co-ordination of movement. People with Parkinson's have a shortage of dopamine.

Dyskinesia – involuntary or abnormal movements that can affect any part of the body.

Can be caused by some anti-Parkinson drug therapy.

Dystonia – a movement disorder characterised by a sustained involuntary contraction of the muscles, causing the affected

part to go into spasm. It can be associated with the wearing off of the effects of the drug levodopa before the next dose is due, or as part of the condition of Parkinson's itself.

Globus pallidus – a small part of the brain that regulates specific body movements. It is the target site for the surgical treatment pallidotomy, and one of the sites for deep brain stimulation.

Implantable Pulse Generator (IPG) – a small unit used in deep brain stimulation. It is implanted (under general anaesthetic) under the skin in the chest, rather like a pacemaker. The IPG contains the battery and electronics to generate the electrical signals for the stimulation. The IPG is programmed by the clinician using a computer, but on a day-to-day basis the stimulation can be switched 'on' and 'off' by the person with Parkinson's using a hand-held programmer or a magnet.

Lesion – in neurosurgery, the term lesion is used to describe any deliberately performed damage to a targeted region of the nervous system.

Levodopa – a natural amino acid that the brain converts into dopamine. Drugs containing levodopa, such as co-careldopa (Sinemet) and co-beneldopa (Madopar), are used to treat Parkinson's.

Magnetic Resonance Imaging (MRI) – a method of analysing brain structure and function that involves placing a person in a strong magnetic field and directing radio waves at them. The magnetic field causes the nuclei of hydrogen atoms in their body tissue to align themselves in a certain direction, in a certain energy state. The radio waves deflect them, and when these waves are switched off and the nuclei swivel back, they remit electromagnetic signals, which can be processed into a series of layered images.

‘On/off’ syndrome – describes the abrupt and unpredictable changes in mobility of some people with long-standing Parkinson’s who take levodopa. In the ‘on’ state, people can move and in the ‘off’ state they can be virtually immobile. Individuals can switch from one state to the other in a matter of minutes or even seconds.

Subthalamic nucleus – part of the basal ganglia; a target site for deep brain stimulation.

Thalamotomy – a surgical treatment for people who have bad tremor with their Parkinson’s. It involves making a lesion in the part of the brain called the thalamus.

Thalamus – part of the brain that is an important relay centre for sensory information to the cortex. It is the target site for the surgical technique thalamotomy.

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January 2007 Code B123