

In this article...

- How deep brain stimulation can alleviate Parkinson's disease symptoms
- A patient's experience of deep brain stimulation surgery
- The role of the deep brain stimulation specialist nurse

Use of deep brain stimulation to reduce Parkinson's disease symptoms

Key points

Treatment for Parkinson's disease largely involves increasing doses of dopaminergic drugs

Deep brain stimulation aims to improve patients' motor performance and quality of life

This technique is not suitable for everyone and adhering to patient selection is crucial to ensure the best outcomes

Research suggests that deep brain stimulation improves patient survival time and means they are less likely to be admitted to a care home

Specialist nurses are involved from patient selection through to long-term management

Authors Deidre Wild is honorary senior research fellow, Faculty of Health and Life Sciences, Coventry University; Caroline Norris is deep brain stimulation specialist nurse, Deep Brain Stimulation Service, Bristol Brain Centre, Southmead Hospital, Bristol.

Abstract Deep brain stimulation is a neurosurgical intervention that aims to improve motor performance and quality of life in people with Parkinson's disease, while enabling the reduction of levodopa medication. Although not a cure, it gives respite from the adverse motor symptoms of Parkinson's disease for most suitable patients, thereby releasing the potential for a new lease of life. This article explains the procedure, the process for selecting patients for surgery, and the role of the specialist in supporting patients before and after surgery. It includes the perspectives of a retired nurse in the later stages of Parkinson's disease and her deep brain stimulation specialist nurse.

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It is estimated that 145,000 people in the UK have Parkinson's disease (Parkinson's UK, 2018). This chronic neurodegenerative disease predominantly affects older people and is clinically characterised by akinesia (loss of voluntary movement), tremor, rigidity and postural instability. It is primarily caused by dopaminergic neuron degeneration of the substantia nigra, a nucleus located in the midbrain that is primarily involved in controlling muscle movement (Hughes et al, 1992). At present there is no cure for Parkinson's disease; treatment largely rests on increasing dosages of dopaminergic drugs according to the progression of symptoms.

Deep brain stimulation

Deep brain stimulation (DBS) is a neurosurgical intervention that involves implanting electrodes into the brain to deliver stimulation with the aim of improving motor performance and quality of life in people with Parkinson's disease. It can be conducted

under a general anaesthetic, although some surgical centres prefer the patient to be awake. An electrode, with four or eight contact points, is implanted into each part of the bilateral brain tissue of the subthalamic nucleus (STN), responsible for motor movement. Access to the STN is gained through two small incisions and holes made in the skull (Fig 1).

Positioning of the electrodes is determined by magnetic resonance imaging (MRI) scans undertaken before surgery; to reduce patient movement such as dyskinesia, the MRI scans are conducted under general anaesthetic. Once the electrodes are in situ, they are brought together behind the left ear before continuing downwards to connect with a neuro-stimulator inserted below the left clavicle (Fig 1).

A patient hand-held remote device permits communication with the neuro-stimulator once the system has been activated and its main stimulation parameters set. This device allows the patient to check

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Fig 1. Deep brain stimulation surgical incision sites

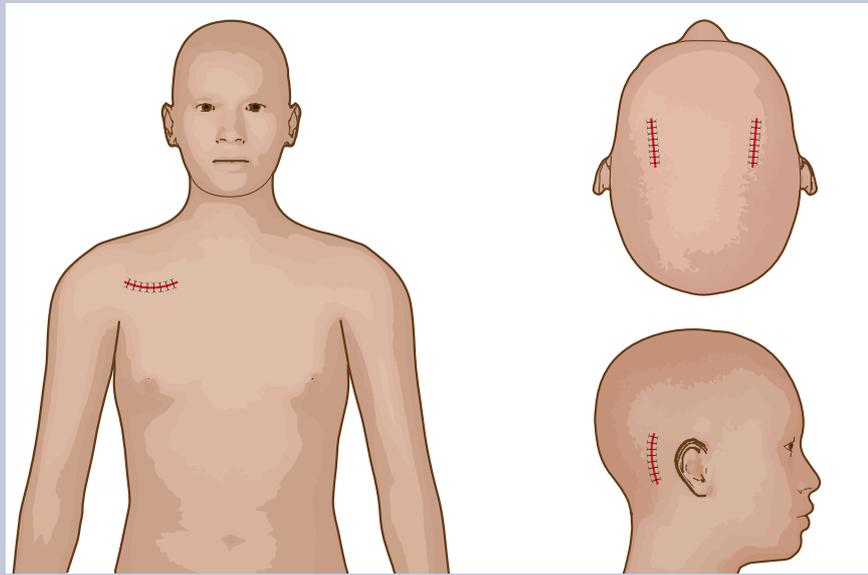


Table 1. Adverse events reported after DBS surgery

Type of SAE	n (%)
Infection	16 (37)
Post-operative confusion	5 (12)
Haemorrhage (including one death)	4 (9)
Urinary retention	4 (9)
Seizures	2 (5)
Pulmonary embolism	2 (5)
Neck pain	2 (5)
Other	8 (19)
Total	43 (100)

DBS = deep brain stimulation. SAE = serious adverse event. * SAEs (n=43) occurred in first year post DBS surgery in 36 of 183 patients

Source: Adapted from Williams et al (2010)

the system is working and make simple changes between hospital appointments, such as reverting to a previous programme or switching the stimulation off and on.

Patient selection

Patient selection for DBS is crucial to ensure the best and safest surgical outcome (Honey and Ranjan, 2012); key inclusion criteria are:

- Idiopathic Parkinson's disease;
- Good response to levodopa medication;
- No diagnosis of psychosis or dementia (Groiss et al, 2009).

Possible adverse events

The potential for serious adverse events (SAEs) arising from DBS surgery was demonstrated in a collaborative study by 13 UK-wide neurosurgical centres (Williams et al, 2010). A study population of 366 patients with Parkinson's disease were assigned to one of two groups: those who had undergone DBS with Parkinson's disease medication (n = 183) and the same number who had Parkinson's disease medication alone. At the end of the first year, 36 (20%) DBS participants had experienced a total of 43 surgery-related SAEs (Table 1).

Uptake and outcomes

One may wonder why the number of patients with Parkinson's disease who benefit from DBS is not higher. Aside from selection criteria, other barriers to its uptake have been reported as:

- Unpredictable results and side-effects;
- Some clinicians' reluctance to refer patients for surgery;

- Procedural costs;
- A shortage of personnel trained in DBS programming;
- Long waiting lists;
- A general fear of 'brain' surgery (Abosch et al, 2013).

Despite such barriers, for those selected for DBS, some positive research outcomes have been reported. In a recent study of 147 patients with Parkinson's disease, 106 underwent DBS and the remaining 41 continued to be treated medically (Ngoga et al, 2014). The two groups were matched for age, gender, ethnicity, duration of disease, rates of pre-existing depression and use of dopaminergic medications. Statistically significant outcomes over a decade suggest that individuals in the DBS group have a longer survival time and are less likely to be admitted to a residential care home.

Patient's perspective

I am a 72-year-old retired nurse; around 12 years ago I was diagnosed with Parkinson's disease. After observing me walking,

by way of a diagnostic explanation, my consultant said: "Unfortunately, Joan,* you do not swing your right arm."

For the first eight years my symptoms were well managed by increasing the oral dose of ropinirole, a synthetic dopamine agonist. When I reached the highest daily dose recommended (24mg), a combination of carbidopa and levodopa was prescribed. For the next three years, I was again well managed until I reached the point when, although my tremor was controlled effectively, my medications were beginning to contribute to dyskinesia (involuntary muscle movement), mainly of my upper torso. The dyskinesia would begin mid-afternoon and last until I got into bed, thus my social life evaporated, particularly in the evenings. Box 1 comprises a diary entry, made three weeks before my DBS neurosurgery and is akin to the findings of Mathers et al (2016) in terms of symptoms causing a sense of loss from life. Fortunately, my consultant neurologist suggested that I might benefit from DBS neurosurgery.

Box 1. Case study diary extract: loss from life before DBS surgery

17 January 2017

Best description of my current state is one of a creeping erosion of my control on life, with the following being its most irritating features:

- Dyskinesia - it shortens my day
- Pain and stiffness in right leg, particularly during the night
- Sleeplessness (night) and sleepiness (day)
- Balance - "a fall waiting to happen"
- Not always able to spontaneously recall words
- My partner sometimes seems, to me, to be overprotective/bossy but perhaps I have forgotten that, just as my life is imploding, so too is his

Box 2. Potential adverse effects of DBS neurosurgery

- Infection
- Haemorrhage/stroke
- Seizures
- Urinary retention
- Pulmonary embolism
- Post-operative confusion

Source: Adapted from Groiss et al (2009)

Selection process

In my selection process, conducted nine months before surgery, I was admitted as an inpatient having been taken off medication the previous night. I was given a series of physical and psychological tests. Without medication, I found the physical tests difficult to complete, and was shocked to experience the severity of my Parkinson's disease symptoms when unmedicated. However, after a dose of levodopa I repeated the tests without difficulty.

Although Parkinson's disease is commonly considered only to affect motor movement, it also has non-motor autonomic and sensory symptoms including difficulty in swallowing, bladder and bowel irregularities, and altered temperature regulation. Of the psychiatric disorders, there is a heightened risk of developing dementia (Garcia-Ptacek and Kramberger, 2016); my suitability for DBS surgery therefore included a detailed medical history and psychometric tests to rule out dementia. I was declared a suitable candidate and placed on the waiting list.

At every pre-operative medical or surgical consultation, I was made aware of the potential for SAEs arising from DBS surgery (Box 2). The most common SAE was infection, which had occurred in just under 9% of patients; the frequencies of the others were 5% or less so I took a pragmatic stance – I decided that the case to proceed was far more persuasive than the one to not do so.

The day of surgery

By 5am at home I was showered and dressed, munching on a piece of toast, which was my last permitted meal. Six hours later I was admitted to the neurosurgical unit for pre-operative preparations. Then it was on with my theatre gown and stockings to prevent deep vein thrombosis before a chat with the anaesthetist. I took pleasure in reporting that I had stopped smoking three months earlier, as it made no sense to have a smoker's cough after my operation!

Despite my outer calm, there was certainly something particularly scary about the prospect of neurosurgery, which was reflected in the type of questions it raised in my mind: Would I be the same person after it as I had been before? How would I know if I had changed? My fear was quite simply of the unknown and, as I waited for my surgery, I felt extremely alone and vulnerable. However, once I had been collected, I walked into theatre and put myself in the safe hands of an experienced neurosurgical team.

As if no time had passed, I was in a bed back in the room where I had been first admitted and a voice was saying: "Joan, all over now – everything just fine. Are you warm enough?" All I could think was that I should at least have a headache – but not so then or at any time since. The neurosurgery had taken 5.5 hours, most of which involved further MRI scans to ensure the electrodes had been placed correctly.

“Deep brain stimulation has given me back a sense of normality in terms of how I am perceived visually by other people...and my dyskinesia... is now almost non-existent”

I remained in hospital under observation for two days post-operatively. The small number of sutures were removed a week after surgery by my practice nurse, after which I was permitted to shower and wash my hair using baby shampoo. What felt like a lump on my chest wall, where the neurostimulator had been implanted was, in fact, barely visible.

Keeping my feet on the ground – realistic expectations

The electrodes were not activated for just over a month to allow my incision sites to heal and any post-operative brain swelling to reduce. Mathers et al (2016), in a qualitative study of post-operative patient experiences of DBS, suggest that during this period, patients seek to establish a new normality based on how they perceived themselves to have been before having Parkinson's disease. I did try to keep my expectations low to avoid disappointment, but not so my partner, who mentally lined up all the activities he perceived we could resume in our life ahead.

The day my electrodes were 'switched on' was the pinnacle of a 10-month wait and

involved the honed observational skills of my DBS specialist nurse as she gauged my functional performance according to different stimulation settings. She describes her role in more detail below.

Now, over a year since my surgery, DBS has given me back a sense of normality in terms of how I am perceived visually by other people. The reduction in my medication has a hugely beneficial effect on my dyskinesia, which now is almost non-existent. As a result, I go out more; I am more sociable and I contribute more readily to my friendships. I have better concentration and working at a computer is less challenging. Overall, I have recovered my confidence and can live life to the full.

The DBS specialist nurse's role

My work involves autonomous practice as well as collaborative working with neurologists and neurosurgeons in selecting candidates for DBS and managing their pre-operative, post-operative and longer-term care. I have to be competent in assessing patients using the Movement Disorder Society Unified Parkinson's Disease Rating Scale (MDS-UPDRS) (Goetz et al, 2008). It is also important to assess cognitive and other psychological disorders as well as non-motor physical symptoms, such as swallowing difficulties, constipation and urinary problems. While some beneficial effects have been reported for DBS in reducing non-motor symptoms, more objective research is recommended (Kurtis et al, 2017).

Use of DBS technology

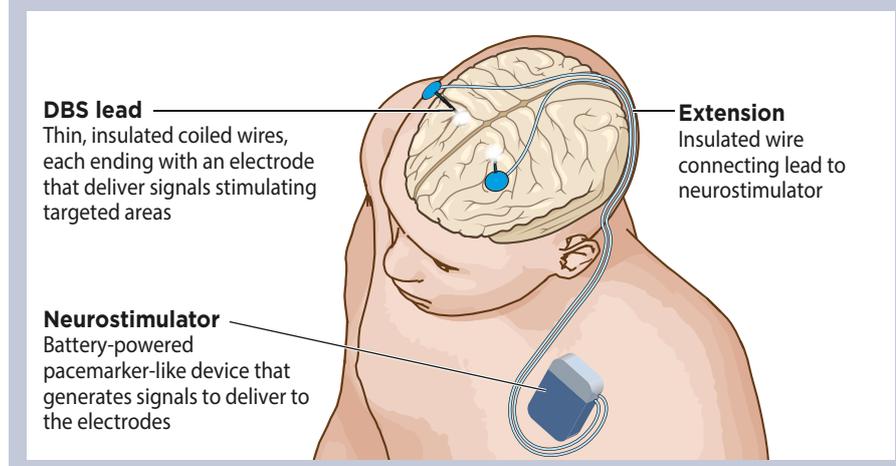
Competence in using the DBS technology that programmes the neurostimulator to deliver electrical stimulation is an essential part of my post-operative patient care-giving. Within the last decade, the accuracy and safety of DBS has been improved using image-guided planning for precision implantation of the electrodes (Khan et al, 2010). Barbe et al (2014) reported on the benefit gained by a patient from a DBS system that reduces Parkinson's disease symptoms without inducing new ones. However, the accuracy of the electrodes' positioning is paramount; if this is not achieved, the system cannot overcome or compensate for this inaccuracy (Steigerwald et al, 2016).

Side-effects

Both the effectiveness and side-effects of stimulation depend on which brain matter responds to the density of electrical current (Bronstein et al, 2015). Each implanted

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Fig 2. The stimulator in situ



electrode is a unique point of contact through which stimulation to a designated area of the brain can be adjusted if the patient experiences side-effects. Even small variations in current can induce unintended side-effects; this can lead to the dilemma of choosing suboptimal stimulation parameters to avoid side-effects at the cost of achieving optimal suppression of motor symptoms.

Buhmann et al (2017) showed that 23% of 82 patients with STN-stimulated Parkinson's disease experienced gait disorders, speech problems, weight gain, urinary incontinence and psychological problems (including depression and apathy) following DBS surgery; the severity level was mild to moderate in 15 of the 18 patients with symptoms. The authors concluded that the relationship between DBS and quality of life is not clear cut and comprises a trade-off between neurological wellbeing with other comorbidities and disease progression.

Activating the electrodes and optimising stimulation

I asked Joan to attend the outpatient clinic having come off her medication for Parkinson's disease from 6pm the evening before so that her motor symptoms could be assessed before her electrodes were activated. When they were activated in sequence using different stimulation currents, the symptoms on each setting were observed comparatively for improvements or side-effects. The activation process lasted around 2.5 hours, by which time patient fatigue had set in. This is the most common factor that, if unaddressed, can undermine the validity of the outcomes.

After a discussion with Joan, one of the two electrodes was selected for further

stimulation on the basis of its greater ability to control her symptoms under test conditions as well as giving her the most comfort. By improving her bradykinesia (slowness of body movement), she was aware that her right arm was swinging spontaneously and her gait was more fluent and controlled. Although she experienced mild dyskinesia, she felt she was functioning well. The consultant neurologist advised a medication regimen, based on Joan's positive response to stimulation. The new levodopa dosage was markedly reduced from her pre-DBS dose.

The time taken to optimise stimulation and reduce medication varies; for some patients it can take 4-6 months, whereas for others it can take up to a year.

Long-term care

An important part of my role is to provide psychological support to enable patients (and their families) to set realistic goals for the future. As Parkinson's disease progresses, patients will most likely be the first to know that their symptoms are becoming less well controlled by DBS. Although attempts will be made to manipulate their stimulator settings to improve motor control, it is likely that medications that were reduced or stopped after DBS surgery may eventually need to be increased or re-introduced. When this occurs, it is likely that stimulation will no longer be effective.

Conclusion

Deep brain stimulation offers suitable patients with Parkinson's disease an opportunity to improve their motor performance and quality of life. The role of the DBS specialist nurse is crucial; it informs and supports patients through the pre- and post-operative assessments, as well as engaging

them in the complex neurostimulation decision making that is at the heart of making DBS a successful intervention. **NT**

● The patient's name has been changed.

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