

# MY DEEP BRAIN STIMULATION JOURNEY

LIFE WITH PARKINSON DISEASE



PAGE

**05** Evaluation and preparation

PAGE

**08** Admission and surgery

PAGE

**12** Care after DBS surgery

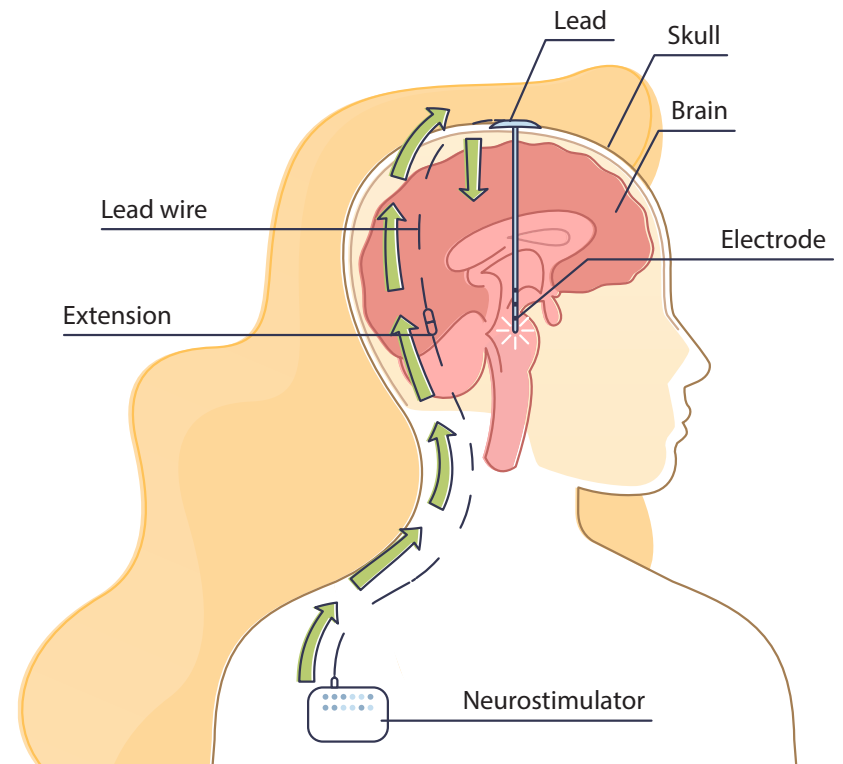
PAGE

**16** Living with the DBS device

Parkinson disease (PD) is a neurodegenerative condition that affects nearly 10,000 people of all races in Singapore. Coping with the disease is a lifelong journey for People with Parkinson (PwP) and their caregivers. Although there is no cure at present, effective therapies are available to manage the condition.

Deep Brain Stimulation (DBS) is an effective, proven therapy for PwP which has been available for more than 25 years. Close to 200 patients in Singapore and over 160,000 patients worldwide have benefitted from DBS therapy.

DBS surgery may be advisable for patients whose symptoms are not well controlled with medications and/or experience significant side-effects from their medications. Your neurologist will discuss with you if DBS is a potential option to help you manage your symptoms.



In DBS, small wires (electrodes) are inserted into the deep structures of the brain, such as the subthalamic nucleus (STN) and globus pallidus interna (GPI). They are connected to a neurostimulator which is placed under the skin just beneath the collarbone. The neurostimulator provides the optimal amount of electrical current to stimulate the appropriate brain structures. This stimulation helps to improve motor symptoms such as tremor, stiffness, slowness as well as motor fluctuations and dyskinesia/dystonia that significantly affect a patient's quality of life.

# Evaluation and preparation

DBS is generally considered to be of low risk. However, any type of surgery carries inherent risks of complications and side effects. These include surgical risks such as bleeding, infection, injury to underlying structures, device malfunction, disconnections and stimulation side effects.

Your multi-disciplinary team will assess and advise if you are suitable for the procedure.

This book serves as a companion and guide for your DBS journey. It is important to understand what the procedure involves and what it is like to live with the DBS implant. Information about DBS is also available via video (scan QR codes). You may also want to speak to someone who has done DBS and our staff can help to arrange this for you.

*Please bring along this booklet for all your DBS related appointments.*

*Note: This booklet only serves as a general guide. Your healthcare team will provide you with specific advice based on what is most appropriate for you. Do check with your healthcare team should you have any questions or concerns.*

## Scan for videos about the DBS journey



Before the DBS surgery, you will need to undergo a series of evaluations conducted by a multi-disciplinary team to determine if DBS is suitable for you.

### Levodopa challenge test (also known as on-off test)

You will be scheduled for this test to assess your motor responsiveness to levodopa medication. If your motor symptoms improve with levodopa, you are also likely to respond well to DBS.

During the on-off test, your motor symptoms will be assessed during medication “off” and “on” states. The test takes about two to three hours, and is usually done in the outpatient setting, which means you do not need to be hospitalised.

#### Instructions for the on-off test:

- Stop all PD medication for at least 12 hours. For example, if your test is scheduled on a Tuesday at 8.30am, you should stop all PD medications by 8.00 pm on Monday. Do not take your PD medications on Tuesday morning.
- Eat a light breakfast, e.g. oats, plain bread before 7am on the day of test.
- Bring your PD medication with you to your on-off test appointment.
- Take your PD medication only when you are instructed to during the test.
- Bring along your reading glasses if needed as the test involves reading paragraphs.
- You are advised to have a relative accompany you for the test.
- Wear comfortable clothings and shoes.



Your specialist nurse will explain DBS in greater detail to you and your caregiver. DBS models are also available for you to experience and visualise life after DBS.

### Other assessments required:

Conducted by	Assessment
Physiotherapist	Walking and movement
Occupational therapist	Activities of daily living (ADL), e.g. ability to get dressed, coping strategies at work
Speech therapist	Swallowing and speech
Dietitian	Nutritional status if needed
Neuropsychologist	Cognition (thinking ability) and emotion
Neurosurgeon (who performs DBS)	Your suitability and potential risks for DBS

The neurosurgeon will also share more about the DBS surgical procedure and answer any questions/concerns that you may have.

### If you are suitable for DBS surgery:

A date will be scheduled for the surgery, and consent will be obtained from you. A detailed brain magnetic resonance imaging (MRI) scan will be booked prior to admission to help your neurosurgeon plan the surgery.

Financial counselling and Pre-Admission Counselling and Evaluation (PACE) clinic appointment will be arranged.

#### Financial counselling

Financial counselling will help you estimate the cost of your DBS surgery. Insurance, Medisave, and Medishield Life claims will vary depending on the individual circumstances. If there are financial concerns, you will be referred to our medical social worker who will assist to apply for further subsidies.

#### Pre-Admission Counselling and Evaluation (PACE) clinic

You will also need to visit the PACE clinic to determine your fitness for anesthesia and surgery. An anaesthetist or trained specialist nurse will assess your medical condition and advise on all medications. They will also inform you of pre-operative and admission instructions.

Please bring along your full medication list and regime. Take note of any special instructions prior to surgery, such as stopping blood thinning medication, selegiline and other medications as necessary.

# Admission and Surgery

## Day before surgery

You will be admitted one day before the surgery for preparation. Write down all your current PD medication doses and pass this list to the doctor in charge of the ward for easy reference.

*For example*

Medication	Dosage	Time each dose is taken
Madopar	187.5mg (3/4tablet) 6 times a day	6am, 9am, 12pm, 3pm, 6pm, 9pm
Ropinirole	1.5mg 3 times a day	6am, 12pm, 6pm

DBS surgeries are usually scheduled in the morning. You will be instructed to stop all your PD medication by 8 pm the day before surgery and to fast from midnight onwards. Your ward doctors and nurses will instruct you about other medications and instructions related to the surgery.

## Day of surgery

You will be brought to the operating theatre (OT). Your surgeon will shave and clean your entire head at the OT. Local anaesthesia will be administered and a metal head frame will be applied in place over your head. You will then undergo a Computed Tomography (CT) brain scan for final planning to ensure the electrodes are precisely inserted into the correct location within the brain.



Photo courtesy of fidsMED.

Metal head frame for DBS surgery.



Next, your head will be cleaned again and sterile drapes will be placed around your head. You will still be able to see and speak to people in front of you and move your hands and/or legs. As there will be infusion lines and monitoring cables attached to your body, do inform the OT staff before you make any movements.

The neurosurgeon will drill a small hole into the skull and insert the electrodes into the targeted location. Your brain waves will also be recorded. The drilling and brain waves recordings might be noisy, but rest assured that you will be comfortable during the surgery.

The PD specialist doctor or nurse will also be in OT to perform examinations on you when the electrodes are inserted and stimulated. This is to check your body's response to the stimulation and to rule out any side effects of the electrode placement. In order to do so, they may ask you to perform some tasks such as moving your hands and/or arms, speaking in short sentences, looking to the left or right. You should also report to the doctor or nurse if you experience arm or leg cramps, numbness or any discomfort.

After insertion of the electrodes on both sides of the brain, you will be given general anaesthesia to let you sleep. The battery will then be implanted under your collar bone and connected to the brain electrodes.

You will have at least three skin wounds after the surgery:

- One on top of the head where the electrodes have been inserted.
- One behind the ear where the wire connecting the electrodes to the battery runs.
- One on the chest where the battery has been placed.

## After surgery

You will be monitored in the Post Anesthesia Care Unit (PACU), and subsequently in High Dependency Unit or Intensive Care Unit for at least one night. A post-operative scan will be performed when the condition permits.

Once you are medically stable, you will be transferred to the general ward for the next one to two days. You may be assessed by our allied health team (physiotherapist, occupational therapist, speech therapist) before your discharge.

While you are in the ward, you and your caregiver will be educated on the DBS surgery aftercare including wound care. You will also be given an educational booklet about the DBS system and a temporary implant card. Outpatient appointments will be arranged with the team.

At this point, the device will not have been turned on. Your PD team will schedule an appointment for programming after your wounds have healed.



# Care after DBS surgery

## Do's and don'ts for 2 weeks after the operation

### Do's:

- ✓ Continue with your diet as it was pre-surgery unless instructed otherwise.
- ✓ Eat more fruits and vegetables and drink adequate water to prevent constipation.
- ✓ Continue with Parkinson medications as per pre-surgery unless instructed otherwise.
- ✓ Continue with your usual activities of daily living as much as possible.
- ✓ Continue to engage in low impact exercise regularly as tolerated.
- ✓ Call your doctor/nurse or go to the emergency department immediately if you experience blurring of vision, loss of speech, limb weakness, difficulty in swallowing and/or seizure symptoms.

### Don'ts:

- ✗ Exercise or do movements that may increase your risk of falls, e.g. climbing on chairs to reach objects.
- ✗ Carry heavy objects above 5kg and weight lifting.
- ✗ Participate in exercises that pose a risk of physically striking the battery or the connecting wires.



## Wound care

- Keep all wounds clean and dry.
- Hair washing and showering are possible, following the instructions from your surgical team.
- Wash your hands frequently to prevent germs from getting into the wounds.
- Your doctor may prescribe antibiotics to prevent wound infection. Do complete the course of the medication.
- The type of wound dressing may vary for each individual. Follow the wound dressing and care instructions as advised by your surgical team.
- Call your doctor/nurse if there are any signs of wound infection such as redness, warmth, pain, swelling, incision gaping (opening of the wound) or fever of more than 38.0°C.
- Do not touch or scratch the wounds.
- Do not apply ointment, lotion or powder on the wounds, unless instructed.
- Avoid running, swimming or activities that may stretch the implants or affect your wounds. Check with your doctor/nurse if you need to resume such activities.

## DBS Programming

The DBS battery is usually turned on one month after DBS surgery. A detailed programming session, which takes about four to five hours, is performed at the outpatient clinic. The programming session is usually done when you have been off medication for 12 hours, similar to when the on-off test was performed. This is because PD symptoms are more obvious during the "off" time, and the improvement from stimulation will be more visible.

### Turning on the DBS battery

During the session, your care team will use a tablet to control your battery remotely to find the best stimulation setting for you. Effects and side effects of the stimulation will be assessed.

You may be asked to perform tasks like speaking, moving your hand, leg and eyes. Let your team know if you experience any cramping, tingling sensation, difficulty in speaking, etc.

After the optimal setting has been determined, your Parkinson medications may be reduced based on your condition and you will be instructed accordingly by your Parkinson specialist doctor and nurse.

### Complications

Complications like dyskinesia, speech problems, mood changes, etc. may arise during the first few weeks after the DBS is turned on and programmed. If these happen, contact your doctor or nurse. Further fine tuning of the setting may be required and regular follow up is necessary.



Devices for DBS Patient Programmer

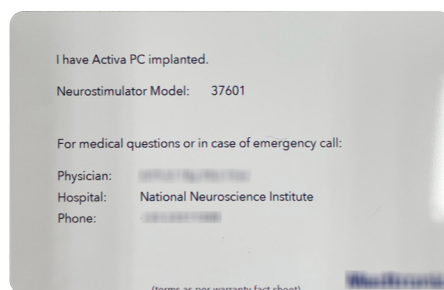
### General advice

You or your caregiver will be taught how to use the patient programmer to turn the DBS system on or off, or check the battery of the DBS system, and adjust settings within limits set by the care team. However, do avoid turning off the DBS system. If the device is turned off for some reason, you may use the patient programmer to turn it back on again. If in doubt, please contact your doctor or nurse.



## Caring for your device and you

- Do not place any electrical or magnetic device on your battery, connecting wires, or implant. Please refer to the DBS system's educational booklet for more details.
- You may use simple daily electrical devices such as vacuum cleaner, radio, computer, kitchen appliance. Avoid using electrical appliances that produce a large magnetic field, e.g. large stereo speakers, as these may turn off your DBS battery.
- You will be given two wallet-sized implant cards after the surgery. One is to be carried with you all the time and can be shown when needed, e.g. airport security, radiographers. The other one is to be kept safely at home as a spare.
- Your PD medications may be adjusted after DBS programming. Do follow your medication regime accordingly.
- It is essential to continue exercise and rehabilitation after DBS surgery.



Implant card

## DBS Battery

The neurostimulator with the battery inside is also known as an 'implantable pulse generator' (IPG), serves as a power source to provide electrical energy to regulate the abnormal signals in the brain for symptom control.




There are 2 types of batteries: non-rechargeable and re-chargeable.

The life span of the battery depends on the amount of current required for each individual's DBS settings. A non-rechargeable battery on average will last between three to six years. This battery is generally recommended for the first insertion of the DBS implant.

The rechargeable battery requires weekly charging and may last up to 15 years. At the last year of battery life, an elective battery replacement will be arranged.

You are advised to check your DBS stimulator battery regularly by using the patient programmer.

The chart below explains the type of icons you may see on your patient programmer's screen:

Self-DBS programmer	What does that mean?	What should I do?
EOS 	Battery has depleted	Kindly call your PD team immediately for replacement of IPG
ERI 	Battery is close to end of service. Require more frequent monitoring	Kindly call your PD team to schedule for replacement of IPG
OK 	Battery is OK	No action is required

When the battery runs out, you will experience worsening of PD symptoms and may require more medication. Changing of battery is usually performed as an outpatient procedure.

## Tests and Procedures

### Diagnostic X-ray / Computed Tomography (CT) scan

- In general, it is safe for patients with PD who have DBS implants to undergo CT scans or X-rays without turning off the DBS neurostimulator (battery). However, if the battery is directly exposed under the ionizing radiation of the CT scan (i.e. the battery is in the imaging field of view such as in CT scan thorax), it is advisable to turn off the DBS battery before the scan.

### Magnetic Resonance Imaging (MRI)

- You will be assessed for your eligibility to undergo MRI scans on a case-by-case basis depending on the DBS implant model and circuit integrity (the electrical conduction of your DBS system). Please contact your doctor or nurse for advice and discuss with your radiologist before the scan is ordered. DBS devices need to be turned off during the MRI scan. If eligible for MRI, you will need to have the DBS system's circuit integrity checked both before the battery is turned off for the scan and after the scan when it is turned back on.

### Invasive procedures and surgery

- You will not be able to undergo therapeutic diathermy (i.e. ultrasound heat treatment, shortwave and microwave diathermy).
- If you have to undergo an invasive procedure e.g., Oesophago-Gastro-Duodenoscopy, Colonoscopy or any surgery, please contact your doctor or nurse for advice. DBS devices need to be turned off for the procedure/surgery. You will need to have the DBS system's circuit integrity checked before and after the battery has been turned off and on respectively for the procedure/surgery.
- Electrical cautery, if required, should only be used in the bipolar mode during the procedure/surgery. Inform your doctor about this if you need to have surgery anywhere on your body.

Equipment related electrical energy transmission or electromagnetic interference may affect the operation or safety of DBS system. Contact your doctor or nurse for further information and assistance when needed.





## Travelling safely

- Plan your travel carefully ahead of time.
- Discuss your medication schedule with your PD doctor or nurse if your destination is in a different time zone.
- Bring along your implant card.
- Bring your DBS patient programmer and sufficient PD medication in your hand carry luggage.
- Bring your charger if you have been implanted with a rechargeable battery.
- Take your medication according to the schedule as discussed with your doctor/nurse.
- When passing through security checks, avoid walking through the metal detector and undergoing checks using handheld metal detectors if possible. Show your implant card to security staff and request for a manual body check instead.
- If you are required to walk through the metal detector, try to walk quickly through the middle to minimise the likelihood of the DBS system being turned off. If it turns off, use your patient programmer to turn it back on.

## Your DBS team members

01 | Neurologist:

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02 | Neurosurgeon:

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03 | Nurse specialist:

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04 | Physiotherapist:

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05 | Occupational therapist:

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06 | Speech therapist:

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07 | Neuropsychologist:

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08 | Dietitian:

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09 | Medical social worker:

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Do not hesitate to contact your DBS clinicians/nurse specialists/allied health professional team members for further information and assistance when needed.

## Checklist for DBS Journey

Date	Date	Done	Remarks
On-off test			
Physiotherapy			
Occupational therapy			
Speech therapy			
Neuropsychologist			
Neurosurgeon			
Financial counseling			
Medical social worker if needed			
Dietitian if needed			
MRI (brain)			
PACE			
Admission date			
Surgery date			
Discharge date			
Outpatient Neurosurgery review			
DBS programming			
Other important dates			
DBS booklet			
Implant card			
Patient programmer			

DBS notes:

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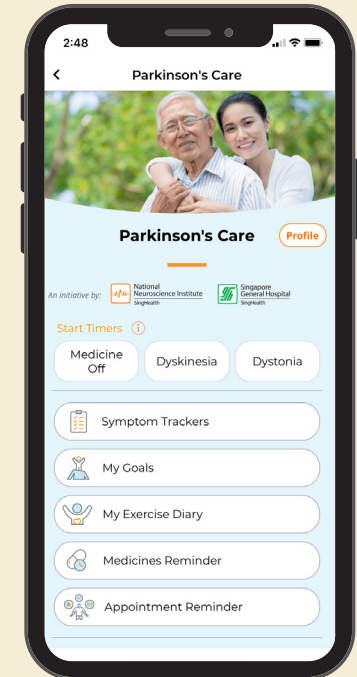


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# Parkinson's Care App Manage Your Symptoms

Track your Parkinson's symptoms and access useful videos, information and guides - all from your mobile phone!

- ✓ Medicine reminder
- ✓ Exercises to help with Parkinson's Disease symptoms
- ✓ Support Groups... *and more!*



Parkinson's Care is now available in **SingHealth Health Buddy!**

**Download** the App now!



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