Functional neurosurgery

# Pre-deep brain stimulation (DBS) assessments

## Information for patients, relatives and carers

## Introduction

This leaflet explains the tests you may need before deep brain stimulation (DBS) surgery to treat your Parkinson's. The tests will take place over several different days and include:

- the levodopa response test
- video assessments for tremor and dystonia
- brain scans
- neuropsychometry (a memory and thinking test)

We want this leaflet to answer some of the questions you or those who care for you may have. It is not meant to replace your consultation with your medical team. Our aim is to help you understand more about what you discussed.

## Levodopa response test (levodopa challenge)

The levodopa response test is part of the pre-assessments for people with Parkinson's. It confirms if deep brain stimulation (DBS) surgery is suitable for you.

There's a link between levodopa and DBS responses. We look for a response when we target the sub-thalamic nucleus (STN). This is one of the regions used to insert the DBS leads to manage Parkinson's symptoms.

We can also use the test to assess the onset, extent, and duration of the levodopa reaction. In later stages, we can check if symptoms, like gait problems, improve with a higher dose of levodopa.

## What is levodopa?

Levodopa is a chemical compound. It converts into dopamine in the brain. It's the gold-standard treatment for Parkinson's disease. It can also treat certain forms of dystonia.

## What do I need to do before the levodopa response test?

To allow us to assess your symptoms at their worst, do not take any of your Parkinson's medication:

- after 8pm the day before your test, or
- on the day of the test.

Please bring:

- all your Parkinson's medications
- your current prescription list
- any recent clinic or discharge letters

Feel free to eat an early light breakfast on the day of the assessment, no later than 7am,

Please wear comfortable clothing and shoes for the assessment. This makes it easier for us to check your movement, balance, and walking.

Keep yourself well-hydrated before the test. Aim to drink six to eight glasses of water per day the week before the test. This is to avoid problems with blood pressure (See What are possible risks and side effects?)

## What happens in the levodopa response test?

We will assess your Parkinson's symptoms using a clinical rating scale during an 'OFF' medication state. (We use the **MDS-Unified Parkinson's Disease Rating Scale – Part III**, or MDS-UPDRS III).

Afterwards, we'll offer you a high dose of Levodopa (Sinemet® or Madopar®). We'll repeat the assessment once your medications start working, during your 'ON' state. An improvement of more than 35 % correlates with a positive result after DBS surgery.

With your consent, we will video record these assessments. The DBS team will discuss these recordings when they meet before your surgery. These videos will be part of your medical records. We will hold them in a safe location.

To understand how Parkinson's disease affects you, we'll also assess you against different scales. The assessment takes about **four** hours. It may take longer if you experience side effects from levodopa.

## What are the possible risks and side effects?

The main side effects include:

- feeling sick (nausea). We may give you anti-sickness medication to control this nausea)
- being sick

- low blood pressure (hypotension) Remember to keep well-hydrated to help avoid this
- dizziness
- involuntary, writhing movements (dyskinesia)

# Video and scales assessment for tremor and dystonia

## What is the video and scales for tremor and dystonia assessment?

If you have a diagnosis of tremor or dystonia, one of the pre-DBS assessments is a video recording of your symptoms.

With your consent, we will video record these assessments. The DBS team will discuss these recordings when they meet before your surgery. These videos will be part of your medical records. We will hold them in a safe location.

We will complete additional scales to understand how tremor or dystonia affects you.

## What do I need to do before the video assessment?

Please stop all your tremor or dystonia medicines from 8pm the day before, unless you are told otherwise.

Please bring:

- all your medications
- your current prescription list
- any recent clinic or discharge letters

Feel free to take a light breakfast on the day of the assessment.

Please wear **comfortable clothing** and shoes for the assessment, as we will evaluate your movement, balance, and walking.

## When can I ask questions about the DBS surgery?

After the assessment, you can discuss the surgical procedure with a member of the team. Please bring a list of questions. You can also bring a family member or a friend who is involved in your care with you.

## What brain scans are needed?

The team will arrange brain scans to plan the path of the leads in the brain. This allows us to target the correct area and avoid major complications.

The scans will be:

- magnetic resonance imaging (MRI), a few weeks before surgery
- computerised tomography (CT), on the day of surgery

Significant tremors or involuntary movements can affect image quality, especially if they affect the head and neck. So, if you have these, you may need **general anaesthesia** or a mild sedation for the planning MRI.

Please talk to your neurologist or nurse specialist if you have any concerns or questions, or any potential reasons why you should not have an MRI scan.

## What is a neuropsychometry assessment?

You will have a memory, mood and thinking test called a neuropsychometric assessment. This is because these processes may be impaired in people with movement disorders. This can be a reason not to have surgery. We also assess your knowledge and expectations about the procedure. This visit lasts about four hours.

## What is the DBS multi-disciplinary team meeting?

The DBS team will review the results of the pre-assessments and confirm your suitability for DBS surgery. If you are considered suitable, the Neurosurgery coordinators will contact you as soon as a surgery date is confirmed.

The team may decide the risks of surgery outweigh the benefits for you and it is not considered suitable for you. Your neurologist may offer other **alternatives**. These include:

- Apomorphine, Produodopa ®, or Duodopa ®, for people with Parkinson's disease
- MR-guided focused ultrasound (MRgFUS) for people with tremor

You will be offered what is appropriate for your specific situation.

## Contact us

Please contact the **deep brain stimulation team** if you have any questions or concerns:

**Telephone secretary:** 020 3311 1182

**Email**: imperial.dbsenquiries@nhs.net

## Find support and advice

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| **Focused Ultrasound (FUS) Foundation** | **www.ukfusf.org and** www.fusfoundation.org/for-patients/ |
| **Dystonia UK** | **www.dystonia.org.uk/** |
| Email: | info@dystonia.org.uk |
| Helpline: | 020 7793 3651 |
| **Parkinson's UK** | **www.parkinsons.org.uk/** |
| Deep brain stimulation | www.parkinsons.org.uk/information-and-support/deep-brain-stimulation |
| Helpline: | 0808 800 0303<br>Free Parkinson's information and support helpline. Monday to Friday, 9am to 6pm and Saturday, 10am to 2pm |
| Text relay: | 18001 0808 800 0303 |
| Email: | hello@parkinsons.org.uk |
| **The National Tremor Foundation** | **www.tremor.org.uk/** |
| Deep brain stimulation | www.tremor.org.uk/about-tremor-menu/deep-brain-surgery |
| Focused ultrasound | https://tremor.org.uk/about-tremor-menu/focused-ultrasound |
| Email: | enquiries@tremor.org.uk |
| Helpline: | 01708 386399 |

## How do I give feedback about my visit?

We want to hear your **suggestions** or **comments**. Your feedback helps us provide the best service. You can always speak to a member of staff.

You can also contact the **patient advice and liaison service (PALS)** on **020 3312 7777** (10am to 4pm, Monday to Friday excluding bank holidays) or email at imperial.pals@nhs.net. The PALS team will listen to your concerns, suggestions or questions and they can help solve problems.

You can make a complaint by ringing **020 3312 1337 / 1349 or emailing** ICHC-tr.Complaints@nhs.net. The address is Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street, London W2 1NY.

## Other ways to read this leaflet

Please email us at imperial.communications@nhs.net if you need this leaflet in a different format. This could be large print, Easy read, as a sound recording, in Braille or in a different language.

## Wi-fi

Wi-fi is available at our Trust. For more information visit our website: www.imperial.nhs.uk

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