

Deep Brain Stimulation Program

DEEP BRAIN STIMULATOR INITIAL PROGRAMMING VISIT Frequently Asked Questions

How long is this appointment?

The appointment will take at least 2 hours.

How should I prepare for this initial programming appointment?

- **Patients with Parkinson's should be "off"** for this appointment. Do not take your Parkinson's medications the day of the appointment.
- **Patients with dystonia and essential tremor** may take your medicines as you normally would, unless instructed otherwise by a DBS team member.

Who should accompany me to this appointment?

Your primary caregiver should come with you. An additional adult who is closely involved in your care is welcome; however, additional people are a distraction during this lengthy procedure and will need to stay in the waiting room. Children should stay at home.

What should I bring?

Please bring your patient programmer and everything that came with it (you received this at your battery placement surgery). Please also bring a list of your current medication schedule and your actual medications to this appointment. You will able to resume your medications, if stopped, after the programming session.

What should I expect?

We will check the device to make sure it is functioning properly. We will then evaluate which stimulator setting improves your symptoms and which ones cause side effects. You will leave this appointment with your stimulator on; however, it may take several weeks to months to achieve maximum benefit. For patients with Parkinson's disease, our goal is to get you to your best "on" more consistently.

Why is there so much time between my surgery and when my programmer is activated?

This waiting period is an important time of healing for your body. Contact neurosurgery regarding any questions about your incisions, if you are not feeling well, or post-operative instructions, including driving restrictions. Continue medications as usual, unless you have been instructed otherwise.

Why was I better right after surgery before the stimulator was even turned on? This is not unusual and is called a microlesion effect. The placement of the electrodes often leads to a reduction of symptoms immediately following surgery. This effect usually lasts one to two weeks post-op until the brain begins to recover from the trauma of the surgery. Most patients' symptoms will return to the pre-op state by the time of initial programming.

How long will it take for my symptoms to improve? Some patients note improvement after the first programming session, while others may require several sessions for improvement. DBS requires patience and an understanding that we may need to try several settings to find the one that works best for you. It often takes 3-6 months to achieve maximum benefit.

How many programming appointments will I need? This varies from patient to patient, but as a general guideline you can expect monthly appointments for several months following the initial programming and then quarterly appointments thereafter. Once the stimulation is optimized, patients will need minor adjustments and battery checks two or three times per year.

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How do I know whether to call neurology or neurosurgery if I have a question? If you are experiencing problems or have questions in the time period between the surgery and initial programming, you should call Neurosurgery. Once your programming has occurred, you should call Neurology.

When can I cut back on my medicine? Taking less medicine is not the primary goal of DBS but often occurs after the ideal stimulator setting is found. Do not decrease your medications unless you have been instructed to do so.

Deep Brain Stimulation (DBS) has its own unique vocabulary. The following are a few terms you will hear during your programming sessions:

- **LEAD:** This is the small wire in your brain kept in place with a small plastic cap (the bump you feel below your scalp). May also be called "**electrodes**."
- IPG (Implantable Pulse Generator): This is the power source and is located in the chest. Some patients may have the IPG implanted in the abdomen. May also be called "battery" or "generator."
- **PATIENT CONTROLLER:** This allows you to turn the DBS on or off and to make certain adjustments as needed. Also known as "**patient programmer**" or "**hand-held programmer**".

FOUR PARAMETERS THAT CAN BE ADJUSTED FOR STIMULATION:

- **CONTACTS** There are metal contacts on the lead that can be used for stimulation. Also known as "electrodes."
- **FREQUENCY** The number of times in a second that the stimulation pulses.
- **PULSE WIDTH** The duration in micro-seconds of each stimulation pulse.
- VOLTAGE & CONSTANT CURRENT Depending upon the device, these are the main parameters used to control the intensity of the stimulation.

REMINDER:

- *MRI Eligibility must be approved by Neurology and your device must be in "MRI mode", if applicable*! X-rays, CT scans & diagnostic ultrasound are allowed.
- **NO DIATHERMY** (therapeutic ultrasound used by some physical therapists and dentists).
- Review ALL surgical procedures with Neurology in advance to ensure the procedure is done safely with regards to your DBS system.
- If in doubt, contact our office or the device's patient support line:
 - o Abbott/St. Jude Medical at: (800) 727-7846
 - o Boston Scientific at: (888) 272-1001
 - Medtronic at (800) 328 0810