

## Deep Brain Stimulation (DBS) Education





# Welcome

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Thank you for choosing Henry Ford Health. This packet has information about the Deep Brain Stimulation (DBS) surgery.

- Once you have read through all of this information, call the DBS Nurse Navigator. They will help answer any questions you have and are there to support you.
- This packet has space for you to write down all of your questions, appointments, and other information in one place.

## **DBS Nurse Navigator**

Julie Loomis, BSN, RN-BC

Office Phone Number: (248) 325-0503

Fax Number: (248) 325-3115

Email: [jloomis3@hfhs.org](mailto:jloomis3@hfhs.org)

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# Intro to DBS

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It may be time to talk to your neurologist about DBS if:

- Your symptoms are lowering your quality of life.
- Your symptoms are not under control even though you get the right amount of medicine.
- You cannot tolerate side effects from your current medicines.

## What is DBS?

- DBS uses a pacemaker-like device in your brain to deliver constant electrical stimulation to problem areas of the brain.
  - DBS requires 2 stages of surgery to put the electrodes on your brain and connect the neurostimulator.
- It is not a cure, but a tool to help manage movement disorders like Parkinson's disease, essential tremor, dystonia, and more.

## How will DBS help?

- DBS can help decrease motor symptoms such as tremor, dyskinesias (uncontrolled, involuntary movement), slowness of movement, and rigidity.
  - It can significantly improve symptoms, but they do not usually go away completely.
- It may not help non-motor symptoms such as speech, balance, or cognition.
- You may still need to take some medicines after DBS.

## What timeline should I expect for DBS?

1. It usually takes 2 to 4 months once you are referred for DBS and to schedule surgery. Stage 1 procedure is scheduled first.
  - You will go through several tests and appointments to make sure you are a good candidate.
  - Write down these appointments on the last page of this packet to help keep track.
2. About 2 weeks later, stage 2 procedure will take place.
3. About 4 weeks after stage 1, you will have a head CT (computed tomography) scan to check lead placement and a post-op incision care appointment with a nurse.
4. After the CT scan is done and ready, you will have a programming visit with your neurologist (this will be a different day than the CT scan and incision care appointment).

## What tests and appointments will I have to decide if DBS is right for me?

There are several tests and appointments you will go through to decide if DBS is right for you. Below is a list of them. Write them all down on the last page to help you keep track of when you have them.

### **Neuropsychological Assessment**

- This appointment will help us:
  - Better understand your baseline thinking skills and psychological state.
  - Address any symptoms of depression or anxiety.
  - Determine if there are any cognitive problems.
  - Provide a baseline assessment in case of cognitive or emotional problems after surgery.
  - Determine target used for surgery for Parkinson's patients.
- Call (313) 874-4846 to schedule.
- Appointments available at One Ford Place in Detroit or Henry Ford West Bloomfield Hospital.

### **Psychiatric Evaluation**

- Only if needed based on Neuropsychological assessment results.
- Appointments at One Ford Place in Detroit or Henry Ford Columbus Medical Center in Novi.

### Pre-Operative (before surgery) MRI

- This will help your doctors to plan for surgery.
- Call (313) 916-2955 to schedule.
- Appointments only offered at Henry Ford Hospital in Detroit.

### Medicine or L-Dopa Challenge

- Only for Parkinson’s disease (PD) patients.
- This appointment will help us:
  - Understand better which motor symptoms do or do not improve with medicine.
  - Establish a baseline and help guide expectations of outcomes to expect with DBS surgery.
  - Make sure DBS would benefit you.
  - Determine where to target in your brain for DBS and if it is needed on both sides of your brain or just one.
- This is done at your neurologist’s office.
- You will need to stop your Parkinson’s medicine at 11 p.m. the night before.
- Bring your Parkinson’s medicine with you to the appointment.

### Neurosurgery Consult

- Meet with the neurosurgeon to talk about surgery.
- See the “Meet the Team” page in this packet to decide which neurosurgeon is the best fit for you.
- Call your DBS Nurse Navigator to schedule this appointment at (248) 325-0503.

### DBS Class

- Done over Webex.
- Email or call DBS Nurse Navigator (Julie Loomis) to schedule your class.
  - [Jloomis3@hfhs.org](mailto:Jloomis3@hfhs.org)
  - (248) 325-0503

### Speech and Swallow Evaluation

- For PD patients and otherwise only if needed.
- Appointments only offered at Henry Ford West Bloomfield Hospital.

## Does insurance cover DBS?

Most insurance companies cover DBS. Once you are scheduled for surgery, Henry Ford Health will get authorization from your insurance for surgery. The codes below may be helpful when you talk to your insurance company about copays and deductibles that you may be responsible to pay.

Test or Procedure	Procedure Code
<b>MRI of Brain with and without Contrast</b>	70553
<b>MRI of Cervical Neck without Contrast</b>	72141
<b>DBS Stage 1 – Electrode implant (AWAKE), inpatient</b>	61867, 61868
<b>DBS Stage 1 – Electrode implant with iMRI (ASLEEP), inpatient</b>	61863, 61864
<b>DBS Stage 2 – Neurostimulator battery implant, outpatient</b>	61885, 61886
<b>Initial programming, activation of system, outpatient clinic</b>	95983, 95984

Diagnosis	Code
<b>Essential Tremor</b>	G25.0
<b>Parkinson’s Disease</b>	G20.0
<b>Cervical Dystonia</b>	G24.3
<b>General Epilepsy</b>	G40.0

# DBS Surgery

## What DBS system will be used?

There are 3 different DBS systems currently available. You will talk with your neurologist to decide which one is right for you. You can find more information at their websites (click the link or scan the QR code).



### **Abbott**

[abbott.com/life-changing-tech/parkinsons-deep-brain-stimulation-dbs-infinity.html](http://abbott.com/life-changing-tech/parkinsons-deep-brain-stimulation-dbs-infinity.html)



### **Boston Scientific**

[bostonscientific.com/en-US/products/deep-brain-stimulation-systems.html](http://bostonscientific.com/en-US/products/deep-brain-stimulation-systems.html)



### **Medtronic**

[medtronic.com/us-en/healthcare-professionals/therapies-procedures/neurological/deep-brain-stimulation.html](http://medtronic.com/us-en/healthcare-professionals/therapies-procedures/neurological/deep-brain-stimulation.html)

To scan the QR code:

1. Open the camera on your smartphone.
2. Place the QR directly in the center of the camera and the link should appear on the screen.
3. Click this link to go to the webpage.

## How do I get ready for surgery?

### **Medical Clearance**

- You may need medical clearance with your PCP (primary care physician) or cardiologist before surgery.
- You will need to schedule your own appointment for clearance.

### **Lab Work and Testing**

- You will need to have blood drawn before surgery.
  - These lab need to be done within 30 days of surgery. However, it is best to do them at least 2 weeks before your scheduled surgery date.
  - If you go to a Henry Ford Health lab, the order for the blood work will be in the computer. You can just walk in.
  - If you go outside of Henry Ford Heath, you will need to bring the script for the labs with you. You will also need to have all results faxed to (248) 325-3115, Attention: DBS Nurse Navigator.
- You may also need to have a urinalysis, EKG (electrocardiogram), medical clearance, and more. Your doctor will tell you what you need to have done and when.

### **Medicine**

- You will get a call before surgery from a nurse to go over what medicines you take. You will also talk about what medicines you need to stop taking.
- Talk to your primary care doctor or cardiologist if you take antiplatelets or blood thinners (like aspirin or Plavix®). You will need to stop these for surgery, but only if you have clearance from your doctor.
- Do not take NSAIDs (non-steroidal anti-inflammatory drugs) such as ibuprofen and naproxen.
  - This is the protocol of the anesthesia team.

## Other Steps

- Follow the instructions the nurse gave you on what to eat and drink before surgery.
- Do not shave your head. This will be done before surgery by your medical team. It is important your medical team does this to decrease the risk of infection.
- You will get 2 pre-op surgery kits. Follow all instructions in the kits. This is to reduce your risk of infection.
  - **Let your nurse navigator know if you did not get these kits.**

## What should I expect for surgery?

### DBS Stage 1

There are 2 options for Stage 1 surgery: awake and asleep. You will talk with your neurosurgeon to figure out which option is best for you.

- The outcomes are similar for both the awake and asleep surgery.
- Awake surgery is done at Henry Ford West Bloomfield. Asleep is done at Henry Ford Hospital.

### DBS Awake Stage 1

#### Pre-Op (Before Surgery)

- You will be awake for the entire procedure.
- When you first arrive for surgery, you will get medicines to make you comfortable, a local numbing medicine, have your hair removed and frame placed.
- You will then have a CT scan with the frame in place.
- You will then go to the OR (operating room).

#### Intra-Op (During Surgery)

- In the operating room, you will be in a reclined position.
- 2 small holes the size of a nickel are made on each side of your skull.
- A small electrode is placed.
- You will need to answer questions and do tasks.
- You will be put to sleep once the electrode is in the right place. Your frame will be removed.

#### After Surgery

- You will stay overnight in the intensive care unit (ICU).

### DBS Asleep Stage 1

- You will get an IV (intravenous line) and be put under general anesthesia for surgery.
- The procedure uses images from an iMRI machine.
- You will stay overnight in the intensive care unit (ICU).



## **DBS Stage 2**

- Stage 2 surgery is done at Henry Ford West Bloomfield about 2 weeks after stage 1.
- You will be asleep for surgery.
- You will have an incision above the ear and an incision on the chest for the battery.
  - Device extensions are attached to the electrodes placed in stage 1. They are tunneled internally (put inside) along the neck to the chest where the neurostimulator will be placed.
- You will go home the same day.
- Your device will not be turned on until you see your neurologist.

## **What are the risks of DBS surgery and after?**

### **Surgery Risks**

Risks of having this surgery done include:

- Stroke or brain bleed
- Infection
- Headaches
- Seizures
- Scarring
- Swelling around the brain
- Temporary pain

### **Hardware Complications**

It is possible that the DBS hardware could not work the right way:

- Malfunction of battery
- Battery needs replacement
- Leads break or move
- Leads not put in the right spot (will need to be revised)

### **Stimulation Risks**

Some possible risks with the stimulation from the DBS system are:

- May not help some symptoms
- Sensory changes
- Muscle pulling
- Tingling
- Numbness
- Visual changes
- Mental or emotional state gets worse
- Buzzing



# After Surgery

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Most patients go home the day after stage 1 surgery, and the same day as stage 2 surgery. However, recovery will be different for everyone. Some other things to be aware of after surgery are:

- After Stage 1 surgery, you will have a CT scan or MRI to check the electrodes before you go home from the hospital.
- You can have imaging scans and other tests after you have the DBS device put in.
  - CT scans and x-rays are safe to have done when the device is turned off.
  - You will need to talk with your neurologist if you need an MRI after you get the device. If you are cleared for an MRI, you need to go somewhere that is able to do MRIs specifically for DBS patients.
  - DBS can affect the reading of an EKG. You will need to turn the device off for an EKG.
- You cannot have diathermy or therapeutic ultrasound.
- Keep taking your normal medicines unless you are told different.
- If you need any dental work in the 6 months after DBS surgery, you will need to take an antibiotic.
- Initial programming for your device will take at least 2 hours. You may also need extra appointments with your neurologist to reach optimal symptom control.

## What are common side effects after surgery?

The side effects below are common after surgery. If you have concerns or questions, talk to your doctor.

- A lump near the incision (electrodes)
- Bruising and swelling under the eyes
- Confusion or brain fog due to swelling – this will get better over time
- Fatigue

## What should I know about care at home after surgery?

Follow these instructions for after stage 1 and stage 2 surgery.

### Driving

- × You will **not** be able to drive for 4 to 6 weeks after surgery.

### Work

- ✓ Expect to be off of work for 4 to 6 weeks.
- ✓ Talk to your doctor before surgery if this is a concern.

### Activity

- ✓ Walk as much as you can each day.
- × Do not lift items that are more than 10 pounds for 4 to 6 weeks after surgery.
- × Do not bend, twist, push, or pull for 4 to 6 weeks after stage 2 surgery.

### Dressing and Incision

- ✓ You will get instructions when you leave the hospital on how to care for your incisions.
- ✓ Watch for signs of infection like drainage, increased pain, redness, swelling, or fever.
  - Call your doctor right away if you have any of these symptoms.
- × Do not submerge your incisions under water for 2 months (no baths, swimming, etc.).
- × Do not use a comb or brush near the incisions.

# Meet the Team

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## Movement Disorder Team

If you need an appointment with Movement Disorder Neurologist, call (248) 661-6466.



**Kari Anglin, NP**



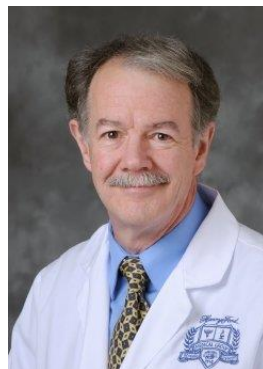
**Dr. Bisena Bulica**



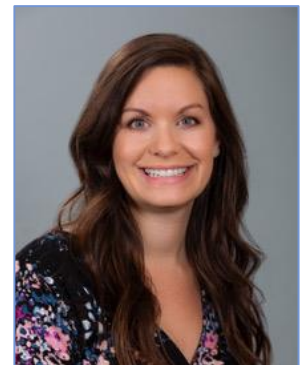
**Dr. Zehra Farzal**



**Dr. Shana Krstevska**



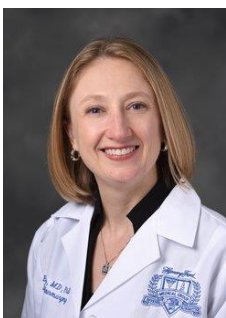
**Dr. Peter LeWitt**



**Julie Loomis, RN**

## Neurosurgeons

Henry Ford Health has 2 neurosurgeons who specialize in DBS.



**Dr. Ellen Air**

[henryford.com/physician-directory/a/air-ellen](http://henryford.com/physician-directory/a/air-ellen)



**Dr. Jason Schwalb**

[henryford.com/physician-directory/s/schwalb-jason](http://henryford.com/physician-directory/s/schwalb-jason)



# Resources

## Surgery Locations

Location	Address	Phone Number	Pre-Surgery Interview
<b>Henry Ford Hospital</b>	2799 West Grand Blvd. Detroit, MI 48282	(248) 916-2241	Call 24 hours before each surgery between noon (12:00 p.m.) and 4:00 p.m. Tell them you are scheduled for surgery and they will direct you to the right person.  (313) 916-7941
<b>Henry Ford West Bloomfield Hospital</b>	6777 West Maple Rd. West Bloomfield, MI 48322	(248) 661-4100	Call 24 hours before each surgery between noon (12:00 p.m.) and 4:00 p.m. Tell them you are scheduled for surgery and they will direct you to the right person.  (248) 661-6455

### Accommodations

We know it can be stressful to get to Henry Ford Hospital for surgery or your MRI. Below are accommodations for staying near both hospitals if you want to stay the night before surgery or your family would like to stay nearby.



Detroit Campus Apartments

[henryford.com/locations/henry-ford-hospital/campus/housing](https://henryford.com/locations/henry-ford-hospital/campus/housing)



West Bloomfield Accommodations

[henryford.com/locations/west-bloomfield/about/campus/accommodations](https://henryford.com/locations/west-bloomfield/about/campus/accommodations)

## Henry Ford Health DBS Ambassador Program

We know it can be a hard decisions to have DBS surgery. HFH has a network of patients who would be happy to talk with you about their personal experience with DBS to help you decide if this is right for you.

- Tell your DBS nurse navigator if you would like to speak with a DBS ambassador.
- You can also find some patient experiences here:



**Henry Ford Health Patient Testimonials**

[henryford.com/services/movement-disorders/patient-stories](https://henryford.com/services/movement-disorders/patient-stories)

## Websites



### **Henry Ford Health DBS**

[henryford.com/services/movement-disorders/treatments/deep-brain-stimulation](https://henryford.com/services/movement-disorders/treatments/deep-brain-stimulation)



### **Michigan Parkinson Foundation**

[parkinsonsmi.org/](https://parkinsonsmi.org/)



### **International Essential Tremor Foundation**

[essentialtremor.org/](https://essentialtremor.org/)



### **Dystonia Medical Research Foundation**

[dystonia-foundation.org/](https://dystonia-foundation.org/)



### **ClearPoint® Navigation System Software**

[clearpointneuro.com/biologics-drug-delivery/neuro-navigation-system-software/](https://clearpointneuro.com/biologics-drug-delivery/neuro-navigation-system-software/)

# Symptom Evaluation and Questions for Doctor

Fill this symptoms tracker out before your visit with your neurologist or neurosurgeon. Bring it with you to your appointment. This will help you and the doctor have a good conversation and answer any questions you have.

Symptom	Check this box if this is a symptom I want DBS to improve	Check this box if this symptom <b>does</b> improve with dopamine medicine	Check this box if this symptom <b>does not</b> improve with dopamine medicine	<b>For your Neurologist:</b> symptom should improve with DBS
Still muscles				
Slow movement				
Tremor*				
Muscle cramps				
Pain				
Speech				
Swallowing				
Gait freezing				
Imbalance				
Falling				
Cognition				
Depression				
Anxiety				
Insomnia				
Dyskinesia*				

\* Tremor and dyskinesia symptoms may not respond to medicine but do respond to DBS.

**My expectations for improvement with DBS are:**

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**Questions I have for my doctors are:**

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# Appointment Tracker

Below are appointments you will have during the DBS journey. Write down the appointment information here to help you keep track. Your MyChart will also keep track of appointments for you.

Appointment	Date	Time	Location	Doctor	Notes
<b>Deciding if DBS is Right for You</b>					
<b>Neuropsychological Assessment</b>					
<b>Medication or L-Dopa Challenge (only for Parkinson's disease)</b>					
<b>Pre-Surgery MRI</b>					
<b>Neurosurgery Consult</b>					
<b>DBS Class</b>					
<b>Speech and Swallow Evaluation (for PD only and as needed)</b>					
<b>Psychiatric Evaluation (if needed)</b>					
<b>Once Surgery is Scheduled</b>					
<b>Surgery Medical clearance with PCP or cardiologist</b>					
<b>Pre-surgery lab work</b>					
<b>Stage 1 Surgery</b>					
<b>Stage 2 Surgery</b>					
<b>After Surgery</b>					
<b>Post-op (post-surgery) wound check</b>					
<b>Post-op CT scan</b>					
<b>Initial Programming Visit</b>					



# HENRY FORD HEALTH®