

# Deep Brain Stimulation Therapy

Guidebook



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# Welcome



On behalf of our entire care team, I would like to welcome you to AdventHealth. For more than 100 years, we have dedicated ourselves to improving the lives of others by delivering advanced health care to the communities we serve. Our mission — to extend the healing ministry of Christ — has inspired us to build a unique health network dedicated to providing comfort, healing and the discovery of new treatments and cures.

We're honored that you have entrusted us with your health. We look forward to caring for you.

Sincerely,

**Daryl Tol**  
President and CEO  
AdventHealth Central Florida Region



## Therapy for Your Life

Deep brain stimulation (DBS) therapy is designed to help improve the quality of life of people with a variety of movement disorders. The information in this guidebook is intended to help educate patients and caregivers about DBS as an option for therapy, as well as to guide you through the DBS process — from initial pre-surgical evaluation to optimization of DBS therapy with stimulation programming. Our team is here to answer any questions you may have along your health journey.

## What is deep brain stimulation?

Deep brain stimulation (DBS) is a therapy that can improve the quality of life for people with movement disorders including Parkinson's disease, essential tremor and dystonia. DBS is not a cure. However, it can provide symptomatic benefit, like maximal benefit achieved with medications, but with reduced motor fluctuations. In some cases, DBS may provide benefit beyond what can be achieved with medications alone. Earlier use of DBS is now being recognized for many patients. Having a discussion with your clinician will ensure that DBS is added at the appropriate time.

DBS provides stimulation to very specific areas of the brain depending on your condition. It includes a thin, implanted wire that connects under the skin to a stimulator. Stimulation is adjusted by your clinician based on your needs.

The goal for DBS therapy is to allow you to live your life. Patients can cautiously return to hobbies, sports and other activities. DBS is known to help manage symptoms as disease states change.



## For Patients With Parkinson's Disease

DBS therapy can benefit motor symptoms of Parkinson's disease including:

- Tremor (shakiness)
- Rigidity (stiffness)
- Bradykinesia (slowness)
- Akinesia (freezing)
- Dyskinesia (involuntary movements)

DBS can provide the best "on" time that you experience with your medications for of Parkinson's disease, and a smoother therapy over time that reduces motor fluctuations between "off" and "on" periods throughout the day.

DBS therapy can also benefit patients with medication-induced dyskinesia (involuntary movement), as well as medication-refractory tremor, rigidity and slowness of movements. Many patients who are not able to tolerate higher doses of medications due to side effects may benefit from DBS. Most people will continue taking medications for Parkinson's disease after DBS surgery. However, with DBS programming, the amount of medication is often reduced.

Non-motor symptoms of Parkinson's that DBS will not benefit include:

- Constipation
- Urinary symptoms
- Mood
- Memory
- Sleep difficulties

These non-motor symptoms are not predicted to improve. It is important to know what DBS can help and those symptoms will not be improved. DBS may not be helpful in patients who do not experience any benefit from their medications. However, these patients should be evaluated by a movement disorder neurologist to determine if they receive the correct medications at enough doses. Some patients who may benefit from higher doses of medication, but are unable to tolerate higher doses due to side effects (such as sedation or lightheadedness), may benefit from DBS.

## For Patients With Essential Tremor

DBS therapy can significantly improve the symptoms of essential tremor, usually superior to the best medical therapy. Patients with essential tremor may have tremors of the hands, head and/or voice. DBS has been used over 20 years for essential tremor and is considered an effective treatment option.

For people with essential tremor, DBS therapy can be considered at any time. Patients often consider DBS therapy when:

- The tremor is impacting quality of life and daily activities.
- Medications are not adequately controlling symptoms.
- Medications may be causing significant side effects.
- Other treatments are not effective.

Most patients with essential tremor can stop medication, only needing DBS to control their tremors.

**If you have any questions, please call our Brain Services Coordinator at 407-303-7944 or email [ORL.NSI.Brain.Services@AdventHealth.com](mailto:ORL.NSI.Brain.Services@AdventHealth.com).**

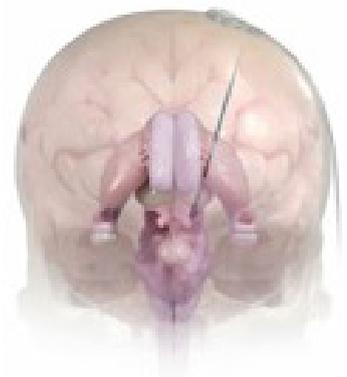


## For Patients With Dystonia

DBS can be effective therapy in dystonia, especially with generalized and primary forms of dystonia. DBS may help patients with other forms of dystonia if medical therapy fails, but the rate of responders may be lower. For people with dystonia, DBS therapy is considered when:

- Medications and other treatments are not providing adequate relief.
- Symptoms are negatively affecting quality of life.

The response to DBS may take longer to see benefit than that of Parkinson's disease and essential tremor. It is difficult to predict who will benefit and to what degree. It could take six months to one year before symptoms of dystonia improve. Evaluation by a movement disorders neurologist is key to determine if DBS is right for you.



# Am I a candidate for DBS?

As part of the DBS evaluation to establish candidacy, you are asked to complete evaluations by a neurologist, neurosurgeon, neuropsychologist, physical therapist, and speech language pathologist. These evaluations help us to determine the best management plan for your care.

## 1. Evaluation by a Movement Disorder Neurologist

The movement disorders neurologists who specialize in DBS work closely with our team. A movement disorder neurologist, or their physician assistant, may videotape your examination during this evaluation.

For patients with the diagnosis of Parkinson's disease, you will undergo an "ON-OFF" evaluation.

- Come to the appointment "OFF" medications. You are asked to hold the medications that you take for Parkinson's disease 12 hours prior to the evaluation.
- You are to bring your medications for Parkinson's disease to this visit.
- You will be first examined using a clinical rating scale during your "OFF" medication state.
- When instructed to do so, you will then take your medications.
- The examination will be repeated during your "ON" medication state.
- The total evaluation will last one to two hours.
- Please keep in mind that if you have difficulty walking during your "OFF" medication state, you should bring a wheelchair or walker to this appointment.

For patients with essential Tremor or dystonia, an "ON-OFF" medication evaluation may not be completed. However, your examination may be videotaped.

## 2. Consultation With a Neurosurgeon

During the initial meeting, the neurosurgeon will explain the surgical procedure, review potential risks and benefits of surgery and evaluate your candidacy for surgery.

Implantation of the DBS system occurs in two stages.

1. Stage 1 involves the placement of the electrode into the brain.
2. Stage 2 involves the placement of the extension and generator (or battery) which is connected to the electrode.

Please note that a consultation with a neurosurgeon does not require you to be committed to DBS surgery. The purpose of the initial consultation is to have your questions answered by the surgeon and to get to know the team.

## 3. Neuropsychological Evaluation

During this evaluation, your memory will be tested, as will facets of language. Plan for a three-to-four hour testing period. You should take your medications as normally scheduled prior to this evaluation.

## 4. Brain MRI

You will be required to have brain imaging done and reviewed by your neurosurgeon and neurologist. This test is an MRI of the brain.

## 5. Physical Therapy Evaluation (if needed)

You may meet with a physical therapist to evaluate your gait and motor function prior to DBS surgery.

## 6. Occupational Therapy Evaluation (if needed)

You may meet with an occupational therapist for an evaluation of your ability to perform your daily tasks prior to DBS surgery.

## 7. Speech Evaluation (if needed)

You may meet with a speech language pathologist for an evaluation of your speech and swallowing prior to DBS surgery.

## 8. Social Work Evaluation (if needed)

You may meet with a social worker for a discussion pertaining to DBS surgery and following DBS surgery and programming.

Once these evaluations are completed, we will discuss your case at our multidisciplinary DBS team meeting. The results of this meeting will allow the team to determine the best treatment plan for you, and after the meeting, we will communicate the plan to you. There are many patients who currently have DBS that would be glad to speak to you about their journey. Please let us know if you would like to speak with any of them.

# The DBS Surgical Procedure

Our expert team of neurosurgeons performs two types of stage-1 DBS surgical procedures.

## 1. “Awake” DBS using Microelectrode Recording (MER)-Guided

The surgeon uses the images from the MRI of the brain that is ordered preoperatively to plan the procedure. On the morning of surgery, a head frame will be placed and a CT scan will be completed. The patient is under light anesthesia and awake for a portion of the surgery. There is little to no pain. This method allows the patient to interact with the surgeon and his team to help identify that the DBS electrodes are placed in the best location to help with their symptoms. This is the method that most patients undergo.

## 2. “Asleep” DBS Using Intraoperative CT or MRI Guidance

The surgeon uses CT or MRI to help guide the electrode placement while the patient is under general anesthesia. There is no testing done at the time of the implant. This method is typically reserved for those patients who are symptomatic off medications or are too anxious to undergo the awake procedure.

*Discuss which surgical procedure is best suited for you with your neurologist and neurosurgeon.*

## Surgical Risks

Potential risks of surgery include complications with bleeding or infection. It is also important to note that it is possible that an individual patient will not benefit from DBS surgery or programming.

## Pre-Operative Requirements and Instructions

You are required to complete basic pre-operative testing before your upcoming surgery. The blood work, EKG, and chest X-ray will be completed at your HealthPAS appointment. HealthPAS is located at:

AdventHealth Celebration  
400 Celebration Place, Suite A340  
Celebration, FL 34747

The following must be completed no sooner than 30 days and no later than seven days before surgery.

- HealthPAS appointment (blood work which includes CBC, BMP, PT/PTT, EKG and chest X-ray)
- Visit with primary care physician for medical clearance (if applicable)
- Specialist clearance (if applicable)

It is your responsibility to complete this testing. If you are required to have medical or specialist clearance, be sure that the clearance is faxed to us at 407-975-0209. Failure to do so will result in rescheduling your surgery for a later date.

Remember to discontinue use of any medication that increases bleeding risk 14 days prior to surgery (see list of medications to avoid before surgery on the following page). **If you experience any mild pain or a headache within one week of surgery, the only approved over-the-counter pain medication to take is Tylenol or the generic equivalent (acetaminophen).**

The day before your surgery, you will receive a call from a pre-operative nurse with:

- Your arrival time
- Your scheduled surgery start time
- Where to report for surgery
- Review of the medications that you may take the morning of surgery
- Instructions for what not to eat or drink after midnight (unless otherwise instructed)

We are unable to confirm your scheduled arrival time until the day before. Unless otherwise directed, the morning of your surgery you may take any regularly scheduled medications with a small sip of water.

**DO NOT TAKE YOUR PARKINSON’S MEDICATIONS THE MORNING OF SURGERY.**

**PLEASE REMEMBER TO BRING YOUR PARKINSON’S MEDICATIONS WITH YOU ON THE DAY OF SURGERY.**

## Medications to Avoid Prior to Surgery

- **Warfarin (coumadin)** - Must be discontinued three-to-five days before surgery under the guidance of your cardiologist or primary care physician. Please contact their office for instructions about stopping this medication and to make sure it is safe to do so. Your PT/INR (blood work) must be completely normal the morning of surgery.
- **Clopidogrel (Plavix)** - Must be discontinued seven days before surgery under the guidance of your cardiologist or primary care physician. Please contact their office for instructions about stopping this medication and to make sure it is safe to do so.
- **Aspirin (Bayer, Bufferin, Ecotrin, St. Joseph and all other brands)** - Must be discontinued 14 days before surgery under the guidance of your cardiologist or primary care physician. Please contact their office for instructions about stopping this medication and to make sure it is safe to do so.
- **NSAIDs (non-steroidal anti-inflammatory drugs)** - Must be discontinued 14 days before surgery. Many NSAIDs are available over the counter and some by prescription only. They are commonly used to treat pain, inflammation and fever. This category of medicines includes:
  - ibuprofen (Advil, Motrin and others)
  - naproxen (Aleve, Naprosyn and others)
  - celecoxib (Celebrex)
  - indomethacin (Indocin), etodolac (Lodine), ketorolac (Toradol), diclofenac (Voltaren, Cataflam), meloxicam (Mobic) and other less-common medicines not listed here

Some of these medications are used in topical forms such as gels and pastes. These must also be discontinued before surgery.

Please remember, the only over-the-counter pain medication that is safe to use within two weeks of surgery is acetaminophen (Tylenol).

- **Miscellaneous Medications (including vitamins and supplements)**

The following medications must be discontinued 14 days before surgery.

- Alka-Seltzer, Midol, Pepto-Bismol
- Vitamin E or any multivitamin that contains Vitamin E
- Fish oil or Omega-3
- Co-enzyme Q10

The following medications must be discontinued 48 hours before surgery.

- Sildenafil (Viagra), Tadalafil (Cialis) and Vardenafil (Levitra)

Please be sure to ask if you are unsure about any medications to avoid prior to surgery.

# Infection Prevention

Infection is a risk of any surgery, but an infection can be more serious in surgeries where a medical device is placed in the body. The following are guidelines to help prevent infections.

## Hibiclens (chlorhexidine gluconate 4% solution)

Hibiclens is a medicated soap that kills germs that normally live on your skin. Its use has been shown to reduce the risk of surgical infection.

### Instructions for Use

- The HealthPAS RN will instruct you on when to begin your Hibiclens soap. Hibiclens should be used in place of your regular soap or body wash. Apply Hibiclens to a wet washcloth and clean from your neck to your toes, including your arms and legs, front and back. To clean thoroughly, this should take about three minutes. Rinse with warm water. Pat yourself dry with a clean towel.
- Do not use regular soap, powders, lotions or creams on areas where Hibiclens was applied.
- Do not use Hibiclens on your face or genital area.
- You will be required to use Hibiclens the morning of surgery.

## How to Get Hibiclens

- You may receive a bottle at your HealthPAS appointment. If you do not, it is available over the counter at most pharmacies.

## Methicillin-Resistant Staphylococcus Aureus (MRSA)

MRSA is a super-bug that is resistant to many antibiotics. Many people have this bacteria living on their skin and it does not cause an infection. However, when the skin is cut, like in surgery, the bacteria can infect the wound. We prophylactically treat everyone with topical iodine, and, in some special cases, mupirocin ointment, which is applied to the inside of both nostrils.

# Stage 1 DBS Post-Operative Instructions

- You will be admitted to the ICU for an overnight stay, often referred to as 23-hour observation. You will be discharged home the next morning around 10 am. A very small number of patients require a slightly longer hospital stay or further rehabilitation at a rehab facility after surgery. The second stage is an outpatient procedure.
- While in the ICU, please be aware of the following.
  - You will be attached to a monitor and will have frequent assessments that will disrupt your sleep.
  - You will have a CT scan very early the morning after surgery (around 5 am).
  - Family is not permitted to sleep in the ICU or the ICU waiting room.
  - Please arrange for transportation for 10 am the morning after surgery as to not delay discharge.
- Although your DBS is not turned on, you might feel like your symptoms are improved for a few days after surgery. This effect should wear off before your initial programming.
- You will likely experience some facial swelling after surgery. Sometimes this swelling occurs immediately, and sometimes it shows up a few days after surgery. Occasionally, it can be very severe and also cause the skin under your eyes to look bruised. This is normal. It will resolve on its own within a few days. However, sometimes it may take a week or more. It will continue to get better every day. Some things you can do to help it along are:
  - Spend more time sitting and standing upright rather than lying flat.
  - Apply an ice pack.
  - Take Tylenol if it becomes painful.

## Wound Care for Stage 1

- Your wound will be left open to air and no bandages will be applied in most cases. If there is a bandage applied, you may remove it after two days.
- It is OK to get your incisions wet and soapy and wash your hair normally. Gently rub some shampoo onto the incision with the pads of your fingers. Do not scratch or scrub with your nails. Washing the incision daily helps to keep the area clean and prevent infection.

# Stage 2 DBS Post-Operative Instructions

- Stage 2 DBS is when the stimulator (or battery) is implanted and connected to the electrode.
- Stage 2 is a short outpatient procedure, and you will go home the same day as the surgery.

## Wound Care for Stage 2

In most cases, your wound will be left open to air, and no bandages will be applied. If there is a bandage applied, you may remove it after two days.

You will have surgical glue applied to your chest. You should shower as normal, and pat the area dry after. The glue will begin to peel off on its own. If it is still present after five days, you may remove it.

## Restrictions

Once you get home, you may resume your normal activities as tolerated. Please refrain from the following:

- No lifting anything greater than 10 pounds for 30 days from your first surgery
- No vigorous exercise for 30 days from your first surgery. This includes anything that increases your heart rate, such as running
- No tub baths, swimming or hot tub use
- No driving for two-to-four weeks after your first surgery. The exact timing will be discussed at your follow-up visit

## Reasons to Call Neurosurgery

- Fever above 101.5°F
- Discharge from your incision
- New concerning symptom that worries you
- Any questions about the post-operative instructions



## Initial DBS Programming

The initial programming visit may take one and a half to two hours. This evaluation will be done “OFF” medications. The clinician will be evaluating what settings will give you the best clinical outcomes for your condition.

- DBS initial programming will take place in the neurologist’s office three-to-four weeks after the initial surgery (first stage).
- Please bring your Parkinson’s and anti-tremor medications to this appointment.
- **Please come to the initial programming visit off Parkinson’s and anti-tremor medications for 12 hours.**

The clinician will instruct you on when you take your medications, and once they have become effective, you will be reevaluated. You may experience side effects of stimulations such as numbness, tingling, slurred speech, balance difficulty, facial pulling or vision change. These symptoms should be temporary, but you must let the clinician know so that adjustments may be made. Most side effects of DBS programming are experienced at the initial programming visit. However, in some instances, side effects may be delayed. Optimizing DBS programming may take a few months. During this period, there may be medication adjustments as your physician deems appropriate.



# About the AdventHealth Neuroscience Institute

The AdventHealth Neuroscience Institute is one of the largest programs of its kind in the United States — providing comprehensive, multidisciplinary care to more neuroscience patients than any other hospital in the nation.\* The Institute's team of elite neuroscience specialists specializes in a variety of treatments and conditions including minimally invasive brain surgery, spine disorders, epilepsy, stroke, sleep disorders and interventional neuroradiology. Our integrated, interdisciplinary team approach combines state-of-the-art, minimally invasive technology with innovative research to provide patients with an exceptional, multi-faceted level of care. From detection and treatment to rehabilitation, the Institute is dedicated to achieving superior patient outcomes in a compassionate environment for our patients.

*\*Source: Based on MedPar & ACHA data*

## AdventHealth: Then & Now

*Established 1866:*

**30** DOCTORS

**1** UNIQUE FACILITY

**106** PATIENTS SERVED

*Today:*

**MORE THAN 80,000** PHYSICIANS AND STAFF

**47** AWARD-WINNING HOSPITALS IN NINE STATES

**5 MILLION+** PATIENTS SERVED ANNUALLY

AdventHealth Orlando is recognized by *U.S. News & World Report* as the highest-ranked hospital in Florida for neurology and neurosurgery.





# Our Health Equity Promise

## Patient Protection and Affordable Care Act: Section 1557

AdventHealth complies with applicable federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability or sex. This facility does not exclude people or treat them differently because of race, color, national origin, age, disability or sex.

AdventHealth provides free aid and services to people with disabilities to communicate effectively with us, such as:

- Qualified sign language interpreters
- Written information in other formats (large print, audio, accessible electronic formats, other formats)

AdventHealth provides free language services to people whose primary language is not English, such as:

- Qualified interpreters
- Information written in other languages

**If you need these services, please call 407-303-5600 x1106707.**

If you believe that this facility has failed to provide these services or discriminated in another way on the basis of race, color, national origin, age, disability or sex, you can file a grievance or request that someone assist you with filing a grievance at 407-200-1324 or [fh.risk.management@adventhealth.com](mailto:fh.risk.management@adventhealth.com).

You can also file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights, electronically, through the Office for Civil Rights Complaint Portal, available at [ocrportal.hhs.gov/ocr/portal/lobby.jsf](http://ocrportal.hhs.gov/ocr/portal/lobby.jsf), or by mail or phone at:

### U.S. Department of Health and Human Services

200 Independence Avenue, SW

Room 509F, HHH Building Washington, D.C. 20201

1-800-368-1019, 800-537-7697 (TDD)

Complaint forms are available at [hhs.gov/ocr/office/file/index.html](http://hhs.gov/ocr/office/file/index.html).

The statements below direct people whose primary language is not English to translation assistance.

ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al número siguiente.

CHÚ Ý: Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi theo số điện thoại dưới đây.

注意: 如果您使用中文, 您可以免费获得语言协助服务。请拨打下面电话号码。

Atansyon: Si ou pale kreyòl Ayisyen, gen sèvis asistans nan lang ou ki disponib gratis pou ou. Rele nimewo ki anba an.

주의: 한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. 아래의 번호로 전화하십시오.

UWAGA: Jeżeli mówisz po polsku, możesz skorzystać z bezpłatnej pomocy językowej. Zadzwoń pod numer podany poniżej.

ملحوظة: اذا كنت لاتتحدث اللغة الانجليزية فان خدمات الترجمة متوفرة لك مجاناً. الرجاء الإتصال بالرقم أدناه:

ATTENTION: Si vous parlez français, des services d'aide linguistique vous sont proposés gratuitement. Appelez le numéro ci-dessous.

PAUNAWA: Kung nagsasalita ka ng Tagalog, maaari kang gumamit ng mga serbisyo ng tulong sa wika nang walang bayad. Tawagan ang numero sa ibaba.

ВНИМАНИЕ! Если вы говорите на русском языке, то вам доступны бесплатные услуги перевода. Для этого позвоните по нижеуказанному номеру.

ACHTUNG: Wenn Sie Deutsch sprechen, stehen Ihnen kostenlos sprachliche Hilfsdienstleistungen zur Verfügung. Rufen Sie die untere Nummer an.

सुचना: जे तमे गुजराती बोवता हे, तो निःशुल्क भाषा सहायता सेवां तमारा माटे उपलब्ध हे. नीचे-नंबर पर सौन करे.

ATENÇÃO: Se você fala português, disponibilizamos serviços lingüísticos gratuitos. Ligue para o número abaixo.

ध्यान दें: यदि आप हिंदी बोलते हैं तो आपके लिए मुफ्त में भाषा सहायता सेवाएं उपलब्ध हैं। नीचे लिखे नम्बर पर सम्पर्क करें।

اگر شما فارسی زبان هستید، خدمات کمکی زبان بطور مجانی در دسترس شما قرار دارد. تو شماره زیر زنگ بزنید.

توجه فرمائیں۔ اگر آپ اردو بولتے/بولتی ہیں تو آپ کے لئے لسانی خدمات مفت میسر ہیں۔ ذیل میں دئیے گئے نمبر پر کال کریں۔

注意: 日本語でお話になりたい場合には、無料の通訳サービスをご利用いただけます。下記の番号にお電話してください。

ໄປດຊາບ: ຖ້າວ່າ ທ່ານເວົ້າພາສາ ລາວ, ການບໍລິການຊ່ວຍເຫຼືອ ດ້ານພາສາ, ໄດຍບໍ່ເສັຽຄ່າ, ແມ່ນມີພ້ອມໃຫ້ທ່ານ. ກະລຸນາໂທນໍ້າເບີຢູ່ຂ້າງລຸ່ມ

LUS CEEB TOOM: Yog tias koj hais lus Hmoob, cov kev pab txog lus, muaj kev pab dawb rau koj. Hu tus xojtooj hauv qab no.

ATTENZIONE: Se parlate italiano, sono disponibili dei servizi di assistenza linguistica gratuiti. Chiamare il numero sotto indicato.

**407-303-5600 ☎ 407-303-3025**



Neuroscience Institute

407-303-7944 | [AdventHealthNeuroInstitute.com](http://AdventHealthNeuroInstitute.com)