Choosing Deep Brain Stimulation Therapy for Dystonia
Choosing Deep Brain Stimulation Therapy (DBS)

This guide helps to answer your questions and give you the information you need for choosing deep brain stimulation therapy and for living with your DBS system.

This information is not intended to be a substitute for professional medical advice from your doctor or other health care provider. You should always talk with your doctor about your treatment and any symptoms you are experiencing.

Dystonia: A Life-Altering Disorder

In general, dystonia is thought to be caused by dysfunction in an area of the brain called the basal ganglia. One of the responsibilities of this area is to control movement. A balance of chemical and electrical signals that communicate between this area and other areas of the brain control movement. When functioning properly, the basal ganglia regulate movement by continuously making automated adjustments. However, in dystonia, the basal ganglia do not function properly, resulting in hyperkinetic movements and muscle contractions, which can affect one muscle or many. These symptoms often occur in different parts of the body, including the head and neck, face, eyelids, voice box, or even the whole body.
Dystonia is a neurologic disorder affecting men and women of all ages. For some patients, dystonia first appears in childhood. And for others, onset does not occur until adulthood. For those patients who experience childhood onset of their dystonia, symptoms can be particularly disabling. Some patients experience symptoms that progress over time and become generalized over the entire body. Others experience symptoms that remain focal to one area of the body and do not become generalized.1

The disorder can be hereditary or various underlying factors can cause it. In most cases, the disorder does not have a known underlying cause. This is referred to as primary dystonia. In other cases, often referred to as secondary dystonia, factors such as birth-related or other physical trauma, infection, or reaction to certain medications can cause the disorder.1

As a first line of treatment, medications are often used to try to balance chemical signals in the brain. When balance is achieved, it provides relief of the motor symptoms, the pain, and/or the depression that often accompanies dystonia.1 However, in some cases, medication treatments are either ineffective or result in intolerable side effects and must be discontinued. Injections of botulinum toxin may also be used to target localized areas of the body to control the involuntary movement and muscle contractions associated with dystonia. But as dystonia symptoms progress over time, medication and injections may not be sufficient to control motor symptoms.

How Do Your Dystonia Symptoms Progress Over Time?

You and your doctor may have discussed how the symptoms of your dystonia will affect you over time. At different times, these symptoms may require different treatment options such as medication, botulinum toxin, implantable drug pumps, physical therapy, and occupational therapy. It is important to understand the treatment options that can be customized to your specific symptoms and needs.

As dystonia symptoms change over time, you may have noticed the following:

- Your dystonia symptoms spreading from one area of your body to other areas of your body
- Your abnormal involuntary movements becoming worse2
- Your medication making it more difficult for you to sustain attention and negatively affecting your verbal memory and processing speed2
- You have built up an immunity to your medications or to your botulinum toxin injections3

Activities of daily living, such as participating in social and academic activities, driving, getting in and out of a car, completing household tasks, dressing and even eating, become increasingly difficult to complete as your medications become less effective.

Your physical symptoms may have progressed to a point where they interfere with your performance on relatively simple and routine tasks, like writing and keeping up in school or work. Other factors such as pain, fatigue, and social or emotional distress may affect your ability to focus, concentrate, and process information.2 These difficulties may even stop you from doing many things you enjoy, impacting you, your family, and the people you care about and who care about you. Make sure to discuss with your doctor all of the options available that may help you return to some of the activities you have not been able to participate in due to the symptoms of dystonia. During this discussion, your doctor can explain to you why deep brain stimulation is an additional treatment option.
DBS: A Treatment Option for Dystonia

DBS has been clinically used as an option for managing some of the symptoms of dystonia when other treatments are no longer sufficient. A medical device is implanted to deliver targeted, electrical stimulation to areas of the brain involved in motor control. While the therapeutic mechanism is not fully understood, stimulation is thought to help restore normal brain communication or “signaling” by delivering mild electrical pulses to the basal ganglia. It uses an implanted medical device, similar to a pacemaker, to deliver mild electrical pulses to precisely targeted areas in the basal ganglia. The levels of stimulation from DBS can be adjusted with an external programmer to meet your specific needs.

How Can DBS Help Me?

By enabling brain circuits that control movement to function better, DBS may relieve some of your dystonia symptoms, such as muscle spasms, twisting, involuntary contractions, posturing, and uncontrolled movements. The goal of DBS is to help reduce the motor-related symptoms of dystonia and improve overall quality of life.

Improvement from DBS is often gradual. The benefit is variable and depends on the type of dystonia and the presence of other conditions or illnesses. In primary dystonia, clinical experience demonstrates sustained long-term benefit. It is important to discuss with your doctor what the realistic expectations are in your individual case.

Is DBS a Cure for Dystonia?

In many cases, DBS has been shown to be effective in managing the movement-related symptoms of dystonia in patients who do not respond well to conventional therapies, but DBS is not a cure for dystonia. Nor does it manage all dystonia symptoms.

In general, DBS does not improve:
- Fixed joint contractures
- Nonmotor symptoms of dystonia, including depression, memory, concentration, or sleep problems
- Comorbidities associated with secondary forms of dystonia
- Speech/voice issues. Some individuals receiving DBS therapy may experience worsening of speech symptoms.

What Are the Possible Risks and Complications of DBS?

As with any surgery or therapy, DBS has risks and complications. Most side effects of DBS surgery are temporary and correct themselves within 30 to 90 days. However, some complications can be more serious and/or permanent. In the event that side effects are intolerable or you are not satisfied with the therapy, the deep brain stimulation system can be turned off or surgically removed. Talk to your doctor about the risks associated with placement and use of a DBS system.
Is DBS for Me?

Each person’s situation is unique, and many factors can impact a person’s response to DBS, including the type of dystonia you have. As you consider DBS as a treatment option, discuss your expectations about DBS with your doctor. This is very important to both you and your doctor. Your doctor will help you understand realistic expectations about the surgery and benefits of a DBS system.

It is also important to discuss your expectations with your carers and family. The decision to undergo DBS is significant for all of you. Open, honest discussion can help you make the transition as smooth as possible.

Knowledge and Expectations to Discuss with Your Doctor

Below you will find a list of things to consider and talk with your doctor about regarding your knowledge and expectations. Use the space below to prepare for your discussion with your doctor. You will also find space to list questions of your own.

Knowledge regarding DBS

- My general concept of DBS is (including my understanding of the procedure)…
- I understand the risks and potential complications, both during and after implantation, to be…

Expectations

- The thing that most frustrates me about having dystonia is…
- I would consider DBS successful if I could…
- If I had DBS, my care partner or family would once again be able to…
- The thing I am most concerned about regarding DBS is…

Additional Information from My Doctor/Other Questions/Notes
Components of a DBS System

Leads & Extensions: The lead is a thin wire that is inserted directly into the brain. The lead tip delivers mild electrical pulses from the neurostimulator to the targeted area of the brain. The extension is the flexible wire connecting the lead to the neurostimulator.

Neurostimulator: The neurostimulator is a small, pacemaker-like device that is the computer of the DBS system. When the system is turned on and the appropriate settings are set in the neurostimulator, it delivers precise electrical signals to the brain to help control movement-related symptoms of dystonia.

Patient Recharger System: If your doctor selects a rechargeable DBS system for you, you will receive a recharging system that will allow you to recharge your implanted pulse generator (IPG) based upon the requirements of your IPG settings.

Patient Controller: In addition, you will receive a controller that will allow you to check the status of your device and to turn it on and off if needed.

Clinician Programmer: The doctor has an external control device to adjust the system’s electrical signals to meet your specific symptom needs. The system can be adjusted as often as needed.
Preparing for Your DBS Surgery

Before you undergo DBS surgery, you will go through a number of evaluations by a multi-disciplinary team to determine if you are a good candidate. This will most likely include an evaluation by a neurologist to determine if your dystonia symptoms are likely to respond to DBS. It may also include an evaluation by a psychologist or psychiatrist to determine the status of your cognitive (thinking skills) and mental health. And it may include an evaluation by a neurosurgeon to determine if you are a good surgical candidate. If you and your health care team decide you are indeed a good candidate for DBS, you will be scheduled for surgery.

Ask your doctor about possible complications associated with the procedure and the therapy, as well as restrictions you will be asked to follow during your recovery and for the long term. Also, discuss any questions or concerns with your doctor. Having questions and concerns is normal and expected. Your doctor will be able to answer your questions or provide you with additional resources. You can also find a list of additional resources at the end of this booklet.

What Happens during the Procedure?

Surgery for DBS may involve a hospital stay, the length of which varies by center. Also, the specific details of the implant procedure vary by center. Ask the neurosurgeon who will be performing your procedure to explain the details of the procedure he or she uses.

The procedure generally involves the following steps:

Imaging: The day of your operation, you will undergo either a head MRI or CT scan. These help the neurosurgeon identify the exact location within your brain to place the leads. In most centers, imaging is done with a frame that is placed on the head prior to the images being taken. Before placement of the frame, you will be given a local anesthetic to ease any pain.

Lead Placement: After the images are complete, you will be taken to the operating theatre. At this stage, local anesthetics will also be used to ease any pain and medication may be given to help you relax. In some centers, you will remain awake during the operation.

Neurostimulator Placement: The neurostimulator may be placed under the skin in your chest immediately following the lead placement or up to several weeks later. Prior to your surgery, your doctor will discuss with you when the neurostimulator will be implanted. Whether your neurostimulator is placed immediately after your leads or several weeks later, you will be under general anesthesia (asleep) during this part of the procedure.

Questions to Ask Your Doctor

- How many days will I be in the hospital?
- How long will the operation take?
- How many incisions will I have from my surgery and where will they be?
- Will you shave all the hair from my head?
- How should I take my medications the day before my operation?
- How should I take my medications on the day of my operation?
- How long will it take for me to heal after my operation?
- What can I do to help the healing process?
- What activities must I limit and for how long?
- When can I resume my normal daily activities?
- When will my stimulation be turned on?

Tips to Help You Prepare for Your Operation

The following checklist will help you prepare for your procedure. You can also use the space at the end of the list to write down any specific instructions from your doctor.

- Check with your surgeon’s office to make sure you know exactly when and where you need to be on the day of your surgery.
- Get instructions from your doctor about when to take your medications, if any, the night before your surgery and the day of the surgery.
Tell your doctor about all medications and supplements you are currently taking. This includes paracetamol, aspirin, vitamins, and herbal supplements.

Ask friends and family to help care for any pets or personal affairs while you are in the hospital. Don’t be afraid to ask for help for you and your carer or family as you recover.

If a student, make sure that you have notified the appropriate contacts of your absence and make arrangements for your assignments to be completed after recovery.

Pack a week’s supply of all of your medications in the original, labeled bottles for your hospital stay. Also, make a list of all of your medicines with dosages and times taken to provide to the hospital staff.

Write down a list of names and phone numbers you might need, including emergency contacts.

Pack a bag of items for your hospital stay, including personal toiletries, reading materials, and clothes to wear for your trip home. Include a shirt with buttons or a zip to make it easier to get dressed after surgery. In addition, consider packing a pair of socks to wear during surgery.

For younger patients, pack a favorite toy or stuffed animal for comfort.

My Questions
What Happens after the Procedure?

Following the operation you will be sent to a recovery area. Then you will be transferred to a ward where you will begin your recovery process.

During the first 24 hours
- You will be closely monitored for any sign of complications.
- You will probably be able to eat a meal, get up and move around.
- Your doctor will provide medication to help control any surgical pain or headache. If your headache becomes too severe or you notice other disturbing effects, such as blurred vision, notify your doctor or the hospital staff.
- Patients often experience exhaustion and some mild confusion after surgery. This is usually only temporary and generally subsides within 24 to 48 hours.

How long will I stay in the hospital?
The length of your hospital stay will vary depending upon the center where your surgery is performed. Some people will be discharged within several days after surgery, while others will remain in the center longer.

What to expect after you leave the hospital
The months following your DBS surgery can be an exciting time as you become familiar with your DBS system. You may begin to return to some of the activities you enjoy. But the first few weeks after your procedure should be dedicated to healing and recovery. Your individual recovery time will vary depending on your body and your exact surgical procedure. Talk with your doctor about what to expect during your recovery.

Recovery
Preventing infection
During your stay in the hospital and for the first several weeks after surgery, the key goal is to prevent infection.
The following are general guidelines your doctor may recommend for reducing the risk of infection and irritation:

- Keep the incision areas clean and dry.
- Wash your hands before touching an incision area.
- If you wear a hat or head covering, make sure that it is very clean.
- Avoid using lotions or creams around incision areas unless instructed by your doctor.
- Avoid bumping or putting pressure on the incision areas. When riding in a car, consider placing a folded piece of soft cloth or a hand towel between the chest and the seat belt to help reduce pain and irritation.
- Do not pick or pull at the skin as it heals. This is especially important and sometimes can be difficult because your skin may itch as it heals.

Call your doctor or nurse immediately if you notice signs of infection, such as the following:

- A fever of 37.8°C or higher
- Redness or swelling at the incision or around your stitches
- Excessive pain around the incision site
- Any type of yellow or bloody drainage from the incision

**What will my recovery be like?**

Recovery is a process that involves your entire body. Allow yourself time to rest and heal. As you begin to recover, you may experience some discomfort around the incision areas or areas where the leads and extensions were placed. Follow your doctor’s instructions regarding the use of pain medications. Your doctor may also recommend ice packs (with a dry cover) to help relieve some pain. Over time, this pain should decrease and your energy and activity levels should increase. The most important thing during this period is to protect the incisions from infection.

Focus on making small improvements each day, and set goals for what you would like to accomplish in the future.

---

The space below is for you to record information about your recovery and DBS therapy expectations you and your doctor have set together. You should also share this information with your carer.

**My Recovery Process**

---

**DBS Therapy Expectations**

What are realistic expectations for me to have about my DBS therapy?

---
How long after my surgery will it be before I see improvements?

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

How often will I need to return to the clinic for visits?

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

Activity Restrictions

Upon discharge, your doctor will provide you with instructions about activities that you should and should not do. Follow these instructions carefully. They are intended to allow your body the time it needs to heal. And be sure to take all of your medications as instructed, including any new antibiotics.

For carers or families of younger patients, try to limit any rigorous activity or play. Take special care to ensure proper wound care for the young patient.

In the first few weeks after your surgery, you should be able to resume a number of your normal daily activities—with some restrictions. Even if you feel great within a week or two, remember that your brain will also need time to heal. Talk with your doctor to understand the recommended level of activity.

When some of the motor symptoms of dystonia are reduced, or go away, you may be tempted to participate in some activities that you used to do prior to the onset of dystonia symptoms or in activities that you’ve always wanted to try, like athletics or sports. It is important to use caution since doing some of these activities too early can lead to an accident or harm. Talk with your doctor about what activities are acceptable during this time and what activities you will be able to participate in going forward and throughout your life.

Your Doctor’s Instructions

Use the space below to write or attach the post-surgical care instructions you receive from your doctor.

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________
Living with Your DBS System

The weeks following the implantation of your DBS system can be an exciting time but also a period of adjustment. As your body heals and you adjust to the effects of stimulation, you should be able to do more of the things you want to do.

What will life be like with DBS therapy?
Following your DBS surgery, it may take weeks or months to see optimal improvement. It is important to remember that DBS does not work simply by turning on the system. Turning the system on is just the start. Over the course of the next several months, you should gain more control over your dystonia symptoms. Although results vary from person to person, this control should help you to return to doing some of the activities that are meaningful to you and that your dystonia symptoms may have prevented you from doing.

Programming
Over the next several months, you and the doctor or nurse programming your DBS system will work together to develop the right combination of stimulation and medication for you.

While you are working together, continue to discuss your expectations, as well as any questions or concerns, with your doctor.

What is a programming session like?
Programming will be done using a device that can “speak” with your stimulator without the use of wires. During the programming session, the clinician will explore a range of stimulation variables to determine the optimal setting for you. These stimulation variables may be modified over the course of months or weeks as you begin to see gradual symptom improvement.

How long will programming take?
The first sessions to program your device may take a considerable amount of time. Be sure to discuss with your doctor or nurse how long your programming session will take and what to expect. Remember to make appropriate arrangements with school or work to accommodate for your programming session.

While your clinician is determining your settings, you may experience some temporary sensations, such as:
- Numbness or tingling, often in the face or hands
- Dizziness or balance impairment
- Twisting movements that resemble dyskinesias
- Muscle spasms, usually in the face or hands
- Seeing stars
- Slurred speech
- Double vision

These temporary sensations should stop when the DBS settings are changed or adjusted. They should not be present at the end of your session or after you get home. If any of these sensations appear when you are at home, notify your doctor.

Your DBS Neurostimulator and Controller

During your initial programming session, your physician should provide you with a handheld controller for your device and a controller User’s Guide. Make sure to keep the User’s Guide in a place where you can easily find it. Refer to your User’s Guide for complete instructions on how to use and care for your controller. If you have a rechargeable battery, refer to your User’s Guide for instructions and information on recharging.

When and how to check your battery status
Your controller allows you to check whether or not your stimulator is on and if the battery is getting low. However, you will not need to do this on a daily basis. Discuss with your doctor how frequently to check the status of your battery.

You should schedule regular follow-up visits with your DBS center to determine if your system is functioning properly and to estimate the life of your neurostimulator battery.

Signs and symptoms that you may not be getting optimal stimulation
Under certain circumstances, your DBS neurostimulator could be switched off by accident, such as when you are walking through an anti-theft device in a department store. Events like these are not harmful to you or your device. However, you may experience a return of your dystonia symptoms when this happens. You can easily check the status of your neurostimulator and, if necessary, turn it back on by using your handheld controller.
In addition, if you experience an unexplained and immediate return of your dystonia symptoms, it is always a good idea to check the status of your device. If you do experience an unexplained return of symptoms, make sure to contact your doctor or nurse as soon as possible.

**Living with Your DBS System: Additional Precautions**

**Traveling with your system**
Listed below are a few reminders that may help you when you are traveling.

**Things to take with you**
- Phone numbers for your neurologist and nurse
- Patient controller and extra batteries

Inform security personnel that you have an implanted device before you approach a theft detector or metal screening device at a security checkpoint. You should request assistance to bypass the device.

If you must pass through an anti-theft or screening device, move quickly through the device. Afterward, use your patient controller to check the status of your neurostimulator and ensure that it is still turned on.

**Medical test precautions**
Always inform any medical personnel that you have an implanted DBS system, especially your general practitioner (GP) and dentist.

**Can I have an MRI?**
People with DBS systems should not have a full body MRI, a full-body radiofrequency (RF) coil MRI, or a head transmit coil MRI that extends over the chest.

People with DBS systems can have common X-rays.

**Can I have diathermy?**
No. People with DBS should never undergo any form of diathermy (the use of high-frequency electrical current for deep heating tissue), which dentists and physical therapists sometimes use for the treatment of pain. Injury can occur during diathermy whether the DBS system is turned on or off.

**Is it safe to have an ultrasound?**
Certain care and precautions should be taken when ultrasound is done on a person with a DBS device. Consult your User’s Guide for additional information.
This section will help address some commonly asked questions and concerns you may have after your procedure.

**When will my DBS system be turned on?**
Your doctor will decide when to turn your stimulator on based upon what is right for you and your recovery. Doctors differ in their opinions about how soon after surgery stimulation should be turned on. Some centers turn stimulation on immediately and others wait several weeks.

**Will I be able to “feel” the stimulation?**
Most people will not be able to feel the stimulation once appropriate settings have been determined. Some people may experience programming-related side effects during a programming session. These side effects almost always disappear once stimulation settings are re-adjusted.

**When will I see improvements in my symptoms?**
During the first six to twelve months, your DBS team will work with you to adjust programming and medication to find the best possible combination for your dystonia symptoms and lifestyle. Programming will be done using a device that can “speak” with your stimulator through your skin. During the programming session, the clinician will explore a range of stimulation variables to determine the optimal setting for you.

**How often will I need to have my settings adjusted?**
In the first twelve months following surgery, the need to adjust your stimulation will be the greatest and may require a number of visits back to the DBS center. As you and your doctor or nurse work together to find the best combination of stimulation and medication, the need for follow-up visits should be reduced.

**Will DBS prevent my dystonia from progressing?**
DBS is not a cure for dystonia. The goal with DBS is to provide adequate motor-symptom control and to help improve your quality of life. In addition, you may be able to reduce the amount of your dystonia medications and reduce medication-related side effects.

**How long will the benefits of DBS last?**
Current data shows a long-term, sustained response in patients who have responded to DBS and whose symptoms have improved. There are additional studies being done to review the longer-term benefits.
Do I keep my DBS system on 24 hours a day?
Most people do keep their DBS systems on 24 hours a day to continue to receive the best possible benefit from the therapy.

How often does the neurostimulator need to be replaced?
Since each person with dystonia has different stimulation needs, it is difficult to predict exactly how long a neurostimulator will last. Rechargeable technology can last at least ten years, reducing the need for the more frequent battery replacements common with conventional neurostimulators. Talk with your doctor about what type of neurostimulator has been selected for you and about how long he or she estimates your neurostimulator may last.

When will I be able to reduce the amount of my medication?
During the initial months with your DBS system, you and your doctor will work together to find the best combination of stimulation settings and medication to manage your dystonia symptoms. In many cases, the amount of medication you are taking can be reduced. In rare cases, patients have been able to stop taking any medication after receiving DBS treatment. Make sure to discuss with your doctor what your expectations should be regarding the amount of medication you might require after DBS. Do not stop taking any of your medications unless your doctor tells you to do so.

What will I be able to do when I get home?
You should always follow your doctor’s instructions regarding activity restrictions. You should be able to resume many of your normal daily activities when you return home. Even if you feel great within a week or two, remember that your brain will also need time to heal. Choose activities cautiously and take things slowly. Trying to do more physically demanding activities too quickly could result in a potential fall or injury.

Remember, you have been living with the physical symptoms of dystonia for a while. During that time, your body has adjusted to your symptoms. Your muscles may not be prepared to perform certain activities. It is important to be aware of what you are capable of doing and slowly engage in more physically demanding activities, if appropriate, to prevent an accident from occurring.

How will I “retrain” my muscles?
In some cases, after you begin to see improvements as a result of DBS, your doctor may recommend that you work with a physical therapist and/or occupational therapist on range of motion exercises aimed at strengthening muscles and improving coordination. Exercises may help to retrain your muscles on some of the basics of everyday living. Your doctor will determine whether or not physical and/or occupational therapy is appropriate for you. Discuss with your doctor any difficulties you might be having after your DBS surgery.

Can I exercise after having DBS?
Most people are able to return to low-impact exercise within four to six weeks after surgery. You should consider avoiding high-impact or heavy-contact activities and sports permanently. Talk with your doctor about what exercises might be appropriate for you after DBS surgery and in your future.

Can I take a bath or go swimming with a DBS system?
Most people with a DBS system can shower and swim once their incisions are completely healed. However, you should check with your doctor before doing either activity. Remember, your programmer is not waterproof. Keep it dry to avoid damage.

Can I use household appliances or mobile phones with my DBS system?
You can use computers and standard household appliances, including microwave ovens with your DBS system. Household appliances that contain magnets may unintentionally cause the DBS system to turn on or turn off. You can also use a mobile phone, but the effects of mobile phones on DBS systems are unknown. Avoid placing mobile phones (on or off) directly over the neurostimulator.

What if a better treatment becomes available?
The DBS system can be completely removed, allowing for many possible future treatment options.
As the spouse, parent, or care partner of someone with dystonia, you are very aware of how dystonia affects both of your lives. Because of the symptoms, you may help with the everyday activities of life, such as dressing, feeding, and managing a household. You may also be experiencing increased social isolation as a result of the motor symptoms of dystonia or the social embarrassment dystonia causes. Dystonia symptoms are probably negatively impacting you and the person with dystonia, so the doctor is recommending DBS as a possible therapy option. Keep in mind that the patient is most likely considering DBS as a way to potentially improve his or her life—and yours as well! The goal of this guide is to answer some of the questions you may have about DBS therapy.

As a carer it is important for you to have all of your own questions answered and to have realistic expectations about how your life may change and what your new carer role may be like after DBS. While the idea of not having to provide so much care to your loved one sounds wonderful, be aware that in reality, some people find it difficult when they are not needed as much after DBS. You may consider preparing yourself for this situation through quiet reflection, talking with a friend, or even talking with a qualified health care professional. In addition, it may be helpful to talk with the carer of someone else who has undergone DBS.

Listed on the following page are some specific questions you may want to discuss with a doctor. In addition, you may want to contact other resources for support, including online chat rooms, carer support groups, or resources available through your DBS center.

**Carer Questions to Consider**

- What can we do prior to the DBS procedure to make sure we have appropriate expectations about the possible benefits of DBS therapy?
- What will be required of me immediately following the surgery and over the next three to six months?
- Will the patient have any special needs over the first three to six months?
- Will the patient be able to return to school or work, or drive after the surgery?
- What are the potential side effects of DBS therapy for the person I care about?

**Special Considerations for Carers of Children and Adolescents**

Early-onset dystonia is often associated with more severe symptoms than adult-onset forms of dystonia. Children with dystonia are often very young when they first begin to experience symptoms and face particular challenges that can be extremely difficult for them.
Special issues in children and adolescents can include:  
- Psychological factors  
- Attachment and psychosocial development issues  
- Social and academic considerations related to school  
- A more difficult and traumatic time with medical visits, surgical procedures, and hospitalizations

The chronic, severe, and progressive nature of early-onset dystonia may create a sense of helplessness and concern with safety and trust in younger patients. Social embarrassment with peers and feelings of being stigmatized can cause social and emotional distress that is often traumatic for younger patients.

As a carer of a child or adolescent with dystonia, you may also at times experience psychological distress. Common carer concerns in childhood illness include:  
- Feelings of helplessness  
- Anxiety  
- Anger  
- Fears about your own health and security  
- Feelings of blame

These feelings are normal. You are not alone. As a carer, it is important to acknowledge these feelings so that you can establish a safe and positive environment for your child or adolescent as your family considers whether DBS is the right choice for your family.

Take extra time to talk to your doctor about the opportunities and challenges that your child or adolescent may face after they have DBS. It is important to have all of your questions answered so that you are aware of and are prepared for the special considerations specific to pediatric DBS patients.

Helpful hints for pre- and post-surgical preparation for you and your child or adolescent include:  
- Encouraging young patients to make choices during therapy  
- Age-appropriate education about DBS  
- Being aware of social and academic considerations related to hospitalization  
- Developing a game plan for the day of surgery  
- Techniques to reduce anxiety  
- Relaxation strategies  
- Counseling with a professional  
- Resources that educate on post-hospitalization adjustment

Most importantly, talk to your doctor and the multidisciplinary team who will be treating your child or adolescent to make sure that you have realistic expectations and are prepared to make the choice for your child or adolescent to have DBS.
Resources and Additional Information

Dystonia Europe – dystonia-europe.org
Dystonia Medical Research Foundation – dystonia-foundation.org
Living Well with Dystonia: A Patient Guide
Authors: Daniel Truong, M.D., Mayank Pathak, M.D., Karen Frei, M.D.
Publisher: Demos Medical Publishing (+1 800 532 8663)

Important Contact Information

Please fill in the information below, so you have easy access to contact information for your care team.

<table>
<thead>
<tr>
<th>Dystonia Doctor</th>
<th>Telephone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Dystonia Nurse</th>
<th>Telephone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>DBS Programmer</th>
<th>Telephone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
References


