If you have Parkinson’s disease or another movement disorder, Cleveland Clinic’s Center for Neurological Restoration can help. Our center is among the first in the world to bring together an interdisciplinary team of renowned neurologists, neurosurgeons, psychiatrists, neuropsychologists, researchers, biomedical engineers, imaging specialists, physician assistants, technicians and other specialists who offer the latest medical and surgical treatments for patients with neurological and psychiatric disorders.

**CHOOSING YOUR CARE**

At our three locations — Cleveland, Ohio; Weston, Florida; and Las Vegas, Nevada — we offer you the most advanced and specialized care, complemented by leading programs in research and education. The Center for Neurological Restoration is nationally recognized for expertise in medical management and innovation in the surgical treatment of movement disorders as well as obsessive-compulsive disorders, depression and chronic pain.

Patients benefit from an integrated approach to care. Team members collaborate to develop individualized management and treatment plans designed to enhance patients’ function and quality of life. A robust research program ensures that patients have access to single-center and multi-center clinical trials.

**USING THIS GUIDE**

Please refer to this guide as you examine your treatment options. Remember, it is your right as a patient to ask questions and seek a second opinion.
Movement disorders treated at Cleveland Clinic

- Parkinson’s disease and “Parkinson-plus” syndromes
- Essential tremor and other tremor disorders
- Dystonia, including torticollis and blepharospasms
- Restless legs syndrome
- Tourette syndrome and tic disorders
- Huntington’s disease and chorea
- Ataxia
- Myoclonus
- Hemifacial spasms
- Gait disorders

Other conditions treated

- Obsessive-compulsive disorder
- Severe depression
- Chronic pain

PARKINSON’S DISEASE

Parkinson's disease is a chronic, progressive disorder that affects nerve cells (neurons) in the basal ganglia, an area of the brain responsible for coordination and fluidity of movement. These cells normally produce dopamine, a chemical that transmits signals between areas in the brain. Working properly, these signals coordinate smooth, balanced muscle movement. Parkinson’s disease, however, causes the neurons to die sooner, leading to a lack of dopamine in the brain. With this loss, patients experience more difficulty controlling their body movements.

What are the symptoms of Parkinson’s disease?

Symptoms of Parkinson’s disease vary greatly among individuals, which can make diagnosis difficult. Common symptoms include:

- **Tremor or shaking** that begins in a hand, leg or other body part. In some cases, tremor is confined to one side of the body. However, it may spread as the disease progresses and it can worsen with stress.

- **Bradykinesia or slowness of movement** may occur with dressing, bathing or other daily activities.

- **Rigidity or stiffness** in the limbs caused by involuntary muscle tensing, makes it difficult for a person to move freely.

- **Muscle aches or pains** seen mostly when medications start losing their effect.

- **Balance and coordination problems** usually surface as the disease progresses, and may include a forward or backward lean, or a posture in which the head is bowed and shoulders slumped.

- **Other symptoms** may include depression, lack of interest in activities, feelings of fear and anxiety, decreased facial expressions, difficulty swallowing and chewing, speech changes, drooling, cramped handwriting, urinary problems or constipation, sleeping problems and even skin problems, such as dandruff and greasy scalp and forehead.
DYSTONIA

Dystonia is a movement disorder in which forceful, sustained muscle contractions cause twisting and repetitive movements or abnormal postures. These involuntary and sometimes painful movements may affect a single muscle; a group of muscles such as those in the arms, legs or neck; or the entire body.

Dystonia causes varying degrees of disability and pain. It is a chronic disorder but, fortunately, does not usually affect cognition or intelligence. While there is no cure for dystonia, multiple treatment options can reduce the severity of symptoms.

What are the symptoms of dystonia?

Early symptoms of dystonia may include deterioration in handwriting, foot cramps, or a dragging foot after running or walking a significant distance. Other possible symptoms include tremor, head-shaking, involuntary blinking, and voice or speech difficulties. About half of these cases have no connection to disease or injury, and are called primary or idiopathic dystonia. Of the primary dystonias, many cases appear to be inherited. Dystonias also can be symptoms of other diseases, some of which may be hereditary. In some individuals, symptoms of dystonia appear in childhood. In others, symptoms may not appear until later in life.

In general, dystonias that appear later in life do not tend to spread to other muscle groups. Called “focal dystonias,” they commonly affect eyelids (blepharospasms), neck (torticollis), forearm (writer’s cramp) and vocal cords (spasmodic dysphonia).

Initially, dystonic movements are intermittent and appear only during voluntary movements or stress. Later, individuals may show dystonic postures and movements while walking or even while relaxed. Dystonic motions may lead to permanent physical deformities by causing the muscles or tendons to shorten.

ESSENTIAL TREMOR

Many people have experienced shaky hands, especially at times of high stress or anxiety. But for 5 million Americans, involuntary shaking — or essential tremor — is a constant problem.

Essential tremor is an uncontrollable shaking of the muscles, usually upon movement. It can occur any time, but commonly begins at middle age. While the cause of essential tremor remains unknown, a family history exists in about half the cases. Essential tremor does not affect life expectancy but it can become disabling for many common activities, such as writing and eating.

What are the symptoms of essential tremor?

Because there is less recognition of essential tremor, it is often confused with Parkinson’s disease. The difference lies in when the tremors occur. With few exceptions, in Parkinson's disease, tremors most commonly occur when a person is at rest and diminish when there is movement. With essential tremor, shaking typically occurs with activity and diminishes at rest. Another difference is that Parkinson’s disease also can include stiffness and slowness of movement.

Other symptoms of essential tremor may include a shaky voice, nodding head and balance problems.

“I can now do things that most people take for granted. I can eat. I can write. I can drink from a glass. I can button my own shirt and shave! My life is as normal as anyone’s now. It’s so amazing.”

— Dirk Hoch, Patient treated with deep brain stimulation for essential tremor
Other movement disorders

Any patient experiencing lack of movement or too much movement most likely has some form of a movement disorder. Other disorders include:

- **Restless legs syndrome** is perhaps the most common movement disorder, experienced by up to 10 percent of the general population. Symptoms include cramping or other sensory discomfort in the legs at night. The condition is relieved by walking, but returns when the patient goes back to bed.

- **Huntington’s disease** is a progressive, hereditary neurological disorder characterized by various degrees of chorea (involuntary twitches, clumsiness, jerking, twisting or dance-like movements) and other involuntary movements. Patients also can experience behavioral and mental problems.

- **Tourette syndrome** is an involuntary disorder often seen in younger patients, with symptoms that include an increasing urge to yell, twitch or move repeatedly, commonly accompanied by obsessive-compulsive behaviors.

HOW ARE MOVEMENT DISORDERS TREATED?

**MEDICAL OPTIONS**

Medical management is the cornerstone of movement disorder care. Pharmacological management (such as oral medications and botulinum toxin injections), patient education and family support are important aspects of the comprehensive treatment plan we provide for each of our patients. As movement disorders are often accompanied by behavioral, cognitive and other “non-motor” complications, our multidisciplinary team also can guide you with issues such as depression, cognitive decline, nutrition and disease prognosis.

**SURGICAL TREATMENT – DEEP BRAIN STIMULATION (DBS)**

Cleveland Clinic ranks among the world’s leaders in innovative applications of deep brain stimulation (DBS) surgery. Having performed hundreds of DBS surgeries, our physicians and scientists continue to gain knowledge about the circuitry that contributes to the development of movement disorders and other neurological and psychiatric conditions. Our staff is continually investigating and developing new treatments to improve the quality of life for individuals with depression, obsessive-compulsive disorder, cluster and migraine headaches, stroke and pain.

**What is DBS?**

DBS uses advanced computer technology to pinpoint areas of the patient’s brain where faulty electrical signals are triggering symptoms. Guided by this information, a neurosurgeon makes a small opening in the skull and implants electrodes in targeted areas of the brain. Depending on the patient’s needs, this procedure is done on one or both sides of the body. In order to ensure that the implants are properly placed, the patient may be awake during part of the surgery so that he/she may communicate with the surgical team. Local anesthesia relieves any pain during this wakeful period.

The patient usually goes home two to three days following surgery and returns to the hospital one week later for a second step. At this time, general anesthesia is used as the surgeon implants a battery-powered pulse generator under the patient’s collarbone.
Thin wires placed beneath the skin connect this “brain pacemaker” to the electrodes implanted earlier in the brain. The pulse generator delivers stimulation to these targeted brain areas, blocking the abnormal signals that produce symptoms such as tremor, stiffness and slowed movement.

The patient goes home in less than 24 hours, and returns as an outpatient two to four weeks later to turn on and program the pulse generator. Several visits might be necessary to fine-tune the device to control a patient’s particular symptoms. This process is painless. At home, the patient has the ability to switch the stimulation on or off. The device’s batteries generally last three to five years.

Who is a candidate for DBS?
DBS is successful in treating patients as young as 13 years of age; however, it is not for everybody.

Generally, DBS candidates are patients under age 75 who:

- Have a movement disorder and a declining quality of life
- Are experiencing worsening of coordination and control of movement
- Have had an adequate trial of medications

A successful outcome depends as much on selecting the right patient as on having a skilled surgical team. That’s why every DBS candidate should first undergo an evaluation conducted by a neurologist, neurosurgeon, psychiatrist and neuropsychologist with special training in DBS.

New advances in DBS
For those patients who cannot tolerate or are not considered candidates for traditional DBS surgery, Cleveland Clinic has developed, installed and established training for an interventional MRI suite attached to a conventional operating room, called IMRIS Neuro. The MRI machine is suspended from the ceiling and moved into the operating room only when needed. Guided by feedback from the system, the neurosurgeon can plan and precisely place the leads while the patient is under general anesthesia. Previously, almost all DBS required awake surgery while this advancement now offers patients the option of being asleep.

Are there risks involved with DBS?
As with any surgery, the DBS procedure is not risk free. There is a risk of brain hemorrhage or stroke that may result in neurological impairments such as paralysis, speech impairment, mental impairment or other neurological problems. Other risks include infection, need for additional surgery, pain and anesthesia-related complications. While there is always a risk of death in brain surgery, this is not common. Most patients will complete the surgery without major complications.
Life After DBS
For an appropriate candidate in the hands of an expert team, DBS can mean the difference between unbearable suffering and the ability to reclaim a productive, meaningful life. More than 70 percent of Parkinson's patients see substantial improvement in all their symptoms, and most people find they can cut back significantly on their medications. The effects of the brain stimulation are reversible and the stimulation can be adjusted without more surgery if a patient's condition changes.

Is DBS approved by the Food and Drug Administration (FDA)?
The FDA has approved DBS for the treatment of Parkinson's disease and essential tremor. It is also approved for dystonia and obsessive compulsive disorder under a Humanitarian Device Exemption.

Does Medicare cover deep brain stimulation?
In most states, DBS surgery is an approved procedure covered by Medicare and most insurance companies for the treatment of Parkinson's disease, essential tremor and dystonia. In some cases, insurance also will approve deep brain stimulation surgery for other, less common movement disorders. Check with your Medicare and/or insurance provider to determine if you are covered for all or a portion of DBS surgery. Please contact us if you need assistance in determining your coverage.
Step 2: Patient registration
When you call to schedule an appointment, our patient service representative will register you as a new patient to Cleveland Clinic. Please have your basic information, including your address, phone numbers, emergency contacts and current insurance information, available when you call.

Step 3: Identifying the appropriate physician
As part of the scheduling process, your patient service representative will ask you a variety of questions in order to schedule you with the appropriate physician. It might also be necessary for your patient service representative to review your medical history before scheduling the appointment. If this is needed, the schedulers will assist you in obtaining your medical records by contacting your primary care provider with you on the phone. Once the patient service representative reviews the records, we will schedule you with the appropriate Cleveland Clinic physician. Please bring all reports or current scans, such as MRIs or X-rays, from your current primary care provider to your appointment.

Step 4: Scheduling the appointment
Once our team reviews your records, we will assist you in scheduling the appropriate appointments:

- For management of movement disorders, the patient service representative will schedule the appointment at the time of your call.
- For deep brain stimulation, several evaluations are required for a complete assessment. Our office will contact you to discuss and coordinate the necessary appointments.
- For other surgical options, additional evaluations in conjunction with your appointment with the surgeon will be needed. We will assist you in coordinating these appointments.

Special assistance for out-of-state patients
Cleveland Clinic’s Global Patient Services has a Medical Concierge program that provides complimentary services to patients who travel from outside Ohio, Florida and Nevada. For more information, call 800.223.2273, ext. 55580, visit clevelandclinic.org/concierge or email medicalconcierge@ccf.org.

HOW DOES THE PATIENT CARE PROCESS WORK?
Quality patient care is of utmost importance at the Center for Neurological Restoration. Many of the treatment options offered by our center require multiple evaluations. Scheduling these appointments with the appropriate physicians can be a difficult task. That is why our staff developed a comprehensive system that walks patients through our care process from the initial phone call to the final evaluation.

If you are interested in scheduling an appointment with the Center for Neurological Restoration, you can expect the following evaluation process:

Step 1: Call our appointment schedulers
To schedule an appointment with the Center for Neurological Restoration in Cleveland, please call 216.636.5860 or toll-free 866.588.2264. For our Weston, Florida, location, call 877.463.2010. For our Las Vegas, Nevada, location, call 702.483.6000. Our patient service representatives are available to assist you Monday through Friday 8 a.m. to 5 p.m.
ACCESS TO CLINICAL TRIALS

Clinical trials are one of the cornerstones to advances in therapy. The most cutting-edge and promising therapies for movement disorders are tested in a safe, comfortable and ethical manner.

Patients have the opportunity to participate in these advancements and to participate in new therapies before they become commercially available. The Center for Neurological Restoration has accelerated its research activities, and now offers more than two dozen clinical trials to patients with movement disorders. A clinical trial consortium links our Cleveland, Florida and Nevada sites to ensure that patients have access to clinical trials regardless of where they are treated.

RESEARCH

Cleveland Clinic continues to conduct groundbreaking research in neurorestorative therapies for patients with disabilities secondary to neurological and psychiatric disorders, including the development of DBS to treat obsessive-compulsive disorders, depression and other neuropsychiatric disorders.

The scope of our research extends well beyond DBS. For example, biomedical engineer Jay Alberts, PhD, is investigating how forced exercise, performed under strict parameters, can alter motor function in Parkinson’s disease patients. This promising and innovative work grew out of a trip during which Dr. Alberts’ tandem bicycle partner, a Parkinson’s patient, pedaled at a given pace and noticed motor function improvements that lasted beyond the duration of the exercise.

SHARED MEDICAL APPOINTMENT: TAKING CONTROL OF PARKINSON’S DISEASE

Cleveland Clinic’s Center for Neurological Restoration offers patients diagnosed with Parkinson’s disease a shared medical appointment (SMA), or group sessions with fellow Parkinson’s disease patients and a healthcare professional.

The unique, eight-hour appointment offers the benefit of more time with a healthcare professional, less time spent in the waiting room, and the ability to learn from others with the same or similar conditions. Because people have different questions, many patients leave the SMA with more information than they might have gathered in a one-on- one meeting with their own physician. These appointments do not take the place of the initial personal evaluation with your neurologist.

For more information on SMAs, please call the Center for Neurological Restoration at 216.445.1108.

HUNTINGTON’S DISEASE COMPREHENSIVE CLINIC

This multidisciplinary clinic provides comprehensive care for patients and families dealing with Huntington’s disease. Our team is comprised of healthcare providers from neurology, psychiatry, neuropsychology, genetics, physical therapy, occupational therapy and speech therapy who work in a coordinated fashion to assess the physical, emotional, cognitive and behavioral needs of patients with Huntington’s disease. Opportunities for participation in clinical research and clinical trials are also available.

For more information, please call the Center for Neurological Restoration at 216.445.1108.

NORTHEAST OHIO YOUNG ONSET PARKINSON’S SUPPORT GROUP

The average age at which Parkinson’s disease is diagnosed is 60. However, roughly 10 to 20 percent of those diagnosed with Parkinson’s disease are under age 50, and about half of those are diagnosed before age 40. When such a diagnosis is made early, it is referred to as young onset Parkinson’s disease. Often, young onset patients face challenges different from those that confront patients diagnosed in their 60s and 70s.

Patients can benefit from attending support group meetings by:

• Learning about Parkinson’s disease treatment, news and research
• Connecting with other young people who understand the challenges firsthand
• Sharing ideas for better self-care
• Inspiring one another to be strong and improve overall quality of life
• Utilizing your own experiences to help others

For questions about our Northeast Ohio Young Onset Parkinson’s Support Group, call 216.444.8860 or email youngparkinsonsgroup@ccf.org.
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