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Managing Your

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A GUIDE
for Patients with Movement
Disorders, their Families,
and Caregivers



Learning About Movement Disorders

“Having a movement disorder can feel at times like being a prisoner in your own body, or as if your body has a mind of its own. I think the hardest part is how misunderstood and isolated you can feel. It wasn’t until I received an accurate diagnosis and treatment that I felt I had control over my life again.”

Movement disorders are chronic, often painful, and debilitating neurological conditions that affect the ability to control movement. Having a movement disorder can make it difficult – even impossible – to do the routine things in life that most people take for granted.

Movement disorders are common. More than 40 million Americans – nearly one in seven people – are affected. Yet many movement disorders are not well known and symptoms may not be recognized by all medical professionals.

A patient with a movement disorder may visit more than 15 doctors over the course of five years before receiving an accurate diagnosis...

...and during this time, people often struggle to cope with new limitations and daily challenges beyond their movement disorder, including misunderstanding and social stigma – at home and at work. But with timely accurate diagnosis, treatment, and the support of your healthcare team, it is possible to live with less pain and fewer daily limitations and restrictions – to live your life more fully “in motion.”

What Are Movement Disorders?

“You need to learn how to live with a chronic illness, but it does not have to define who you are or what you do.”

Movement disorders are conditions that originate in areas deep within the brain. They are caused by changes to specific regions of the brain and nervous system, the cause of which is mostly unknown. These special areas, which control movement, send chemical messages to other parts of the brain. These signals set off a chain of events that eventually result in movement of muscles. In people with a movement disorder, this communication system is disrupted and interferes with the ability to produce and coordinate voluntary movements or the inability to stop unwanted involuntary movements.

There are two basic types of movement disorders:

- **Hyperkinetic (too much movement):**
Disorders that include excess, unwanted movement and muscle contractions. Disorders include dystonia, tremors, and tics.
- **Hypokinetic (too little movement):**
Disorders associated with slowness of movement (bradykinesia), stiffness or rigidity, and other symptoms. Disorders include Parkinson's disease, multiple system atrophy, and others.

What Causes Movement Disorders?

Movement disorders are caused by damage to, or malfunction in, specific regions of the brain and nervous system that are responsible for voluntary and involuntary movements. Movement disorders result from trauma or injury to the brain or spinal cord, inherited disorders (e.g., Huntington's disease, Wilson's disease), stroke, and certain types of medications. In many people the cause of a movement disorder is unknown.

What Are the Symptoms of Movement Disorders?

Symptoms – the abnormal movements themselves – vary widely among disorders, from person-to-person, and even from day-to-day. The sidebar on page 3 describes some of the symptoms a person with a movement disorder might experience.

Having a movement disorder takes a substantial physical and emotional toll.

Abnormal movements can make even the simplest of daily tasks difficult – or impossible. Without treatment...

- A woman with tremors in her hands or spasticity in her arms may lose the ability to write, hold a glass, or hold her child.
- The uncontrollable blinking of blepharospasm, which affects muscles controlling the eyelids, may leave a person unable to see because they can't keep their eyes open.
- A man with cervical dystonia is not able to straighten his neck and finds it impossible to drive.

When daily life is challenged this way, it is not unusual for people coping with movement disorders to become depressed and withdrawn, or anxious and fearful about the future.

“It can be hard for people to understand that even though this disorder is not life-threatening, it has a profound impact on a person – physically, emotionally, and socially.”

Some Symptoms of Movement Disorders

- **Changes in Coordination** clumsiness, instability, or lack of precision
- **Changes in Voice and Speech** difficulty with articulation, monotone or breathy sound
- **Changes in Vision** difficulty keeping eyelids open, or excessive blinking
- **Changes in Movement Patterns** may appear slow or fast, irregular, prolonged, stiff or rigid
- **Slow or Irregular Movement** an unnatural stillness or frozen quality, shakiness or tics
- **Tremor-like Movement** shakiness, or uncontrolled movements
- **Changes in Posture or Position** the inability to relax body parts to normal positions
- **Changes in Sensory Perception** feeling of restlessness, tingling, cramping, crawling sensations in one or more areas of the body, diminished sense of smell
- **Other Symptoms** sleep disturbance, drooling, muscle cramping, confusion, or depression

How Are Movement Disorders Diagnosed?

Movement disorders are complex neurological conditions, and it may take a series of doctors' visits, referrals, and testing to reach a correct diagnosis. It is common for the symptoms of a movement disorder to be attributed to emotional problems. If you or your primary care physician suspect you have a movement disorder, a referral to a neurologist, physiatrist, or other specialist familiar with these conditions for further evaluation is appropriate.

Accurate diagnosis of a movement disorder depends upon a careful medical history and a thorough physical and neurological examination. Diagnostic tools may include:

- **Laboratory tests**, which may include a complete blood count, urinalysis, and DNA analysis. These tests are used to exclude other conditions with similar symptoms.
- **Advanced imaging techniques**, including CT (computerized tomography) and MRI (magnetic resonance imaging) scans. These may be used to determine whether there is any brain damage or structural abnormalities, or whether a stroke has occurred.
- **Nerve conduction studies**, including EMG (electromyogram) and EEG (electroencephalogram), may be performed to monitor electrical activity in the muscles (EMG) or brain (EEG), and detect any abnormalities.

- **Muscle biopsy**, which involves the removal of a small sample of muscle for examination under a microscope and can help distinguish between muscle and nerve disorders.

In addition, some physicians skilled in the management of movement disorders may use video recording to analyze movement patterns and track progress of the disorder and its treatment.

After the diagnosis...take action

It is normal to feel overwhelmed. But many patients find that taking action after the diagnosis creates a feeling of empowerment and helps them to be more successful in managing their condition and the changes it may bring.

"An accurate diagnosis and treatment brought me peace of mind, hope, and a sense of well-being. Finally getting the right diagnosis helped me research my condition and I no longer had to struggle to find answers."

How Are Movement Disorders Managed?

Most movement disorders are chronic conditions that cannot be cured. When accurately diagnosed, treatment can focus on relief of symptoms to help you do the things that are most important to you. Your treatment plan may include one or more of the following:

- **Medication** is prescribed to many people with movement disorders to control symptoms. You can expect that medications will be added, changed, or reduced depending on the severity of symptoms, response to therapy, and treatment priorities. Classes of drugs used in the management of movement disorders include:
 - Anti-convulsant medications (e.g., primidone/Mysoline®, gabapentin/Neurontin®, etc.)
 - Antispasmodics (e.g., baclofen/Lioresal®, tizanidine/Zanaflex®, etc.)
 - Beta-blockers (e.g., propranolol/Inderal®, etc.)
 - Dopaminergic agents (e.g., levodopa-carbidopa/Sinemet®, ropinirole/Requip®, pramipexole/Mirapex®, apomorphine/Apokyn® etc.)
 - MAO-B inhibitors (e.g., selegiline/Eldepryl®)
 - COMT inhibitors (e.g., tolcapone/Tasmar®, entacapone/Comtan®, levodopa-carbidopa with entacapone/Stalevo®, etc.)
 - Benzodiazepines (e.g., diazepam/Valium®, clonazepam/Klonopin®, etc.)

Talking With Your Doctor About Movement Disorders

Here are some tips for making the most out of every office visit:

Be prepared.

Make a list of the things you want to discuss before each appointment, and ask about the most important ones first. Think about the things that have happened or symptoms that have occurred since your last visit – make a list of these – and make a point of sharing this information with your doctor.

Share any symptoms.

It is important to be clear and concise when describing your symptoms. Your description will help identify the problem and point the doctor in the right direction. Be prepared to tell when your symptoms started, what time of day they happen, what seems to trigger them or make them better, how often they occur or how long they last (e.g., seconds, hours, days?), if they seem to be improving or getting worse, and if they keep you from going out or doing your usual activities. Remember: it is not a sign of weakness to be concerned about your symptoms. It is important to be honest with your doctor about what you are experiencing.

Write it down.

Bring along a notebook and pen, and take notes to help you remember what you are told. Whenever possible, ask the doctor or staff to provide written advice and instructions.

Bring a family member or friend.

This person can remind you of things you wanted to talk about and can help you remember what was said. The support of having someone with you can be a big help, especially early on when you may be most confused or worried about your diagnosis and the progress you will make.

Ask questions.

Don't be afraid to ask questions. Otherwise, your doctor may think you understand or assume you don't want more information. Write down the questions you have before your visit. Don't hesitate to ask about words or medical terms you do not understand. It is important that you feel comfortable with your doctor.

Intramuscular Injection Therapies are targeted treatments that use therapeutic neurotoxins or chemicals to disrupt the flow of nerve impulses to excessively contracted or spastic muscles. Botulinum toxin injection therapy inhibits the release of the chemical “messengers” that signal the muscles to contract, and is a well-accepted therapy for treating both large and small muscle groups. Examples of botulinum toxin therapies include:

- Botulinum toxin type A (BOTOX®)
- Botulinum toxin type B (Myobloc™)

Other injection therapies use alcohol or phenol to destroy overactive nerves in larger muscle groups.

Implantable Devices may be recommended for the management of movement disorders that may not be controlled by oral medication or injection therapy. There are two basic types of devices used:

- Deep brain stimulation (DBS) involves the surgical implantation of one or more electrodes in the brain, connected to a battery-operated medical device (a neurostimulator) which is implanted in the chest. The device delivers an electrical charge through the electrode that blocks the nerve signals triggering abnormal movement.
- Medication pumps deliver drugs directly to the space around the spinal cord increasing their effectiveness.

Surgery may be recommended for some patients with severe movement disorders if other treatment options do not effectively control symptoms. Destructive surgery uses a heated probe to locate the specific area of the brain triggering the abnormal movement.

Your Healthcare Team: Who Treats Movement Disorders

The effective management of a movement disorder usually involves a multi-disciplinary team:

- **Primary Care Practitioner:** A medical doctor who is the primary point of contact and is instrumental in coordination of care.
- **Neurologist:** A medical doctor trained in disorders of the nervous system. The neurologist diagnoses the neurological disorder; prescribes treatments, including medications; and refers the patient for rehabilitation or surgical evaluation, if necessary.
- **Physiatrist (FIZZ-ee-AT-rist):** A medical doctor specializing in physical medicine and rehabilitation. The physiatrist diagnoses movement disorders, prescribes treatments, and designs the rehabilitation program.

Questions to Ask Your Doctor About Treatment

It's important that you discuss your condition with your doctor and be clear about what your treatment goals are. Discuss the treatment outcomes that are most important to you.

Ask yourself:

- Which symptoms are most troubling to me?
- What activities or parts of my life are most affected by my movement disorder?
- Which of these are most important to me, and how do I expect treatment to help?

Ask your doctor:

- How do we establish treatment goals?
- What treatments are available for my specific condition?
- Which treatment will best help me achieve my treatment goals?
- How long will these treatments take to work?
- What side effects or other risks can I expect with the recommended treatment? How long will they last? Is there anything I can do to prevent or manage possible side effects?
- If I need to consider surgery, what are the potential benefits and risks, and what can I expect afterward?
- If I undergo this test, what are we going to learn from it, and, based on this test, what are we going to do differently?

- **Physical therapist (PT):** Facilitates therapeutic exercises to maintain the range of motion of limbs and directs the application and fitting of braces, splints, or casts.
- **Occupational therapist (OT):** Adapts the physical environment to meet the patient's needs and teaches the patient and caregiver techniques to assist in the activities of daily living.
- **Neurosurgeon:** Performs surgery on the nervous system, including the brain, spinal cord, and nerve network throughout the body.
- **Ophthalmologists and ocular surgeons:** Can diagnose and treat movement disorders affecting the eyes.
- **Orthopedic surgeon:** Performs surgery to reduce or correct joint and bony deformities.

Nurses with special training in neurology or rehabilitation are instrumental in the day-to-day management of these disorders. Speech-language pathologists, social workers, teachers, and psychologists may be involved in caring for patients with movement disorders.

"It's true that I wish I did not have this disorder. However, I am learning to live with it and I continue to feel that I am living a fulfilling life and that I am blessed."

Working With Your Healthcare Team: Tips for Managing Your Care

People with movement disorders often find that several different healthcare providers get involved in their ongoing care. Sometimes it may be difficult to keep track of who's who and what their responsibilities are, and to keep all the members of your healthcare team communicating and up-to-date with your treatment and your progress. Patients (and often their families and other caregivers) need to take an active role in this process. Here are some suggestions for helping things go more smoothly:

Make a record, and share information.

Dedicate a notebook or file for your notes taken at each office visit, the questions you have, written instructions and information you obtain from your doctors and your own research. Keep the addresses and phone numbers of your healthcare team all together in one section.

Medication diary.

Maintain a current list of your medications and the doses you take, and make copies to regularly update the medical records kept by each of your healthcare providers.

Keep a symptom diary or journal.

Use this to track your progress and take notes to share with your healthcare team. As part of this process, ask your doctor if he or she can provide you with self-assessment tools (e.g., symptom rating scales, self-scoring tests) to measure the effects of treatment and help you provide consistent information.

Talk to other members of your healthcare team.

Today, healthcare is a team effort. Other professionals, including nurses, physician assistants, pharmacists, and occupational or physical therapists, play an active role in your healthcare and may be able to spend additional time with you answering questions or providing guidance.

Moving On!

As you learn more about movement disorders, you will discover that valuable and accurate information is freely available. It may be obtained from specialists in the field, in books and articles, and on the Internet. Some of the richest resources, however, are to be found among those who have also been challenged by a movement disorder and have actively moved ahead with their lives. Remember, as you go forward from your diagnosis and treatment, you are not alone. Reach out to family and friends and those in your community who can be supportive. Tap into organizations in your area that offer support groups and can put you in touch with other people who share your experience. You do not have to do this alone.

How the *Life in Motion* Campaign Can Help

WE MOVE recognizes that diagnosis and appropriate treatment remain challenges for many people living with movement disorders. As a part of the *Life in Motion* campaign WE MOVE brings together more than 40 patient advocacy organizations, foundations, and professional societies that are all committed to raising awareness about these conditions, emphasizing the importance of early diagnosis, and illustrating available treatment options.

As part of this nationwide campaign, WE MOVE has established the *Life in Motion* Resource Center. It includes a Web site, www.life-in-motion.org, which offers downloadable patient education brochures, information on more than 20 movement disorders, a glossary of terms, and other valuable resources. It will also give you easy links to *Life in Motion* member organizations and to the WE MOVE Web site, www.wemove.org, the most comprehensive resource for movement disorder information and education.

To learn more, visit the *Life in Motion* Resource Center at www.life-in-motion.org, or call this toll-free number 1-866-LIM-3136 (1-866-546-3136). Additional information will be sent to you free-of-charge.

About WE MOVE

WE MOVE is a not-for-profit organization that has been educating and informing the movement disorder community for more than a decade. WE MOVE believes that increased knowledge and understanding promote timely, accurate diagnosis, and up-to-date treatment, resulting in a better quality of life for individuals affected by movement disorders.

Over 130,000 people visit the award-winning WE MOVE Web sites each month to access accurate, timely, and balanced information and resources... medical information, chat rooms, discussion forums, and newsletters. WE MOVE provides information to meet the educational needs of medical professionals, patients, and caregivers.

Life in Motion Coalition Members

