Tremor THE BASIC FACTS

MULTIPLE SCLEROSIS



Some people with MS experience tremor, an involuntary rhythmic shaking movement of the muscles. The most common type of tremor seen in people with MS is caused by loss of myelin on nerve fibers in the pathways that coordinate voluntary muscle movement and balance.

Tremor can affect the limbs, head, body, or the muscles needed for speech or sexual functioning. Some tremors are slight and don't interfere with daily living while other tremors can significantly affect important basic activities. Gross tremor is characterized by wide back and forth motions, usually of the arms or legs. Intention or action

tremors are activated when a person reaches for something. When tremor is severe, it can prevent a person from eating, writing, speaking clearly, or walking.

There is no cure for tremor, and it remains one of the most frustrating MS symptoms. Options for management include physical and occupational therapy techniques, medications, stress management, neurosurgery, and electrode implants. Some of these options will work for one individual; others will not. Coping with tremor requires patience, good communication with healthcare professionals, and some creative problem-solving.

Don Denton, of Lubbock, Texas, has been dealing with intention tremors due to his MS for over 20 years. He's worked as a peer counselor with his chapter of the Society. When he talks to people who have problems with MS tremor, he tells them frankly that there is no easy answer. However, he also reassures them that they may be able to reduce their problems. Don has found some relief with medication. He has also learned strategies that allow him to perform daily tasks better, and he plans ahead so that tremor-related problems don't take him by surprise. For Don, tremor has become just one more piece of this challenging chronic disease.

Occupational and physical therapy techniques

An occupational therapist or physical therapist is the recommended source for both practical strategies and adaptive aids that can reduce the negative impact of tremor on daily life. Your doctor should be able to refer you to a professional with MS experience — or, call the National MS Society.

Some tremor can be controlled through the use of braces. A rigid brace can support an affected limb while a person performs a specific activity. Afterwards, the brace can be removed. In some cases, however, bracing may actually increase other problems such as spasticity. Consult a rehabilitation specialist to explore this option.

Some people find it helpful to hold their arms close to the body or to prop an elbow against the chest in order to gain more control over forearm movements. Weights fastened to the wrists or ankles with Velcro strips can stabilize an affected limb. Weighted boots are also used. Putting weights on canes or walkers, or using weighted spoons or forks can make these tools easier to use when tremor is active. The use of weighted devices has to be balanced against the added fatigue they might cause. Therapists commonly offer samples for a try-out.

Adaptive equipment, such as wrist rests that facilitate writing or typing, and plates and cups with lips to minimize food spills, are also helpful to some people.

Physical or occupational therapists may be able to reduce the effects of tremor by teaching specific positions for some activities or by balance and coordination exercises. These might include repeating a series of movements related to an activity like eating, for example, until those muscles "learn" a pattern sufficiently well to override disruptions of the nervous system. Rehab therapists may also teach exercises that focus on stimulating the balance centers of the brain. Computers can provide biofeedback that teaches people to recognize balance problems in time to compensate for them.

Tremor and speech problems

If tremor affects the muscles necessary for speech, a person will want to consult a speech therapist. A speech therapist can show a person how to slow down or concentrate on phrasing so that speech is more intelligible. If this is not possible, a person with speech tremor may need to learn alternative communication skills.

Electronic aids, communication charts, or computer-assisted alternative communication systems are available. However, tremor this severe is not common for people with MS.

Stress management and tremor

People with MS-related tremor may find that the unwanted muscle movements are worse in stressful situations. As Dr. Robert R. Young, former professor of neurology at the University of Southern California, explains, "Stress, excitement, and anxiety all result in the body releasing adrenalin which produces a temporary aroused condition. All of us experience this at some time. Stage fright is one example." For people with MS tremor, this temporary condition can make the existing tremor worse.

Stress management techniques can be an essential tool for such situations. Dr. Young would also prescribe a beta-adrenergic blocking agent such as propranolol

(Inderal®) in pill form for someone who is facing a particularly stressful event such as giving a speech or appearing in public.

Medications for the management of tremor

At present, there are no medications specifically for tremor, but several medications have been shown to have secondary effects that can be more or less helpful. Some people respond well to one medication; some benefit from a combination; some find no benefit. People with tremor will have to work patiently with their physicians in investigating which therapy might be useful to them.

(The following list is adapted from Managing the Symptoms of MS, 6th Edition, Randall T. Schapiro, MD, 2014, Demos Medical Publishing Co., Inc.)

- Hydroxyzine (Atarax, Vistaril®) Antihistamine that can help minor tremor worsened by stress
- Clonazepam (Klonopin®) Anti-anxiety agent with sedative effect
- Propranolol (Inderal®) Beta-blocker with modest relief for some tremor

Buspirone (Buspar®) Anti-anxiety agent with some antitremor effect

Ondansetron (Zofran®) Anti-nausea medication with anti-tremor effect, but very expensive

Primidone (Mysoline®) Anti-epileptic medication with some antitremor effect in low doses; sedating effect

Acetazolamide (Diamox) Diuretic; some help for postural tremor

OnabotulinumtoxinA (Botox®) Neurotoxin that temporarily paralyzes targeted muscles; may be effective for tremor in the arms and hands

Other medications that may be tried include gabapentin (Neurontin®), isoniazid (Laniazid, in the US; Isotamine in Canada); and trihexyphenidyl (Artane). Some gross tremor can also be treated with baclofen. which is primarily an agent for treating spasticity.

The question of whether marijuana produced from the flowering top of the hemp plant, cannabis sativa — should be used for symptom management in MS is a complex one. More and better therapies are needed for tremor; still, there are uncertainties about the benefits of marijuana relative to its side effects.

The National MS Society recommends that people diagnosed with a relapsing form of MS begin treatment with one of the disease modifying therapies. These medications may not have any direct effect on existing symptoms, including tremor, but they may slow down the progress of the disease and help avoid additional damage to central nervous system tissues.

Thalamotomy and deep brain stimulation

Tremor in MS occurs when there is damage to nerve fibers in a section of the brain called the thalamus. Tremor is sometimes treated with a neuro-surgical technique called thalamotomy which involves permanently destroying targeted nerve tissue in the thalamus.

There has been some success reported in the treatment of MS tremor from using electrode stimulation of areas in the thalamus. This is called deep brain stimulation or DBS. A tiny electrode is implanted in a targeted area of the thalamus during open-skull surgery. The electrode is connected to a wire lead that is inserted under the skin of the neck. It connects to a control device inserted under the skin in the chest area. This device is programmed to send impulses to the electrode in the brain. These impulses interfere with the nerve signals that are causing muscles to make involuntary tremor movements.

DBS was originally developed for the treatment of tremor due to Parkinson's disease. It is still a new therapy and is not yet FDA-approved for MS tremor. The Center for Neurological Restoration at The Cleveland Clinic Foundation has performed approximately 40 DBS operations for people with MS. The Center is enthusiastic about this new neurosurgical technology but cautions people to have reasonable expectations. Tremor in MS is

often associated with poor coordination (also called ataxia) and loss of the ability to judge distances (dysmetria). DBS may reduce tremor, but it doesn't abolish these disabling symptoms.

Like any surgery, the DBS procedure has risks — a 2–3% risk of serious complications due to the surgery itself. Then, over time, DBS recipients tend to build up tolerance to a particular electronic signal. This means that they must frequently return to their doctor's office to have the impulse generator reset, either to a higher or lower level. This is done using non-invasive radio signals.

Andrea Kool-Tucker of Columbus, OH made the assessment and decided that the benefits would outweigh the risk of complications or the bother of frequent office visits. She was often unable to feed herself or to write due to the intention tremors in her arms. Her doctors had prescribed medications, but none had provided relief for her. The fact that the DBS procedure is reversible helped her decide to try it. In 2000, Kool-Tucker had the operation. Since then, she has been able to feed herself and write again. At first, it was necessary to get her impulse generator reset every few months, but now this occurs less frequently. She does not find her implanted device noticeable or intrusive, but she has noticed that her problems with gait seem to increase when the device is turned on, so she simply turns it off when she needs to walk.

In 2008, Kool-Tucker began to experience essential tremors in her left arm. She had another DBS in 2009 to address this problem and then had additional surgery to implant a new implantable pulse generator. Unlike persons with Parkinson's who always receive Bilateral DBS, persons with MS generally only get Unilateral DBS. Therefore, Kool-Tucker had to have the second surgery.

Coping over the long term

It can be maddening to feel that your own body is no longer in your control. Many people feel painfully embarrassed when other people witness their tremor. Simple changes — like grasping a glass with two hands instead of one — can be a big help. Don Denton handles embarrassment by being upfront with people about all his MS symptoms, including tremor. When ordering coffee at a restaurant, he'll tell the server, "I can't always control my hand shaking, so pour me half a cup — otherwise, I'm going to spill some." Denton also knows that his tremor can increase with fatigue, so he'll try to plan certain activities for early in the day.

If tremor is having an impact on your social life or making you wary about going out in public, a professional therapist or counselor may help you arrive at solutions more acceptable than simply staying at home.

Keep trying

It's hard to predict which strategies will work for an individual's tremor. Tremor can be discussed with a physical or occupational therapist, or other healthcare provider. If balance exercises fail, try biofeedback. If one medication has no effect, or the side effects are too troublesome, talk to your doctor about other options. Celebrate every moment of progress — whether it's learning the exact angle needed to sign your name clearly or reaping benefits from Swiss ball balance exercises.

In dealing with this frustrating symptom, make use of all the available resources. These include a responsive healthcare team therapists, nurses, and counselors as well as your physician, your family and friends, and the National MS Society. Educate yourself and those closest to you about tremor and all the possible therapies for it, including creative coping. And try to keep tremor in perspective.

Medications and neurosurgical technologies now offer somewhat better outcomes for long-term management of tremor in MS. New developments are expected from research. There is hope for the future. But until improvements come to fruition, people who live with tremor will continue to piece together the strategies that best address their own individual situations.

For additional information

Educational videos

nationalMSsociety.org/videos In the Symptom Management category, look for feature presentation called Managing Your Symptoms in MS: Tremors, Seizures, and Loss of Balance.

Society publications:

- Managing MS through Rehabilitation
- Taming Stress in Multiple Sclerosis

For more information on deep brain stimulation, go to clevelandclinic.org and search the site for deep brain stimulation.

By Lorna Smedman, PhD.

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