

PATIENT INFORMATION HANDBOOK

If you have essential tremor (ET) or you know or care for someone who has the condition, you're likely looking for information. This booklet is a great place to start to familiarize yourself with ET.

Hope through research, awareness and support

What is Essential Tremor:

Essential tremor is a neurological disorder that causes the hands, head, voice, legs, or trunk to shake rhythmically. Although there are many possible causes of tremor, ET is the most common. Generally, tremor occurs during action such as while eating, drinking, or writing. This is called *action tremor* or *kinetic tremor*. The tremor of ET can also occur in positions against gravity. Holding your arms out in front of your body, for example, is *postural tremor*.

ET can be frustrating and embarrassing, and it can even lead to social isolation. In some cases, ET can be quite disabling, causing difficulty with such normal daily activities as writing, eating, drinking, and speaking. In many cases, ET progresses with time, leading to more severe tremor or tremor in additional parts of the body. Sometimes, however, ET progresses so slowly that changes may not be apparent in the person's lifetime.

ET does not affect life expectancy. People who have ET have life expectancy equivalent to that of the population as a whole.

ET can affect people of any age, gender, and race. Although the condition is often genetic and can occur in many members of the same family, it sometimes occurs when there doesn't appear to be any known family history of tremor. Age of onset, severity of tremor, body parts affected, and response to treatment vary from person to person, even within the same family.

Who gets ET?

ET is one of the most common movement disorders. Up to 10 million people in the United States and many more worldwide have ET. While tremor is more commonly seen in older people, ET can affect anyone at any time between early childhood and old age. Researchers estimate that 4 to 5.6% of people aged 40 to 60 have ET. The incidence rate for people aged 60 and older is estimated at 6.3 to 9%.

This publication is not intended to provide medical advice or be a substitute for qualified medical care. Appropriate treatment for your condition should be obtained from your physician. The content of this publication offers information to those with essential tremor. The IETF does not endorse any product advertised in this publication unless otherwise stated.

How is ET diagnosed?

There are no medical tests to confirm the diagnosis of ET. It is diagnosed during a neurological examination after the physician evaluates symptoms and rules out other potential causes of tremor such as:

- medication side effects,
- thyroid disease,
- excessive stress or trauma,
- excessive use of caffeine or other stimulants,
- presence of other movement disorders such as Parkinson's disease.

During the neurological examination, your doctor will generally collect a complete medical history as well as specific information about your tremor. Here are some questions your doctor may ask.

- Do you have a family history of tremor?
- Have you ever had a head injury?
- Does your tremor occur during action or while you are at rest?

- How long have you had tremor and did it begin after a particular incident?
- What parts of your body are affected?
- Did it come on suddenly and has it gotten worse over time?
- Are there specific factors that make your tremor worse such as stress, caffeine, or alcohol intake?
- Are there specific things that improve your tremor such as alcohol?
- What medications – both over-the-counter and herbal – and prescriptions are you taking and what medications have you taken in the past? (Certain medications may cause tremor, so it's a good idea to bring a list of the medications you are taking or the pill containers themselves. It is also helpful to list any medications you have taken in the past.)

What causes ET?

ET is thought to be related to a part of the brain called the cerebellum, and there are now some pathological findings that confirmed this. There is no certain cause. In most cases, ET appears to be an autosomal dominant disease. That means each child of a parent with ET has a 50% chance of inheriting ET. However, not everyone who inherits a gene develops symptoms.

Some people who have ET do not have a family history of tremor. This suggests the possible influence from other factors such as exposure to environmental toxins. There is currently no genetic test for ET.

What are other causes of tremor?

Many things can cause tremor. To avoid a misdiagnosis, it's important that you see a doctor who has been trained to diagnose and treat tremor disorders. Some causes of tremor include:

- Enhanced physiologic tremor (the natural tremor that occurs during stressful or fear-provoking situations),
- Medication-induced tremor (including prescription medications such as beta-adrenoceptor agonists, valproic acid, thyroxine, tricyclic antidepressants, selective serotonin reuptake inhibitors, procainamide, methylxanthines, antipsychotics, and lithium),
- Over-the-counter medications,
- Herbal remedies and illegal drugs,
- Post-traumatic tremor resulting from a head injury,
- Presence of another neurological disorder, most commonly Parkinson's disease or dystonia (involuntary muscle contractions).

Because it is possible to have both ET and another disorder that causes tremor, ET is often confused with Parkinson's disease (PD). Here are some differences between ET and PD.

- The type of tremor is often different. PD tremor generally occurs at rest, while ET occurs during action.
- PD has additional features, such as slowness and stiffness, while ET is generally associated only with tremor.
- People who respond to ET medications do not generally respond to medications used for PD. muscles is a potential side effect. This treatment can be expensive, so be sure to check with your insurance provider about coverage.

Medications for ET

If your ET is mild and not bothersome to you, you may not need treatment. If, on the other hand, ET interferes with your ability to work, perform daily activities, or interact socially, you may want to consider available therapies.

Because there is currently no cure for ET and medications are estimated to be effective for about half of patients, it is important for you to have realistic expectations about therapy. Treatment goals are to reduce the severity of the tremor and to improve daily functioning and quality of life. Achieving these goals may take time because each person responds differently to the available treatments.

In addition, you may need to try more than one treatment before you and your physician find the best one for you.

First Line Therapies

Beta-Blockers

Propranolol (Inderal®)

Propranolol is currently the only medication approved by the Food and Drug Administration (FDA) for the treatment of ET, and approximately 60% of persons with ET receive benefit. It is available in both immediate and long-acting formulations. Propranolol is in a class of drugs called *beta-blockers*, which are used primarily for treating high blood pressure. It is not clear exactly how propranolol works in treating ET. Your doctor may prescribe propranolol to be taken as needed, such as during particularly stressful situations, or daily if disability is persistent. Tremor reduction generally occurs one to two hours after a single 10 to 40 milligram (mg) dose, and the effect generally lasts about four hours. A once-daily, long-acting preparation is also available. Although propranolol is most effective for hand tremor, it may also be effective for head and voice tremor. Individual response is variable and complete tremor reduction is rare.

Side effects of propranolol are usually mild and are more frequent at higher doses (more than 120 mg/day). The main side effects are decreased pulse rate and blood pressure. Less common side effects are fatigue, depression, impotence, nausea, weight gain, rash, and diarrhea. If you experience unpleasant side effects, be sure to talk with your doctor. If you have heart failure, diabetes mellitus, or asthma, be sure to talk with your general medical doctor before you take propranolol.

Propranolol is typically started in divided doses from 10 to 60 mg/day. While most patients benefit from doses less than 120 mg/day, the daily dose can be increased to 240 to 320 mg/day if necessary. No additional benefit has been seen in doses greater than 320 mg/day. Older patients should start with 10 mg/day, and the dose should be slowly increased to 80 – 100 mg/day. Propranolol-long acting (LA) should be started at 60 mg/day and can be slowly increased to 120 mg/day or higher as needed and tolerated. Do not abruptly stop this medication without first talking with your physician.

Other beta-blockers such as atenolol, metoprolol, and nadolol may also be beneficial for ET.

Primidone (Mysoline®)

Primidone is an anti-seizure medicine that also reduces tremor. It is used widely to treat ET. Approximately 60% of people with ET are helped by primidone, and the benefit usually lasts 24 hours after each dose. When you first start taking primidone, you may experience nausea, poor balance, dizziness, fatigue, drowsiness, and flu-like symptoms that generally subside after a couple of days. You can reduce the possibility for these symptoms by starting with a small dose at bedtime and gradually increasing the dose until tremor is suppressed. If you experience more serious side effects, you should contact your doctor. Although primidone may have initial side effects, there are few long-term problems. Primidone can be used successfully for many years with occasional dose adjustments.

Primidone should be started at 12.5 mg (one quarter of a 50 mg tablet) or 25 mg (half a 50 mg tablet) at bedtime. After one week, the dose can be increased to 50 mg at bedtime. The dose can be increased by 50 mg a week typically only up to a dose of 250 mg/day or until adequate tremor control is achieved. Doses of up to 750 mg/day may provide benefit in some patients. Primidone can be taken as a single dose at bedtime or in divided doses throughout the day.

Combination Therapy

If your tremor is not well controlled by propranolol or by primidone alone, you may experience better results when you take both medicines together.

Benzodiazepines

Clonazepam (Klonopin®), diazepam (Valium®), lorazepam (Ativan®), and alprazolam (Xanax®) are frequently used to treat ET. These drugs are especially helpful in patients with associated anxiety. Although diazepam has been shown to improve tremor, it is typically not as effective as propranolol. Alprazolam has been shown to significantly reduce tremor as well as symptoms of anxiety, but side effects such as mild fatigue and sedation have been reported. The effectiveness of alprazolam has been found to be equal to that of primidone.

If benzodiazepines are used for long periods in large dosages, they can become addictive. There is also risk of withdrawal symptoms if the drugs are stopped suddenly.

These drugs may be useful in patients who do not respond to other medications or who have associated anxiety. Side effects include sleepiness, dizziness, depression, fatigue, loss of coordination, memory loss, and confusion.

Alcohol

Adults with ET often notice that drinking alcohol reduces tremor for one to two hours. When you use alcohol responsibly, it can be very effective in temporarily reducing tremor. It may even be helpful to have one or two drinks during social events to suppress tremor. There are, however, important issues to consider in using alcohol for ET. Rebound tremor may occur after excessive alcohol use, making tremor temporarily more severe the next day. If you use alcohol to reduce tremor, be sure to talk with your doctor about it. You should avoid excessive use of alcohol. And never consume alcohol if you plan to drive.

Second Line Therapies

Gabapentin (Neurontin®)

Gabapentin is an anticonvulsant. It has a modest benefit in ET and should be considered as second- or third-line therapy or tried by patients whose tremor is unmanageable by other medications. Gabapentin is generally well tolerated. Side effects include fatigue, slurred speech, drowsiness, impaired balance, and nausea especially when beginning drug therapy. The drug has a short half-life and requires multiple doses a day. In older patients, gabapentin should be initiated at 100 mg three times daily and in younger patients it is often initiated at 300 mg three times daily. Satisfactory dosing may require 1200 to 1800 mg per day.

Topiramate (Topamax®)

Topiramate is an anticonvulsant that has been shown to be effective in controlling tremor in some patients. Starting with a low initial dosage and slowly increasing the dosage over time can minimize side effects. Doses should be started at 25 mg or 50 mg at night for the first week and increased by 25 mg to 50 mg/day each week, depending on side effects, to a total dose of 300 to 400 mg/day. Side effects include numbness or tingling (paresthesias), memory loss, and weight loss.

Miscellaneous Agents

Mirtazapine (Remeron®)

Mirtazapine is an antidepressant. Due to its lack of effectiveness for the majority of patients and its significant side effects, mirtazapine is not recommended for the routine treatment of ET. Adverse effects include confusion, dry mouth, weight gain, frequent urination, balance and gait difficulty, nausea, and blurred vision.

Botulinum Toxin Injections (BOTOX®, Myobloc®)

If medications fail, you may consider therapy that involves injecting botulinum toxin into muscles. Botulinum toxin injections have been useful in the treatment of some patients with head and voice tremor and sometimes hand tremor. The toxin must be placed into target muscles by a trained specialist and repeat injections will be needed approximately every three months. Transient weakness of the injected

Surgical Alternatives

If medical treatment is not successful and your tremor continues to cause disability, surgical alternatives such as deep-brain stimulation (DBS) of the thalamus or thalamotomy might be an option. You can learn more about surgical treatments for ET in “Surgical Treatment of Essential Tremor,” which is available from the IETF office.

Are there other treatments for ET?

Many people have tried acupuncture, hypnosis, and massage therapy with unconfirmed benefit. People whose tremor worsens with stress or anxiety may find biofeedback or behavioral therapy helpful. Other people have found physical and occupational therapy helpful in terms of suggestions for using heavier utensils, cups, and glasses; wrist weights; plate guards; heavier, wider writing instruments; and other adaptive devices. These can provide considerable benefit in activities of daily living.

Getting the most out of doctor visits

You should work closely with your doctor to find the most effective treatment for you. And you need to remember that you may have to try several treatments before you find the one that works best for you. Take an active role in your treatment and learn as much as you can about ET.

Visit the IETF website (www.essentialtremor.org) to learn more about what treatments are available and what their limitations are. If you don't have Internet access, you can call the IETF toll free at 888-387-3667 to get printed copies of the information. Discuss your symptoms with and ask questions of your doctor. It is important to discuss expectations of treatment results, side effects, and other issues such as employment. The more you know about ET and its treatment, the easier it will be to adapt and minimize daily disability.

Practical Suggestions

There are many ways to minimize the degree to which ET interferes with your life and work. Here are some practical suggestions.

- Learn as much as you can about ET.
- Make sure your physician is knowledgeable about ET and is actively working with you to control your tremor.
- Don't hide your tremor. Talk about it to friends, relatives, and colleagues. The more everyone learns about ET, the faster public awareness will increase. Greater awareness will bring attention to ET and facilitate research so desperately needed to help find appropriate treatments and a cure.
- If your child has ET, you may want to meet with his/her teachers to discuss. Order the free IETF booklet "Children with ET: A guide for parents and other caring adults" and share it with your child's teacher. "Tremor Disorders in Children: A Clinical Discussion" is an IETF booklet you may want to share with your physician.
- Find ways to reduce stress and learn some relaxation techniques.
- Avoid things that may worsen tremor such as caffeine and certain prescription medications.

You can get many more ideas by calling the IETF and asking for the booklet "Coping with Essential Tremor."

Support Groups

Call the IETF toll free at 888-387-3667 or visit the website (www.essentialtremor.org) for information about joining or starting an ET support group. We need volunteers to lead support groups in many areas of the country. Please take the time to reach out to help others help themselves. Support groups don't happen until people volunteer to start them.

3 Ways to Learn More About the IETF and ET:

MAIL THIS FORM TO:

IETF
PO Box 14005
Lenexa, Kansas
66285-4005 USA

CALL:

913-341-3880 or Toll Free 888-387-3667

LOGON TO:

www.essentialtremor.org

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Mission of the IETF

To provide global educational information, services and support to those affected by essential tremor (ET), and to health care providers, while promoting and funding ET research.