

ESSENTIAL TREMOR INFORMATION

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National Tremor Foundation

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INSIDE...

- Description of Essential Tremor
- Who are the National Tremor Foundation?
- Symptoms and treatments
- Essential Tremor coping tips
- Frequently asked questions
- Primary Orthostatic Tremor
- Drugs that physicians may use

Who are we?

Over one million people in the United Kingdom suffer with a neurological tremor of some type. For many, tremor impacts intrusively into their daily activities. The foundation is a charity dedicated to people with tremors – its mission is to provide advice, support, publish information and promote research.

The National Tremor Foundation (NTF) has established support groups throughout the country and plans to open many more.



These groups provide regular meetings for both patients and carers. In a friendly and sympathetic environment help, counselling and friendship is readily available.

The NTF was first brought to the UK from the USA in 1992 as part of the International Tremor Foundation and in 1994 became a registered charity in its own right.

Each year the NTF holds an annual conference, subsidised by the NTF providing members and friends with the opportunity of not only meeting and spending some time together but also asking a panel of experts questions that help with improving quality of life.

Misguided beliefs and a lack of awareness mean that many people with this condition never seek medical care though most would benefit from treatment.

The NTF dedicates its website to the thousands of people in the UK whose lives are affected by tremor.

Find out more on our website at www.tremor.org.uk

Symptoms and treatments

Trembling head or hands may mean that drinking a cup of tea is impossible without special aids. For many, any form of legible handwriting is also impossible and even holding objects securely is a major problem. When the legs are subjected to tremors most patients can only stand for short periods, and must walk with aids. Treatments depend on accurate diagnosis as to the cause of tremor. Many medications are only partial in their effect and can carry the risk of side effects. New surgical procedures are being explored to obtain long term relief from tremors in suitable patients.

It is important to seek advice from a specialist i.e. a neurologist or physician with special interest.

Various surgical treatments are available for some patients with tremor including the insertion of deep vein stimulators (electrodes). The Foundation's mission is to foster research and to maintain links across the world with close contacts in USA, Europe and Australia in order to find the latest research data and disseminate knowledge.

Some facts...

- Tremors arise as a result of dysfunction of the nervous system.
- Tremors affects both sexes and different age groups.
- The condition often causes an increase in shaking.
- Shaking can be found in the head, arms, legs and hands.
- Speech is also frequently impaired, making communication difficult.

A description of Essential Tremor

Tremor is defined as an involuntary, rhythmic oscillatory movement of a part or parts of the body, resulting from alternating or irregularly synchronous contractions of antagonist muscles.

Tremor is the most common form of involuntary movement. Almost all individuals have experienced tremor at some point in their lives; however, only a small fraction of those with tremor seek medical attention. Tremors may result from normal (physiologic) or pathologic processes and may be characterised by their etiology or phenomenology (i.e., activation state, frequency, amplitude, waveform). With the exception of those affecting the facial region, tremors are frequently defined or characterised by the joint around which the body part moves.

Essential tremor (ET) is a common movement disorder. Estimates suggest that ET may be as much as ten times as common as Parkinson's disease (PD), affecting up to 1 million people in the United Kingdom. In the past, the condition was often referred to as "benign essential tremor." However, many experts consider use of the term "benign" unfortunate, since it may inappropriately minimize the impact of ET on disability, handicap, and quality of life (QOL).

Rest tremor occurs when muscle is not voluntarily activated, whereas action tremor is present with voluntary contraction of muscle. Subtypes include postural, kinetic, and isometric tremor. Postural tremor is present while voluntarily maintaining a position against gravity. Kinetic tremor may occur during any form of voluntary movement. Intention or terminal tremor refers to exacerbation of kinetic tremor toward the end of a goal-directed movement. (Please refer to the Tremor Map on our website.)

Tremor may be further delineated by anatomic distribution (e.g., the head, including the chin, face, tongue, or palate, or the upper or lower extremities); frequency; and coexistent neurologic conditions, use of tremorogenic medications, or other causative states. Once established, ET does not recruit.

A description of Essential Tremor – *continued*

Table 1. Classification of Tremor by Clinical Phenomenology

Rest tremor	Present when skeletal muscles are not voluntarily activated and the relevant body part is fully supported against gravity. Associated with PD, secondary parkinsonism, hereditary chin quivering, and severe ET. Often suppressed with voluntary muscle contraction.
Action tremor	Occurs upon any voluntary muscle contraction and may include any combination of postural, kinetic, task or position-specific, or isometric tremor.
Postural tremor	An action tremor that is present while voluntarily maintaining a position against gravity. Associated with ET, primary orthostatic tremor, physiologic and enhanced physiological tremors, drug-induced and toxic tremors, neuropathic tremor, cerebellar head tremor (titubation), and dystonic tremor.
Kinetic tremor	An action tremor that occurs with any form of voluntary movement including visually or nonvisually-guided actions, such as speaking, pouring water into a cup, or finger-to-nose testing. Associated with ET, classic cerebellar tremor (e.g., seen in multiple sclerosis, infarction), dystonic tremor, drug-induced or toxic tremors, and midbrain lesions. Includes dynamic or terminal tremor, which occurs with target-directed movements, and simple kinetic tremor, which is present with nontarget-directed actions.
Task or position	A kinetic tremor that occurs during performance of highly specialized, complex movements, such as specific tremor writing, speaking or smiling. Primary writing tremor and isolated voice tremor are included.
Isometric tremor	A kinetic tremor present during voluntary muscle contraction against a rigid stationary object, such as making a fist or flexing the wrist against a horizontal, flat surface.

Essential Tremor Coping Tips

Eating, drink & food preparation

- 1 Use heavier glasses and mugs instead of light-weight cups.
- 2 Soup mugs are also a good choice for drinking.
- 3 When holding a mug or small glass, place your thumb along the rim and place your fingers across the bottom.
- 4 Fill cups, mugs and glasses half full.
- 5 Consider using dishes that have vertical sides or buy rubber bumper guards from a medical supply store to place around the edges of your plates so you can more easily scoop your food.
- 6 Try using covered ice-cube trays.
- 7 Get a rubberized placement that sticks to the table so plates do not slide.



Applying make-up & jewellery

- 1 Apply Mascara by resting your elbows on the counter-top. Put the wand in one hand and use the other hand to keep the wand steady.
- 2 Apply eyebrow pencil, mascara, eyeliner, or lipstick by resting your finger or the palm of your hand on your face to steady your hand.
- 3 Put on earrings by resting your elbows on a table. If you have a head tremor, place your chin on an upended facial tissue box to steady your head.

Essential Tremor Coping Tips

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Writing

- 1 Print rather than type script.
- 2 Write in small letters—its easier than writing in large letters. Rest your forearm on a table while writing.
- 3 Hold the pen between your index and your middle finger.
- 4 Place writing paper on a soft surface such as a newspaper to help control shaking hand movements.



General

- 1 Learn how to use your tremor-free hand for as many activities as possible including writing.
- 2 Hold your chin toward your chest, or turn your head to its side to control a head tremor.
- 3 Use your tremor free hand to steady your tremoring, and whenever possible use two hands.
- 4 Use lids on drink when you're on the go when possible to avoid injury.
- 5 Carry straws with you. You can find sturdy, thick, plastic straws in many warehouse sections of stores if thin plastic straws are too flimsy.
- 6 Avoid Caffeine, Mahuang, ephedra, and other over-the-counter medications and herbs containing ingredients that increase your heart rate and can increase tremor temporarily,
- 7 Keep your elbows close to your body when performing tasks to help control hand tremor.
- 8 Carry a small tape recorder with you to take notes.
- 9 Carry and use larger handled weighted pens and eating utensils.
- 10 Use a signature stamp if necessary to sign your name.
- 11 Consider using online banking to pay your monthly bills.
- 12 Use credit/debit cards instead of writing cheques,

Personal care

- 1 Use an electric razor when shaving.
- 2 Have a manicurist care for your nails.
- 3 Have a cosmetologist wax or pluck your eyebrows.
- 4 Use disposable floss holders.
- 5 Hire a seamstress to do your mending, or find a volunteer to sew your buttons, thread needles and pin fabrics. Use Velcro fasteners rather than buttons.
- 6 Use an electric toothbrush or a child's toothbrush for better control.



Essential Tremor Coping Tips

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Dental visits

- 1 Ask for adrenaline-free anaesthesia shots.
- 2 Notify your dentist of all the medications you are taking. (head tremor only)
- 3 Request that your dentist stop periodically so you can massage and rest your jaw and your head
- 4 Ask your dentist whether a bite block will help steady your jaw during dental procedures.
- 5 Talk with your dentist about having a person in addition to the dental assistant help with your procedure.
- 6 The third person can gently hold your head to help control tremor.

Technology

- 1 Use a telephone with Large Buttons. Avoid phones with speed dial and redial buttons too close to the number buttons
- 2 Use speakerphone, a headset or Bluetooth device when using phones.
- 3 Ask your security alarm representative to give you a remote to turn it on and off.
- 4 Use voice-activated dial on your phone if possible.
- 5 Go to a store seeing all types of computer mice and try them out for yourself to see which one best suits you.
- 6 When choosing a digital camera, pick one with image stabilization technology.

Eating in restaurants

- 1 Request that your meat be cut in the kitchen before it is served to you.
- 2 Consider ordering finger foods to reduce the amount of use of utensils.
- 3 Ask for your soup to be served in a mug.
- 4 Request the drinking mug or glass is to be only half full
- 5 Ask for a straw.



Airport security

- 1 Give yourself plenty of time to arrive well before a flight so that you don't have to rush through security.
- 2 When dressing for air travel, wear slip on shoes that are easily removed to put into checkpoint trays and easily put back on afterwards.
- 3 Place everything you have in your pockets into a plastic bag beforehand so its easier to put into trays.
- 4 Have your ID and other travel documents together and in your hand before entering security.

Drugs that physicians may use to treat Essential Tremor

CLASSIFICATION	GENERIC NAME	TRADE NAME
Beta Blockers (non selective)	Propanolol	Inderal
	Propanolol LA	Inderal LA
Anti-Seizure	Primidone	Mysoline
Benzodiazepines	Alprazolam	Xanax
	Clonazepam	Rivotril
	Diazepam	Diazepam
	Lorazepam	Lorazepam
Anti-Depressant	Trazodone	Molipaxin
	Mirtazapine	Zispin
Anti-Seizure	Gabapentin	Neurontin
	Phenobarbitone	Phenobarbitone
	Topiramate	Topamax
Centrally Acting Alpha-Agonist	Clonidine	Catapres
Bronchodilator	Theophylline	Nuelin
		Lasma
		Slo-Phyllin
		Theo-Dur
		Uniphyllin
Reversible Muscle Denervator	Botulinum Toxin Injections	

Essential Tremor in childhood

Essential Tremor (ET) may occur in children and has a prevalence of 4.6%-5.3% of the childhood population. There is often a family history of tremor. In a study of hereditary essential tremor, 25% of people with ET developed tremor in their first decade, and 60% in their second decade. No tremor related disability was present before the age of young people with ET had a disability, and 25% reported social handicap by the age of 20 years old.

ET inevitably affects the hands in childhood and head tremor is relatively rare, being apparent in about 5% of children. ET in a child creates difficulty with:

- Holding a hot drink • Drinking from a cup
- Using a spoon • Writing • Typing
- Drawing • Using tweezers
- Painting Nails
- Playing a musical instrument

Tremor in children may be associated with dystonia (sustained muscle spasms) or tics.

There are few studies on the treatment of ET in childhood, although small doses of propranolol (20-60mg) have been reported to help small numbers of children. There are no proper randomized placebo controlled studies of any treatment for ET in children.



Frequently asked questions about Essential Tremor

What causes ET?

Essential Tremor is due to abnormal communication between certain areas of the brain, including the cerebellum, thalamus and brain stem. In the majority of people with ET, the tremor seems to be inherited as an autosomal dominant trait. This means that each child of a parent with ET has approximately a 50% chance of inheriting a gene that causes ET. Researchers have already located two genes that predispose to ET and are currently trying to locate others. Not everyone who inherits a gene develops symptoms, and some people have ET and do not have a family history of tremor, possibly suggesting other causes. At this time, there is no genetic test for ET.

Does ET cause death or shorten life?

ET neither kills nor shortens lifespan. At best ET is a nuisance. At worst ET disables. Most causes of ET fall somewhere in between the two extremes,

Who gets ET?

ET is found in all races and in all parts of the world. No one group of people is more likely to develop ET. Men and Women are affected equally.

At what age does ET start?

Though ET may first appear at any age between childhood and old age, onset is rare before the age of 10. Most commonly onset is after the age of 40.

Does ET get worse with age?

No one can predict how much your tremor will worsen with time. The course of ET is variable and may be progressive over many decades.

How is ET diagnosed?

Doctors who are trained to evaluate tremor can accurately diagnose ET on the basis of the symptoms and the neurological examination. There are no blood, urine or other tests for ET. Before making a diagnosis of ET, your doctor may want to investigate other possible causes of tremor such as thyroid disease, excessive caffeine ingestion or medication side effects. During your physical exam, your doctor will be gathering as much information as possible about your tremor.

Can a diagnosis of ET be made from looking at a brain scan?

A brain scan is not required to diagnose ET. Your doctor might order a magnetic resonance imaging (MRI) scan or a computerised axial tomography (CAT) scan if there is a suspicion of some other cause of tremor. ET does not have associated abnormality on routine scans.

Frequently asked questions about Essential Tremor - *continued*

Are all tremors caused by ET?

There are many causes of tremor, and not all tremors are ET. There are more than 20 kinds of tremors. For instance, excessive caffeine, alcohol withdrawal, problems with thyroid or copper metabolism or the use of certain medications may cause tremor. A major difference between ET and other Tremor types is that in ET tremor is the only symptom, and muscle tone, strength and balance are not usually affected.

What medications help ET?

If you have mild ET, you may not need treatment. There is no evidence that early treatment stops or slows the natural progression of ET symptoms. With adequate knowledge, many people learn ways to live well with ET. If possible, you should be taken off any medications that may be aggravating tremor.

If ET is interfering with your ability to work or perform daily tasks, or you find it socially disabling, you may want to consider available therapies. It is important to have realistic expectations for therapy. At present, there is no cure for ET. For the oral medications, a 50% reduction of tremor severity is considered good.

The goals for treatment are to reduce tremor severity, improve the ability to function, and to decrease social handicap. Achieving these goals can sometimes take time, so be patient. While almost two thirds of people with ET benefit from medical therapies, your doctor may have to try two or three different medicines before finding the one that works best for you.

The common medicines that are used for ET are propranolol (Inderal) and primidone (mysoline). Both can be quite effective. Your doctor may recommend other drugs/medicines.

Can surgery help ET?

If treatment with medications is not effective and ET is very disabling or is putting your livelihood at risk, your doctor may suggest a surgical technique, such as thalamotomy or thalamic stimulation (Active tremor control therapy). Surgical procedures may be expensive but may be beneficial. Deep brain stimulation is another possible operation.

Are there helpful alternative therapies for ET?

Though there is no evidence that so-called “alternative therapies” are helpful for ET, people have tried a variety of treatments. No good scientific studies are available to encourage the use of alternative therapies. Always talk to your doctor before starting any alternative therapies. While some herbs that induce relaxation may be helpful, others, such as a Chinese herb called ma huang, can worsen tremor. Many people have tried acupuncture, hypnosis and massage therapy. People whose tremor worsens with stress or anxiety may find biofeedback helpful. Others have found physical and occupational therapy to be helpful in terms of providing suggestions for using wrist weights, plate guards and other adaptive devices. These devices can provide considerable benefit in activities of daily living.

Frequently asked questions about Essential Tremor - *continued*

Does pregnancy affect the severity of ET?

Tremor severity may fluctuate during pregnancy and after delivery. You should discuss the use of ET medication with your physician.

How does the consumption of alcohol affect ET?

Adults with ET often notice that consumption of alcohol reduces the their tremors for 1-2 hours. While it is true that alcohol can temporarily reduce tumor, it may be an appropriate form of “treatment”. Use of alcohol to reduce tremor should be discussed with you physician.

How can I minimize the affects of ET on my life?

Become informed about your condition and learn as much as you can about living with ET. Instead of restricting your life because of what others may think, explain your condition simply and honestly when you meet new people. If your child has ET, you may want to talk to teachers in person about the neurological basis of symptoms. Find ways to reduce stress and learn some relaxation techniques. Avoid things that may worsen tremor, such as caffeine and certain prescription medications.

How can I get the most out of my doctors visits?

Work closely with your doctor to find the most effective treatment. Take an active role in your treatment. Discuss your symptoms and questions with your doctor. The more you know about ET and treatment, the easier it will be to adapt, minimizing the interference with your daily life. Its important to discuss expectations results, side effects and other issues such as employment.

How can I learn more about the medications I'm taking?

Consumer Reports Best Buy Drug is a free public education service from the nonprofit Consumers Union, publisher of Consumer Reports. Go to www.crbestbuydrugs.org to learn more about affordable drug treatment options to discuss with your physician. You'll also learn what you need to know about the effectiveness, safety, and cost of many widely used prescription drugs.

Do medications for Parkinsons Disease help ET?

No, medications for Parkinsons disease (PD) do not help ET. Symptoms of PD are caused by changes in dopamine levels in the brain. Serotonin levels are affected in ET. Although PD may look like ET to an untrained eye, PD tremor, generally occurs at rest. Tremor due to ET occurs during action. PD also causes progressive slowness, stiffness and loss of balance. In other words, those with PD will usually develop other symptoms and signs in addition to the tremor.

Primary Orthostatic Tremor

POT occurs in an otherwise intact nervous system (in this it is very similar to the more common Essential Tremor). The patient rarely complains of tremor but will present to the doctor with unsteadiness, imbalance or shakiness on standing.

The symptoms rapidly disappear on walking, sitting and are improved dramatically if the individual is in any way supported, i.e. by leaning on an object. In other words, this is a tremor confined to the erect posture and involving the lower extremity i.e. the legs. On standing there is a short delay after which an unsteadiness or imbalance occurs.

If electrical recording devices are placed on the legs in this situation, it would be seen that there is a very fast tremor i.e. regular muscle contractions (16 cycles per second). It causes such intrusive symptoms because muscles in the two legs are contracting synchronously i.e. together (normally in hand tremors, the contractions of muscles in two hands, are not in harmony). Therefore, this synchronous activity in both legs results in a much greater instability than one would predict from a very fine fast tremor.

The term “Orthostatic Tremor” does apply to any tremor which occurs on standing. It may be seen in such conditions as cerebellar disease, essential tremor and Parkinson’s disease. However, in these conditions, the tremors occur in other positions and activities and are not confined to standing. Furthermore, they do not have the characteristic of a very fast tremor which is all the muscles contracting together (synchronously).

In 1984 it was suggested that the term “Primary Orthostatic Tremor” be given to this disorder and that other conditions in which tremor can occur on standing, should be called “Secondary Orthostatic Tremors”.

Weight bearing and the erect posture are the conditions necessary for the development of POT. Patients do not complain of tremor per se but may complain of vague symptoms such as dizziness. Indeed POT may be misdiagnosed as a disturbance of the balance system or other neurological disorder. In patients with POT if the limb is palpated in a standing position, a fine quivering sensation is felt.

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Primary Orthostatic Tremor - *continued*

The patient will be seen to be contracting the small muscles of the feet in order to maintain stability. In some patients if artificially weight bearing is transferred to the arms, similar tremor may be recorded from the upper limbs. POT is quite different in its behaviour and presentation to the more common essential tremor of the upper limbs. However a number of patients have been described with POT as well as essential tremor (ET) of the upper limbs.

Much neurophysiological research and metabolic brain scanning have been carried out on POT. As with ET, no single area of brain dysfunction or damage has been discovered in other words, it is not associated with progressive disorder of the nervous system.

Metabolic scanning (PET) has shown that cerebellar blood flow is increased on both sides of the brain in POT. This finding is similar to what is seen in ET and related tremors.

The strong evidence is that it represents dysfunction of the cerebellar system in the brain and its connection to brainstem

and to higher and lower structures. It is clearly an abnormality in the oscillatory systems inherent in the nervous system which are necessary to allow normal movement control.

In general the medications which have been found to be helpful in some patients with ET i.e. Propanolol or Mysoline, are not generally as effective in the control of POT.

Alcohol which may sometimes transiently suppress ET, in general will not suppress POT. Drugs that work through the Gaba system in the brain such as Clonazepam, can be successful in suppressing POT and relieving symptoms. Initially the doctor may recommend very small doses of Clonazepam in the first instance as sedation is an inevitable side effect with higher doses.

Second line drugs such as Neurontin or Topamax, may also be tried though there are no clinical studies to show their effectiveness.

As with ET, once POT develops, it does not remit.

**We aim to provide help,
support and advice to
those with all forms of
tremor, irrespective of age**



NTF

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**TOGETHER
WE CAN BEAT IT**



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