



Essential Tremor (ET)

Children with Essential Tremor

a guide for parents and other caring adults

Growing up with ET

Most children button a shirt, tie a shoelace, and color a picture with ease. For children with essential tremor (ET), daily tasks like these can become a test of will, ingenuity, and stamina. The normal challenges of growing up are magnified by ET.

As children mature, they learn increasingly complex ways of moving, thinking, feeling and relating to others. From birth to age 12, children experience a wide range of physical, emotional, and intellectual changes. In addition, children with ET often feel different from their peers and the resulting low self-esteem can affect their ability to function well with others.

Children with ET may withdraw from peer groups. They may refuse to try even the simplest tasks. They may be sad and angry.

Although parents and other caregivers of children with ET are the first line of support, every adult who touches children's lives—from teachers to physicians to activity leaders—can provide additional care and support.

Armed with accurate information, caring adults can identify problems and find solutions, educate others, and become advocates for all children affected by ET.



Boosting self-esteem—early and often—is one of the most important things adults can do for children who have ET.

Challenges

Children with ET may have difficulty with a variety of activities and interactions. They may avoid certain activities and social situations rather than face the negative feelings and critical comments of peers and adults. Parents report instances in which their children are accused of not trying to control their shaking, are suspected of being anxious, nervous or on illegal drugs. Often children don't ask for help because they don't want to be treated differently from their peers.

Children with ET may have difficulty with:

- Eating and drinking without spilling
- Using fine motor skills
- Cutting with scissors
- Tracing or coloring within the lines
- Writing legibly
- Buttoning shirts, blouses, and coats
- Playing with toys that contain small pieces
- Filling in bubbles on scanner sheets for standardized tests such as ACT or SAT
- Tying shoelaces
- Speaking in class
- Writing legibly on blackboard/whiteboard
- Completing tests and other projects too quickly, which sometimes results in lower grades
- Handwriting because they must press hard to stabilize the tremor



Children are incredibly resilient. They can accomplish amazing things -- with a bit of determination and a lot of support.

Ways you can help

At home. Children with ET need to know their value does not depend on their ability to accomplish tasks. They need to understand that everyone makes mistakes and that it's okay for them to make mistakes too. Simple acts of love, acceptance, and understanding make a huge difference to children who have ET.

- Have your child accurately diagnosed by a pediatric movement disorder neurologist.
- Praise your child for their accomplishments and encourage perseverance when they have set-backs or encounter new challenges.
- Set realistic goals with your child.
- Be honest with your child about his/her condition.
- Never make sarcastic, hurtful remarks about your child's shaking.
- Buy pullover shirts so your child doesn't have to deal with buttons.
- Encourage your child to talk about their tremor with others to help ease their anxiety.
- Provide informational materials about ET to everyone in your child's life. Explain that your child has ET and that their shaking is not simply nerves or anxiety.
- Purchase weighted, child-sized eating utensils, compartmentalized plates, plate guards and other assistive devices (available online or from specialty catalogs).
- Buy shoes with Velcro® closures.
- Encourage your child to type whenever possible.
- Utilize built-in keyboard and mouse accessibility options in your home computer's operating system for easier operation.

Simple acts of love, acceptance, and understanding make a huge difference.

At school. Taking an active role in your child's school life can help eliminate problems quickly. Educate school professionals to help them understand the condition and accommodations needed for children with ET. Doing so demonstrates to your child that many adults care about them and want to help them be successful. Parents and other caregivers of children who have ET suggest these solutions that may help avoid some of the difficulties children may face at school:

- Give the school a copy of this flyer. Ask that the information be included in your child's permanent record.
- Provide a note from the physician stating a positive diagnosis of ET and ask that it be included in your child's permanent record.
- Ask that everyone who works with your child be familiar with symptoms of the condition, in order to properly help the child when difficulties arise.
- Do assignments require copying the question as part of the answer? Ask the teacher to eliminate this requirement so your child can complete the assignment more quickly.
- Ask teachers to allow additional time for your children to complete written assignments.
- Obtain large, weighted pens to help improve handwriting and drawing.
- Obtain a stationary mouse, such as a trackball, to make using the computer easier.
- Some schools allow students to use tablets, laptops or tape recorders to take notes. Some schools will provide this equipment for those with special needs free of charge.
- Be sure your child's friends and classmates understand what ET is. This helps reduce teasing.
- Request alternative forms of ACT, SAT, and other standardized tests. Information on alternative tests is available under "Nonstandard Administration of Tests" in the test booklet.

In the community. Join the International Essential Tremor Foundation (IETF) as a member and help make your community aware of ET! Here is how you can help:

- Distribute IETF brochures and flyers at your local schools, physicians' offices, libraries, churches, and community organizations such as Boy Scouts, Camp Fire and Girl Scouts.
- Join thousands who "like" the IETF on Facebook or follow the IETF on Twitter.
- Purchase and share IETF bookmarks: printed with the Facts About ET and the IETF's contact information.
- Participate in Essential Tremor Awareness Month activities every March.
- Request that family and friends make donations to the IETF in your child's name (in honor of their birthday or to celebrate other holidays and special accomplishments).
- Start or participate in an ET support group.
- Visit the IETF website frequently for the latest ET updates.



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important information for teachers

Teachers are familiar with the nervous student whose voice shakes during an oral presentation, or whose hand shakes so badly their handwriting is illegible. Teachers are also familiar with the restless student who fidgets or who struggles to complete in-class assignments. Often, teachers believe that these students suffer from psychological or behavioral problems, but some of these students may suffer from a movement disorder called essential tremor (ET).

What is essential tremor?

Essential tremor is a neurological disorder with symptoms of shaking of the hands, but also can include the head, voice, legs, and/or trunk. Tremor occurs during action such as eating, drinking, speaking or writing. It also occurs when the body or body parts are held in positions against gravity such as when holding their arms extended out in front of their body.

Often a genetic condition, ET affects people of any age, gender, or race. Age of onset, severity of tremor, body parts affected, and response to treatment varies, even within the same family. Approximately 10 million people in the United States have ET, including infants and children.

ET is frustrating and embarrassing for children and adolescents, and can lead to anxiety, depression, and social isolation. The most important things a teacher can do for a student who has ET is to be patient and give lots of positive reinforcement.

Signs of ET

- A visible, mild to severe shaking of the hands, head, arms, legs or trunk; or a complaint of “trembling inside.” Some types of tremor are not visible.
- A quavering or shaking of the voice.
- Poor, shaky handwriting that does not improve.
- Poor fine motor skills and/or poor manual dexterity.
- A worsening of tremor when tired, hungry, stressed or excited.
- A nervous, anxious, or restless disposition.



ET does not affect a student's ability to learn.

Accommodations

ET does not affect a student's ability to learn. However, the frustration and embarrassment associated with the symptoms can hinder a student's education, unless the teacher is able to make appropriate accommodations. Special accommodations reduce children's frustration and promote task completion; reinforce independence and accountability; support and strengthen self-image. Applying accommodations to the entire class, when possible, is preferable so that the student with essential tremor does not feel singled out or different from their peers.

General.

- Help students with ET fit in with other students, but not to the point that they feel different.
- Avoid lengthy hand-written assignments.
- Avoid grading handwriting for neatness.
- Provide extended time for assignments and testing.
- Provide short breaks.
- Encourage the use of weighted pens and pencils.
- Allow the wrist of the writing hand to be held by the other hand when writing on paper or the blackboard.
- Encourage oral responses, even in math.
- Allow the use of a computer for written homework and the use of speech recognition software.
- Allow the use of metal rulers and protractors and pointed-end compasses.
- Allow the use of weighted eating utensils, cups and straws.
- Allow technology such as overhead projectors, video or computer presentations and audio recorders.
- Allow the use of a podium during presentations so students can grasp it and steady their hands while still having materials readily available.
- Allow the use of a bookstand to steady a book when reading.
- Use non-standardized answer sheets where an “X” can mark the correct answer.

More accommodations

Math class.

- Allow verbal testing.
- Allow inaccuracy when drawing angles.

Science lab.

- Allow items to be handled with two hands, and encourage working with partners.
- Encourage the use of test tube holders, rubber gloves and extensions.
- Encourage keeping the elbows close to body when pouring liquids.
- Provide alternative activities if necessary.

Early elementary students.

- Encourage a student to “slow down” when showing increased tremor.
- Provide time for dealing with buttons, zippers, shoelaces, and toys with small parts.
- Provide assistance when needed.
- Tape a student’s paper into position for printing, painting and coloring and check the student’s grasp on the utensil.
- Avoid activities that require staying inside the lines or tracing.

Team sports, physical education.

Some students with essential tremor have increased tremor during sporting activities. The following are general guidelines for consideration.

- Use large playground balls and tees.
- Vary distances and paces of activities.
- Encourage the use of a dominant hand or foot.



*Every adult who touches
children's lives—from
teachers to physicians
to activity leaders—can
provide additional care
and support*

This publication was developed for the IETF by Beth A. Prokesch, M.Ed. who is a teacher of middle-school English. She provided this information after her son was diagnosed with essential tremor at the age of two.

*This Children's Guide is not intended to provide medical advice or be a substitute for qualified medical care.
The IETF does not endorse any product advertised in this publication.*



Our Mission:

The IETF funds research to find the cause of essential tremor (ET) that leads to treatments and a cure, increases awareness, and provides educational materials, tools, and support for healthcare providers, the public, and those affected by ET.