

POSTURAL ORTHOSTATIC TACHYCARDIA

What is it?

Postural Orthostatic Tachycardia Syndrome (POTS) is a form of dysautonomia, a disorder of the autonomic nervous system. The autonomic nervous system regulates functions not consciously controlled such as heart rate, blood pressure, sweating, and body temperature. POTS is characterized by the exaggerated increase in heart rate upon standing. People with POTS cannot coordinate the balancing act of blood vessel squeeze and heart rate response. In most people diagnosed with POTS, symptoms result from a combination of lower amount of blood in circulation, excessive pooling of blood below level of heart when upright, and elevated levels of certain hormones in the body.

Individuals, especially teenagers, develop the disorder during years of rapid growth. POTS diagnosis is rare under the age of 10 but most common in those ages 12-50 years. Approximately 1 in 100 teens is affected and there is roughly a 5:1 female to male ratio. There is often a family history of POTS but research also shows that POTS can occur after a virus or extreme stressors such as trauma, surgery, or even chemotherapy. POTS or POTS-like symptoms can also appear secondary to other autoimmune conditions

There are several forms or classifications of POTS but categories are not exclusive and a person may experience symptoms from more than one. POTS symptoms may spontaneously lessen or disappear but may also reappear just as unexpectedly.

What are the characteristics or complications?

Symptoms vary from person to person and each can be affected differently day to day. Precipitating factors for symptoms include prolonged periods of sitting or standing, exposure to heat, eating, stress and menstruation. POTS symptoms may also worsen with a common cold or infection.

- Orthostatic Intolerance
- Excessive fatigue
- Mood swings
- Tachycardia (rapid heart beat)
- Exercise intolerance
- Weakness
- Low blood pressure
- Nausea
- Anxiety
- Lightheadedness
- Visual disturbance
- Vertigo
- Gastrointestinal problems
- Shortness of breath
- Difficulty with recall
- Brain fog
- Sensitivity to light and noise
- Inability to concentrate
- Insomnia
- Appetite disturbance

What is the treatment?

- Medications may include vasoconstrictors and volume expanders
- Increasing fluids to 2-3 liters a day
- Drinking at least every 2 hours
- Increasing salt intake to 3,000-10,000 mg a day
- Use of compression garments like stockings, abdominal binders
- Avoid sleeping > 12h/day
- Recumbent exercise to stay active like swimming, biking and rowing



Kennedy Krieger Institute

The Specialized Health Needs Interagency Collaboration (SHNIC) program is a collaborative partnership between the Kennedy Krieger Institute and the Maryland State Department of Education.

Suggested school accommodations

Accommodations should always be individualized to the student's specific issues. Since the symptoms of POTS vary for the student from day to day it is important for accommodations to address the signs and symptoms that the student has experienced having this condition. Supporting students with this condition in the school require educators and parents/guardian to work as a team. Some accommodations to consider for a 504/IEP could include:

- Assistive technology
- Flexibility in scheduling (students feel worse in AM when blood pressure lowest)
- Partial days, offer in person and online courses
- Accommodations and/or adapted curriculum for memory issues, poor concentration and processing information.
- Coordination with teachers regarding testing, and homework
- Elevator privileges
- Extra set of books
- Copies of teacher notes
- Student permitted to move around in class
- Flash pass
- Temperature control in classrooms
- Rest breaks
- Staff education/training as appropriate
- Emergency Evacuation Plan (EEP)

Specific health issues for Individualized Healthcare Plan

- Student's signs and symptoms of orthostatic intolerance
- Current medication list
- Baseline assessment and parameters for heart rate, blood pressure
- Nutrition orders including salt intake if applicable
- Fluid intake goals
- Monitoring student's fatigue level
- Monitoring student's tolerance in the school setting including supervision as needed
- Communicate with school staff, parents/guardian, and provider any changes or concerns about the disease
- Emergency Care Plan(s) (ECP) related to medical needs in the school setting and staff education/training as appropriate for each

Resources & Manuals

Kennedy Krieger Institute: Pediatric Postural Orthostatic Tachycardia Syndrome Clinic
<https://www.kennedykrieger.org/patient-care/centers-and-programs/pediatric-postural-orthostatic-tachycardia-syndrome>

Dysautonomia International
<http://www.dysautonomiainternational.org/>

Genetic and Rare Diseases Information Center (GARD): Postural orthostatic tachycardia syndrome
<https://rarediseases.info.nih.gov/diseases/9597/postural-orthostatic-tachycardia-syndrome>

Standing Up to POTS
<http://standinguptopots.org/>