

Postural orthostatic tachycardia syndrome (POTS) is the most common and least severe type of dysautonomia, which is a malfunction of the autonomic nervous system (ANS). Without our knowing it, the ANS automatically controls our heart rate, blood pressure, gastrointestinal motility, and many other bodily functions.

The cause of POTS is unknown. Some patients have it after a viral syndrome, like mononucleosis (Epstein-Barr virus). Others have it in association with joint hypermobility, where their joints are very stretchy (sometimes referred to as “double-jointed”). Still others have it after recurrent brain trauma or concussions. In a small number of people, it is associated with a metabolic disorder, a disease in which abnormal chemical reactions occur in the body.

Because the exact cause of POTS is unknown, the syndrome cannot be cured, but symptoms can be managed. Some experts believe that up to 75% of patients with POTS may see their symptoms improve or disappear by age 21–25 years. However, those expectations may not be true for everyone.

### POTS Symptoms

There can be many symptoms that occur with POTS. These include:

- Dizziness
- Passing out (syncope)
- Fast heart rate (tachycardia)
- Chest pain
- Headache
- Severe fatigue
- Difficulty concentrating (“brain fog”)
- Feeling worse in very hot or very cold temperatures
- Nausea or vomiting
- Diarrhea and/or constipation
- Feeling full quickly with eating (early satiety)
- Blood collecting in the legs (venous pooling)
- Joint and/or muscle pain
- Worsening symptoms with bright lights or loud sounds

Not everyone is alike in their POTS diagnosis. Different people can have different combinations of these symptoms. It is important to know that symptoms may vary from hour to hour, day to day, week to week. There is also the “October slide,” in which some patients worsen as the autumn progresses.

It may be difficult for family members, friends, teachers, etc., to understand these changes. They may question whether the illness is real. Work with your or your child’s school to help educators and administrators understand POTS, and tell them how they can best support your or your child’s education. Some children and teens even give talks in their schools to help their peers and teachers understand their illness.

### Nonpharmacologic Interventions

POTS symptoms can be controlled by using a combination of medications and nonpharmacologic treatments.

Nonpharmacologic interventions include the following:

Category	Interventions and Tips
<b>Food and Drink</b>	<ul style="list-style-type: none"> <li>■ Take care to not skip meals.</li> <li>■ Have salty snacks (e.g., pretzels, saltines, pickles) on hand.</li> <li>■ Salt tablets can be used with caution.</li> <li>■ Drink 60-80 ounces of fluid (including water, milk, and juice) each day</li> <li>■ Avoid caffeine. Caffeine is a diuretic, so it makes the body release needed fluids.</li> </ul>
<b>Sleep</b>	<ul style="list-style-type: none"> <li>■ Raise the head of the bed on something firm, like cinder blocks. This helps reduce dizziness upon waking in the morning.</li> </ul>

Category	Interventions and Tips
<b>Sleep</b> (cont.)	<ul style="list-style-type: none"> <li>■ Lower the lights one hour before bedtime. Do a relaxing activity, such as reading under low light, massage, meditation, yoga, stretching, or a warm bath before bedtime.</li> <li>■ Turn off the television, computer and video games, and stop cell phone use.</li> <li>■ Ensure that the sleep environment is completely dark (no night lights) and comfortably cool.</li> <li>■ Use melatonin as a sleep aid. Take 0.5 to 9 mg one hour before bed. Start at the lower end of the dosing range. If there is no improvement, slowly increase the dose weekly. Don't use more than 9 mg unless instructed by your doctor.</li> </ul>
<b>Exercise</b>	<ul style="list-style-type: none"> <li>■ Start with a small amount of leg and core strengthening exercise, such as 5 minutes per day. Increase the duration by 5 minutes per day every week until you reach 30 to 60 minutes per day.</li> </ul>
<b>Clothing</b>	<ul style="list-style-type: none"> <li>■ Wear compression stockings, which are worn from waist to toe while the patient is awake. These stockings can sometimes be helpful for patients with dizziness, and will also keep patients warm. Compression stockings are available by prescription.</li> <li>■ Wear a cooling vest with gel inserts that can be cooled in the freezer, then inserted into the vest and worn when it is hot outside. Patients who cannot tolerate the heat often appreciate these. Some insurance companies may cover these with a prescription.</li> </ul>
<b>Additional Symptom Triggers to Avoid</b>	<ul style="list-style-type: none"> <li>■ Have a consistent bedtime and amount of sleep (10-14 hours for adolescents).</li> <li>■ Avoid extreme heat or cold.</li> <li>■ Avoid alcoholic beverages.</li> </ul>

## Medications

There are several options for treating POTS with medications. The goal is to match the prescribed medications with the symptoms being experienced. Some patients may require multiple medications for this reason. Additionally, some patients with POTS are very sensitive to medications, so very low doses are needed to avoid side effects.

What works for one patient doesn't always work for another, so it is important to be patient until the right therapy, or combinations of therapies, is found. The hope is to reduce symptoms so that important things, like the activities of daily living and education, can be easier for patients.

## Additional Information

It is important to let your doctor know about any side effects from the prescribed therapies. Adjustments can be made so that you or your child doesn't have further complications in addition to the POTS symptoms. Make sure to write down any questions for your doctor and bring them with you to your next office visit.

Additional information and support can be found at:

- Local support group for POTS patients and their families—search for one in your area, or start your own.
- The Dysautonomia Youth Network of America ([www.dynainc.org](http://www.dynainc.org)).
- The Dysautonomia Information Network ([www.dinet.org](http://www.dinet.org)).