

# I know a kid who has POTS

Fact sheet to help you understand



If you know a child or teen who has been diagnosed with something called POTS, you may be scratching your head. You're not alone. POTS stands for Postural Orthostatic Tachycardia Syndrome. Although POTS was identified in the 90's, many physicians are still unfamiliar with the illness. There is still an average wait time of 5 years and 11 months from the onset of symptoms to diagnosis and treatment. That is a very long time to wait for help for an illness that can be completely debilitating.

No one knows what causes POTS but it frequently begins after the child has had a prolonged viral illness, like the flu or mono. POTS is not contagious.

POTS is the result of the dysfunction in the autonomic nervous system (dysautonomia). Put simply, the autonomic nervous system helps to control many of the things our bodies do automatically - without thinking about them. A person's heart rate, pupil dilation, blood pressure, sweating, salivating, etc. - all things that our bodies do without us giving it a second thought. But when a person has POTS, some of these things stop operating correctly. Although many teens outgrow symptoms as they age, it is a very debilitating illness while it lasts.

# Symptoms & Complaints

Some of the symptoms that you may notice or the child may complain about are:

- Feeling lightheaded or like they are going to faint when they stand up.
- Tachycardia (fast heart rate) and palpitations within 10 minutes of standing.
- Weakness, extreme fatigue and headaches
- Nausea and stomach pain or discomfort
- Sweating inappropriately

These are only a few of the symptoms a child may experience. But these are the more common symptoms that are easily noticed and the most common complaints a child might have.

## Action

So, now that you know what it is, how can you help if the child is in your care?

- **HYDRATE!** Remind them to drink! POTS is greatly affected by the child's level of hydration. Water helps but the best aids are electrolyte based drinks.
- **STAND AND WAIT!** Remind them to stand slowly and give their bodies a chance to adjust to being upright. A child is more at risk of being injured if they jump up and run before adjusting to any light-headedness they might be feeling.
- **CARRY MINTS** Peppermint is a natural way to soothe nausea for some people.
- **SALTY SNACKS** What kid will argue with you if you remind them to eat some chips or pretzels? Salty foods as a snack throughout the day will help the child's hydration as well as their sodium level.
- **COOL TOWELS** If you notice the child is sweating severely or complains of feeling lightheaded or weak, a cool cloth can help revive and rejuvenate the child. Place the towel on the back of the child's neck. A cool cloth placed where the head meets the neck can help to relieve feelings of weakness.

Don't be afraid to ask questions. The better you understand what the child is going through, the the more help you can be.

**Call 911 immediately** if the child loses consciousness, is unresponsive or exhibits any other symptom that causes concern.

For more information about POTS and other types of dysautonomia, visit [www.dinet.org](http://www.dinet.org)  
Also, consider making a donation on behalf of the child or parents living with this illness to DINET. We are a 501C3 non-profit, all volunteer organization dedicated to supporting patients and educating the medical community about all forms of dysautonomia. Visit <https://www.dinet.org/get-involved/donate/> for ways you can help.