

## **Autonomic Dysfunction with Orthostatic Intolerance**

(also known as Postural Orthostatic Tachycardic Syndrome, dysautonomia, orthostatic intolerance)

### **Recommendations**

- Increase fluid intake to 2-3 liters per day, about 100 ounces
- Increase salt consumption to 3-4 grams sodium per day. (Holds the extra fluid in your blood vessels)
- Wear compression leggings, shorts and /or socks (15-22 mmHg). Or consider abdominal binder
- Recognize your symptoms and sit/squat/lie down to avoid passing out
- Your urine should be clear during the day if you're drinking enough fluids
- Be physically active EVERY day, start slowly but work up to 30-60 minutes per day
- Consider raising the head of the bed 4-6 inches by putting blocks under bed frame. Your feet should be lower than your hips. (May help to retain fluid)
- Eat a healthy diet including a variety from all food groups. Limit processed foods. Limit added sugar. Aim for 5 servings of fruits and vegetables a day. Make half of the grains be whole wheat.
- Practice good sleep hygiene. Try to get 8-10 hours of consistent sleep per night. Start a bedtime routine

### **What are common symptoms?**

Dizziness, lightheadedness, fast or abnormal heart rate, headaches, fainting, inability to concentrate well, fatigue, abdominal pain, nausea, vomiting, diarrhea or constipation, early fullness with eating, sensitivity to hot or cold, purple splotchy arms or legs, abnormal sweating.

### **What's happening in my body?**

The body has an "auto-pilot" setting called the autonomic nervous system (ANS). It controls everything in your body you don't have to think about like your heartbeat, breathing, blood flow, digestion, and temperature. For some reason, it isn't working properly and the normal responses to gravity are faulty. Usually, when a person stands from a lying or sitting position, the ANS tells blood vessels to tighten. This gives the body a constant flow of blood to deliver oxygen. When the blood vessels don't tighten, it's like the body doesn't have enough blood to pump around.

This starts a cycle where you sit and lie down more to avoid the dizziness. Your body and muscles become weaker or deconditioned, your strength decreases, and you are more tired and weak. Your muscles and blood vessels don't squeeze as well.

While the cause of orthostatic intolerance is not completely understood, ways to treat symptoms have been well studied. The first step is to increase blood volume with water intake and add extra salt to keep the fluid in the blood vessels. This also increases the blood pressure. Compression clothing is also helpful to prevent blood volume from pooling in the abdomen and legs.

Living with a chronic condition is difficult and stressful. Our brains and our bodies are connected but that doesn't mean your symptoms are "all in your head" and you aren't lazy. When you feel a lot of stress, the body's autonomic nervous system prepares to protect itself. This high alert status tends to make your symptoms worse. Cognitive Behavioral Therapy skills help to decrease the body's stress response and begin to improve your symptoms. A mental health counselor can help.

Medications that might be used to improve symptoms of orthostatic intolerance in teens are off-label meaning the FDA hasn't approved drugs for this treatment. It is best to try fluid, salt, compression, and regular exercise first.

Currently, there is no cure for orthostatic intolerance but a good percentage of patient's symptoms fade or resolve over time.

### Who gets it?

Symptoms usually begin during early puberty and after a recent illness or injury like a concussion. It is more common in females and Caucasians. It tends to occur in high achieving and athletic teens. There can also be other disorders, too, like joint hypermobility.

### Water and Sodium

**GOAL: 3 liters of fluid/day (~100 ounces) and 3-4 grams sodium/day**

Sodium options	Sodium	Potassium	Sugar	Serving size	Serving Cost
Gatorade	270 mg	80 mg	34 g	20 oz	\$0.81
Liquid IV Hydration	500 mg	370 mg	11 g	1 packet/ 500 ml	\$0.75
LMNT	1000 mg	200 mg	stevia	1 packet/500ml	\$1.50
NUNN Sport	300 mg	150 mg	1 g	1 tab / 500 ml	\$0.59
Propel	230 mg	60 mg	-	1 bottle/ 500 ml	\$0.64
V8 100% vegetable juice	940 mg	640 mg	10 g	12 oz	\$0.46
Chicken broth	800 mg	-	1 g	8 oz	varies
Thermotabs	180 mg	15 mg	-	1 tablet	\$0.09
Vitassium, Salt Stick	215 mg	63 mg	-	1 capsule	\$0.22

**Salt 1 teaspoon = 2300 mg sodium= 2 grams**

SALTY SNACKS

Tortilla chips with salsa  
Cottage cheese  
Beef or turkey jerky  
Pickles  
Olives  
Salted nuts or seeds  
Salted popcorn  
Edamame with Sea salt  
Baked potato chips  
Pretzels

SALT TABLETS

Take with meals  
Can cause nausea or upset stomach

THERMOTABS

Take with meals  
May be easier on the stomach

VITASSIUM

Has other electrolytes  
Take with meals  
May be easier on the stomach

### Compression Clothing

Aim for 20-30 mmHg.

Wearing compression clothing can decrease symptoms of dizziness by preventing blood from dropping or pooling in the lower half of your body. It is most effective when worn during the day when you are active. Try them consistently for 1-2 weeks. There are many options on Amazon.

- Waist-high compression leggings. Brands to consider. (Might be less than 20mmHg)  
Under Armour, Second Skin, Old Navy High-Waisted PowerPress Leggings  
SPANX, Lululemon, CEP compression.com, Therafirm, Bauerfeind

### Exercise

Physical exercise is necessary! Many specialists believe regular exercise is the best way to reduce symptoms so you feel better. It supports your heart and blood vessels and increases blood volume. Strengthening core muscles and lower leg muscle groups helps prevent blood from quickly draining to your legs. It is best to start slowly. You can start by doing exercises while lying down or sitting, if needed.

[Reclined and Chair exercises](#)

Using stationary bikes and rowing machines will help prevent dizziness. This structured exercise program, originally from Children's Hospital in Philadelphia, is recommended.

[CHOP Modified Dallas Protocol](#)

These simple exercises can help prevent fainting while you are standing. It's best to be able to touch a wall or other support.

- Leg crossed and bending at the waist
- Raising on toes to constrict calf muscles
- Tighten stomach, thigh, and buttock muscle
- Slow marching in pace
- Squat down (but be careful when standing back up)

## Recommended Book

*Tired Teens: Understanding and Conquering Chronic Fatigue and POTS* Dr. Phillip Fischer (2021)

### Sleep

- Be physically active during the day. It can help you fall asleep more easily at night
- Avoid taking naps during the day
- Avoid caffeine and large meals before bedtime
- Use your bed only for sleep
- Establish a relaxing bedtime routine
- Be consistent. Go to bed at the same time each night and get up at the same time each morning, including on the weekends
- Make your bedroom quiet, dark, relaxing, and a comfortable temperature
- Turn off electronic devices 30-60 minutes before bedtime
- Remove electronic devices, such as TVs, computers, and smart phones, from the bedroom
- If you don't fall asleep after 20 minutes, get out of bed. Do a quiet activity without a lot of light exposure. (No electronics)

### Websites

- The Dysautonomia Youth Network of America [www.synainc.org](http://www.synainc.org)
  - This website is especially for children adolescents and their parents
- Standing Up To POTS [www.Standinguptopots.org](http://www.Standinguptopots.org)
- Dr. Jeff Boris, pediatric POTS specialist. Video [www.jeffreyborismd.com/about-dr-boris](http://www.jeffreyborismd.com/about-dr-boris)
- Dysautonomia International [www.dysautonomiainternational.org](http://www.dysautonomiainternational.org)
  - information, salty meals/snack ideas, support, patient advocacy, crisis hotlines
  - helpful tips for living with dysautonomia or POTS
- Videos: [vimeo.com/dysautonomia](https://vimeo.com/dysautonomia). Autonomic disorders video library

### Other considerations

- Avoid caffeine because it is a diuretic. It increases urine and decreases fluid in your body
- Having symptoms? Drink 8-16 oz water quickly and add a salty snack or add powdered electrolyte supplement to the water
- Avoid diets high in carbohydrates- it may impair blood vessel tightening
- Eat frequent, small meals so less blood flow is sent to the abdomen
- Avoid activities that worsen symptoms – long hot showers, hot tubs, saunas
- Use a shower chair
- Consider sitting while shaving, applying make-up or doing your hair
- Avoid falling