



## Orthostatic Intolerance (including POTS and dysautonomia)

If your major symptoms are dizziness, headaches, fatigue, and/or passing out, the most important thing for you to do first is to concentrate on NEVER getting dizzy. When you get dizzy, your body has to compensate in order to provide adequate blood flow to your brain. It is this compensation (the body makes adrenaline) that leads to the fatigue and headaches. Once you get control of the dizziness, it may be as long as 1-2 months before your energy level comes back. Some patients need more fluid and salt than others and until we meet your body's demands for this, symptoms will continue

The goal is to decrease and stop dizzy spells with 1) drinking more fluids, 2) eating more salt and 3) behavior changes. If this is not successful, medications and other strategies will be added.

### DRINK MORE FLUIDS

- **Increase fluid intake to 64-72 fluid oz/day**, at least. Drink a large share of this in the morning. Drink immediately when getting out of bed (keep a thermos on the nightstand). Eat breakfast and drink fluids prior to your morning shower. Then space out the rest of your fluid intake throughout the day
- Drinking fluids until your **urine is clear/colorless** is one way to know that hydration is assured. If your urine is yellow, you are likely not drinking enough. If you need an excuse for carrying a water bottle at school, we will provide this
- Needing to drink excessive amounts of fluid >>100-120 fluid oz/day likely is not helpful and instead points toward a deficiency in treatment somewhere else

### EAT MORE SALT

- Increase salt in your diet, especially at breakfast. **A diet that leads to at least 3 to 5 grams of SODIUM intake per day** is a good benchmark (this number may need to be smaller for smaller patients). You can continue to add more and more salt to your diet until dizziness improves. Salt does not have calories, and will NOT make you gain weight.
- You can also take salt tablets, which are available over the counter and online as a salt source. **Salt sticks (Vitassium) tablets (blue label)** are a buffered form of sodium chloride that are easy on the digestive system. Almost all patients tolerate these well. They are 250 mg of sodium per tablet (each tablet = same amount of salt as 2 strips of bacon), so four tablets = 1 gram of sodium. Some patients take as many as 10 a day, but start with 1-2 with breakfast or 30-60 minutes prior to sports and increase as needed. You will know you have done enough when you can change position without getting dizzy. Remember to drink fluids with the salt tablets.

### BEHAVIOR CHANGES

- **Stretching and leg/muscle exercises** while lying in bed, prior to standing up in the morning, is helpful.
- If you cannot sit up without getting dizzy, drink **cold water from a thermos cup** using a straw while you are lying down. This will constrict the blood flow to your stomach and allow more blood to be available for your brain.
- **Avoid rapidly changing position** and instead do this gradually. Decreasing the number of dizzy episodes tends to lead to even less dizziness with time. The goal is to minimize dizzy episodes each day with hydration, salt, and behavior.
- **Avoid caffeine** as much as possible. Caffeine makes you urinate, and this can worsen your dizziness. It also increases palpitations
- **Counter-pressure maneuvers** have been shown to help lessen dizziness. These include tensing your arm muscles (bicep contractions), leg crossing, clenching your pelvic muscles like fighter pilots, and leg crossing with lower body muscle tensing. Do these if you have to stand for a period of time (choir, school assembly) or in the morning (prior to and just after getting out of bed)
- Of course, it is also recommended that **if you begin to feel dizzy**, you should sit, sit while hugging your knees, or lie down immediately and drink some fluids. Remember, we are trying to decrease dizzy episodes and this will also prevent you from passing out completely
- **If you are having trouble getting out of bed without getting dizzy**, even after doing all of the above measures, then have some light weights at your bedside and lift them for 2 to 3 minutes BEFORE you sit up. Then sit up on the side of the bed for 15 to 30 seconds. If you get dizzy, lie back down immediately. If you have to lie back down, use the weights again for 5 minutes, and try again to sit

up. If you do not get dizzy, then stand beside the bed for 15 to 30 seconds - do not walk away until you are sure you are not going to get dizzy. If you do get dizzy, lie down immediately. If you have to lie back down, use the weights again for 5 minutes, and try again to sit up. This will get better with time but we are trying to start your day off without dizziness to decrease the total episodes with time

- Some patients with **extreme orthostatic intolerance** take as many as 30 minutes to be able to get out of bed without getting dizzy. This will get better with time and applying the techniques consistently
- **Physical activity is extremely important.** Even if you do not feel like it (even if you have to start by exercising in bed), increasing your muscle strength and tone is very helpful – particularly the legs. Increased leg muscle strength and tone improves venous compliance and prevents a lot of the venous pooling that leads to the symptoms of orthostatic intolerance. Some patients get out of bed and do Pilates while lying on the floor. Others benefit from swimming, rowing or a recumbent bike. Some people benefit from getting a physical trainer, as long as the trainer will teach them activities that can be done without becoming dizzy at the time. Focusing on leg strength and tone is the key. Sometimes physical therapy can be helpful, however this might or might not be covered by insurance. Let us know if we can help with this. Try to exercise daily – this will make everything easier with time! There are also POTS protocols (Dallas protocol) online for those having difficulty getting started
- Some patients with orthostatic intolerance need to wear **compression stockings** or tight running socks to keep blood from pooling in their lower legs (patients with more significant symptoms tend to pool blood in the legs more than other people). Try to get pairs that are at least 20-30 mmHg in pressure, closed toe, and come up to the knee. You should wear them during the day but not during exercise or sleeping. Previous patients have reported a preference for stylish varieties of compression stockings, which can be found at [www.trampshosiery.com](http://www.trampshosiery.com) and many other websites (for older teenagers or young adults).

#### **ADDITIONAL MEDICATIONS, SUPPLEMENTS, & STRATEGIES**

- **Vitamin D deficiency and iron deficiency** are both associated with worse orthostatic hypotension. Blood work can be done to see if these are present. Vitamin D deficiency occurs when we are inside a lot as sunlight helps us make vitamin D. A goal level is 25 Vitamin D > 40 ng/mL. In those that are deficient, sun exposure plus Vitamin D3 2-4000 IU is recommended, depending on patient size. Iron deficiency can result from dietary deficiency or blood loss, such as occurs with heavy menses. If your ferritin level is < 30 ng/mL, taking iron (Ex: Slow Fe 160 mg (=50 mg elemental iron) once or twice a day depending on patient size and extent of deficiency) plus treating the cause (discussing with pediatrician regarding treating heavy menses) is recommended. We can give you a Rx for this as well, or you can discuss it with the pharmacist re: available types and what is easiest on the stomach.
- **Medications**, such as fludrocortisone, beta blockers (atenolol, propranolol, etc), and midodrine, can be helpful. These do not help in isolation, but instead help to augment the above strategies by helping to retain fluid or prevent low blood pressure. These medications can be added to the regimen above if we are seeing improvement already but need to do more. We will discuss possible side effects in clinic prior to prescribing but feel free to look these up ahead of time to help with questions you might have
- **Anxiety or depressed mood** is exceptionally common in patients with POTS/orthostatic intolerance. This does not mean symptoms are “made up,” but instead means that symptoms are anxiety provoking and improving coping skills tends to be a VITAL component of sustained improvement. We recommend counseling for ALL patients with substantial symptoms. Dr. Aaron Fobian is here at UAB and has been excellent for many of our patients.
- **Medications for ADHD (for concentration) or SLEEP** can be helpful. Your pediatrician should be involved in the decision regarding stimulant medication – sometimes these medications can help and sometimes they make symptoms worse. Melatonin is a safe medication for sleep and is available over the counter – use the lowest dose possible (0.5-1 mg) 1 hour prior to sleep. **Sleep hygiene is MOST important** to help with falling asleep on time. Decreased screen/TV/computer time late in the day, exercise late in the day, and a hot shower or bath prior to sleep are particularly helpful. More info: <https://www.choc.org/wp/wp-content/uploads/2016/04/Sleep-Hygiene-Children-Handout.pdf>  
<https://drcraigcanapari.com/should-my-child-take-melatonin-a-guide-for-parents/>

Orthostatic intolerance may take many months to improve, and even then can improve and worsen along the way. Do not get discouraged if you are having bad days - concentrate on your daily plan and NOT GETTING DIZZY. Feel free to make an appointment anytime to help troubleshoot