

POTS and Dysautonomias

What is "dysautonomia"?

Generally speaking, dysautonomias are conditions resulting from dysregulation or misfiring of the autonomic nervous system (ANS). The ANS controls many of the *automatic* functions, like breathing, heart rate, blood pressure, and blood vessel constriction. While much is known about dysautonomias, more remains unknown, including what specifically causes dysautonomias. But when the ANS is dysregulated or misfiring, there is temporary decreases of blood flow to the brain. This leads to several types of symptoms, ranging from Neurally mediated hypotension (NMH), Orthostatic hypotension (OH), orthostatic intolerance (OI), and postural orthostatic tachycardia syndrome (POTS).

I view all of these dysautonomias as being a **wide spectrum** of conditions, **ranging from quite mild to debilitating symptoms**. Most patients have symptoms when changing position (e.g. standing up), but many also experience symptoms when stationary, sitting, or even lying down.

What can I do to feel better?

Lifestyle changes, particularly drinking extra water and avoiding trigger situations such as standing still or getting hot, are necessary for all patients. Some patients also benefit from the addition of other treatments, such as certain medications. Except for circumstances when symptoms are very frequent and/or very severe, my usual practice is to try aggressive hydration and lifestyle changes prior to prescription medications.

Here's a checklist of things you can do, and I recommend you try and do all of them (within reason):

STAGE 1:

1. Identify your symptoms. Everybody experiences this differently. What bothers you when this occurs? If you have multiple symptoms which ones bother you most? How long has this been going on? And how much is it impacting your daily life?
2. Identify your triggers. What seems to bring this on for you? Common triggers include heat, changes in body position, dehydration, bearing down, caffeine, irregular eating habits, eating specific foods, illness, stress, pain, and sedentary behavior.
3. Avoid or reduce exposure to all those triggers.
4. Hydration.
 - Gradually increase the amount of water consumed per day. **The end goal is not a specific intake volume, but rather is improvement in symptoms.** I find that most patients that urinate every 2-3 hours and have urine that is practically clear/colorless are well hydrated.
 - He should be allowed to carry a water bottle at all times, drink from it freely, and be excused for bathroom breaks as needed.
 - Pre-hydrate prior to AND during any periods of exercise or exertion.



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- Sugar-free sports drinks may be helpful.
 - Eliminate caffeine.
5. Diet/eating habits.
- Eat regularly and consume a well-balanced diet. No skipping meals.
 - Get plenty of sodium/salt. I do not recommend using salt tablets, because they can move water into the gut and out of the circulation. Simply measure out an extra 1/2 tsp into a small plastic ziplock bag, and disperse it over food throughout the entire day.
6. Rest.
- Get regular sleep. Aim for at least 8-10 hours per night.
 - Elevate the head of the bed by 4-6 inches.
 - Avoid napping during the day. Reclining or laying down for hours at a time only works against all your hard work.
7. Exercise therapy. This one is important. Gradually get back into the habit of regular exercise. You should stop exercising if you feel palpitations, unusual tachycardia, chest pain, or dizziness. You may also need to adapt for the presence of joint hypermobility, instability, and injury.
- Aerobic activities with local resistive component for the lower limbs are preferred, such as reclined cycling and swimming.
 - Dynamic exercise (exercise with lots of movement and little straining) is better tolerated than isometric exercise (straining without much movement, like weightlifting).
 - Exercising in the supine (seated) position is better tolerated than upright position.
 - Avoid overheating during exercise. Exercise in the heat can be counterproductive.
 - The target is to reach a heart rate of ~75% the estimated maximum heart rate, for about 30 minutes per session, 2-3 sessions per week.
 - Increase the fluid intake, preferably with added sodium.
 - Use pressure garments during and after exercise.
 - Avoid meals 1 hr prior to an exercise session.
 - Prevent a sudden drop in BP after training sessions by engaging in a low-intensity cooling-down activity.
 - Keep a log of your exercise.
8. Transitions and standing.
- Stand up gradually, especially after prolonged lying or sitting.
 - If you feel dizzy or lightheaded, lie or sit down immediately. If you cannot lie or sit down quickly, or if you are standing for any period, stand with your legs tightly crossed while squeezing your leg and gluteal muscles.
9. Reducing venous pooling. Try elevating your legs, or try abdominal and/or lower limb compression garments/stockings.
10. Vitamins.
- Make sure you are getting enough Vitamin D, calcium, and iron.
 - A daily multivitamin with iron may help lessen symptoms.



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11. Look for medication side effects. What medications are you taking? Could they be making your symptoms worse? Could you withdrawing medications that might worsen symptoms?
12. Support groups. Connect with others with similar symptoms, and see what works for them.
 - POTS support group on the 2nd Tuesday of each month here at WDH led by Dr. Farhad, a local neurologist.
 - Zebra Crossings (zebra-crossings.org)

Is one of these more effective than the other?

None of the treatments available is universally effective, and several treatments, used together, are likely to be needed. I recommend you try and do as many of the STAGE 1 interventions as is reasonable and possible in order to give yourself the best chance at success.

What if STAGE 1 doesn't work for me?

In those with moderate-severe impairment of daily function, and poor response to non-pharmacologic treatments, medications are available for STAGE 2. The names include:

- Fludrocortisone
- Midodrine
- Low dose beta-blockers
- Several other second line medications, including stimulants, contraceptives, desmopressin, pyridostigmine, clonidine, SSRI, octreotide, IV fluids, and ruscus aculeatus (butcher's broom).

Your pediatrician or family doctor should also try to rule out other diseases such as anemia, thyroid disease, hyperadrenergia, Addison's, diabetes mellitus, celiac, pregnancy, alcohol use, trauma, and vitamin deficiency.

When can I expect to feel better?

Most patients will respond to some form of treatment. **It is critical to remember that this problem did not develop overnight, and will not disappear overnight.** Luckily, most patients will see some improvement and sometimes full resolution, but it may take months to years. *Remember that the first month of exercise can (and often does) cause increased fatigue. Sticking with the program, in the face of this fatigue, is essential. Remember that most patients will see some improvement within 3 months of returning to exercise.*

This program will take time and work, but you can do it! We are here to help you feel better. We will meet regularly to monitor your progress, and make changes as needed. Please bring in your exercise log at each visit.



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