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How to Treat Orthostatic Intolerance (OI)

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My previous article [1] describes orthostatic intolerance (OI), which includes both POTS and NMH, and how to diagnosis it. OI is an integral part of ME/CFS [2] (also called chronic fatigue syndrome), and it is often present in fibromyalgia [3] and Lyme disease [4], too. That first article discussed a simple standing test in any doctor's office to help diagnose the condition. Once OI has been diagnosed, there are many ways to treat it that can lead to improvements in all symptoms, the ability to be more active without "crashing," and improved quality of life.

Non-Pharmacological Orthostatic Intolerance (OI) Treatment Options

Increase Salt & Fluids

One of the simplest things that patients can do (with a doctor's approval) is to increase intake of salt and fluids. One of the underlying causes of OI in patients with these illnesses is that endocrine dysfunction causes an inability to hold onto sodium and fluids, creating lower than normal blood volume. Increasing blood volume decreases OI symptoms.

Drink water constantly, and use sea salt in your food while cooking and at the table. Simply increasing salt in your food is rarely enough, though. You can also take buffered salt tablets (like Thermotabs or SaltStick) and electrolyte drinks that contain sodium. Gatorade and Powerade work but contain loads of sugar and artificial colors. There are natural alternatives like Vitalyte powder (contains sugar), Nuun tablets (contain sorbitol), and GU Brew powder and tablets. You can also get extra sodium from V-8 or other vegetable or tomato juices.

Saline IVs are a more effective way to increase fluids and sodium, pumping up blood volume directly rather than going through your gastrointestinal tract. Saline IVs have been proven to be very effective for many patients; however, the effects are temporary, usually lasting 24 – 48 hours. Your body quickly reverts back to its "natural" state of lower-than-normal blood volume. Despite this drawback, many patients have had good outcomes from the use of saline IVs weekly or twice-weekly, especially when combined with one or more of the medications outlined below.

Lifestyle Changes & Body Positioning

By simply understanding how hard your body has to work to keep blood pressure (BP) and heart rate (HR) steady when you are upright, you can make simple changes: lying down when possible, elevating feet to prevent blood pooling, and avoiding standing still. If you have to

stand, try to cross your legs, crouch, find a place to sit, elevate one foot on a step or other surface, or move around and tense and release your lower leg and feet muscles to keep the blood flowing. Although, it looks a little strange, but it beats passing out or getting sicker!

Never sit on a high surface, like a bar stool or the table in the doctor's office, with legs dangling, as this causes more blood pooling in the feet and legs. Instead, rest your feet on a surface, sit cross-legged with feet tucked up, or choose a seat where your feet can rest flat on the ground. You can also elevate the head of your bed by 10-15 degrees (search for "bed wedge" or "bed risers" online); this reduces loss of fluid during the night through frequent urination, thereby improving OI.

Avoid hot environments, like a bath, hot tub, or sauna. Heat dilates blood vessels, making OI much worse, often resulting in a "crash" that lasts for days. Bath water should be lower than body temperature, and keep showers short and not too hot. Try sitting on a stool in the shower to eliminate the combined stress of a warm environment and standing. In contrast, cool water helps OI by constricting blood vessels and providing gentle pressure to keep blood circulating to heart and brain, so floating in a pool, lake, or ocean can improve symptoms. Note that alcohol has the same effect as heat in dilating blood vessels and is also dehydrating, making OI worse, and should be avoided.

Compression Garments

Because the muscles and veins aren't contracting like they should with OI, blood pools in the pelvic area and lower extremities instead of circulating adequately to your heart and brain. You can help your body overcome this somewhat with compression garments, like knee socks, tights, or shorts.

Monitoring Heart Rate

If you have POTS, a heart rate monitor (HRM) can give you a simple way to know when you are doing too much and triggering a crash. Estimate your Anaerobic Threshold (AT) for ME/CFS with this simple formula:

(220 – your age) * 0.6 = anaerobic threshold (that is, 60% of your maximum heart rate)

Choose a HRM with continuous monitoring, so you can always see your HR, and set the upper alarm for your AT. That alarm will tell you when you are going over your limit and need to sit, lie down, or otherwise rest. Before you treat OI, you may not be able to even stand up without that alarm going off, but OI treatments can help to control your HR so that you can do more while staying within your limits.

Note that although exercise and physical therapy are often prescribed for patients who only have POTS, they may worsen symptoms for those with these chronic illnesses, especially ME/CFS with

its exercise intolerance. However, if you first treat OI, then you may be able to exercise (gradually and slowly) while staying within your limits. As a starting point, try some gentle strengthening exercises while lying on your back and wearing your HRM – strengthening your legs and core muscles will help to further improve OI. Those with severe symptoms or pain can try a specific type of manual physical therapy designed for OI patients with these illnesses that utilizes nerve gliding and begins with the patient entirely passive and lying down.

Pharmacological Treatments for OI

While the lifestyle changes discussed above may help, many patients with these diseases need medication for OI to experience significant improvement. The medications listed below can be used singly or in combination, depending on the needs of each patient. They are all older medications that every doctor should be familiar with. Always start with the lowest dose possible. Medications often require trial and error to find just the right one and the right dose, so it requires some patience and persistence but is well worth the effort.

Florinef (fludrocortisone)

Florinef is used for those with OI (both POTS and NMH) to increase blood volume, and it can also help blood vessels to constrict. Although it is technically classified as a steroid, it is used in tiny amounts and lacks the side effects of other drugs in that class. Its main effect is to help your body hold onto more sodium and fluids (in doing this, it can deplete potassium, so prescription potassium supplements are recommended for anyone taking Florinef). Start with a low dose of Florinef (often a half pill or 0.05 mg a day) and gradually work up to as high as 0.2 mg per day, if needed; you may not see any change at all until you hit the effective dose for you. Florinef, combined with plenty of extra sodium and fluids, can be effective, especially in kids and teens.

Midodrine

Midodrine is a vaso-constrictor; it helps your body to constrict blood vessels that may not be responding properly due to OI. It can be used on its own or in combination with other treatments, like Florinef.

Beta Blockers

There are many different types of beta blockers, but they all work by blocking various hormones (like adrenaline) to help POTS by bringing your HR down. Beta blockers are often used to treat high blood pressure, but they are still helpful in treating NMH (where the BP drops low when upright) because they can help to stabilize BP. People with these illnesses should always start with the lowest possible dose (maybe even cutting pills in half), as too much beta blocker causes fatigue. If it doesn't work well enough, gradually increase the dose. If you have side effects, try a different beta blocker; there are over three dozen of them on the market that work in different ways. Keep trying until you find the right one and the right dose for you.

Medications Used for Other Purposes

Many common medications have side effects that can influence OI, either positively or negatively. Medications that cause fluid retention or bloating (i.e. increased blood volume) can help OI; these include birth control pills, vasopressin, and clonidine. Conversely, avoid any medications or supplements that act as diuretics – they will flush excess fluid out of your body, further decreasing blood volume.

Medications that act as vaso-constrictors can be helpful for OI, like the decongestant pseudoephedrine (found in Sudafed), SSRIs (a type of antidepressant), and stimulants used for ADD, like Ritalin. The opposite is also true: medications and supplements that act as vaso-dilators are harmful for those with OI. These include nitroglycerin, niacin and other medications commonly used to treat high triglycerides, and alcohol. Read labels for side effects of any medications or supplements you take.

Treating orthostatic intolerance effectively requires multiple approaches and some trial and error, but the effort is well-rewarded by improvements not only in OI but in all symptoms of ME/CFS, fibromyalgia, and Lyme disease because OI is often such an integral part of these diseases. Treating OI can bring dramatic improvements, resulting in improved quality of life and the ability to be more active.

For more detailed information on orthostatic intolerance treatment options to share with your doctor, refer to the Orthostatic Intolerance Brochure [5] written by Dr. Peter Rowe of Johns Hopkins.

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[3] fibromyalgia: **https://www.prohealth.com/library/evergreen_pages/what-is-fibromyalgia**
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[15] Pacing by Numbers: Using Your Heart Rate to Stay Within the Energy Envelope: **http://www.cfidsselfhelp.org/library/pacing-numbers-using-your-heart-rate-to-stay-inside-energy-envelope**

[16] Manual Therapy in CFS: **http://solvecfs.org/manual-therapy-in-cfs-part-1-of-2/**

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[19] Midodrine: a role in the management of neurocardiogenic syncope: **http://heart.bmj.com/content/79/1/45.full**

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[21] Randomized double-blind, placebo controlled trial of oral atenolol in patients with unexplained syncope and positive upright tilt table test results: **http://www.sciencedirect.com/science/article/pii/0002870395901507**

[22] Effects of paroxetine hydrochloride, a selective serotonin reuptake inhibitor, on refractory vaso-vagal syncope: a randomized, double-blind, placebo-controlled study: **http://www.sciencedirect.com/science/article/pii/S0735109798006949**