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What is Orthostatic Intolerance and How to Diagnose It

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By Suzan L. Jackson

Orthostatic Intolerance (OI) is an integral part of ME/CFS (chronic fatigue syndrome) [1] and is present in most fibromyalgia [2] patients and many of those with Lyme disease. [3] Caused by dysfunction in the endocrine and autonomic nervous systems, it is a natural outcome of these diseases. In fact, many of the most common symptoms – fatigue, exercise intolerance, brain fog, headaches, and more – stem in part from OI. The good news is that OI is easily diagnosed, effective treatments are readily available, and treating OI often improves all symptoms.

What is Orthostatic Intolerance (OI)?

Orthostatic Intolerance or OI is an umbrella term that encompasses several different conditions. Generally, it means an inability to maintain a steady blood pressure (BP) and heart rate (HR) while upright. The two most common types of OI in ME/CFS, fibromyalgia, and Lyme are Postural Orthostatic Tachycardia Syndrome (POTS), where the HR goes up when the patient is upright, and Neurally Mediated Hypotension (NMH), where the BP goes down when upright. There are also rarer forms of OI that occur in these illnesses, such as where BP goes up, but the hallmark symptom in OI is not being able to keep BP and HR stable when upright.

Patients with severe OI may actually faint when they stand up. Dizziness and light-headedness are also common. However, for many with these diseases, OI simply manifests as a worsening of symptoms – more fatigue, more brain fog, worsening of sore throat or headache, etc. – when upright. Chest pain and related back pain may also occur. Many patients are completely unaware that OI is a part of their illness, but it explains why they feel better lying down and so much worse when standing.

What Causes Orthostatic Intolerance?

Just like the underlying illnesses behind it, OI is caused by a complex cycle of dysfunctions within the body. Endocrine dysfunction, where your body does not release and clear the right hormones at the right times, is an integral part of ME/CFS, fibromyalgia, and Lyme disease. Hormones regulate everything in the body, and some of those hormones control BP and HR.

In a healthy body, sudden stress or fear (and to a lesser degree, standing up) causes the body to secrete norepinephrine and epinephrine (aka adrenaline) for that classic "fight or flight" response, causing increased heart rate and contraction of the blood vessels in the lower body to help keep blood circulating adequately to the heart and brain. Those excess hormones are

quickly cleared out of the bloodstream once the danger is past. In these illnesses, though, the hormones are not released in the right amounts and are not cleared away quickly. Instead, the vessels in the lower extremities don't contract as they should, with blood pooling in the feet and legs, leaving too little blood flow to the heart and the brain, and heart rate stays high long after it should have returned to normal.

Hormones also regulate blood volume so that people with these illnesses don't have enough blood in their bodies, which further contributes to OI. Because of these dysfunctional hormones, those with OI have low levels of sodium and cannot hold onto fluids. Even if you drink water constantly, your blood volume remains low. And when you do get dehydrated, that triggers the release of more epinephrine, making OI even worse.

All of this is a part of the autonomic nervous system, the way the body regulates automatic functions, like heart rate, blood pressure, digestion, and temperature. With the endocrine system not responding correctly, these functions that are normally automatic don't work as they should. As a result, most patients with these illnesses struggle with poor temperature regulation, poor vascular control (i.e. the way the veins should contract and expand automatically), and poor regulation of BP and HR (OI).

How Do You Diagnose Orthostatic Intolerance?

Many patients with these diseases are unaware they have OI because it rarely shows up in a normal blood pressure or pulse check at the doctor's office (11). Patients' blood pressure may look perfectly normal with a single measurement done while sitting (or if it is a bit low, the nurse may be pleased). Heart rate (pulse) may be a little high with a single measurement while sitting, but the nurse or doctor may think you are nervous or were walking fast. Further, POTS is often misdiagnosed as anxiety because its symptoms are similar: racing heart rate, feeling sick, nausea, dizziness or shakiness, etc. The only way to test accurately for OI is to watch what BP and HR do while standing for at least ten minutes.

The gold standard for an orthostatic intolerance diagnosis is a tilt table test (TTT), where the patient is strapped to a table and the head of the table is slowly raised. Often, doctors will focus solely on POTS (heart rate going high) and ignore or be unaware of the possibility of NMH (BP going low). However, many patients with these particular chronic illnesses have both conditions. There are some downsides to a TTT: It is expensive, requires a specialist and special equipment, is likely to make the patient very ill (from intentionally bringing on severe OI), and may not pick up OI in a single test. One study shows that POTS was diagnosed through a single test in only 46% of patients who had it.

An alternative is an in-office standing test. This can be done by any doctor in any office and costs nothing more than a regular appointment. The only equipment needed is a blood pressure monitor and a watch for monitoring heart rate (a heart rate monitor makes this even easier). It takes only about 20 minutes of the doctor or nurse's time. Best of all, the standing test mimics

real life conditions and is often more accurate than the TTT.

A standing test begins with the patient lying down (feet bare) for ten minutes. The doctor or nurse measures and records resting BP and HR. The patient then stands up, leaning against a wall for stability. It is critical that the patient stand absolutely still, not even wriggling fingers or toes. Our bodies automatically try to keep BP and HR stable, without us even noticing, for example by moving limbs to try to keep blood flowing. While the patient stands completely still for at least ten minutes, the doctor or nurse takes BP and HR readings every two minutes. In addition, they also record any observations and patient-reported symptoms, like the feet turning purple, as blood pools there, or the patient becoming very pale or suddenly feeling hot or light-headed or just plain sick. The test can be stopped early, if the criteria is met or the patient faints or gets too sick.

POTS is an increase in HR of at least 30 beats per minute (bpm) in adults during the 10 minutes of standing or a 40 bpm increase in children OR the HR going above 120 bpm at any time during the test. NMH is defined as a drop of 25 mm Hg in systolic BP (the top number) while standing; however, in NMH, BP can often take longer than 10 minutes to drop (though symptoms may occur immediately), so the doctor can draw conclusions based on symptoms, how the BP is trending, or even extend the test a little longer, if the patient can tolerate it. If NMH is suspected and doesn't show up in the standing test, a TTT can be ordered, which is longer. Remember that a single test may not pick up OI even when it is present (results are best in the morning).

NASA has established clear instructions and forms for an OI standing test [4] to print and share with your doctor. If your doctor is unfamiliar with OI, POTS, and NMH as a part of your illness, Dr. Peter Rowe of Johns Hopkins is one of the top experts in the world and has written an excellent article, all about OI [5], what it is, and how to diagnose and treat it. Read it yourself and print a copy for your doctor.

OI is an integral part of these chronic illnesses for most patients. It is behind many of the symptoms you experience, including the most debilitating ones. Diagnosing OI [6] is important because treating it can often bring dramatic improvement to many symptoms and a significant increase in quality of life, allowing you to feel better and do more.

For details on the many ways to treat OI, check out part 2 of this article: Treating Orthostatic Intolerance [7].

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References:

1. Stewart JM, Gewitz MH, Weldon A, Arlievsky N, Li K, Munoz J. "Orthostatic intolerance in adolescent chronic fatigue syndrome. [10]" *Pediatrics* (1999) 103(1):116–21. doi:10.1542/peds.103.1.116.

2. Rowe PC, Calkins H. "Neurally Mediated Hypotension and Chronic Fatigue Syndrome [11]." *The American Journal of Medicine* (September 28, 1998) Volume 105, Issue 3, Supplement 1, Pages 15S–21S.

3. Rowe PC, Bou-Holaigah I, Kan JS, Calkins H. "Is Neurally Mediated Hypotension an Unrecognized Cause of Chronic Fatigue? [12]" *Lancet* (March 11, 1995) 345(8950):623-4

4. Berne K, *Chronic Fatigue Syndrome, Fibromyalgia and Other Invisible Illnesses*. Hunter House Publishers (2002), pp. 54-5, 162-3.

5. El-Sawy N, El-Tantawi G, Achmawi GAH, Sultan H, Younis S. "Autonomic Changes in Fibromyalgia: Clinical and Electrophysiological Study [13]." *Alexandria Journal of Medicine* (September 2012) Volume 48, Issue 3, pages 215-222.

6. Kanjwal K, Karabin B, Kanjwal Y, Grubb BP. "Postural Orthostatic Tachycardia Syndrome Following Lyme Disease [14]." *Cardiology Journal* (2011) 18(1):63-6.

7. Stewart JM, Medow MS, Messer ZR, Baugham IL, Terilli C, Ocon AJ. "Postural neurocognitive and neuronal activated cerebral blood flow deficits in young chronic fatigue syndrome patients with postural tachycardia syndrome [15]." *American Journal of Physiology, Heart, and Circulatory Physiology* (2012) 302:H1185. doi:10.1152/ajpheart.00994.2011.

8. Ocon AJ, Messer ZR, Medow MS, Stewart JM. "Increasing orthostatic stress impairs neurocognitive functioning in chronic fatigue syndrome with postural tachycardia syndrome [16]." *Clinical Science* (2012) 122(5):227–38. doi:10.1042/CS20110241.

9. Rowe PC. "General Information Brochure on Orthostatic Intolerance and its Treatment." [5] *Dysautonomia International* (March 2014) p. 4-5.

10. Bell, DS, Streeten, DHP. "Circulating Blood Volume in Chronic Fatigue Syndrome." *Journal of Chronic Fatigue Syndrome* (1998) Volume 4, issue 1, pp. 3-11.

11. Rowe, PC, Underhill, RA, Friedman, KJ, et. al. "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Diagnosis and Management in Young People: A Primer [17]." *Frontiers in Pediatrics* (June 19, 2017).

12. Moon J, Lee HS, Byun, JI, et. al. "The Complexity of Diagnosing Postural Orthostatic Tachycardia Syndrome: Influence of the Diurnal Variability [18]." *Journal of the American Society of Hypertension* (March 2016) Volume 10, Issue 3, Pages 263–270.

13. Hyatt, KH, Jacobson, LB, Schneider, VS. "Comparison of 70 degrees tilt, LBNP, and Passive Standing as Measures of Orthostatic Tolerance [19]." *Aviation, Space, and Environmental Medicine* (June 1, 1975) 46(6):pp. 801-808.

14. Freeman R, Wieling W, Axelrod FB, et. al. "Consensus Statement on the Definition of Orthostatic Hypotension, Neurally Mediated Syncope and the Postural Tachycardia Syndrome [20]." *Clinical Autonomic Research* (April 2011) Volume 21, Issue 2, pp. 69-72.

URLs in this post:

[1] ME/CFS (chronic fatigue syndrome): **https://www.prohealth.com/library/evergreen_pages/symptoms-of-chronic-fatigue-syndrome-myalgic-encephalomyelitis**
[2] fibromyalgia: **https://www.prohealth.com/library/evergreen_pages/fibromyalgia-symptoms**
[3] Lyme disease.: **https://www.prohealth.com/library/evergreen_pages/lyme-disease-symptoms**
[4] clear instructions and forms for an OI standing test: **https://batemanhornecenter.org/wp-content/uploads/2016/09/NASA-Lean-Test-Instructions.pdf**
[5] an excellent article, all about OI: **http://www.dysautonomiainternational.org/pdf/RoweOIsummary.pdf**
[6] Diagnosing OI: **https://www.prohealth.com/library/42476-42476**
[7] Treating Orthostatic Intolerance: **https://www.prohealth.com/me-cfs/library/orthostatic-intolerance-part-2-treating-oi-82949**
[8] http://livewithcfs.blogspot.com: **http://livewithcfs.blogspot.com**
[9] http://bookbybook.blogspot.com: **http://bookbybook.blogspot.com**
[10] Orthostatic intolerance in adolescent chronic fatigue syndrome.:

https://www.ncbi.nlm.nih.gov/pubmed?Db=pubmed&Cmd=ShowDetailView&TermToSearch=9917448

[11] Neurally Mediated Hypotension and Chronic Fatigue Syndrome: **https://link.springer.com/article/10.1007/BF02267785?no-access=true**

[12] Is Neurally Mediated Hypotension an Unrecognized Cause of Chronic Fatigue?: **https://www.ncbi.nlm.nih.gov/pubmed/7898182**

[13] Autonomic Changes in Fibromyalgia: Clinical and Electrophysiological Study: **http://www.sciencedirect.com/science/article/pii/S2090506812000267**

[14] Postural Orthostatic Tachycardia Syndrome Following Lyme Disease: **https://www.ncbi.nlm.nih.gov/pubmed/21305487**

[15] Postural neurocognitive and neuronal activated cerebral blood flow deficits in young chronic fatigue syndrome patients with postural tachycardia syndrome: **https://www.ncbi.nlm.nih.gov/pubmed?Db=pubmed&Cmd=ShowDetailView&TermToSearch=22180650**

[16] Increasing orthostatic stress impairs neurocognitive functioning in chronic fatigue syndrome with postural tachycardia syndrome: **https://www.ncbi.nlm.nih.gov/pubmed?Db=pubmed&Cmd=ShowDetailView&TermToSearch=21919887**

[17] Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Diagnosis and Management in Young People: A Primer: **http://journal.frontiersin.org/article/10.3389/fped.2017.00121/full**

[18] The Complexity of Diagnosing Postural Orthostatic Tachycardia Syndrome: Influence of the Diurnal Variability: **http://www.ashjournal.com/article/S1933-1711(16)00036-X/abstract**

[19] Comparison of 70 degrees tilt, LBNP, and Passive Standing as Measures of Orthostatic Tolerance: **http://europepmc.org/abstract/med/1156287**

[20] Consensus Statement on the Definition of Orthostatic Hypotension, Neurally Mediated Syncope and the Postural Tachycardia Syndrome: **https://link.springer.com/article/10.1007%2Fs10286-011-0119-5**