

# DYSAUTONOMIA + POTS

## *What is Dysautonomia?*

Dysautonomia is an umbrella term used to describe several different medical conditions that cause a disruption of the Autonomic Nervous System (ANS). These conditions including postural tachycardia, inappropriate sinus tachycardia and vasovagal syncope. The ANS controls the "automatic" functions of the body such as heart rate, breathing, blood pressure, digestion, and temperature control. When the body has a hard time controlling these functions, there can be a variety of symptoms such as lightheadedness, fainting, unstable blood pressure, abnormal heart rates and malnutrition.

## *POTS - Postural Orthostatic Tachycardia Syndrome*

Postural Orthostatic Tachycardia Syndrome (POTS) is a type of dysautonomia. There is an increased risk for POTS if you have experienced the following:

- Significant medical event
- Head injury
- Viral illness
- ME/CFS
- Pregnancy

Typically when you stand, gravity causes blood to pool in your legs and abdomen. The ANS will cause blood vessels to constrict and increase your heart rate slightly so that it can get blood up to your heart and brain. With POTS, the ANS is not able to regulate these functions effectively to maintain blood flow and your heart rate increases significantly to try to compensate.

Possible symptoms include:

- Heart palpitations
- Lightheadedness
- Shortness of breath
- Chest pain
- Nausea
- Headache
- Brain fog
- Shaking
- GI upset
- Temperature regulation problems

POTS symptoms can vary in terms of severity: some people can manage the symptoms and continue with regular activities, while others can find it hard getting through their daily routine.

## *Do I have POTS?*

There are a number of tests that your family doctor or cardiologist might suggest to determine if you have POTS, including blood tests, ECG, Active Stand Test or Tilt Table Test. The Tilt Table test requires special equipment and may not be readily accessible. An Active Stand Test can be conducted at home or with your doctor to see if your symptoms indicate POTS.

The Active Stand Test is also known as the NASA Lean Test. The link below outlines the procedure for the test. It is advised that you do this test with someone else so they can support you if you start to feel unwell. You can also stop the test at any time if you do not feel well enough to continue. If you are on any medications that alter your heart rate or blood pressure, this test may not be appropriate as it can mask some of your symptoms. **Speak to your doctor about this and do not stop taking your medications to do this test.**

<https://batemanhorncenter.org/wp-content/uploads/2016/09/NASA-Lean-Test-Instructions-1.pdf>

## *Criteria for POTS*

- A group of symptoms that occur frequently in an upright position (usually standing) and are relieved by lying down.
- Persistent increase in heart rate of 30 beats per minute or more on standing for 10 minutes (40 beats per minute if 12-19 years) without a drop in blood pressure.
- Symptoms have lasted for more than 3 months.

## *Management of POTS*

Your doctor may prescribe medications to help manage the condition. If your doctor is not familiar with POTS, the *Canadian Cardiovascular Society Position Statement on Postural Orthostatic Tachycardia Syndrome (POTS) and Related Disorders and Chronic Orthostatic Intolerance* outlines screening/assessment and management/treatment options. The article can be found here: <https://www.onlinecjc.ca/action/showPdf?pii=S0828-282X%2819%2931550-8>

*Figure 4* in the article outlines a potential treatment algorithm for POTS with suggested management strategies and medication. Consult your GP or Cardiologist regarding the treatment that is right for you.

## Non-medical management strategies:

- **Hydration:** Drink plenty of water throughout the day (2.5-3L), especially in warmer weather. Consider keeping a thermos of cold water at the bedside to drink first thing in the morning. Drink a glass of cold water, lay down for 15 minutes and then get out of bed slowly.
- **Increase salt in the diet:** Increase your salt intake to 1-2 tsp/day. This will help retain the water in your body and increase your blood volume. Depending on your health, increasing your salt intake may have risks like increasing your blood pressure; **discuss this with your doctor beforehand.**
- **Limit/eliminate caffeine and alcohol intake**
- **Electrolyte supplement:** Consider taking an electrolyte tablet once a day. You could do this *instead of increasing salt in your diet*. **Discuss with your GP prior to starting to rule out any risks.**
  - \*Watch out for added sugar, caffeine or stimulants as they are often added to electrolyte packets/tablets.
- **Eating small meals:** If you are symptomatic after eating, smaller meals more frequently throughout the day that are not rich in carbohydrates may help.
- **Getting up and moving slowly:** Move slowly from a lying to sitting to standing position. When getting out of bed, sit on the edge of the bed for a minute before standing. When going from sit to stand, count slowly to 10 before walking.
- **Movements to help with circulation:** There are certain movements that help with your circulation and may reduce symptoms.
  - In lying: knee to chest, flex and point your feet, squeeze buttocks
  - In sitting: flex and point your feet, squeeze your buttocks, bend and straighten your arms
  - In standing: avoid standing still; step side to side/march on the spot, go up and down on your toes, squeeze buttocks, cross legs and squeeze
  - Visit these links for movements that can help prevent increased dizziness/prevent fainting:
    - <https://cpr.heart.org/en/resuscitation-science/first-aid-guidelines/first-aid/description-of-recommended-physical-counterpressure-maneuvers>
    - <https://www.dysautonomiasupport.org/counter-pressure-maneuvers/>

- **Compression garments:** These may help improve blood flow and reduce symptoms. Wearing waist-high compression stockings at a higher compression is recommended but this can be uncomfortable (can sometimes cause GI discomfort). Start with a lower compression 15-20 or 20-30 mmHg and at a shorter length (knee or thigh high) and try to work your way up. If you have any workout leggings with compression, this might be a good place to start. Some people also use abdominal binders for compression around their torso.
- **Stress Management/Parasympathetic Nervous System Activation**
  - Diaphragmatic Breathing
  - Meditation/Mindfulness- body scans
  - Calming activities – nature sounds, soft music, restorative yoga

If your doctor is not able to manage your POTS symptoms, they can refer you to a specialist who specializes in POTS. These are the doctors listed on the Dysautonomia International website:

In Toronto - Dr. Paula Harvey, Women's College Hospital:

<https://www.womenscollegehospital.ca/care-programs/cardiology/cardio-rheumatology-clinic/>

Outside of GTA - Dr. Juan Guzman, Hamilton General Hospital:

<https://www.hamiltonhealthsciences.ca/wp-content/uploads/2019/03/Referral-Form-HHS-Cardiology-Fillable.pdf>

Typical management of POTS encourages scheduled and progressive exercise, from a recumbent position to an upright position as tolerated. However, in the context of Long COVID and the presence of post-exertional malaise/post-exertional symptoms exacerbation (PEM/PESE), this approach may not be appropriate. It could be helpful to work with a physiotherapist, who is familiar with POTS and Long COVID, for guidance on how to manage and safely progress your activities.

### *Day to day with POTS or other forms of Dysautonomia*

Symptoms can vary in severity and some people find it difficult to do their daily activities. Here are some tips that might make daily life easier:

**Limit your standing** – Sit whenever possible. After standing, it can be helpful to lie down for periods of rest to minimize your symptoms. For example, after standing for 5 minutes, you may need to lie down for 10 minutes so your body does not have to work so hard to manage your blood flow.

**Showers/hygiene** – Consider a shower chair to minimize symptoms in the shower. Avoid long hot showers and use warm water. Lifting your arms to wash/dry your hair can be more tiring and cause more symptoms, so may want to get help with that, or use tools like a blow dryer holder or a long-handled device. Same for bending down, a long handled sponge and help you reach your feet more easily.

**Avoid being too hot/cold** – even slight changes in temperature may be hard for your body to tolerate. Heat can trigger symptoms, so try your best to stay cool: air conditioning, cooling towels/vests, fans, stay in the shade, have cold drinks, limit time outside in the summer.

**Disability parking permit** – Depending on the severity of your symptoms, you can ask your doctor to help you apply for a disability-parking permit to limit your walking.

**Walking aid or wheelchair** – A cane, walker or wheelchair can help you get around and help you feel steadier on your feet or safer in the community. This may not be how you imagined getting around, but if the effort of walking means you cannot participate in another important activity, using these devices can help when you are feeling unwell.

### *Additional Resources*

Dysautonomia International: <http://www.dysautonomiainternational.org/page.php?ID=34>

Dysautonomia - Long COVID Physio: <https://longcovid.physio/dysautonomia-pots>

Managing POTS - POTS UK: <https://www.potsuk.org/managingpots/>

Non-Pharmacological Treatment Guide for POTS - Calgary Autonomic Investigation & Management Clinic:

[https://cumming.ucalgary.ca/sites/default/files/teams/65/POTS\\_NonPharmaTreatmentGuide%2001.05.22.pdf](https://cumming.ucalgary.ca/sites/default/files/teams/65/POTS_NonPharmaTreatmentGuide%2001.05.22.pdf)

Orthostatic tachycardia after covid-19 infographic - The British Medical Journal:

<https://www.bmj.com/content/380/bmj-2022-073488/infographic>

Stop Fainting.com - <https://stopfainting.com/long-covid-resources/>