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Postural Orthostatic Tachycardia Syndrome (POTS)

Good Health Physical Therapy and Wellness

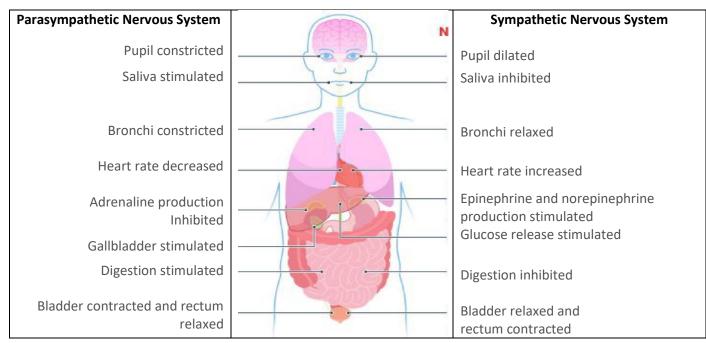
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You are Strong and Courageous

You are strong and courageous. How do we know? If you are reading this you have likely been facing one or many health challenges for some time. And you have been doing your best to live and function each day. That takes strength and courage. We are here to listen to you and to support you in your healing journey. In particular, we hope to support you being even more empowered to get your symptoms under control, to know the best ways to manage the health challenges and to get back to doing what you want to and need to be able to do for all the life you deserve. This is one of a series of patient education handouts – the Strong and Courageous Series – aimed at helping you to learn more about your condition, learn the controllable triggers of flareups, and learn the steps you can take to claim back your power and your ability to function.

Your Nervous System (some brief background)

The human nervous system reaches almost every inch of the body and serves as the control system for our amazing bodies. There are two major parts to the nervous system. The voluntary nervous system controls conscious movement. But there is another major portion of the nervous system: the involuntary nervous system also called the autonomic nervous system. This controls things like heart rate, blood pressure, constriction of pupils, and in most cases the dilation (opening) or constriction (closing) of small blood vessels. There are two halves to the involuntary, autonomic, nervous system. One half, the sympathetic part, speeds up body systems, the other half, the parasympathetic part, slows systems down. The healthy body has an autonomic nervous system which exists in a careful balance between these two portions.



Autonomic Nervous System

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Postural Orthostatic Tachycardia Syndrome (POTS)

Postural Orthostatic Tachycardia Syndrome (POTS) is one of a number of different kinds of conditions where the autonomic nervous system stops acting in good balance. The general term for this is dysautonomia. As you might guess looking at the chart on the last page, this can affect the functioning of multiple parts of the body including the eyes, heart, breathing, energy levels, digestion and bladder function.

Most commonly though, the name of the problem describes what happens. When the person with POTS changes position (postural), especially going from lying to sitting or sitting to standing, the column of blood in the body moves downward (orthostatic) away from the heart and brain and in to the legs. This causes the person to feel dizzy and the heart to calculate that there is too little blood so it begins to beat fast (tachycardia). The reason for this condition is not fully understood, but one theory is that the overly stretchy connective tissue in hypermobility spectrum disorder (HSD) and hypermobile Ehlers Danlos Syndrome (hEDS) disrupts the sensitivity of the involuntary nerves throwing the system out of balance.

Symptoms

Below is a list of some of the common signs and symptoms of POTS. This is a general list and not intended for self-diagnosis.

- ✓ Rapid heart rate (average normal heart rate at rest for most adults is between 70-85 beats per minute, tachycardia is when the heart beats at 100 times per minute or more)
- √ High or low blood pressure
- ✓ Chest pain
- ✓ Dizziness or lightheadedness
- ✓ Fainting or almost fainting
- ✓ Anxiety or jitters
- ✓ Poor tolerance of exercise

- √ Fatigue/ exhaustion
- ✓ Diarrhea, constipation or GI distress
- √ Temperature dysregulation (feeling too hot or too cold)
- ✓ Brain fog
- ✓ Headaches
- ✓ Blurred vision
- ✓ Insomnia
- √ Redness or whiteness in the hands or feet
- ✓ Increased or decreased sweating

Diagnosis

POTS is a diagnosis which must be made by a medical practitioner after considering the patients medical history and medications, interviewing for signs and symptoms as above, and then performing a test called the Orthostatic Hypotension/ NASA Wall Lean test.

The patient lies down for five minutes during which time heart rate and blood pressure are recorded. Then the patient stands for from 1 to 10 minutes (depending on tolerance) and these vital signs are repeated after one minute and at 5 and 10 minutes. Symptoms are noted.

A positive Wall Lean Test is one in which the blood pressure goes up 20 points (mmHg) or more on the first (diastolic) number and/or 10 points (mmHg) or more on the second (systolic) number especially with dizziness or lightheadedness. A positive test may also be indicated by an increase in heart rate of 30 beats per minute or more for an adult (or 40 beats per minute for a child less than 18 years of age) when there are no other diseases that can account for this.

In severe cases, the patient may be tested on a tiltable table. Other tests, looking at sweating, nerve function and gastric function, may be part of the diagnostic workup.

As we have already said, POTS is commonly associated with hypermobility spectrum disorder (HSD) or with hypermobile Ehlers Danlos Syndrome (hEDS). Together with mast cell activation syndrome (MCAS) these three conditions form a common triad of conditions with the connective tissue disorders. HSD, EDS and MCAS are diagnosed by other means and will be discussed in other Strong and Courageous educational handouts.

Treatment

The pillars of POTS management include:

- ✓ Education and understanding of the condition. Taking some of the fear out of the condition by itself helps to balance the nervous system.
- ✓ Reducing triggers
- ✓ Pharmaceutical treatments
- √ Natural supplements
- ✓ Self-care strategies
- ✓ Gradual progression of strengthening and activity with careful monitoring of symptoms.

Triggers

POTS is sometimes triggered and often worsened by individual triggers. Below is a list of many factors which can trigger or worsen a POTS flareup. This list is so broad that it can be frightening to look at. But as you begin to study what makes you feel worse (and better) you will discover which things on this list are most crucial for you personally to watch out for.

- ✓ Dehydration
- √ Low electrolytes
- ✓ Too little sleep
- ✓ Stress/ psychological trauma
- ✓ Physical trauma
- ✓ MCAS flare-up
- ✓ Food sensitivities or reactions
- ✓ Illness

- ✓ Over or under exercise
- ✓ Weather changes especially rapid changes in the barometer
- ✓ Temperature changes
- ✓ Alcohol
- ✓ Anxiety
- ✓ Overstimulation

Medications

Working with a skilled medical practitioner can often be the crucial step in bringing POTS under control. Common medications used for this condition include low dose beta blockers, fluidrocortisone or midodrine for low blood pressure, and occasionally Dramamine for persistent heart racing. If you or your therapist feel exploring medication options might be wise, you will want to turn to one of the medical practitioners on your support team. If unsure which, your physical therapist might suggest who to turn to.

➤ Homework 1: Steps to Control the Symptoms

Sleep	✓ Try to sleep at least 8 hours at night.
Avoid inflammatory triggers	 ✓ Such as stress and foods you are sensitive to. Begin studying what events, foods and emotional situations make you feel worse. ✓ A health notebook or journal can be helpful for this. In the health journal, record your resting heart rate each day, exercise you engaged in and your body's response and any other potential triggers you suspect. Over time, these will likely form a pattern. ✓ Avoid alcohol
Drink coffee (or other caffeinated beverage) in moderation for low energy	 ✓ Drink coffee or tea or other caffeinated beverages for low energy – in moderation. ✓ Be careful about increased fluid loss from urination which can leave you dehydrated.
Hydrate	 ✓ Drink plenty of water during the day. Patients with POTS often suffer from decreased absorption of the essential minerals that the body needs in the blood, electrolytes. ✓ Shoot to consume at least 64 ounces of water or other beverages per day. We recommend drinking electrolyte enriched water for at least half of your daily intake. ✓ Gatorade and Pedialyte are two premade liquids. There are also supplements which can be added to water such as Nuun and Endure. We know you will be mindful of cost. Watch labels for how much sugar you are consuming. ✓ Add more salt to your diet.
Compression Garments	 ✓ Support stockings, TED hose, compression garments and sometimes abdominal wraps can help keep the blood from pooling in the thighs, legs and feet making you feel dizzy and your heart race. ✓ Start with an online search for reasonably priced support hose or sports compression garments and try one.

Exercise	✓ Note: too little and also too much exercise can be triggers for POTS. How much is right for you is very individual. Your therapist will help here.
	✓ If you are fatigued or in the middle of a flare up, begin with light exercises lying down. (More about this in the second homework assignment.)
	✓ To begin with, exercise at 50% of your effort avoiding pain. Whenever possible begin aerobic exercise on a recumbent bike. As your body gets used to exercise you may build up to 80% effort and progress to walking and, if right for you, running.
	✓ Again, this is an area in which you will actively work with your therapist in the clinic, so when in doubt, wait.
	✓ Be sure to stretch after exercises and sit down or lie down to cool down – avoid prolonged standing.
Reclining	✓ Reclining helps to bring the blood out of your legs and back to the heart especially if your feet are elevated. Reclining is a friendly position especially when you are in a flareup.
Transfers	✓ When you change positions from lying down to sitting up and from sitting to standing, do this slowly.
	✓ If you easily become dizzy, be sure you have something to hold to support your balance.
	✓ See the beginning exercises below to assist with this.

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> Homework 2: Beginning Exercises: Muscle Pumps (Muscle Squeezing)

When transfers, such as going from lying down to sitting or sitting to standing, cause symptoms such as dizziness, faintness, or heart racing, we recommend warming up before changing position and then performing some movements after.

While lying down, before sitting up x3 each

(Do one or more exercises as needed. Experiment to find what works best for your body.)

Ankle pumps



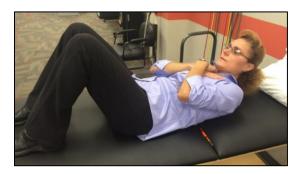


Bridges





Crunches



Before standing after prolonged sitting, 3-10x

(Do one or more exercises as needed. Experiment to find what works best for your body.)

Ankle pumps





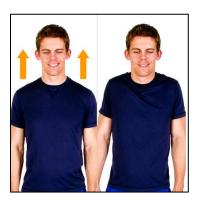
Kicks



Backward ab crunch ("Sit Backs")



Shrugs



For prolonged standing, do 3-10x

(Do one or more exercises as needed. Experiment to find what works best for your body.)

Calf Raises



butt squeeze



Weight Shifts

