A guide to understanding & diagnosing

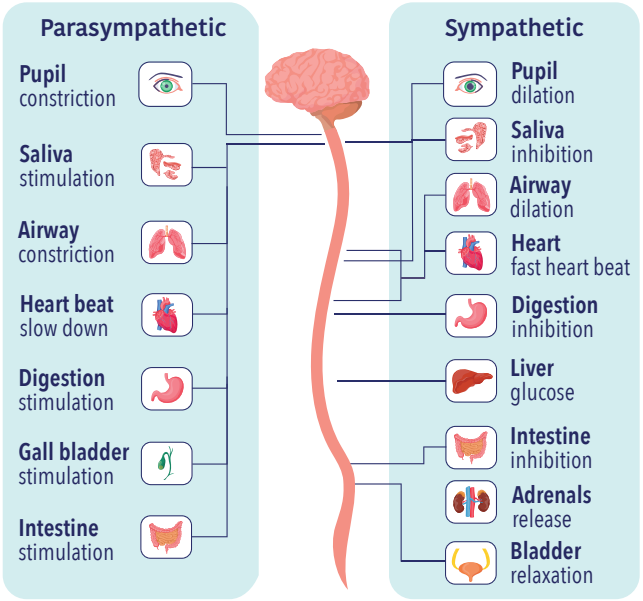
Postural Orthostatic Tachycardia Syndrome

Learn more at www.POTSinfo.com

What is POTS?

POTS is a disorder of the autonomic nervous system which is referred to as a dysautonomia.

The Nervous System



Dysautonomia is not rare. Over 70 million people worldwide live with various forms of it. People of any age, gender or race can be impacted.

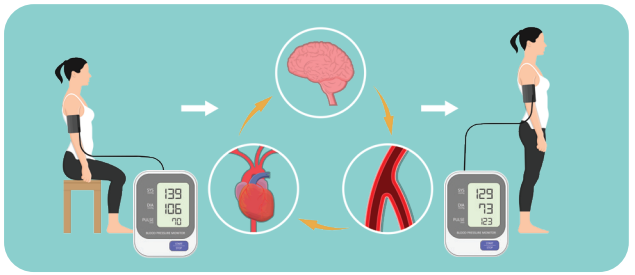
POTS is estimated to impact 1 out of 100 teenagers and including adult patients, a total of 1,000,000 to 3,000,000 Americans.

"POTS" was coined in 1993 by a team of researchers from Mayo Clinic. However, POTS is not a new illness; it has been called other names throughout history such as DaCosta's Syndrome, Soldier's Heart, & Chronic Orthostatic Intolerance.

POTS was mistakenly believed to be caused by anxiety & that harmful misconception is still believed today. Modern researchers have proved that POTS is not caused by anxiety but by a malfunction of the patient's autonomic nervous system.

What is happening?

When standing, gravity pushes blood downward & blood vessels tighten. A person with POTS is unable to make or maintain that tightness. To compensate & not faint, the brain tells their heart to beat faster. Often it compensates enough & fainting does not occur but the person is unable to maintain perfusion.



How is POTS diagnosed?

POTS is diagnosed with a Tilt Test, also know as Autonomic Function Test. An At Home Tilt Test & heart rate monitors are also valid data. POTS is **not** diagnosable by ECG, Stress tests, or bloodwork.

Diagnostic criteria

Patients lay down for 10 minutes & have their vitals taken. Then are tilted (or stand up) & have their vitals taken every minute for 10 minutes.

- Adults: a heart rate increase of 30+ beats per minute (bpm), or over 120 bpm, within the first 10 minutes of standing.
- In children & adolescents: 40+ bpm increase

Resources

dysautonomiainternational.org • clevelandclinic.org • myheart.net • potsuk.org • thedysautonomiaproject.org • hopkinsmedicine.org • www.standinguptopots.org

POTS subtypes

Source: www.hopkinsmedicine.org

Neuropathic POTS

POTS that is associated with damage to the small fiber nerves (small-fiber neuropathy). These nerves regulate the constriction of the blood vessels in the limbs and abdomen.

Hyperadrenergic POTS

This is known as Adrenaline POTS, or HyperPOTS. It is associated with elevated levels of the stress hormone norepinephrine.

Hypovolemic POTS

POTS that is associated with abnormally low levels of blood (hypovolemia)

Secondary POTS

POTS that is associated with another condition known to potentially cause autonomic neuropathy, such as diabetes, Lyme disease, or autoimmune disorders such as lupus or Sjögren's syndrome.

Commorbid disorders

- **Small Fiber Neuropathy (SFN)**
- **Mast Cell Activation Syndrome (MCAS)**
- **Ehlers Danlos Syndrome (EDS)**

Sources & Disclaimer

- dysautonomiainternational.org
- clevelandclinic.org
- myheart.net
- potsuk.org
- thedysautonomiaproject.org
- hopkinsmedicine.org
- standinguptopots.org

This brochure is made to help people recieve quality medical care. Information is from the above sources. POTSinfo.com is not run by a doctor and legally cannot give medical advice. It's recommended to talk with your doctor about what is best for you.

Lifestyle changes

Source: www.potsuk.org/managingpots

Exercise

Exercise training has been proven to expand blood volume & plasma volume & increase cardiac muscle mass &heart size. These in turn have been associated with symptom improvement.

- POTS patients usually fare better with exercises that do not cause orthostatic stress.
- Build up the number of minutes exercising very slowly, building up to 30 minutes a days.

Compression clothes

Compression tights are sometimes recommended in PoTS, vaso-vagal syncope or orthostatic hypotension. Compression of the lower limbs causes an increased blood return to the heart from the superficial veins in the legs.

Salt

A high salt diet of an extra 3-10g of salt per day may be recommended. This has been found to increase circulatory blood volume and therefore lowers heart rate and increases blood pressure. However, excessive salt can be dangerous in some patients

Fluids

Increased fluid intake is advised to increase circulatory blood volume, particularly in the morning.

Commonly prescribed medications

Source: www.potsuk.org/managingpots/medication-2

Beta Blockers

These help with adrenaline symptoms.

Clonidine & Methyldopa

May be used in Hyperadrenergic POTS. These lower the heart rate and may reduce blood pressure by working directly on the brain.

Fludrocortisone

This is a synthetic steroid that retains salt and produces an increase in the volume of blood within the blood vessels. It does not have all the same side effects as other steroids.

Ivabradine

This is not an FDA-approved drug for POTS but due to its ability to reduce HR, it has shown improvement in POTS patients in many studies

Pyridostigmine

This acts on the nervous system to reduce heart rate by increasing:

- Vagal tone – part of the parasympathetic 'rest and digest' nervous system
- Sympathetic tone – influences of the sympathetic nervous system on muscle tone

Midodrine

The aim of an alpha agonist is to narrow blood vessels to help return the blood back to the heart. Side effects are high blood pressure and sometimes worsening of symptoms.

Modafinil or other stimulant medications

is a stimulant normally used in some sleep disorders, and may improve alertness and decrease mental clouding in those with POTS.