- What causes PoTS?
- Is PoTS a serious condition?
- Is PoTS genetic?
- What medication and treatment are currently available?
- Can betablockers help PoTS?
- Can PoTS affect pregnancy?
- What causes PoTS in teenagers?
- Are there other conditions linked to PoTS?
- What can I do to improve my symptoms?
- Can I exercise if I feel well enough?
- Would CBT help me cope with this chronic condition?

Questions to **Ask Your Doctor**



"Finding an appropriate specialist to secure the right diagnosis can take perseverance but do not lose hope."

Trudie Lobban MBE,
Founder & CEO STARS

Want to know more?

If you have any questions, would like further advice or information, please contact our Patient Services Team

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Email: **info@stars.org.uk**

or visit: **www.stars.org.uk**

For more information on our online and in-person Patient Educational Events, please scan the QR Code

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FOR PATIENTS & CAREGIVERS

Take Fainting to Heart

Standing up to PoTS



Postural Tachycardia Syndrome (PoTS)

This Guide is to help individuals diagnosed with PoTS and who are struggling with the many issues raised by this condition

Discussion Guide

FAQ Questions

What is PoTS?

(Postural Tachycardia Syndrome also known as Postural Orthostatic Tachycardia Syndrome PoTS), is a complicated disorder that manifests itself in a variety of ways. Symptoms vary and are often exacerbated by daily activities such as modest physical exertion or what you eat.

It is defined as a persistent increase in heart rate of over 30 beats per minute (bpm) or to higher than 120 bpm when standing upright over 10 minutes. Typically, there is no fall in blood pressure, although fainting can occur.

What is the difference between PoTS and Dysautonomia?

Dysautonomia is an umbrella term to describe several different conditions that are due to the malfunction of the autonomic nervous system (ANS). These can include a fast resting heart, orthostatic hypotension, and irregularities with the body's thermostat.

PoTS is one form of dysautonomia with major symptoms that arise when an individual is standing and are relieved by lying down.

What causes PoTS in teenagers?

It is thought a rapid growth spurt at the start of puberty, often between 12 – 14 years, can be the cause of these debilitating symptoms in young teenagers.

How do I obtain a diagnosis?

Diagnosis is usually made by a cardiologist who is a heart rhythm specialist (an electrophysiologist) or in a dedicated autonomic centre.

Investigations into suspected PoTS may include an active stand test or tilt table test to diagnose PoTS but further tests may be necessary to exclude other conditions or diagnose associated conditions.

Classification of PoTS

PoTS is a group of different disorders associated with similar autonomic manifestations. Doctors will classify PoTS as 'primary' or 'secondary'.

Primary is when there is no other identifiable medical condition and cause maybe:

• Viral illness (glandular fever) • Pregnancy • Sepsis • Surgery • Trauma • Adolescent growth spurt

Secondary is the presence of a medical condition causing or relating to PoTS symptoms:

- Joint hypermobility syndrome
- Diabetes
- Lupus
- Sjogren's syndrome
- Chemotherapy

Hyperadrenergic PoTS is when a genetic link is considered. Symptoms may include:

• Anxiety • Tremor • Migraine • Orthostatic hypotension • cold and sweaty hands and feet

Misdiagnosis of PoTS

PoTS is a relatively new condition, first acknowledged by medical professionals in 1993. There are still few PoTS specialists, and it is recognised that obtaining the right diagnosis can be difficult, frustrating, and upsetting when no-one appears to understand.

During this period, patients can be misdiagnosed with chronic fatigue syndrome (CFS), inappropriate sinus tachycardia (IST), panic attacks and anxiety.

If you suspect that you may be struggling with PoTS, then share this discussion guide with your GP and ask if they will consider a referral to a cardiologist with a special interest on PoTS.

The best advice a doctor can offer

Be patient, be motivated, be hopeful!
Treatment of PoTS is seldom dependent on medication but an entire lifestyle change.

You may have to adjust your diet, including understanding the important impact of fluid and salt on your symptoms, and alter your activity levels in your daily routine but never forget your goal to return to a quality of life that you can enjoy.



Common symptoms of PoTS

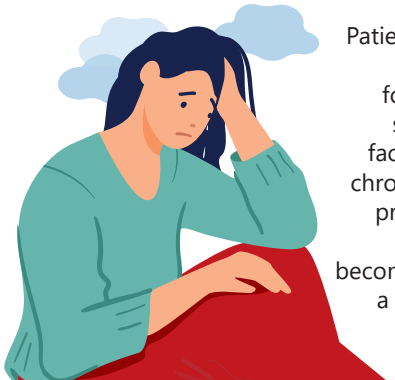


PoTS can manifest symptoms in a variety of ways, including

- light headedness
- fatigue
- brain-fog
- palpitations
- chest pain
- shortness of breath
- anxiety
- sweating
- lack of focus.

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I do not understand brain fog



Patients complain about difficulty in computing information, focusing, communicating, and simply thinking. Contributory factors can be lack of sleep and chronic fatigue, dehydration, and prolonged standing. High fluid intake with salt and avoiding becoming too hot can help, as can a fan in the bedroom or office.