

# STARS

Syncope Trust And Reflex anoxic Seizures®

[www.stars.org.uk](http://www.stars.org.uk)

## Postural Tachycardia Syndrome (PoTS)



Working together with individuals, families and medical professionals to offer support and information on syncope and reflex anoxic seizures

[www.stars.org.uk](http://www.stars.org.uk)

Registered Charity No. 1084898

# Glossary of terms

**Autoimmune disorders** Occur when our immune system produces antibodies against our healthy tissues

**Autonomic nervous system** The part of your nervous system that controls involuntary functions of the body such as the heartbeat and breathing. When something goes wrong it can cause problems with blood pressure control

**Cognitive behavioural therapy (CBT)** A talking treatment directed at the ways you respond and cope with present difficulties

**Joint hypermobility syndrome (JHS)** Sometimes referred to as Ehlers-Danlos type III is often associated with PoTS

**Orthostatic hypotension** An excessive lowering of blood pressure when you assume an erect or partially erect posture

**Orthostatic intolerance** An inability to move to an upright position without experiencing symptoms

**Presyncope** Refers to the symptoms typically preceding a faint

**Tilt table test** An autonomic test used to induce an attack whilst connected to heart and blood pressure monitors

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# What is PoTS?

Postural tachycardia syndrome (PoTS) is an abnormal response by the autonomic (involuntary) nervous system when changing to an upright position/posture. It is defined as a persistent increase in heart rate of over 30 beats per minute (or to higher than 120 beats per minute); (40 bpm in those age 12-19) when standing upright. Typically there is no fall in blood pressure, although fainting (syncope) can occur. The increase in heart rate may be associated with symptoms of orthostatic intolerance (symptoms that are triggered by moving from lying or sitting to standing up). Symptoms can vary and are often made worse by daily activities, e.g. modest physical exertion or eating food. It is a disorder that is gaining increasing recognition by healthcare professionals.

It is acknowledged that those affected by PoTS are mainly between 15 – 40 years when first diagnosed, and predominantly female. The trigger can be linked to infection, trauma, stress or surgery. Unfortunately, PoTS is still not understood by many clinicians. The condition was first described as 'soldier's heart' during the Civil War, and was officially recognised in 1993 by the American Autonomic Society. Misdiagnosis is a frequent occurrence. It is acknowledged that many individuals diagnosed with ME or chronic fatigue syndrome do have PoTS. Psychogenic blackouts and PoTS share similar symptoms which have contributed to misdiagnosis for some individuals.

However, one key factor that points towards PoTS is that symptoms are usually triggered when standing upright rather than in a situation that causes distress or worry.

This booklet is for individuals who have been diagnosed with postural tachycardia syndrome (PoTS). It has been written to provide information on the symptoms, causes and treatment of this condition. It may also be of interest to families, friends and carers of people struggling with the condition.

Patients with PoTS can sometimes be misdiagnosed with other conditions such as stress or anxiety and chronic fatigue syndrome.



# How do I obtain a diagnosis?

The diagnosis is usually made by a cardiologist who is a heart rhythm expert (an electrophysiologist) or in an autonomic centre. Patients may undergo an active stand test or tilt table test to diagnose PoTS (see STARS Diagnostic tests for syncope booklet). Further tests may be necessary to exclude other conditions or diagnose associated conditions.



## Investigations into suspected PoTS

Investigations into suspected PoTS may include:

**Comprehensive blood tests:** These will encompass kidney and liver function, thyroid function, calcium and diabetes tests.

**12 lead electrocardiogram (ECG):** Every patient experiencing unexplained blackouts or a related condition should undergo a resting ECG as it is an important test to help rule out many underlying heart conditions with similar symptoms to PoTS.

**Active stand test:** The patient lies down whilst heart rate and blood pressure readings are taken. Upon standing, further recordings are noted at regular intervals over ten minutes.

**Tilt table test:** If PoTS is suspected, a head-up tilt table test may be requested to help confirm a diagnosis. A tilt table test allows the doctor to observe changes in your pulse and blood pressure when you go from lying down to standing up and remain so for a period of up to 45 minutes. Normally, when an individual stands up, the heart rate increases by up to ten beats per minute. With PoTS, the heart rate is likely to increase by 30 bpm within the first ten minutes.

**Further tests may be necessary to exclude other conditions or diagnose associated conditions.**

# Symptoms

Symptoms of PoTS can be challenging and life-altering, but do not affect life expectancy. They may include:

- Dizziness or light-headedness
- Palpitations (sensation of heart pounding)
- Pooling or discolouration of the legs or feet
- Body temperature regulation issues
- Gut problems e.g. nausea, diarrhoea
- Coldness of hands and feet legs and fingers
- Shortness of breath
- Bladder problems e.g. incontinence, urgency, frequent infections
- Chest pain
- Hyperventilation (very fast breathing) that can further affect the control of blood pressure and increase the risk of fainting and feelings of anxiety
- Fatigue
- Syncope
- 'Brain fog'
- Insomnia
- Blurred vision
- Migrainous headache

## What causes PoTS?

Joint Hypermobility Syndrome (Ehlers-Danlos Syndrome III/hypermobility type III) often co-exists with PoTS. It can also occur in autoimmune disorders, after a significant event (e.g. surgery, accident, vaccination, serious illness) or in association with a viral illness, a growth spurt or pregnancy.

# Classification of PoTS

PoTS is a group of different disorders associated with similar autonomic manifestations. Doctors classify PoTS as 'primary' or 'secondary'. Primary refers to PoTS with no other identifiable medical condition. Secondary refers to PoTS with the presence of another medical condition which is known to cause or be related to PoTS symptoms.

## Primary

- Viral illness (glandular fever)
- Pregnancy
- Sepsis
- Surgery
- Trauma
- Developmental in adolescents (rapid growth spurt)

### Hyperadrenergic PoTS

*Thought to have a genetic link, symptoms may include:*

- Anxiety
- Tremor
- Cold sweaty hands and feet
- Migraine headaches
- Orthostatic hypertension
- Frequent need to pass urine when upright

## Secondary

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

# What help is there?

## Simple self-help measures:

- Hydration (two to three litres orally per day). The patient should have at least one glass or cup of fluids at meal times and on at least two further occasions daily.
- Increase daily salt intake by approximately 6g/1 teaspoon, by adding it to your food or eating salty snacks (only on the advice of your doctor as excessive salt can be harmful to some people).
- Incorporate physical counter-maneuvres before and during the upright posture.
- Avoid any risk factors or triggers for PoTS, e.g. warm environments, prolonged standing, large meals with high carbohydrate content.
- Maintain physical activity as best and as safely as possible to prevent/reduce physical deconditioning.
- Compression tights/sports compression leggings.

## Medication:

Some specialists do recommend medication; this can include drugs to slow the heart rate (beta blockers or ivabradine), increase blood volume (fludrocortisone or desmopressin) or narrow blood vessels (midodrine). Other drugs that are occasionally used include SSRI, modafanil and octreotide.

## Psychological Therapy:

PoTS is not a psychological illness, but long term physical illness can have an effect on mental health and can worsen symptoms and distress. Structured talking therapies such as Cognitive Behavioural Therapy (CBT) can help to improve mood and the ability to adjust and cope. See STARS Cognitive Behavioural Therapy for chronic health conditions booklet.

“With appropriate management, the prognosis of PoTS is favourable, with many patients improving within five years of diagnosis, and 60% returning to their level of function before symptom onset.”

Prof. Christopher Mathias, Postural tachycardia syndrome – current experience and concepts: Nature Reviews, January 2012



## Immediate action to prevent syncope:

The second you feel your usual symptoms coming on:

1. If symptoms are mild or you are unable to sit or lie down, cross your ankles and tense your calf muscles tightly. Combine this movement with buttock clenching to make effects more pronounced (this will help to get the blood pumping around your body and increase your blood pressure thus relieving symptoms). It is also important not to strain while doing this as this might make fainting more likely. Being able to talk while straining can help prevent this.
2. If you are able, sit down immediately or, if possible lie down flat and put your legs in the air - for example against a wall or propped up on pillows and, if you can, it is preferable to do a cycling movement with your legs.
3. Don't try to fight your symptoms; you are not stronger than your blood pressure, and it will win!
4. Get up cautiously when you feel well again. Slowly sit up and gradually stand up.

If symptoms continue, promptly repeat immediate action steps and get something cold to drink.

## Exercise

One of the symptoms of PoTS is exercise intolerance. Patients tend to feel exhausted or unwell during or after quite limited activity, and this can continue for some hours or days afterwards. Some patients, therefore, avoid exercise, becoming increasingly unfit and this can cause PoTS to deteriorate further. However, there is evidence that if regular exercise is undertaken in the correct manner, a patient's symptoms and quality of life can improve.

People who struggle with exercise should start at a very low level of activity, preferably in a horizontal position. This may include pilates, swimming or recumbent (horizontal) exercise biking. Intensity and duration should increase very gradually. PoTS patients can initially feel worse with exercise and should expect that improvement in PoTS symptoms may not occur for many weeks.



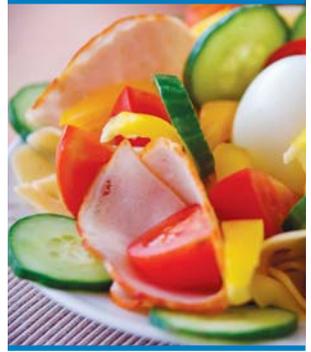
## Autonomic nervous system and low blood pressure

The symptoms of PoTS and orthostatic hypotension can be very similar. In fact a number of people experience both problems at the same time. During a stand test or tilt table test, people with PoTS have an increase in heart rate of 30 beats per minute or more within ten minutes of becoming upright – or to more than 120bpm.

In vasodepressor syncope or presyncope, there is often an increase in heart rate that accompanies the drop in blood pressure. This is called a reactive or reflex tachycardia and can look like PoTS. Treatment for both conditions is similar.

## Healthy eating

Blood pressure and pulse rate can be influenced by what we consume. These changes can be quite dramatic in PoTS, working to the advantage or disadvantage of the patient. Individuals with PoTS find that their symptoms are worse if they eat heavy meals or become hungry. Try to eat little and often i.e. graze all day long. Some foods, especially carbohydrate-rich ones or very spicy or hot foods may make the symptoms worse.



Patients with PoTS are often hypovolaemic. This means that their blood volume is reduced in relation to the capacity of their blood vessels. Blood has a tendency to pool in hands, feet and abdominal (splanchnic) blood vessels. Increased fluid intake can boost blood volume and improve symptoms. Try to keep body weight within normal limits (BMI 18.5 to 25), as low body weight can lower blood pressure and make you prone to fainting. Obesity will increase blood pressure but has other cardiovascular disadvantages.

## Compression tights for PoTS

Compression tights are sometimes recommended for PoTS and orthostatic hypotension because compression of the lower limbs causes an increased blood return to the heart from the superficial veins in the legs. There has not yet been research to prove that compression tights improve symptoms but some patients have reported them to be helpful.

GPs can now prescribe compression tights but not all brands are available on prescription. You can also purchase compression tights from a pharmacy or the internet. For PoTS, the heavy duty and expensive tights are recommended.

However, it is suggested that initially the lighter support tights are tried. If these are not tolerated then the more expensive stronger ones are unlikely to be managed. Compression tights can be harmful for individuals with conditions that reduce the artery blood supply to the legs like diabetes or peripheral vascular disease. It is, therefore, important to consult your doctor before purchasing these garments (although these problems are very rare in younger people). Sports compression clothing can also be helpful and may be more acceptable to wear.

## PoTS during pregnancy

PoTS should not be considered a contraindication to pregnancy nor does the pregnancy need to be managed differently – patients usually deliver normally although may need intravenous fluids during labour to help. However, as many patients take midodrine and other medications with this condition, it is important to discuss with your doctor BEFORE becoming pregnant.



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Please remember this publication provides general guidelines only. Individuals should always discuss their condition with a healthcare professional.

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