

STARS

Syncope Trust And Reflex anoxic Seizures™

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Postural Tachycardia Syndrome (PoTS)



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

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Glossary of terms

Autoimmune disorders occur when our immune system produces antibodies against our healthy tissues.

Autonomic nervous system is 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) is a talking treatment directed at the ways you respond and cope with present difficulties.

Joint hypermobility syndrome (JHS), which is sometimes referred to as Ehlers-Danlos type III is often associated with PoTS.

Orthostatic hypotension is an excessive lowering of blood pressure when you assume an erect or partially erect posture.

Orthostatic intolerance is an inability to move to an upright position without experiencing symptoms.

Presyncope refers to the symptoms typically preceding a faint.

Tilt table test is 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 (see below). 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.

Misdiagnosis is common and patients are often advised that symptoms are “all in their head”. Historically, many patients with PoTS were given a diagnosis of Chronic Fatigue Syndrome/ME, anxiety or panic disorder.

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.

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.

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 and anxiety and chronic fatigue syndrome.



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 legs and fingers
- Bladder problems e.g. incontinence, urgency, frequent infections
- 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
- Shortness of breath
- Migrainous headache
- Chest pain

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.

What help is there?

Non-pharmacological measures:

- Hydration (2-3 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 times daily.
- Increasing 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).
- Incorporating physical counter-manoevres before and during the upright posture, (see Immediate action to prevent syncope).

- Avoiding any risk factors or triggers for PoTS, e.g. warm environments, prolonged standing, large meals with high carbohydrate content.
- Maintaining 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 and 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, adjustment, and ability to cope.

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).
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 10 minutes of becoming upright – or to more than 120bpm. Although the definition says that there is no blood pressure (BP) drop in PoTS, some people with PoTS also drop their BP and, occasionally, heart rate. This is because the abnormalities in the autonomic nervous system that cause PoTS, can also cause a drop in blood pressure. This combination of findings is common in joint hypermobility syndrome and chronic fatigue.

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 the pharmacist or off 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).

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.

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

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Authors: Dr Nicholas P Gall, Consultant Cardiologist, Lesley Kavi, GP and Dr Charlotte D'Souza
STARS medical writer & reviewer

Reviewed by: STARS Medical Advisory Committee

PO Box 175
Stratford upon Avon
Warwickshire
CV37 8YD UK

☎ +44(0)1789 867503
@ info@stars.org.uk
➔ www.stars.org.uk

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