

Postural Tachycardia Syndrome (PoTS)

This information sheet is designed for patients who have been diagnosed with postural tachycardia syndrome (PoTS).

It contains information on the diagnosis, treatment and management of PoTS.



What is PoTS?

Postural tachycardia syndrome (PoTS) is an abnormality of functioning of the autonomic (involuntary) nervous system. It is defined as an increase in heart rate of over 30 beats per minute (40 bpm in those aged 12-19) when standing upright. Typically, there is no postural fall in blood pressure, although fainting (syncope) can occur (see below).

The symptoms can vary but mostly involve orthostatic intolerance (symptoms that develop on standing up and are relieved by lying down) and are often made worse by various daily activities, e.g., modest physical exertion or food. It is a disorder which is slowly being recognised by the medical profession.

PoTS is often underappreciated by physicians, which can impact on the patient's quality of life through misdiagnosis or being informed 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 in PoTS is that symptoms generally occur when standing upright rather than in a situation that causes distress or worry, as in panic disorder.

The diagnosis is based on typical symptom pattern and an active stand test, when heart rate and blood pressure are recorded lying down and then

over several minutes, when standing. A tilt test may also be recommended to exclude other conditions with similar symptoms.

Symptoms

The main symptoms of PoTS include:

- Syncope (fainting)
- Dizziness or light-headedness
- fatigue
- Insomnia
- Palpitations (a sensation of the heart pounding)
- Blurred vision
- Weakness
- venous pooling or discolouration of the ankles or feet
- Chest pain

Potentially related symptoms:

- Loss of concentration
- Migrainous headache
- Fatigue
- Shortness of breath
- Coldness of legs and fingers
- Body temperature regulation issues
- Hyperventilation (very fast breathing) that can further affect the control of blood pressure and increase the risk of fainting and feelings of anxiety

What causes PoTS?

In many cases, the underlying cause is unknown. Sometimes teenagers with PoTS find that their symptoms disappear with age. It is more common in females and can develop during or after pregnancy. Hypermobility spectrum disorder often co-exists with PoTS. It can also occur in autoimmune disorders, following a significant event (surgery, accident, serious illness) or in association with a viral illness or growth spurt.

Management options

Non-pharmacological measures:

- Elastic support stockings. *
- Hydration (2-3 litres orally per day). The patient should have at least one glass or cup of fluids at meal time and at least two at other times each day to obtain 2-3 litres per day.
- Increasing daily salt* intake by approximately 6g/1 teaspoon if your blood pressure is within the normal range and you don't have kidney or heart problems (consult with your doctor before changing your diet).
- Incorporating physical counter-manoevres before and during the upright posture, e.g., calf activation and getting up from lying slowly to reduce the chance of fainting.
- 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.

Medication:

There is currently no licensed medication for the treatment of PoTS, however some specialists may prescribe drugs to try to improve symptoms. These can include drugs to slow the heart rate (beta blockers), increase blood volume or the resistance to blood flow in blood vessels.

Midodrine is well known as a drug that can help sufferers lead a more normal life. Other drugs that are used include *fludrocortisone, beta blockers, *ivabradine, *SSRI/SNRI antidepressants and occasionally octreotide.

Therapy:

Cognitive Behaviour Therapy (CBT) has had some success in helping patients come to terms with PoTS and manage their lives.

*There is currently no evidence to support these treatments, but they are usually recommended by specialists.

If you feel faint or dizzy, take these actions:

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 your symptoms continue, repeat the above steps.

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