Postural Tachycardia Syndrome (PoTS)

Postural tachycardia syndrome (PoTS) is an abnormal response of your body when you are upright (usually when standing). It is caused by a problem with the nervous system which controls the autonomic functions in the body. This part of the nervous system is called the autonomic nervous system.

The symptoms of PoTS occur when you are upright and are relieved when lying down. These symptoms are associated with an abnormally high and persistent increase in heart rate within ten minutes of standing.

Lifestyle adjustments are usually very effective for the treatment of PoTS but some people with PoTS need medication to control the symptoms. The outcome (prognosis) is very good for most people with PoTS but some may have severe long-term difficulties with normal daily activities.

What is the autonomic nervous system?

Your autonomic (involuntary) nervous system controls involuntary actions, such as the beating of your heart and the widening or narrowing of your blood vessels. When something goes wrong in this system, it can cause problems which can affect different functions of your body, including:

- Your blood pressure.
- Your heart rate.
- Your breathing and swallowing.
- Your gut (bowel) and bladder function.

What is postural tachycardia syndrome (PoTS)?

PoTS is not properly understood. It seems that, when standing up, there is an abnormal response by the nervous system which controls the autonomic functions in the body.

When a healthy person stands up, the heart rate increases slightly. This is important to maintain the blood supply to the heart and brain. The normal response to standing is an increased heart rate of only up to 20 beats per minute. In PoTS, this response to standing does not work properly and there is an excessive rise in heart rate. The symptoms of PoTS are associated with an abnormally high and persistent increase in heart rate of 30 beats or more per minute (40 beats or more per minute if under 19 years of age) within ten minutes of standing. The blood pressure does not usually decrease when standing in people who have PoTS.

How common is postural tachycardia syndrome (PoTS)?

It is not known exactly how common PoTS is. It is thought that PoTS is often missed and not diagnosed. Therefore, PoTS is probably more common than we realise.

PoTS is about five times more common in women than in men. It can occur at any age but those aged between 15 and 50 years are most often affected.
What are the causes of postural tachycardia syndrome (PoTS)?

The cause of PoTS is often unknown or may follow after a viral infection. PoTS is often not associated with any other condition. However, PoTS may sometimes be associated with various conditions, including:

- Other causes of problems with the autonomic nervous system - for example, diabetes.
- Ehlers-Danlos syndrome.
- Myalgic encephalomyelitis/chronic fatigue syndrome. PoTS is estimated to affect around one third of people who have chronic fatigue syndrome.
- Autoimmune conditions that have been associated with PoTS include systemic lupus erythematosus (SLE), Sjögren's syndrome and antiphospholipid (Hughes') syndrome.
- Other conditions associated with PoTS include sarcoidosis, multiple sclerosis, alcohol abuse, Lyme disease and cancer.

What are the symptoms of postural tachycardia syndrome (PoTS)?

The symptoms are very variable and range from mild to severe. The symptoms of PoTS occur when you are in the upright position and may include:

- Dizziness.
- Light-headedness or fainting.
- Awareness of your heartbeat (palpitations).
- Headaches.
- Difficulty in thinking, poor concentration and poor memory.
- Poor sleep.
- Tiredness.
- Feeling anxious and shaky.
- Sweating.
- Chest pain.
- Hands and feet may look purplish due to the pooling of blood in the blood vessels.
- Problems with vision.
- Gut (bowel) problems, such as feeling sick (nausea), diarrhoea and tummy pain.
- Bladder problems.

The symptoms of PoTS may be made worse by a variety of situations. Examples include:

- Excessive heat.
- Following a meal.
- Standing up quickly.
- Lacking in fluid in the body (dehydration).
- When you first get up from bed (especially if you have needed prolonged bed rest).
- After drinking alcohol.
- After intense or prolonged exercise.

The symptoms of PoTS may also develop after an illness such as a viral infection or after an operation. Women may find the symptoms are worse during a menstrual period.

How is postural tachycardia syndrome (PoTS) diagnosed?

The symptoms often indicate the diagnosis of PoTS. Your doctor will arrange blood tests to rule out other causes of your symptoms. You will need to be referred to a specialist to confirm the diagnosis. The investigations used to confirm the diagnosis of PoTS or to exclude other conditions may include:

**Active stand test.** You lie flat for a few minutes and your heart rate and blood pressure are recorded. After standing up, further recordings of your heart rate and blood pressure are taken over the following 10 minutes.

**Tilt table test.** You lie flat on a special bed and your heart rate and blood pressure are recorded. The bed is then tilted (head end up) for up to 45 minutes while further recordings of your heart rate and blood pressure are taken.
Both the active stand test and the tilt table test are stopped if you faint or if enough recordings have been made either to confirm or to exclude the diagnosis.

Other tests may include a 12-lead heart tracing (electrocardiogram, or ECG), 24-hour ECG, 24-hour blood pressure monitoring and a heart ultrasound scan (echocardiogram). Other specialist tests will depend on your symptoms and the results of initial investigations.

What are the treatments for postural tachycardia syndrome (PoTS)?

**Lifestyle advice**

General lifestyle changes may be all that are needed to control symptoms. The following are usually effective at helping to reduce the symptoms of PoTS:

- **Drink lots of fluids.** At least 2-3 litres of fluid per day is usually advised.
- **Restrict or avoid drinking alcohol.** Alcohol may make symptoms worse.
- **Caffeinated drinks.** Coffee and other caffeinated drinks may worsen symptoms.
- **Salt.** A diet high in salt may be recommended. Extra salt can be dangerous in some conditions such as high blood pressure, and in kidney and heart disease. Extra salt should therefore only be taken if recommended by your doctor.
- **Eating little and often.** Eating small amounts and often can be helpful. Symptoms can become worse after a large meal.
- **Diet.** Avoid sugary foods and those containing white flour. Eat lots of unprocessed foods such as vegetables, fruit, beans and wholegrain foods.
- **Posture.** The risk of fainting can be reduced by standing up slowly if you have been sitting for a while. Raise the head end of your bed. Avoid prolonged standing or sitting. Elevating legs can also be helpful.
- **Compression stockings.** These should be worn waist-high to help reduce the amount of blood pooling in your legs.
- **Temperature regulation.** Excessive heat worsens symptoms. Wear thin layers of clothes, so that one or two layers can be removed to prevent overheating. A fan or a bottle of water to cool you down can be helpful.
- **Fitness and exercise.** Light to moderate exercise can be very effective to reduce the symptoms of PoTS. However, physical exertion can sometimes initially worsen PoTS; therefore, it is very important to start with light exercise and gradually increase.
- **Psychological support and treatments,** such as cognitive behavioural therapy (CBT), can be useful.
Are there any medications that can be used for postural tachycardia syndrome (PoTS)?

When lifestyle changes are insufficient to control symptoms, one of a range of different medicines may be recommended. All medicines used in PoTS are unlicensed which means that they have not been officially approved for this use. The medicines most often used for PoTS include:

- Fludrocortisone.
- Beta-blockers (may be helpful but may also make symptoms worse).
- Ivabradine.
- Desmopressin.
- Antidepressants called selective serotonin reuptake inhibitors (SSRIs).
- Methyldopa.
- Midodrine.

What is the outcome (prognosis) for postural tachycardia syndrome (PoTS)?

The prognosis is variable and will depend on the nature of any underlying cause. For many people, PoTS will improve with time and often completely resolves. There are other forms of PoTS that are unlikely to go away but can improve through lifestyle changes and, if necessary, medication.

Many patients with long-term symptoms learn to manage the condition and return to a normal or near-normal level of functioning. However, a minority of people with PoTS will have severe symptoms causing them to remain bed-bound or wheelchair-dependent.

Further help & information

**PoTS UK**

Web: www.potsuk.org

**STARS - Syncope Trust and Reflex Anoxic Seizures**

PO Box 175, Stratford-upon-Avon, Warwickshire, CV37 8YD

Tel: (Helpline) 01789 450 564

Web: www.stars.org.uk

**Driver and Vehicle Licensing Agency**

Web: www.gov.uk/driving-medical-conditions

Further reading & references
