

PoTS

(POSTURAL TACHYCARDIA SYNDROME)



This factsheet aims to provide answers to some of the frequently asked questions about **PoTS – Postural Tachycardia Syndrome**.

It explains how PoTS is diagnosed and what it means for you. It also covers the symptoms of PoTS, what we know about its causes, and how to discuss PoTS with your doctor.

What is PoTS?

PoTS is a neurological disorder which is common in many people with long-term health problems, including Long Covid. PoTS stands for:

Postural: the symptoms are related to whether you're standing or sitting.

Tachycardia: increased heart rate

Syndrome: many symptoms which come together. You may have some or all of them.

In PoTS, the autonomic (involuntary) nervous system reacts oddly to a change in posture. This can affect processes throughout the body – how your blood circulates, your heart rate, and even how your gut, eyes, and brain function. Symptoms caused by PoTS can often be relieved by lying down.

What are the symptoms of PoTS?

PoTS has many different symptoms, which affect someone when they stand up. PoTS may present as:

- Dizziness or lightheadedness
- Heart palpitations or a feeling that your heart is racing
- Muscle weakness
- Tremors or shakiness
- Blurred vision
- Fatigue
- Exercise intolerance – finding it hard to do as much exercise as normal

You may also experience other symptoms, including gut problems like constipation or trapped gas.

How is PoTS diagnosed?

PoTS is diagnosed when any of the above symptoms regularly happen when you stand up, and there is no other clear cause for them.

To be diagnosed with PoTS, you have to meet certain criteria:

- Your heart rate consistently rises by 30 beats per minute or more when you stand up, and this lasts for a while
- Your symptoms are clearly responsive to standing up
- Your blood pressure is normal when you stand up, and does not drop sharply

If your blood pressure does drop for a while when you stand up, you may have **orthostatic hypotension**, a condition which causes similar symptoms to PoTS.

You can find out more about living with orthostatic hypotension at www.potsuk.org/managingpots/advice-for-living-with-low-blood-pressure

What tests are there for PoTS?

Stand test: you may be asked to lie flat for a few minutes while your resting heart rate and blood pressure are taken. You will then be asked to stand, and heart rate and blood pressure will be measured for around 10 minutes. This highlights any changes from standing, and tells the doctor how long they last.

Tilt table test: you will be asked to lie flat on a special table with a footplate. Similar to the stand test, your heart rate and blood pressure will be taken while the table is tilted (head up) for up to 45 minutes.

Electrocardiogram (ECG): the electrical activity of the heart is recorded using stickers which can be applied to your chest wall.

Differential tests: these tests will rule out other possible causes of your symptoms, such as anaemia, thyroid problems, or heart abnormalities. They may include:

- blood tests
- echocardiogram or other imaging techniques
- other tests

Do I have anxiety?

PoTS is often **misdiagnosed as anxiety or a panic disorder**, because many of the symptoms of PoTS (such as high heart rate, dizziness, and breathlessness) are also symptoms of clinical anxiety.

If you aren't sure whether your symptoms are caused by anxiety or by PoTS, consider the following questions:

Do my symptoms ever occur when I am sitting or lying down, or are they a response to standing up?

Are my symptoms often present even when I feel quite calm?

Am I usually frightened, uneasy, or panicky when my symptoms hit?

You have the right to question your diagnosis, and if you feel you have been diagnosed incorrectly, you should speak to your doctor about the possibility of further tests.

How do I manage my PoTS?

There are several potential treatments for PoTS. You can try increasing fluid or salt levels, under medical supervision, or using specific exercise regimes to build up your exercise tolerance. Other therapies, like compression garments or immunotherapy, are sometimes used.

If these lifestyle changes are not effective, you may be prescribed a medication, such as beta-blockers, to reduce your symptoms.

However, **if your PoTS was caused by COVID-19 infection**, it's possible that these management techniques may not be helpful – they have been tested mostly in people with slightly different syndromes. As we explore the long-term effects of COVID, the way forwards may start to become clearer.

Advice and support

PoTS UK

Website: www.potsuk.org

Email: support@potsuk.org

A national charity which provides a network for people with PoTS and specialists in the condition.

NHS Inform

Website: www.nhs.uk/conditions/postural-tachycardia-syndrome

Information from the Scottish NHS on recognising, managing, and treating PoTS.

STARS

Website: www.heartrhythmalliance.org/stars/uk

A charity working with people who experience fainting or regular dizziness.