

# POTS

## (POSTURAL TACHYCARDIA SYNDROME)

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### KEY POINTS

- PoTS is characterised by dizziness, light-headedness, heart palpitations, and fatigue, specifically when standing or sitting up.
- PoTS is often misdiagnosed as anxiety, but PoTS occurs at rest and can be differentiated from anxiety by medical testing.
- PoTS is a neurological condition and responds to treatment differently in different people.
- PoTS affects a small number of people in the general population, but among people with Long Covid, almost one in ten have PoTS. It is usually associated with other health issues.
- PoTS can be managed through lifestyle changes, certain medications, or stress management. You can also use certain positions and movements to help relieve symptoms.

# 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.

PoTS can also be expanded to "Postural Orthostatic Tachycardia Syndrome". Orthostatic means "standing up".

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. These symptoms can usually be relieved by lying down.

## Symptoms of PoTS

PoTS has many different symptoms, which affect you when you stand up or change position rapidly. 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.
- Breathlessness.
- Exercise intolerance – finding it hard to do as much exercise as normal.
- Sweating, chills, or other problems with managing your body temperature.
- Difficulty with thinking, memory, or concentration.

You may also experience gut problems, like feeling sick, constipation, or trapped gas/wind.

## Orthostatic intolerance

PoTS is a form of **orthostatic intolerance**, which refers to any symptoms which happen in response to standing up. However, PoTS is not the only form of orthostatic intolerance:

If your blood pressure does drop sharply when you stand up, you may have **orthostatic hypotension**, a condition which is similar to PoTS. However, orthostatic hypotension is caused by blood circulation problems, whereas PoTS is ultimately a problem with the nervous system.

You could also have a condition called **postural syncope** (syncope means fainting) or **acute orthostatic intolerance**, where your heart rate does not rise and there is no heart problem, but you faint or collapse when you stand up. These symptoms usually pass quickly.

## How do I know if I have PoTS?

It is worth asking your doctor, nurse, or other health professional whether you could have PoTS if:

- You regularly feel sick, dizzy, or unsteady on your feet when you stand up suddenly.
- When you stand up, you can feel your heart racing, or are more aware of your heartbeat.
- These symptoms are only present when you are standing up, and start to get better when you sit down or lie down.
- People frequently tell you that you look pale or unwell, but only when you have just stood up.
- Your symptoms are worse when it is very hot or very cold, or when you are tired.

If you menstruate, your symptoms may also be worse when you are having your period.

## Do I have anxiety?

PoTS is often misdiagnosed as an anxiety or panic disorder, since many PoTS symptoms (such as high heart rate, dizziness, and breathlessness) are also symptoms of 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 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 (40 beats per minute if you are aged between 12-19).
- This rise in heart rate lasts more than 30 seconds.
- Your symptoms are clearly responsive to standing up
- Your blood pressure is normal when you stand up, and does not drop sharply.
- You have had these symptoms for at least three months.

If you think you may have PoTS, speak to a GP or nurse practitioner, and ask for them to investigate your symptoms.

## What tests are there for PoTS?

### Stand test:

A stand test means you are 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. These tests may include:

- Blood tests.
- Echocardiogram or other imaging techniques.
- Urine tests.
- Hormonal tests.

# The wider picture

## PoTS and other health conditions

PoTS can exist on its own, but it is often part of a larger picture of symptoms. People with other neurological conditions (such as Long Covid, ME/CFS, connective tissue issues, or a stroke or brain injury) may develop PoTS as a result.

This can make it difficult to recognise PoTS as its own set of symptoms, or even think to ask for a diagnosis. It can seem less important than other symptoms, or you may feel overwhelmed by other medical needs.

Diagnosing PoTS separately from a diagnosis of a condition like Long Covid can have advantages - it allows your PoTS to be treated, and can give you a better framework to understand how to manage those symptoms.

## How common is PoTS?

It is hard to know how many people have PoTS, because many do not get a diagnosis. However, there are several studies which estimate that only around 2 people in every 1,000 are diagnosed with PoTS.

Among people who have Long Covid, though, this number increases to almost 100 people out of every 1,000.

The majority of people who have PoTS are women (9 out of 10 PoTS sufferers) and aged between 15 and 50. It can either come on rapidly, or it can slowly develop over a course of months or years.

## Invisible conditions

PoTS is what is often referred to as an “invisible” condition - a condition with no visible physical signs. People with PoTS do not necessarily “look” disabled to others, and because symptoms come and go, they may not be recognised by the people around them.

It is important to remember that just because people cannot see your health issues, or because you feel well at times, that does not mean you are unaffected. You have the right to speak about your experiences, and to be believed and taken seriously by the health professionals around you.

If you feel that your condition is not being taken seriously, or that your doctor is mistreating you around your condition, you might want to check our factsheet on **Making The Most of a Visit to your Doctor** for more information on your rights as a patient and ways to manage medical stigma.

Living with PoTS and other invisible conditions can take a toll on your mental wellbeing. Speak to your doctor about whether counselling might be available. You can also see our booklet on **Mental Wellbeing** for more information and support.

# Managing 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 helpful.

A high-salt diet can help to increase your blood pressure, provided you drink plenty of water. This means that when your blood pressure drops as a result of PoTS, it causes fewer problems. However, since high blood pressure can cause other health risks (including a higher risk of heart problems or stroke), you should only switch to a high-salt diet if your doctor thinks it is safe.

You might be given **beta-blockers** or **ivabradine**, which work by slowing down your heart rate, reducing the impact of your PoTS.

Other medications you might be recommended include selective serotonin reuptake inhibitors (SSRIs) or steroids. You could be prescribed **fludrocortisone** or **midodrine**, which narrow your blood vessels and increase the volume of blood in your body, raising your blood pressure.

Stress can make PoTS worse, so it is important to take any steps you can to relax and address stress in your life.

When you are experiencing faintness or dizziness as a result of PoTS, lying down with your legs raised higher than your head can help to improve blood flow. If you cannot lie down, try the following:

- Rock back and forwards on your toes.
- Clench and unclench your fists. Flex the muscles in your belly and buttocks.
- Cross one leg in front of the other while you are standing up.

## Help and support

### PoTS UK

Web: [www.potsuk.org](http://www.potsuk.org)

Email: [support@potsuk.org](mailto:support@potsuk.org)

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

### STARS

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

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

### NHS Inform

Web: [www.nhsinform.scot/long-covid/postural-orthostatic-tachycardia-syndrome-pots](http://www.nhsinform.scot/long-covid/postural-orthostatic-tachycardia-syndrome-pots)

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

### NHS UK

Web: [www.nhs.uk/conditions/postural-tachycardia-syndrome](http://www.nhs.uk/conditions/postural-tachycardia-syndrome)

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

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## Chest Heart & Stroke Scotland

2nd Floor, Hobart House  
80 Hanover Street  
Edinburgh EH2 1EL  
Tel: 0131 225 6963

Scottish Charity Number: SC018761  
Limited company number: SC129114

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