

# Information Booklet



## Postural Tachycardia Syndrome



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\* The star symbol used throughout this booklet indicates that there is no research evidence to support a statement. The statement is based on patient experience or agreed by experts.

# Glossary

**Antibody** is a protein produced to counteract foreign substances in the body.

**Antiphospholipid syndrome** (previously called Hughes Syndrome) is an autoimmune condition that can cause sticky blood resulting in stroke, vein thrombosis (blood clot) or miscarriage.

**Autoimmune disorders** occur when our immune system produces antibodies against our body's own tissues.

**Autonomic nervous system** is the involuntary nervous system that controls bodily functions that we do not have to think about. It is important in 'fight and flight' and 'rest and digest' responses.

**EEG** is an electroencephalogram, a test that records electrical activity of the brain.

**Electrophysiologist** is a cardiology doctor with special expertise in managing heart rhythm problems.

**Epinephrine and norepinephrine** are also called adrenaline and noradrenaline and are **catecholamines**, chemicals that are released into the bloodstream in stressful, 'flight or fight' situations.

**Mast cells** are part of the immune system and are involved in allergic and inflammatory responses.

**MRI scan** is magnetic resonance imaging.

**Orthostatic intolerance** means symptoms that develop in the upright position that are relieved by lying down.

**Phaeochromocytoma** is a catecholamine-producing tumour that is usually not cancerous.

**Pooling** is dropping of blood with gravity into abdominal cavity and limbs.

**Sjögren's syndrome** is an autoimmune condition that causes a number of symptoms including dry mouth and eyes, joint pains and fatigue.

**Syncope** is brief loss of consciousness due to altered blood supply to the brain.

**Tilt table test** is an autonomic test used to induce an attack or episode whilst connected to heart and blood pressure monitors.

# What is Postural Tachycardia Syndrome (PoTS)?

**Postural tachycardia syndrome is an abnormal response by the autonomic (involuntary) nervous system to standing up. To be diagnosed with PoTS, an individual must experience the following:**

- 1** A group of symptoms that occur frequently in an upright position (usually standing) and are relieved by lying down.
- 2** Persistent increase in heart rate of 30 beats per minute or more on standing (40 beats per minute if 12-19 years).
- 3** Symptoms should have lasted more than 3 months

♥ Some symptoms of PoTS are similar to those experienced by people with abnormally low blood pressure (BP), but blood pressure does not necessarily drop in PoTS.

♥ PoTS can develop in association with a number of different diseases or situations. The reason for this is not properly understood but it is possible that there is a malfunction of the nervous system that controls autonomic functions in the body.

♥ When a healthy person stands up, to avoid blood dropping down into the limbs and abdominal cavity, blood vessels contract immediately and heart rate increases slightly to maintain blood supply to the heart and brain. In PoTS, this automatic adjustment to standing does not work correctly, resulting in an excessive rise in heart rate, increased epinephrine in the blood and altered blood flow to the brain.

♥ PoTS is more common in girls and younger women, but can also occur in boys and men.

# What are the symptoms of Postural Tachycardia Syndrome (PoTS)?

**Individuals with PoTS experience 'orthostatic intolerance' which means that they mostly experience symptoms on moving to an upright position. Symptoms can be debilitating, ranging from mild to severe and varying from day to day.**

**Hyperadrenergic features can include tremulousness, a sense of anxiety, migraine and chest pain.**

## Symptoms of PoTS

- ♥ Dizziness or pre-syncope (almost fainting)
- ♥ Palpitation (awareness of heart beat)
- ♥ Fatigue
- ♥ Headaches – orthostatic headaches (due to upright posture)/migraine
- ♥ Brain fog (difficulty in thinking)
- ♥ Sense of anxiety
- ♥ Syncope (fainting)
- ♥ Shakiness
- ♥ Visual problems (greying, tunnel or glare)
- ♥ Gut problems (including nausea, diarrhoea, pain)
- ♥ Sweating
- ♥ Chest pain
- ♥ Poor sleep
- ♥ Purplish discolouration of skin due to blood pooling in hands and feet
- ♥ Bladder problems

## Triggers that can worsen PoTS

- ♥ Excess heat
- ♥ Eating – especially refined carbohydrate (e.g. sugar, white flour)
- ♥ Standing up quickly
- ♥ Dehydration
- ♥ Time of day (especially rising after wakening)
- ♥ Menstrual period
- ♥ Deconditioning (lack of fitness) or prolonged bed rest
- ♥ Alcohol (as it dilates blood vessels)
- ♥ Inappropriately excessive exercise
- ♥ Temporarily during illness such as viral infections or after operations\*

# How is PoTS diagnosed?

If PoTS is suspected, an active stand test (also known as a NASA lean test) should be arranged.

♥ **Active stand test** The patient rests flat for a few minutes and heart rate and BP are recorded whilst lying. After standing up, further recordings are taken over 10 minutes.

If the diagnosis is not clear some patients are referred to a specialist for a **tilt table test**. This may be arranged by an electrophysiologist (a heart rhythm expert), neurologist or other hospital physician. These specialists are often found in blackout or syncope clinics, although only a minority of people with PoTS experience blackouts.

♥ **Tilt table test** The patient rests flat on a special bed with a footplate whilst BP and heart rate recordings are made. The bed is then tilted (head end up) for up to 45 minutes while further recordings are taken. (Stand and tilt tests are stopped earlier if the patient faints or if satisfactory recordings have been made).

The following tests are mostly used to rule out other conditions and may not all be necessary in every patient:

♥ **12-lead electrocardiogram (ECG)** Electrical activity of the heart is recorded through little stickers on the chest wall

♥ **24 hour ECG** Similar to above, but the stickers are left on for 24 hours and results are recorded on a small portable machine as the patient undertakes normal daily activities.

♥ **24 hour blood pressure monitoring** A small machine is worn continuously and takes intermittent recordings as the patient undertakes normal daily activities.

♥ **Blood tests** These may include full blood count, kidney and liver function, thyroid function, calcium, diabetes tests, lying and standing norepinephrine levels.

♥ **Echocardiogram (cardiac echo)** A simple test where the structure of the heart is visualised through jelly on the chest wall. It is quick and painless and rules out structural heart abnormalities.

♥ **Exercise Test** The patient exercises in a laboratory and heart rate, blood pressure and ECG recordings may be made during and after the test.

**The following tests are more likely to be used in autonomic or PoTS clinics:**

♥ **Autonomic screening tests**

♥ **Thermoregulatory sweat test**

## Misdiagnosis

**PoTS was first recognised by medical journals in 1993, but many medical professionals are still unaware of the condition today.**

Obtaining the right diagnosis can therefore be a lengthy and frustrating process. Meanwhile, patients are commonly misdiagnosed with other conditions such as anxiety and depression, reflex syncope (vasovagal syncope) and chronic fatigue syndrome.

If you think you could have PoTS, it may help to share this booklet with your GP.

In complex cases it may be necessary to obtain a referral to a specialist with an interest in PoTS. There is a list of such doctors and nurses on the PoTS UK website at [www.potsuk.org/specialists/](http://www.potsuk.org/specialists/)

## What causes PoTS?

♥ There are a number of factors and disorders causing or associated with the condition but in some cases a cause is never identified.

♥ PoTS can follow a viral illness such as glandular fever or COVID 19 infection, or be linked to pregnancy or a traumatic event.

♥ Sometimes teenagers are affected after a rapid growth spurt although many will improve within a few years.

♥ Some patients develop PoTS-like symptoms due to lack of fitness and the heart pumping inefficiently after being confined to bed for some time.

# Conditions associated with PoTS

## Hypermobile Spectrum Disorder and Hypermobile Ehlers-Danlos Syndrome

Hypermobile (excessively flexible) joints can be a normal finding in some people and even an advantage in sport and dance. However, in some people it is part of a hypermobility spectrum disorder and hypermobile EDS, a spectrum of inherited conditions that is associated with other problems including painful joints, dislocating joints, abnormal skin (stretchy soft skin, stretch marks and wide scars), allergies, gut problems, bladder problems, and abnormal functioning of autonomic nervous system including PoTS.

There is more information about hypermobility and EDS on the websites below:

[www.ehlers-danlos.org](http://www.ehlers-danlos.org)   [www.hypermobility.org](http://www.hypermobility.org)

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## Low blood pressure

Low blood pressure can be healthy, but if it drops very low on standing it is called orthostatic hypotension and can cause symptoms similar to PoTS. Reflex syncope occurs when a drop in blood pressure results in fainting.

PoTS, low blood pressure and reflex syncope can exist together in the same patient and this combination can be seen in hypermobility spectrum disorder / hypermobile EDS and chronic fatigue syndrome. When blood pressure drops there is sometimes an increase in heart rate. This is called a **reactive tachycardia** and can look like PoTS. Treatments for PoTS and low blood pressure are similar.

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## Chronic Fatigue Syndrome (CFS)

PoTS may be underdiagnosed in those with chronic fatigue syndrome and is estimated to affect up to one third of people with CFS.

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## Mast Cell Activation Disorder

This needs to be considered if flushing or allergies are prominent.

## **Inappropriate Sinus Tachycardia (IST)**

IST has similar symptoms to hyperadrenergic PoTS, but the high heart rate may be higher when lying down (around 90–100bpm) and rapidly accelerates with exertion or stress.

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## **Autoimmune conditions**

Recent research has shown that autoantibodies affecting the autonomic nervous system are more common in people with PoTS.

Autoimmune conditions that have been associated with PoTS include Sjögren's syndrome and antiphospholipid syndrome. Treatment of underlying autoimmune conditions can improve symptoms of PoTS.

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## **Abnormally functioning genes**

There is new evidence emerging of an abnormality in the gene that regulates epinephrine in the body.

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# What can I do to improve my condition?

**For some, lifestyle changes may be all that is needed to control symptoms.**

## Fluids

**Patients with PoTS often have a low blood volume and this can be increased with extra fluids.**

♥ At least 3 litres per day is usually advised in adults.

♥ Children should drink sufficient fluids for their urine to become pale straw coloured.

♥ As symptoms can be worse in the morning, it may help to boost fluids before getting out of bed. In an emergency, drinking 2 glasses of water



quickly can rapidly elevate blood pressure and lower heart rate.

♥ Intravenous fluids have been used, but may cause serious complications with regular use.

♥ Alcohol dilates blood vessels and may make symptoms worse.

♥ Coffee and other caffeinated drinks may also worsen symptoms, although some find them helpful.

## Food and salt

**A high salt diet of up to 2 teaspoons per day in adults may be recommended (less in children).**

♥ Extra salt can be dangerous in some conditions such as high blood pressure, kidney and heart disease, and therefore should only be taken if recommended by your doctor.

♥ Salt tablets can also be prescribed.

♥ Slow Sodium tablets are available in the UK on prescription and are coated to reduce nausea. (6g salt = one teaspoon = 10 Slow Sodium tablets).



♥ Eating small amounts and often can be helpful.

♥ Symptoms can worsen after a large meal as blood is diverted to the digestive tract and away from other areas.

♥ Some people may find refined carbohydrates aggravate symptoms.

♥ Avoid rich sugary foods and those containing white flour.

♥ Eat lots of unprocessed foods such as vegetables, fruit, beans and foods that contain whole grain.



## Posture

**To avoid fainting or near fainting:**

♥ Take notice of early warning signs such as light-headedness, dizziness, and nausea

♥ Lie down immediately and, if possible, elevate your legs

### **If your circumstances make this difficult:**

- ♥ Cross your legs while standing or rock up and down on your toes
- ♥ Clench your buttocks and abdominal muscles
- ♥ Clench your fists

### **The risk of fainting can also be minimised by:**

- ♥ Standing up slowly if you have been sitting for a while

♥ Avoiding prolonged standing. Fidgeting can be helpful\*

♥ Avoiding having your hands over your head for any length of time

♥ Avoiding prolonged sitting, which can cause symptoms in some people.\* Elevating legs when seated can be helpful.

## **Compression tights**

Compression tights should be waist high and give at least 30mmHg of pressure at the ankle (Grade II compression) in order to help reduce the amount of blood pooling in the legs. Compression socks or sports compression clothing may also help.\*

## **Temperature regulation**

**Heat worsens symptoms and so many people find their symptoms are worse during the summer.**

♥ Dress in layers of clothes, so layers can be removed to prevent overheating.

♥ Salt and fluid intake should be increased if you feel hot or sweat more.

♥ A spray bottle of water for your face and neck will cool you down as the water evaporates from your skin.

♥ A fan or air conditioning can be helpful.

♥ Some people use cooling vests.

## **Fitness**

**Light to moderate exercise can improve symptoms in PoTS in some cases. However, some patients experience significant and prolonged debility after exercise and expert guidance may be needed to plan a rehabilitation programme.**

♥ Increasing leg strength and core (central) muscles helps to pump blood back to the heart.

♥ Begin with recumbent (sitting or lying down) exercise if you are starting for the first time.

♥ Gradually increase duration and intensity.

♥ Upright exercise can be added after 2–3 months of recumbent exercise. Factor in recovery time afterwards.

Suitable exercise may include:

♥ Swimming

♥ Rowing

♥ Walking

♥ Recumbent biking, progressing on to upright biking

♥ Pilates – mostly horizontal exercise focusing on core strength\*

♥ Lower limb resistance training



## Sleep

### PoTS patients often have poor quality sleep.

Potential causes of sleep disturbance need to be identified such as underlying pain, anxiety or depression.

## Pacing

- ♥ Symptoms tend to be worse in the morning so it may be best to plan activities for later in the day.
- ♥ Set yourself achievable goals and avoid rushing.
- ♥ Plan time for rest.
- ♥ Live within your body's limits – it will tell you if you have done too much.

## Hygiene

- ♥ Drink a glass of fluid before and after showering.
- ♥ Avoid taking a hot or long shower or bath as this dilates your blood vessels and can make symptoms worse. Finishing your shower with cool water may help.
- ♥ Sit on a stool by the basin and in the shower.
- ♥ Dry shampoo spray and wet wipes may be an option on a bad day!

## Psychological support

### Having PoTS can mean that a previously active person will need to make significant lifestyle changes.

Psychological support can help you to find optimal ways to look after your mental and physical needs, getting you in the best shape to manage your condition most effectively.

PoTS symptoms (e.g. racing heart, chest pain and dizziness) are very real and can be frightening; it can be helpful to learn to prevent any anxious responses that may cause these symptoms to worsen.

**Cognitive behavioural therapy (CBT)** is a structured talking therapy that can help you work towards accepting your limitations, adjusting to the unpredictability of chronic illness, and helping you pace yourself to achieve the challenges of daily-living whilst still maintaining activities which most help you feel positive and fulfilled.



## Travel

**Driving** – By law you must tell the DVLA of any health condition that may affect your ability to drive. Failure to do so could lead to prosecution and invalidate your insurance.

Problems that you should consider reporting include palpitations, fainting and dizziness. You should ask

your GP or specialist if you need to inform the DVLA. It does not always mean that you will be stopped from driving.

There is further information about medical fitness to drive and the Blue Badge Scheme on this website:

[www.gov.uk/health-conditions-and-driving](http://www.gov.uk/health-conditions-and-driving)

## Flying

- ♥ Drink more fluid than normal.
- ♥ You can take an empty drinks bottle through security and ask the flight attendants to fill it on the plane.
- ♥ Avoid alcohol and wear compression tights/socks.
- ♥ Elevate your legs when possible and keep mobile to prevent pooling.
- ♥ Remember to take medication in your hand luggage in case there are problems with lost luggage.
- ♥ Advise your travel insurer about your condition to ensure you are fully covered.

# Education & Work

**Some people with PoTS require additional support.** In school, the Special Educational Needs Co-ordinator (SENCO) can help. Colleges and universities have a disability adviser whose team can provide extra support for students.

If you are struggling to meet deadlines or are unfit to sit examinations, inform your tutor or head of department immediately. A medical report may be required, so see your doctor as soon as possible as they cannot write a report unless they have seen you at the time.

Larger employers have access to an occupational health department that will provide advice to your employer regarding adjustments that may be necessary to allow you to work to your full potential.

Smaller employers will not usually have this facility. Provide as much relevant information to your managers as is necessary so they can understand any difficulties you may be facing.

**Further information is available on [www.dwp.gov.uk](http://www.dwp.gov.uk)**

## TOP TIPS FOR STUDYING OR WORKING\*

- ♥ Eat and drink regularly.
- ♥ Working or studying with your feet elevated may help avoid brain fog.
- ♥ Don't sit too long in one position. Move around or fidget.
- ♥ Keep cool – physically and mentally!
- ♥ Keep as fit as you can – consider swimming or pilates.
- ♥ If you cannot meet deadlines, tell your teachers or employer as soon as possible.
- ♥ Keep everyone informed – providing a copy of this booklet may be helpful.

# Do medicines help?

**When these lifestyle changes are insufficient to control symptoms, medication may be recommended.**

All medicines used in PoTS are unlicensed which means that they have not been officially approved for this use. Although GPs may prescribe some medications, some have to be initiated and monitored by a specialist.

## Medicines more commonly used include:

Beta blockers e.g. Propranolol  
Midodrine

Fludrocortisone  
Ivabradine

Desmopressin  
Pyridostigmine

Clonidine  
Methyldopa

# PoTS & Pregnancy

**Pregnancy can be a rewarding experience, even for those severely affected by PoTS. Some women experience an improvement in symptoms during this time, but for others there can be a deterioration, especially in early pregnancy if nausea or vomiting cause dehydration.**

To ensure the best possible outcome for mum and baby, speak to your doctor BEFORE becoming pregnant. The effects on the unborn baby of many medicines are unknown, and some medications such as ivabradine are thought to be harmful. Some women choose to stop medication before conceiving – ask your doctor first.

The benefits of staying on medication versus the consequences of stopping need to be discussed with someone who is knowledgeable about PoTS and its treatment and effects of the medications during pregnancy.

- ♥ The majority of women have a normal delivery and a healthy baby.
- ♥ Caesarean section and epidurals are also safe in women with PoTS.
- ♥ It is important to maintain fluid intake during labour and an intravenous infusion may be helpful.
- ♥ Medication containing epinephrine should be avoided.
- ♥ It is helpful to ensure that your obstetrician and anaesthetist have some knowledge of PoTS and this booklet may be useful to them.
- ♥ If you feel too unwell or are taking large amounts of medicines, it may be sensible to delay becoming pregnant.
- ♥ Ask your GP or practice nurse about contraception.
- ♥ There is a more detailed leaflet and a list of medical journal papers on the PoTS UK website that may help your anaesthetist or obstetrician to obtain further information.

# What will the future look like for me?

**For many, PoTS will improve with time and in some individuals it will disappear altogether. There are some forms of PoTS that are unlikely to go away but can improve through lifestyle changes and, if necessary, medication.**

The majority of patients learn to manage the condition and return to something close to their previous level of functioning. Whilst many of the symptoms like a racing heart, dizziness or chest pain can be frightening before you understand their origin, they do NOT cause physical harm when caused by PoTS. Support from a good and well-informed healthcare professional and from patient support groups can help enormously.

It can be very hard work making all the necessary life-changes to live with PoTS. It can help to know that after making these changes and adjusting to what they cannot do, whilst focusing on actively engaging in what they can, many patients with PoTS report enjoying happy and fulfilling lives.

As with many long-term health conditions, although we would never wish them upon ourselves or others, a positive consequence can be a new appreciation for the things that really do matter to us, and an opportunity to re-establish priorities, living life thereafter to our full potential.

## Medical Disclaimer

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

## Sources of Evidence

Details regarding the sources of evidence used in the production of this booklet are available on the PoTS UK website. See [www.potsuk.org/sources\\_of\\_evidence](http://www.potsuk.org/sources_of_evidence)

## Further Information

There is more detailed information about all the topics discussed in this booklet on the PoTS UK website [www.potsuk.org](http://www.potsuk.org)

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## Our Mission, Vision & Values



PoTS UK supports and educates patients, family, friends and healthcare professionals within the United Kingdom about this under recognised and commonly misdiagnosed condition by sharing up to date evidence and resources.

We work with healthcare professionals and other charities in the UK and abroad, and advocate for our members by seeking better NHS services, more research, and targeted treatments for people with PoTS. We aim to connect patients in a safe environment to empower them to self-manage their condition and reduce isolation. We produce evidence-based educational content for healthcare professionals which will improve awareness of PoTS, diagnosis and management, and improve health services for patients.

### Our Mission:

♥ To provide accessible evidence informed support, education and awareness for our growing community.

### Our Vision:

♥ To optimise the health and quality of life of everyone impacted by PoTS.

**Our Values:** We are committed to supporting the PoTS community by:

- ♥ Ensuring PoTS is universally known.
- ♥ Promoting fair and equitable access to healthcare.
- ♥ Facilitating ongoing advancement of our understanding of the condition and its management.
- ♥ Providing trusted and evidenced informed resources.
- ♥ Challenging ourselves to be more inclusive, sustainable, and connected.
- ♥ Leading the change for a compassionate and open mindset.
- ♥ Collaborating with others who share our ambitions.

PoTS UK endeavours to produce high quality evidence-based information.

PoTS UK has met the requirements of the PIF Tick quality mark for health care information.



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