



# What is PoTS?

**Postural Tachycardia Syndrome (PoTS) can be a life altering and debilitating chronic health condition.**

Simply standing up can be a challenge for people with PoTS as their body is unable to adjust to gravity. This is due to a dysfunction of the autonomic nervous system. Symptoms include headaches, fatigue, palpitations, sweating, nausea, fainting and dizziness. This is associated with a persistent increase in heart rate on standing of greater than 30 beats per minute.

A diagnosis of PoTS can be life changing. Often sufferers are left unable to work full time or attend school on a regular basis. Some have to give up work altogether and become isolated by their condition. In severe cases, the patient will require a wheelchair to mobilise or become bed bound due to their symptoms.

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## Who we are

We are a small team of five trustees and two members of staff, who are supported by a number of medical advisors and our wonderful volunteers.

[Please click here to read about us](#)

# 10 Things you need to know about PoTS

- 1** **Postural tachycardia syndrome (PoTS) is an abnormal response by the autonomic nervous system to upright posture.** On standing up, patients experience multiple symptoms that include rapid palpitations, chest pains, light-headedness, blackouts, nausea, fatigue, difficulty thinking, gut problems, headaches, tremulousness, sleep abnormalities, and more!
- 2** **Disability caused by PoTS is severe** - equivalent to Congestive Heart Failure and Chronic Obstructive Pulmonary Disease (conditions that usually affect older people).
- 3** **PoTS can occur at any age but the most common age for PoTS to develop is in young adulthood.** 50% of patients are unable to attend work or school. The costs are enormous, both economically to the country and personally to sufferers and their families, given that many educational and career opportunities at this critical stage are irrecoverably lost.
- 4** **PoTS is often misdiagnosed.** Mean time to diagnosis in the UK from symptom onset is 7 years.
- 5** **PoTS is caused by or associated other conditions** including Covid-19 infection, chronic fatigue syndrome and autoimmune conditions. Anecdotally, it may be triggered by trauma or pregnancy.
- 6** **Up to 85% of POTS patients are told that their symptoms are “all in their head”** and given psychiatric labels of anxiety and depression, but research shows that PoTS patients are no more likely to have psychiatric disorders than the rest of the population.
- 7** **Many healthcare professionals are not aware of PoTS** yet it is estimated to affect 0.2% of the population.
- 8** **Many patients are denied access to NHS specialists and treatments.** Management is often complex and requires an informed physician. Some regions of the UK have no specialists and services in large centres (often in London) are overwhelmed with referrals. Children are especially affected by poor NHS healthcare provision for PoTS.
- 9** **Over 90% of patients will respond to treatment,** thus heightening the tragedy of delays in diagnosis and treatment. As it affects so many body systems, a multidisciplinary approach is recommended, but there is no such service available in the NHS for UK patients.
- 10** **What does PoTS UK seek to achieve?**
  - Ensure that PoTS patients have equitable access to healthcare
  - Raise awareness amongst healthcare professionals and the general public
  - Support research into causes of PoTS, impact on patients and effective treatments

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# PoTS Awareness Day

## 25th October

Our very first awareness day back in 2019 was a spectacular success and continues to go from strength to strength. The last five years have seen a growing number of iconic landmarks and buildings 'Lighting Up in Purple' across the UK.

October is Dysautonomia Awareness Month and we make sure it is 31-days jam packed with awareness raising ideas to get involved with!

Last year, with the support of many iconic landmarks and organisations, we saw over 60 buildings, monuments, bridges, piers, cathedrals and churches light up in purple across the UK.

Please help us spread the word that October 25th is our day!

[Click here for  
more information](#)

Throughout October we raise awareness on our social media platforms using the tag @potsuk and the hash tags #PoTSUK #TakeAStandForPoTS #PoTSAwarenessDay #LightingUpinPurpleforPoTSUK

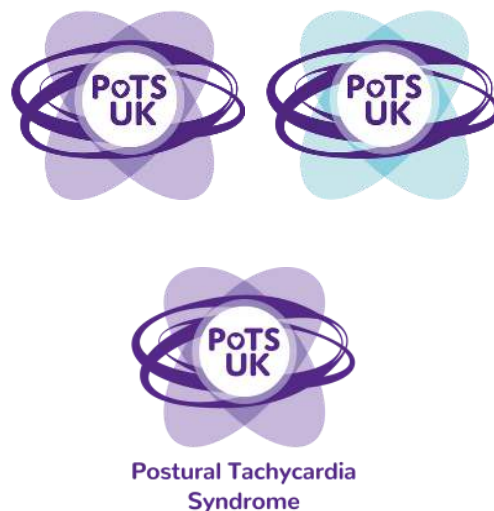
We hope that you will be able to help us raise awareness.

Please contact us  
[admin@potsuk.org](mailto:admin@potsuk.org)

# Help Raise Awareness with our PoTS UK Resources

Please right click on the images to download our posters and logos in a new tab.

(If you prefer you can then right click to copy the image)



We have a range of email and social media banners which can be downloaded from our [website](#).

## How to donate to PoTS UK

We are always extremely grateful for any donations made to PoTS UK and our [website](#) lists the various methods on how to do this.

Please also share our donation QR code.

