



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.

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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 complex often 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.

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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