



PoTS Fact Sheet

Prevalence

Estimated 1 in 600 people pre COVID - more common since COVID-19 pandemic.

Disability

- Health related quality of life is worse than people living with diabetes, HIV, cancer, cardiovascular disease, kidney disease, COPD
- PoTS patients present with multiple symptoms, most commonly including light-headedness (99%), tachycardia (97%), presyncope (94%), headache (94%) and difficulty concentrating (94%) (5)
- 37% are unable to work due to PoTS (2)
- 28% have reduced working hours due to PoTS (2)
- Half of patients develop symptoms in adolescence (5)
- 50% of children are unable to attend school for over 3 months and 16% are unable to attend school long-term (2)

Access to Healthcare

- Average of 7 years to obtain a diagnosis (1)
- 58% of people are misdiagnosed with a psychiatric condition – this occurs more often in women compared to men (1)
- Despite affecting approximately 1 in 700 people, there are no care pathways in the UK for PoTS, and no national guidelines (4)
- About a quarter of patients were told that PoTS does not exist by a healthcare professional
- Overall, 60% of patients in Scotland with PoTS had to seek private medical care

Use of NHS Resources

- Patients visited a doctor (GP) or specialist to discuss their PoTS symptoms an average of 10 times in the year before their diagnosis (1)
- After receiving treatment, there were some reductions in the percentage of participants that utilised hospital outpatients, A&E, ambulance and GP (1)
- On average participants travelled 90 miles (return) to see the healthcare professional who diagnosed their PoTS

Social Impact

- 41% of affected people face financial difficulties due to PoTS (2)
- Ability to work improved for many after receiving the diagnosis, but did not improve for most until after they received treatment (1)

References

1. PoTS survey of over 2000 patients 2023, (not yet published)
2. Kavi et al, BJ Cardiol 2017
3. Seeley et al, Clinical Autonomic research, 2023
4. FOI requests to all acute commissioning bodies and trusts in the UK
5. Shaw et al, JIM, 2019