Postural Tachycardia Syndrome (PoTS)

Summary of key issues:

- PoTS is a common, complex, disabling condition affecting both adults and children.
- Despite this, there are no specialist services available in Scotland. The only specialist service was in Inverness – it was closed in 2024.
- Healthcare professionals lack guidance on recognition and appropriate management of PoTS – there are no national SIGN guidelines.
- Health Boards and hospitals impose significant barriers to patients accessing secondary care services when needed.
- Affected people have inequitable access to healthcare with exceptionally long delays to diagnosis and limited or non-existent access to treatments.

The Condition

Postural Tachycardia Syndrome (PoTS) is an autonomic nervous system abnormality where sitting, standing and exercise can cause symptoms including shortness of breath, chest pain, brain fog, dizziness, blackouts, pain, fainting, vomiting and fatigue. Many people suffer a combination of fluctuating symptoms, which can be chronic and debilitating, and, in some cases, leaves people housebound or bedridden.

Health related quality of life is worse in PoTS than in diabetes mellitus, neoplasms, cardiovascular disease, chronic obstructive pulmonary disease, human immunodeficiency virus infection, and chronic kidney disease (Seeley et al, 2023).

Most affected people have associated co-morbidities such as Ehlers-Danlos Syndrome, ME/CFS, MCAS, autoimmune conditions and Long Covid which further compounds their disability. It was estimated that there were over 9000 people in Scotland living with PoTS before the COVID-19 pandemic. As 7% of people with Long COVID have PoTS this number is likely to have doubled.

Access to Healthcare

Patients commonly see multiple care providers due to fragmented care and limited healthcare professional knowledge; the average diagnosis time is 7 years. The majority of those impacted are younger women and children. A 2025 PoTS UK survey shows the reality for PoTS patients in Scotland:

- 90% of respondents had difficulty accessing healthcare (compared to 85% in England).
- 41% of patients said their GP does not know how to manage PoTS.
- 59% said their GP has not heard and/or does not believe in PoTS.
- 41% were misdiagnosed with a mental health diagnosis.
- 50% sought private healthcare for diagnosis or management of their PoTS.
- 14% had to travel to England to obtain healthcare.
- 46% attended A&E due to PoTS, with some describing hundreds of visits.

Many GP referrals are rejected by secondary care providers. Reasons include:

1. We do not commission a service for PoTS patients.
2. Our service is currently overwhelmed.
3. PoTS is not a cardiology problem (despite presenting with cardiology symptoms and requiring cardiology tests and medications).
4. PoTS patients do not need a referral to secondary care/ patients only need secondary care support if they faint
5. PoTS is too complex and requires tertiary centre referral outside our region.
6. There are no national guidelines.

Freedom of Information requests

Freedom of Information Requests were circulated to all NHS commissioning organisations and acute trusts in England, Wales, Scotland and Northern Ireland. They reported that there are no established care pathways or formally commissioned services in place for people diagnosed with PoTS. There is limited specialist service provision available to patients with PoTS (21 trusts) across England, and no service provision generally available in Scotland, Wales and Northern Ireland, which is extraordinary for such a common, complex and disabling condition. Service provision for children is especially poor.

Socioeconomic Impact

People affected by PoTS want to attend school, university or work, and participate in society. Lack of NHS healthcare denies them these opportunities and the social and economic costs to the individual and the Scottish Government are profound.

In Scotland:

- 62% of under 18s with PoTS have lost over 3 months of school.
- 38% of under 18s with PoTS are completely unable to attend school.
- 31% of 19-24 year olds with PoTS dropped out of university or college.
- 38% of 25-50 year olds have lost their jobs due to PoTS.
- 33% of 25-50 years olds reduced their working hours due to PoTS.

Scotland Patient Voices:

"I can barely cope anymore. No one in my area listens, wants to take this on, or can help."

"I have had lifelong PoTS which became more severe after 5 bouts of Covid thanks to being a teacher. I now have no employment prospects and had no sick pay. I have two disabled children that I am the sole carer for. The lack of support is very damaging for my mental health. There are NO support services or specialists available. I am alone and scared."

Recommendations

- Development of national guidelines (eg SIGN) for PoTS and related disorders.
- Ensure every region of Scotland has a service adequately resourced with clinicians, specialist nurses, secretarial support, specialist physios, OT, dieticians, and clinical psychologists. Provide access to necessary equipment and estates/clinic space to properly assess and safely diagnose and manage patients.
- Include PoTS training in junior doctor specialty training to ensure education and the future continuation of appropriate services.
- Provide opportunites for training for GPs.
- Require that every Health Board develops a care pathway for PoTS in association with experts and patients/stakeholders.

PoTS UK would be pleased to help Health Boards develop care pathways, support training of healthcare professionals and offer guidance to the government.

We fully acknowledge the immense pressure the NHS faces.

We do not wish to be part of the problem - we want to be part of the solution!