PE1952/K: Specialist services for patients with autonomic dysfunction

Petitioner and Dr Lesley Kavi written submission, 24 November 2025

Lack of needs assessments and healthcare provision

The Minister again incorrectly assures the Committee that there is sufficient expertise in neurology clinics for PoTS patients; however the national charity (PoTS UK) is not aware of any neurology specialists in Scotland who manage PoTS and related conditions.

PoTS is not generally part of conditions listed in the Minister's response, not part of neurology specialty training curriculum, and not within the usual remit of neurologists in Scotland. In a recent survey only 1.63% of PoTS patients in Scotland were diagnosed by a neurologist, likely based in England.

We have asked repeatedly for details of these specialists: instead, the Minister has recommended that the Committee contact territorial NHS Boards. In fact, PoTS UK made FOI requests to all Health Boards. The 2022 results were reported previously and the 2024 findings revealed that:

- only 2 of the 14 Health Boards see PoTS patients in neurology clinics (these may not be specialist clinics), and one board rejects or redirects **all** neurology referrals for PoTS.
- 4 Health Boards had no idea where patients with PoTS are seen. Western Isles refers all patients to Glasgow, and Grampian refers all patients to Inverness. However, the Inverness clinic was recently closed.
- No Board could name a specific clinic into which patients could be referred.

If Health Boards and Trusts do not know where patients are seen, how can GPs possibly know where to refer when patients need secondary care support?

The Government expects Boards to:

- 'take into account local circumstances and the reasonable needs of their patient populations,' but the 2024 FOI requests show that no Boards know the numbers or needs of their PoTS patients.

- 'provide high quality, person-centred care and support for everyone, including people with dysautonomia', but shows little concern for our strong evidence of extremely poor healthcare.

The size of the problem

There were an estimated 9400 people in Scotland with PoTS pre-pandemic. It is thought that 7-14% of people with Long COVID have PoTS i.e. there may be an additional 16,800 affected. The socioeconomic impact of this is enormous as autonomic dysfunction is one of the most debilitating aspects of Long COVID. COVID infections and reinfections continue to increase the number of patients with autonomic dysfunction and cardiological conditions.

Specialist care provision
PoTS patients who can access healthcare are mostly seen by cardiologists because patients present with cardiac-type symptoms, often need cardiology tests and medication.

However, there are no cardiologists known to us in Scotland who manage PoTS patients. Additionally, Lothian's PoTS guidance tells GPs **not** to refer to cardiology unless the patient faints; these patients likely have vasovagal syncope, not PoTS. https://apps.nhslothian.scot/refhelp/guidelines/cardiology/postural-tachycardia-syndrome-pots/

Training
The training mentioned by the Minister is focused on the underlying conditions — Long COVID and ME/CFS — and does not significantly impact GP learning (see below).

Evidence from patients: new survey results
A large 2025 survey of people with suspected and diagnosed PoTS revealed that:
- 90% of patients in Scotland experienced difficulty in accessing NHS healthcare.
- 59% said their GP has not heard of PoTS or does not believe it exists.
- Almost half were misdiagnosed, with their physical symptoms inappropriately attributed to mental health conditions.
- 50% have to seek ongoing private healthcare.
- 14% travel to England to access healthcare.

Most affected patients are children or young adults under the age of 50.
- 38% cannot attend school and many more are off long term
- One third of students had to drop out of college/university
- 38% lost their job due to PoTS
- One third had to reduce working hours due to PoTS

These statistics paint a shameful picture of inequitable access to healthcare and its impact.

A recent Parliamentary drop-in session in Westminster was attended by many interested MPs from Scotland. They had received large numbers of emails from constituents on this issue, one having never received so many individual emails on one subject before.

Scotland has no clinical pathways for dysautonomia and no specialist hubs. PoTS patients, for example, need a care pathway for PoTS in every Health Board, a named service in secondary care that GPs can refer into, and national clinical guidelines. These measures are in place for most other conditions as common and disabling as PoTS.

We sense the Citizen Participation and Public Petitions Committee is repeatedly 'fobbed off' by the Government's responses. We urge you to consider our evidence and encourage the Government to make an urgent assessment of the numbers and needs of patients with dysautonomia in order to address the inadequacy of current services.