

PoTS UK submission of 17 December 2022

PE1952/C: Specialist services for patients with autonomic dysfunction

Thank you for inviting our charity to provide information in response to the Citizen Participation and Public Petitions Committee. I am a trustee and chair of PoTS UK, and a recently retired GP. I have a special interest in autonomic dysfunction (including PoTS) and have been answering enquiries from patients and healthcare professionals for over 10 years. I work closely with specialist healthcare professionals who have an interest in PoTS both within and outside the UK.

It has long been apparent that patients with PoTS, despite experiencing significant disability, do not have equitable access to healthcare in Scotland. Psychological labelling (or 'medical gaslighting') is common.

We disagree with the *Scottish Government submission of 29/8/22 in response to petition PE1952: Specialist services for patients with autonomic dysfunction*. In practice, many patients with autonomic dysfunction do not have access to the best possible care and support, and are not placed at the centre of their care. PoTS is not well recognised within the cardiology profession, and is not managed effectively. In fact cardiologists often report that they do not have the skills or equipment to manage such patients, that they do not provide a PoTS service, or that no treatments are available. Patients are sometimes denied access to services commissioned by NHS England.

A recent FOI request revealed that the majority of health boards have no established pathway to diagnose and treat PoTS in adults, and we are not aware of any specialist services in Scotland for children.

Based in pre-covid USA estimates, 0.17% of the population of Scotland have PoTS, and during the past 2 years it is likely that numbers have increased.

Our charity recently undertook a survey of 123 people in Scotland with PoTS (or likely to have PoTS). All health boards were represented except Orkney. The majority of respondents were women between the ages of 18-49; some parents completed the survey on behalf of affected

children. Key findings are reported below and a detailed report of the survey results can be provided, if helpful.

- The average time taken to obtain a diagnosis was 5 years.
- On their diagnostic journey, 75% of patients were misdiagnosed, most commonly with anxiety (50%), medically unexplained symptoms (35%), panic disorder (19%), hypochondriasis (19%), ME/CFS (19%) and depression (18%).
- 75% of patients were advised by their attending clinician that the same clinician knew nothing about PoTS.
- Only 4% of patients were diagnosed by their GP; the majority were diagnosed in secondary care.
- 67% of patients were advised by their clinician that there are no NHS services in Scotland for patients with PoTS.
- 11% were declined referral to NHS England specialist services.
- 36% of patients had to obtain private referrals as they were unable to access NHS services for PoTS in Scotland.
- Only 15% of patients in Scotland were able to fully access treatment.
- Around half of affected patients are unable to work and have applied for disability benefits for care and mobility.

After patients have been diagnosed by a private specialist or services in England, we hear that local clinicians decline to follow the recommended treatment strategy.

The survey findings clearly suggest that there is a need for NHS Scotland to provide guidelines, training and a clinical pathway for the diagnosis and treatment of patients with suspected or proven autonomic nervous system dysfunction (including PoTS) for both adults and children.

If indeed specialist services are available for people with PoTS, as the Scottish Government claims, we request that the details of these services (lead clinician and NHS hospital or community service) be provided so that patients can be directed appropriately.

Our charity can facilitate training on PoTS (and autonomic dysfunction in long covid) for NHS Scotland if asked to do so.