

PE1952/I: Specialist services for patients with autonomic dysfunction

Petitioner and Lesley Kavi submission, 14 May 2024

We thank the Committee for an opportunity to respond to the 4 April 2024 submission by the Minister for Public Health and Women's Health.

We are dismayed by the Minister's statement that Scotland has robust and well-established processes to assess the need for new services or for providers of specialist services. PoTS UK has seen no evidence of investigations into the needs of people with Postural Tachycardia Syndrome (PoTS) and related dysautonomia. Recent FOI requests to all Scottish health boards revealed that they have no knowledge of the prevalence of PoTS in their community and no evidence of expertise. The exception to this was a clinic in Inverness which we understand is no longer accepting referrals.

Dr Amy Small, Clinical Advisor to Chest Heart and Stroke Scotland (CHSS), reports that patients contacting the Advice Line are struggling to get their PoTS symptoms recognised by GPs:

"There appears to be a lack of education and understanding around PoTS, and when it is diagnosed, there are significant delays to access appropriate testing and treatment. Many cardiology services do not provide support and prompt review for these patients whose symptoms can be utterly disabling and lead to an inability to maintain their jobs. With the rise in Long Covid and the subsequent development of PoTS and other autonomic diseases, CHSS supports requests made by PoTS UK to ensure a better service is offered to these patients."

The Minister states that "[m]ost people with autonomic symptoms experience them as part of other underlying conditions, such as Parkinson's disease or related disorders, neuropathies, diabetes and multiple sclerosis. These people are cared for within existing pathways for their underlying condition." Unfortunately, these services are not accessible to the many PoTS patients, especially those who are young or have different co-morbidities. Medicine for the Elderly and diabetic clinics will generally not accept referrals for younger PoTS patients.

"Fainting and dizzy spells, fatigue and gastric problems. Sent home from school frequently."

— *Grampian patient*

PoTS UK works with the majority of clinicians with an interest in PoTS throughout the UK. We are not aware of any neurologists in Scotland who are happy to manage this condition. We are confident that the vast majority of general neurologists in Scotland would not want to accept referrals for PoTS. Specifically, we would be grateful if the Minister has evidence to the contrary as we would be able to direct patients to them if they exist.

"My GP has tried to make a referral for me, however this was rejected due to a lack of specialist clinics...My condition [Long Covid with PoTS] remains severe and

prevents me from undertaking basic activities and caring for myself. I am urgently and desperately needing medical support — which requires interdisciplinary expertise across cardiology and neurology — in order to improve my health and quality of life.”

— Lothian patient

While we welcome the National Strategic Network Long Covid PoTS pathway, it does not provide adequate guidance for more complex patients requiring secondary care assessment or interventions.

“Previous syncope doctors wanted to prescribe [medication] but could not get a local Scottish doctor to help apply for funding or ‘share care’.”

— Fife patient

The Minister expects “all boards to provide care that is person-centred, effective, and safe and to deliver services that meet the needs of their local populations. Therefore, we would expect that all boards ensure that people who require care for the symptoms of autonomic dysfunction have access to a range of professionals to provide the appropriate management of their condition.” That is our request with this petition, but unfortunately, 78% of affected patients in a recent survey (April 2024) of 114 Scottish PoTS patients disagree or strongly disagree with the Minister’s statement.

Only 37% had received a diagnosis or treatment via an NHS specialist or GP. The majority of patients had either not received a diagnosis via the NHS, or had been unable to access NHS specialist treatment. Additionally:

- 24% were advised by their GP that there were no specialists in Scotland that could manage PoTS in secondary care
- 14% had their GP referral rejected
- Some expressed frustration that they were unable to obtain further treatment after diagnosis for reasons such as lack of available specialists, closed clinics, referral rejection at the board level, and unavailability of cross-board referrals.

“[I’ve] severe fatigue. I struggle to look after myself and my living environment. I am currently not in work and I feel like a burden to those around me....I was referred by the Covid Recovery Service however the clinic has since stopped due to no funding.”

— Highland patient

Of the patients who were seen in secondary care, only 23 were offered support; the remainder saw specialists who either did not have knowledge of dysautonomia or were unable to offer helpful treatment. Overall, 60% of patients in Scotland with PoTS have had to seek private medical care for some aspect of their condition.

“[I]ts causing depression [and] financial difficulty because [I’m] not working... This is a condition that could be so easily treated and maybe I would be able to work which would benefit the country, not just me.”

— Tayside patient

We would ask that the Committee requests the following evidence from the Minister:

1. Evidence that the NHS National Services Division has properly investigated the prevalence and needs of people with PoTS and dysautonomia (including the large number of younger people who currently cannot access secondary care services).
2. We ask once again that the Minister provide details of at least one trained clinician or named clinic where staff are appropriately trained in each region and happy to accept referrals for adults with PoTS and one who will accept referrals for children who do not respond to the usual treatments recommended in primary care.