

Petitioner submission of 25 January 2024

PE1952/G: Specialist services for patients with autonomic dysfunction

(Written by Jane Clarke, Petitioner and Patient and Dr Lesley Kavi, Chair of the national charity, PoTS UK)

Petition PE1952 raised concerns around the lack of specialist autonomic support in Scotland for **all** patients with dysautonomia. We are disappointed that the Committee's questions and Scottish Government comments mostly do not address the original petition question and focus mainly on Long Covid.

It is important to note that autonomic neurologists diagnose and treat various forms of dysautonomia in their specialist clinics, including the management of PoTS. Autonomic (or neurovascular) neurologists and cardiologists are the experts in autonomic dysfunction at the forefront of research, learning and treatment.

There are no specialist autonomic clinics in Scotland to the detriment of patients, their employers, and their families.

PoTS is a complex multi-system condition. Due to the way in which it presents, patients are sometimes referred to cardiology clinics. The Government has previously said that *"PoTS is a well-recognised condition within the cardiology professions. And can be managed effectively within Scottish cardiology services."*

However, the experience of the national charity and patients is the opposite. Consultants in cardiology tell us that they do not have the expertise to manage such patients. Patients are unable to access appropriate tests and therapies or obtain referral to clinics in England (which are currently overwhelmed).

We would like to respond to the Scottish Government's response to the committee's questions as follows:

- 1. Whether the Scottish Government's evaluation of the Implementation Support Note and if this has increased knowledge of Long Covid and PoTS**

The Minister highlighted that only 60% of Scottish GP practices are aware of the Long Covid SIGN guidelines. This does not mean that every practitioner within that practice has read or implemented it and provides no evidence of proper assessment or management of patients with autonomic dysfunction.

Only 21.5% of practices were aware of the Implementation support note and only 11.7% found this to be helpful.

We are pleased that the National Strategic network developed a pathway for PoTS in long COVID, but we are aware that there is still no pathway for the majority of PoTS patients whose illness was not triggered by COVID-19.

2. How diagnostic and treatment pathways for people with Long Covid are monitored and tracked to ensure appropriate care is provided in a quick and coordinated way, including to people with dysautonomia.

Again, the focus of the Minister's response is on Long COVID services. Regarding PoTS, the Minister refers to the Government's previous response of August 2022, stating that the services for non-COVID PoTS patients have already been covered in the document. In the August response, the Government agreed that, 'Specialist medical assessment may be required for those who don't respond to first-line measures' and claimed that *'Within local and regional clinical services across Scotland there is expertise in a number of clinical specialties to investigate and manage these conditions 'and there are 'pathways are in place to allow access to services commissioned by NHS England'.*

The national charity, PoTS UK is not aware of these services and this expertise. In a recent survey by PoTS UK, 70% of Scottish PoTS patients were informed by their healthcare professional that there are no specialist services in Scotland that they can access, and many had to resort to private healthcare. A recent freedom of information request to Scottish Health Boards revealed that 11 boards do not have a specialist. Of the 2 that do, one reported that their service has an uncertain future. If such specialist services exist, we challenged NHS Scotland to provide locations of the expert services and names of specialist healthcare professionals. We were unable to obtain a response.

Dysautonomia is a complex neurological issue, and as the nervous system affects all body systems, a multi-disciplinary approach is usually

recommended. We are not aware of any PoTS specialists with access to a trained multidisciplinary team in Scotland.

3. Whether the Scottish Government will request that training is provided to GPs on dysautonomia.

The Minister refers to the 'Turas' training platform which gives healthcare professionals access to a video and PowerPoint. Whilst we welcome these additions, we would like to make it clear that these are not a substitute for specialist services. For example, they do not contain detail about prescribing medication, which can be complex. There is also no information about the autonomic battery of tests including tilt table testing and their interpretation.

In summary, despite the Government's claims, our experience and evidence from Health Boards and patients' surveys is that people with PoTS throughout Scotland do not have access to knowledgeable autonomic or cardiology specialists.

We ask the Committee and Scottish Government to provide evidence of specialists and specialist clinics so that patients and GPs may be directed to them appropriately. If there are indeed only 2 specialists in Scotland (as Scottish Health Boards report), then we request that further services are commissioned to ensure patients have local or regional access to the care that the Scottish Government agrees that they require.