

Citizen Participation and Public Petitions Committee

8th Meeting, 2023 (Session 6), Wednesday
17 May 2023

PE1952: Specialist services for patients with autonomic dysfunction

Petitioner	Jane Clarke
Petition summary	Calling on the Scottish Parliament to urge the Scottish Government to instruct Scotland's NHS to form specialist services, training resources and a clinical pathway for the diagnosis and treatment of patients exhibiting symptoms of autonomic nervous system dysfunction (dysautonomia).
Webpage	https://petitions.parliament.scot/petitions/PE1952

Introduction

1. The Committee last considered this petition at its meeting on [9 November 2023](#). At that meeting, the Committee agreed to invite evidence from the Brain Charity, Chest Heart and Stroke Scotland, Postural Tachycardia Syndrome (PoTS) UK, Professor Alan Carson and NHS National Services Scotland.
2. The petition summary is included in **Annexe A** and the Official Report of the Committee's last consideration of this petition is at **Annexe B**.
3. The Committee has received new responses from PoTS UK, Chest Heart and Stroke Scotland and NHS National Services Scotland which are set out in **Annexe C**.
4. Written submissions received prior to the Committee's last consideration can be found on the [petition's webpage](#).
5. Further background information about this petition can be found in the [SPICe briefing](#) for this petition.

6. The Scottish Government's initial position on this petition can be found on the [petition's webpage](#).
7. Every petition collects signatures while it remains under consideration. At the time of writing, 1,754 signatures have been received on this petition.

Action

The Committee is invited to consider what action it wishes to take on this petition.

Clerk to the Committee

Annexe A

PE1952: Specialist services for patients with autonomic dysfunction

Petitioner

Jane Clarke

Date lodged

18 August 2022

Petition summary

Calling on the Scottish Parliament to urge the Scottish Government to instruct Scotland's NHS to form specialist services, training resources and a clinical pathway for the diagnosis and treatment of patients exhibiting symptoms of autonomic nervous system dysfunction (dysautonomia).

Previous action

I have spoken with Mr Daniel Johnson MSP on 09/05/22 regarding the current gaps in NHS services for dysautonomia. Mr Johnson offered to submit a motion for a members' debate and to table written parliamentary questions.

Others have raised questions within Scottish Parliament and Westminster. On 1, 4 and 21 Jun 2016, MSP Ms Aileen Campbell's responses to parliamentary questions revealed existing national gaps in diagnosing and treating autonomic dysfunction's many conditions.

Background information

Autonomic nervous system disorders are common. Some cause mild symptoms, but many severely impact upon quality of life or significantly reduce life expectancy. Despite this, Scotland has no clinical pathway for dysautonomia and no specialist hub to diagnose and treat patients. Dysautonomia is a common complication of Long COVID.

With no autonomic clinics in Scotland, most patients do not have access to local or regional healthcare. A fortunate few may be referred to specialists via NHS England, but many are declined referral despite

clinical need. Diagnosed patients returning to Scotland can find themselves unable to access necessary medication or follow-up. Treatment may be delayed for years, leaving sufferers unable to work or attend education. It is especially difficult for children to access dysautonomia healthcare.

As many doctors are untrained to recognise and manage symptoms of autonomic dysfunction, dedicated training resources are also needed.

The aims of this petition align with the commitments of the Neurological Care & Support Framework & the UK Rare Disease Strategy.

Further key info: <https://dysautonomiapetition.wordpress.com/>

Annexe B

Extract from Official Report of last consideration of PE1952: Specialist services for patients with autonomic dysfunction on 9th November 2022

The Convener: PE1952, on specialist services for patients with autonomic dysfunction, was lodged by Jane Clarke. The petition calls on the Scottish Parliament to urge the Scottish Government to instruct Scotland's NHS to form specialist services training resources and a clinical pathway for the diagnosis and treatment of patients exhibiting symptoms of autonomic nervous system dysfunction, or dysautonomia.

Jane tells us that autonomic nervous system disorders are common and that they are also often a complication of long Covid. She highlights the severe impact of the condition on people's quality of life and life expectancy. Jane says that, in Scotland, there is no clinical pathway for dysautonomia, no specialist hub to diagnose and treat patients, and no access to local or regional healthcare for most patients. She highlights challenges and referrals to specialists in England, and lengthy treatment delays and the related impacts of that on individuals, including children.

In a further submission, Jane has provided additional information and comments on the Scottish Government's response. According to Jane, a member of the NICE expert panel on long-term effects of Covid-19 has said that Scotland does not currently follow the relevant guidance in relation to multidisciplinary doctor-led services. Jane notes that a lack of data on the prevalence of such conditions in Scotland means that there is also no data on whether services are adequate.

The Scottish Government response states that there is expertise in Scotland to manage such conditions and that, where additional expertise is required, pathways are in place to allow patients to access services in England. It also states that the clinical guideline on identifying, addressing and managing the long-term effects of Covid-19 is supported by the Scottish Government's implementation support note, which has been circulated to all NHS health boards.

Do members have any comments or suggestions?

Alexander Stewart: I suggest that we write to stakeholders, seeking their views on the actions asked for in the petition. The committee could write to the Brain Charity, Chest Heart & Stroke Scotland, PoTS UK, Professor Alan Carson and NHS National Services Scotland. We could also write to the petitioner, alerting them to the funding schemes that are available through the chief scientist office.

The Convener: Thank you, Mr Stewart. As no colleagues have any other comments or suggestions, are we content to progress as Mr Stewart has suggested?

Members *indicated agreement.*

The Convener: Thank you. We will keep the petition open and proceed on that basis.

Annexe C

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.

Chest Heart and Stroke Scotland submission of 20 December 2022

PE1952/D: Specialist services for patients with autonomic dysfunction

Chest Heart and Stroke Scotland is pleased to have the opportunity to respond to the Petition above.

Dysautonomia is a collective term for a group of conditions affecting the autonomic nervous system. People living with Long Covid often experience dysautonomia as part of the condition, particularly as the condition POTS (postural orthostatic tachycardia syndrome). POTS causes dizziness, palpitations, fatigue and fainting (syncope), and can be disabling for people living with this condition.

Prior to COVID 19, POTS was relatively rare, with estimates that this affected between 0.2 per cent (POTSUK) and 1 per cent (Zadourian et al, 2018) of the population. However, dysautonomia appears to be becoming more common as a result of Long Covid. Nearly 200,000 people in Scotland live with Long Covid (ONS figures), with the most common symptoms being dysautonomia; tiredness, shortness of breath and difficulty concentrating, as well as fainting and palpitations. A study released early this year among Long Covid patients found 76 per cent had symptoms of dysautonomia (Edokla et al 2022).

People living with Long Covid still struggle to access medical support for their condition, and people living with POTS often wait years for a diagnosis ([Kavi](#) et al, 2016). According to SIGN Guidelines, patients with postural symptoms as part of Long Covid should receive blood pressure testing and pulse rate recordings to test for POTS. However, given that knowledge of Long Covid and POTS in primary care is already low, we are concerned that Long Covid patients with dysautonomia are unlikely to be referred for these tests or for further support.

There are ways to manage symptoms of dysautonomia, and medication may be effective for some people. But a lack of specialist resource within the NHS – or even a recognition of which speciality should be responsible for dysautonomia – puts patients at a significant disadvantage. We continue to campaign for better treatment and support for people with Long Covid. Our Long Covid Action Plan, released in

2021, called for quicker and more coordinated diagnostic and treatment pathways, as well better awareness and resources for clinicians.

We agree with the petitioners that more action is needed to support people living with dysautonomia. Training for GPs is essential, and the creation of a clinical pathway that integrates with existing SIGN guidelines for Long Covid is needed. People living with Dysautonomia would benefit from specialist support, and we would support further scoping to ascertain the size of this need.

NHS National Services Scotland submission of 21 December 2022

PE1952/E: Specialist Services for patients with autonomic dysfunction

May I begin by thanking you for your recent correspondence regarding the petition for specialist services for patients with autonomic dysfunction and specifically the quantification as to the scale of the problem in Scotland.

The role of NHS National Services Scotland, National Services Division (NSD) includes commissioning of nationally designated specialist services in Scotland. NSD work closely with colleagues and providers in NHS England to ensure access to highly specialised healthcare for those Scottish residents who following assessment by a specialist clinician in Scotland require specific clinical expertise, investigation or interventions which are not available within Scotland. In many cases such expertise is concentrated within either a single or small number of centres due to either the small number of patients requiring this service (rare disease) or because there is a need to concentrate technical expertise within a clinical team to ensure that case volumes are adequate to provide assurance of clinical quality and safety (specialist surgical services).

The term autonomic dysfunction is associated with many different underlying conditions and such conditions are normally investigated and managed within either local secondary care services or regional tertiary units in Scotland. Depending on the needs of each patient, specialists such as cardiologists, diabetologists and neurologists will be involved

with their care and investigations. These services are typically commissioned locally by the Health Board in which the patient resides.

Where specialist clinicians feel that a patient requires more specialist specific investigations or expertise unavailable in Scotland there is the option for the clinician to seek funding approval via their Health Board from NSD. This allows referral of the patient to a highly specialised service such as that provided by the National Hospital for Neurology and Neurosurgery, Queens Square, London.

As most patients with an autonomic dysfunction are investigated and managed within Scotland, NSD does not hold information on the numbers of people affected by autonomic dysfunction nationally, or the resources required to support these patients. Similarly, with the broad range of local services and specialities involved for autonomic dysfunctions, we would not anticipate NSD to be invited to commission a national specialist service, training resources or development of a clinical pathway.