Citizen Participation and Public Petitions Committee
Wednesday 11 December 2024
19th Meeting, 2024 (Session 6)

PE1952: Specialist services for patients with autonomic dysfunction

Introduction

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

1. The Committee last considered this petition at its meeting on 6 March 2024. At that meeting, the Committee agreed to write to the Scottish Government.

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 written submissions from the Minister for Public Health and Women's Health, and a joint submission from the Petitioner and Lesley Kavi, 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 gave its initial response to the petition on 19 August 2022.

7. Every petition collects signatures while it remains under consideration. At the time of writing, 1,917 signatures have been received on this petition.

Action

8. The Committee is invited to consider what action it wishes to take.

Clerks to the Committee
December 2024

Annexe A: Summary of petition

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 on 6 March 2024

The Convener: PE1952, which was lodged by Jane Clarke, 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. We last considered the petition at our meeting on 17 May 2023.

A recent submission from the Minister for Public Health and Women's Health highlights the results of a questionnaire to a sample of general practices, which included questions on the clinical guideline "Managing the long-term effects of COVID-19". The survey found that 60 per cent of responding practices were aware of the guideline and 25 per cent were aware of the implementation support note. The content of the implementation support note is being reviewed and updated.

The University of Leeds has been contracted to support the initial evaluation of long Covid services in Scotland. That work will provide an analysis of demand and capacity and of longer-term outcomes for patients, and will compare differences in service models where possible.

The petitioner has stressed that the petition concerns all patients with dysautonomia and not just those with long Covid. She notes that there are no specialist autonomic clinics in Scotland and that cardiology consultants have told PoTS UK that they do not have the expertise to manage patients with dysautonomia. The petitioner welcomes the training resources that are available to healthcare professionals but would like to make it clear that those are not a suitable substitution for specialist services.

Do members have any comments or suggestions for action?

David Torrance: The committee should consider writing to the Scottish Government to ask whether it will work to create specialist autonomic clinics in Scotland and, if not, how it can be confident that the expertise in local and regional clinical services is sufficient to treat those with autonomic dysfunction.

The Convener: If there no other suggestions, are we content to proceed on that basis?

Members indicated agreement.

Annexe C: Written submissions

Minister for Public Health and Women’s Health written submission, 4 April 2024

PE1952/H: Specialist services for patients with autonomic dysfunction

Thank you for the Committee’s correspondence to the Scottish Government of 8 March 2024 regarding petition PE1952: ‘*Specialist services for patients with autonomic dysfunction,* and the opportunity to respond to the Committee’s query following its meeting of 6 March 2024.

The Committee states that it is keen to understand whether the Scottish Government will work to create specialist autonomic clinics in Scotland and, if not, how the Scottish Government can be confident that the expertise in local and regional clinical services is sufficient to treat those with autonomic dysfunction.

Scotland has robust and well-established processes to assess the need for new services or providers of specialist services These processes are administered by NHS National Services Division. There are no current plans to develop a dedicated specialist autonomic service in Scotland.

Most 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.

We are advised that it is well within the remit of neurologists to diagnose and manage these symptoms as part of their routine practice in the vast majority of cases. Where required, secondary care services also work with GPs and community nursing teams to help people manage their condition and symptoms outside of hospital.

Cardiologists may also see people with autonomic symptoms for assessment and investigation, particularly if the nature of their autonomic dysfunction is suspected to be cardiovascular, or when autonomic symptoms do not occur as part of a separate neurological disease.

Primary autonomic failure is uncommon and may require input from further specialties if there is diagnostic difficulty or more complex testing of autonomic function is required. In circumstances where the local or regional specialist teams feel they do require additional expertise - which is not available within Scotland - pathways are in place to allow access to services commissioned by NHS England.

Regarding long COVID specifically, as the committee is aware, in June 2023 the National Strategic Network developed a recommended pathway for the assessment and management of Postural Orthostatic Tachycardia Syndrome in people living with long COVID, for use by NHS Boards.

While the Scottish Government's role is to set the strategic policy for the NHS in Scotland, the provision of healthcare services is the responsibility of NHS boards, taking into account national guidance, local service needs and priorities for investment. We expect 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.

I hope this reply is helpful to the Committee.

Jenni Minto MSP

Petitioner and Lesley Kavi written submission, 14 May 2024

PE1952/I: Specialist services for patients with autonomic dysfunction

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.