

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.