

ACTIONS TO TAKE TO SUPPORT YOUR CONSTITUENTS



Your constituents with postural tachycardia syndrome (PoTS) need your help.

PoTS is a common debilitating condition that mostly affects children and younger adults. People with PoTS are underserved by our NHS. Consequently, they are often unable to attend school or work due to their ill health, when we know that treatments can help them function and go on to have rewarding purposeful lives.

Access to services

Patients in many regions in the UK do not have access to secondary care services. Why is this? Some healthcare commissioners (ICBs and health boards) claim that services are not necessary as GPs can manage all PoTS patients. Conversely others tell us that it is too complex a health condition and all patients are referred outside their region to specialist centres (all of which are currently overwhelmed).

The truth lies somewhere in between. Some patients can be diagnosed and managed by GPs, some require referral to local or regional hospitals (where specialists should have some knowledge of PoTS), and a small number require care at a national tertiary centre.

FOI enquiries revealed that there are currently no care pathways for patients with PoTS anywhere in the UK.

ACTION 1:

Please write to your ICB or Health Board to demand that they develop a care pathway for PoTS, and ensure that there is a high-quality secondary care service available locally that patients can access when required.

Lack of guidelines

Contrary to claims by many ICBs and politicians, there are no PoTS national guidelines.

ACTION 2:

Please write to your Health Secretary requesting that they:

- 1. ensures a a secondary care service is available to patients in every region of the UK**
- 2. asks the NHS to commission national guidelines (such a NICE and SIGN guidelines) to improve patient care and their healthcare professionals' confidence in managing them.**

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