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The Rt Hon Wes Streeting MP
Secretary of State for Health and Social Care
Department of Health and Social Care
Ministerial Correspondence and Public Enquiries Unit
39 Victoria Street
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Our Ref: MP02425 14 October 2025

Dear Secretary of State,

Re: Access to Diagnosis, Treatment and Support for Patients with Postural Tachycardia Syndrome (PoTS)

Thank you for your reply to my letter of 17 June, written on behalf of constituents affected by Postural Tachycardia Syndrome (PoTS). While I appreciate the response, my constituents and I remain deeply concerned about the lack of effective NHS provision for this condition and the absence of any meaningful plan to address it.

The information cited in your letter, such as the Royal College of General Practitioners' Syncope Toolkit and the NICE Clinical Knowledge Summary on blackouts/syncope, provides only minimal reference to PoTS. These resources are embedded within materials about fainting, even though the majority of PoTS patients do not experience syncope. As a result, the information reaches very few GPs and does not equip them to recognise, diagnose, or manage PoTS comprehensively. These resources cannot be considered a substitute for access to appropriate secondary care services.

While we welcome the Government's stated ambition to improve services for people with long-term and complex conditions, your response did not offer reassurance that people living with PoTS will be able to access such improvements in practice. In theory, Integrated Care Boards have a statutory duty to commission services that meet local needs. However, in reality, not one ICB provides equitable access to appropriate care for PoTS patients. This raises a fundamental question as to who is holding ICBs accountable for failing to commission these essential services? The Department of Health and Social Care has been repeatedly alerted to these issues over many years, yet there is no evidence of intervention or oversight to ensure patients' rights to care are upheld.

Specialist clinicians for PoTS are few in number, under-resourced, and overwhelmed by patient demand. They lack the capacity to undertake vital research or expand services. Moreover, there are currently no NICE guidelines dedicated to PoTS, nor any indication that research into this condition has been prioritised. PoTS UK, which is registered as a stakeholder for NICE's blackout guidelines, was not notified or consulted when those guidelines were updated in November 2023, contrary to standard stakeholder engagement practice.

The Government expects ICBs to draw on NICE guidance and best practice when designing local services, but without a comprehensive NICE guideline for PoTS, this is impossible. I urge you to support the development of dedicated NICE guidelines for PoTS, which would

have a significant and immediate impact on patient care and service design across the NHS.

At present, there are no national clinical pathways for PoTS, and in many regions, no service provision at all. GPs' referrals are frequently rejected (sometimes before patients are even seen) simply because "PoTS" appears in the referral. In some cases, ICBs and trusts cite reasons that are wholly unacceptable, including, "All PoTS patients can be managed by GPs"; "PoTS is too complex and requires referral outside our region"; "PoTS patients only need care if they faint"; "No clinicians in our trust are willing to manage PoTS patients"; "We do not commission a service for PoTS."

This situation represents a serious breach of NHS commissioner and provider responsibilities. It is further compounded by reports of hospitals being instructed to close successful PoTS clinics or limit patients to a single outpatient appointment. This would not be tolerated for other complex or disabling conditions.

The ongoing NHS reorganisation and the forthcoming ten-year plan must not be used as an excuse to delay or sidestep the urgent action required. Simply passing responsibility to ICBs and NICE, without oversight or accountability, is not acceptable. Patients continue to be denied access to appropriate, evidence-based care.

I would therefore be grateful if you could confirm:

1. What steps the Department of Health and Social Care is taking to ensure that ICBs are held accountable for meeting their statutory duty to commission services for people with PoTS;
2. Whether the Department will support the development of comprehensive NICE guidelines for PoTS; and
3. What measures are being taken to ensure that existing specialist services are protected and expanded rather than closed.

My constituents, and all those who live with PoTS, deserve better than continued exclusion from the NHS services to which they are entitled.

Yours Sincerely,

Dr Manuela Perteghella MP
Member of Parliament for Stratford-on-Avon