Postural Tachycardia Syndrome (PoTS)

Summary of Key Issues

- PoTS is a common, complex, disabling condition affecting both adults and children.
- Healthcare professionals lack guidance on recognition and appropriate management of PoTS – there are no UK national guidelines.
- Affected people have inequitable access to healthcare with exceptionally long delays to diagnosis and limited or non-existent access to treatments.
- Within the UK there are no formally commissioned services or care pathways.
- The small number of existing clinicians are overburdened, and barriers further limit their ability to deliver a service to PoTS patients.

The Condition

PoTS results from a damaged nervous system. When patients stand up, blood drops into their abdomen and feet and can't circulate properly around their body. They experience many debilitating symptoms all at once such as near-fainting and blackouts, palpitations, chest pain, shortness of breath, diarrhoea, vomiting, profound fatigue, and cognitive dysfunction. Many are housebound, bedbound or wheelchair users. Half of affected children are unable to attend school long-term and many adults cannot complete higher education or attend work. The financial impact on individuals and the economy is considerable.

With access to healthcare, 90% would improve significantly.

Access to Healthcare

Patients commonly see multiple care providers with the average time to diagnosis being 7 years.
60% of patients, often with limited income, resort to private healthcare due to lack of NHS service provision.

Reasons for poor access to healthcare:

1. Lack of healthcare professional knowledge.
2. Few specialist services in the UK, with some regions having no access to secondary care services.
3. No succession planning when clinicians retire.
4. 50% of patients are 'medically gaslit' and advised that their physical symptoms are of psychological or psychiatric origin. This is especially common in women.
5. Increased incidence, in part due to a relationship with long-COVID.
6. Rejection of GP referrals by secondary care providers. Reasons include:
    i. We do not commission a service for PoTS patients.
    ii. We do not accept referrals from outside our locality.
    iii. Our service is currently overwhelmed.
    iv. PoTS is not a cardiology problem (despite presenting with cardiology symptoms and requiring cardiology tests and medications).
    v. PoTS patients do not need referral to secondary care.
    vi. PoTS is too complex and requires tertiary centre referral outside our region.
    vii. PoTS patients only need secondary care support if they faint.
    viii. No-one within our trusts wants to manage PoTS patients.
    ix. There are no UK national guidelines.

Many of these policies breech current NHS commissioner/provider contracts.

A number of successful clinics where PoTS patients received care have been closed or activity reduced as the trust reports that a service has to be specially commissioned and will therefore not permit patients to be seen. Complex and unwell patients have been discharged back to their GP (who do not have the skills or resources to manage them) without consultation with the patient or provision of any ongoing care.

Freedom of Information requests

Freedom of Information Requests were circulated to **all NHS commissioning organisations and acute trusts** in England, Wales, Scotland and Northern Ireland. They reported that there are no established care pathways or formally commissioned services in place for people diagnosed with PoTS. There is limited specialist service provision available to patients with PoTS (21 trusts) across England, and no service provision generally available in Scotland, Wales and Northern Ireland, which is extraordinary for such a common, complex and disabling condition.
Service provision for children is especially poor.

The View from the Front Line

A recent survey of existing clinicians providing PoTS services confirmed these FOI findings. In addition, they reported being overwhelmed with referrals, having long waiting lists, restrictions around acceptance of referrals, and lack of access to other specialties and services as part of the recommended MDT approach.

Previous MP and DOH response

A recent response from the DOH to MPs in the previous government stated that GPs have been provided with guidance on PoTS by NICE and that the Rare Disease Framework benefits PoTS patients, improving awareness and access to care. These statements are factually incorrect; there are no NICE guidelines and PoTS is too common to qualify for the Rare Disease Framework.

Integrated Care Boards are responsible to NHS England, which in turn is responsible to our government. We ask MPs to hold the goverment accountable on behalf of their constituents.

Recommendations

1. Development of UK national guidelines (eg NICE, SIGN) for PoTS and related disorders.
2. Ensure every region of the UK has a service adequately resourced with clinicians, specialist nurses, secretarial support, specialist physios, OT, dieticians, and clinical psychologists. Provide access to necessary equipment and estates/clinic space to properly assess and safely diagnose and manage patients.
3. Include PoTS training in junior doctor specialty training to ensure education and the future continuation of appropriate services.
4. Investment in the small number of services already provided by overburdened clinicians at least to the level of similar common and disabling conditions such as multiple sclerosis.
5. Publicising the condition to GPs and notifying them of where to refer their patients.
6. Require that every commissioning body develops a care pathway for PoTS in association with experts and patients/stakeholders.
7. Eliminate the current NHS healthcare discrimination and medical gas-lighting of PoTS patients to provide equitable access to medical services.

PoTS UK would be pleased to help ICBs develop care pathways, support training of healthcare professionals and offer guidance to the government.