Information for Primary Care on Postural Orthostatic Tachycardia Syndrome

Postural Orthostatic Tachycardia Syndrome (PoTS) is a benign condition that is commonly referred to the Cardiology clinic. It typically presents as symptoms of palpitation on standing, sometimes accompanied by light-headedness or fainting, which are relieved when laying or sitting down. Some patients also have non-cardiac symptoms such as bladder and gastrointestinal problems. It can be associated with other non-cardiac conditions such as joint hypermobility. This information is intended to help referrers to decide who needs to be referred to the Cardiology Arrhythmia clinic.

The diagnosis of PoTS can be confirmed in a community setting by performing an *active stand test* (see below). In patients with typical symptoms and a confirmatory active stand test, further investigations such as echocardiography, ambulatory ECG recording, or tilt table testing are not usually necessary.

When symptoms are atypical, referral to the Arrhythmia clinic can be helpful to differentiate between PoTS and other causes of palpitations and orthostatic intolerance, such as vasovagal syncope, inappropriate sinus tachycardia, and SVT. Symptoms that point to alternative diagnoses can include palpitations when supine, sudden syncope whilst standing, or other cardiac symptoms not described above.

Symptoms of unheralded syncope, an abnormal ECG, or in someone with a family history of an inherited cardiac disorder should always trigger a referral to the cardiology clinic.

Care for patients with PoTS is supportive (see below). In a small number of patients, drug treatment (for example Ivabradine 2.5mg bd or a beta-blocker such as Bisoprolol 2.5mg od with dose uptitration as required) may add additional symptom control. However, NNUH is not commissioned to provide a Neuro-Cardiology service and can only offer help in making the diagnosis and in providing supportive advice when the diagnosis is confirmed. Specialist quaternary centres with a Neuro-Cardiology service have limited capacity but do take referrals for complex cases and are listed on the PoTS UK website.

We would encourage you to direct patients who meet the diagnostic criteria for PoTS syndrome without ‘red flag’ symptoms to www.potsuk.org as a first step, and also to consider a trial of simple medical therapy when supportive advice has not helped. PoTS UK is an excellent resource for patients and relatives to help manage their symptoms. They have also published a one-page guide for GPs (see below) and more help is available on their website.

PoTS UK

PoTS on a Page – GP Guide

www.potsuk.org
info@potsuk.org

What is PoTS?

PoTS stands for postural tachycardia syndrome
First characterised and defined in 1993

PREVALENCE estimated to be 0.2%

Abnormal response by the autonomic nervous system to upright posture. In some, mechanism is lack of vasoconstriction on standing causing pooling of blood in abdomen and limbs, reduced venous return to heart, compensatory tachycardia and altered cerebral circulation

More common in females age 15 - 50

DISABILITY - equivalent to disability found in heart failure + COPD

ASSOCIATED WITH

- hypermobile Ehlers-Danlos syndrome and hypermobility spectrum disorder
- after viral infection eg COVID-19, EBV
- chronic fatigue syndrome /ME
- autoimmune conditions
- growth/puberty in children

When to suspect PoTS

SUSPECT PoTS in

- medically unexplained symptoms
- CFS/ME
- hypermobile or post-COVID patients

SYMPTOMS
3 commonest symptoms are

- lightheadedness (presyncope)
- fatigue
- palpitations

Other symptoms include

- fainting
- nausea, bloating, abdominal pain
- cognitive dysfunction - 'brain fog'
- poor sleep
- exercise intolerance
- shakiness, sweating
- postural headaches and migraines

SIGNS *occur on standing/prolonged sitting*

- tachycardia
- acrocyanosis - red/purple puffy hands and feet (50% of patients)

How to diagnose PoTS

DIAGNOSTIC CRITERIA
Sustained increase in heart rate of 30 beats per minute (40bpm in teenagers) from lying to standing associated with symptoms of PoTS.

STAND TEST - rest supine and record HR and BP. Then stand in a safe place and record BP and HR every 2 minutes to 10 minutes.

INVESTIGATIONS - ECG. Exclude anaemia, hyperthyroidism, postural hypotension, phaeochromocytoma

MISDIAGNOSIS
Mean time to diagnosis is 7 years
Meantime 50% of patients receive a psychiatric misdiagnosis e.g. anxiety, depression, hypochondriasis
Other misdiagnoses - CFS/ME

REFERRAL
To a specialist with an interest in PoTS - there is a list on the PoTS UK website:
https://www.potsuk.org/specialists

How to manage PoTS

AVOID TRIGGERS - heat, large meals, alcohol - drugs that lower BP

FLUIDS - at least 2 litres /day in adults
SALT - Adults: +6g/day (unless contraindicated)

EXERCISE - initially supine, graduated regimen, can take several months to improve symptoms

POSTURAL MANOUVRES to avoid fainting - avoid prolonged standing, elevate legs, tense buttocks + thighs, fold arms, tiptoe)

COMPRESSION - class 2, waist high tights

DRUGS - include β blockers, calcium channel blockers, ivabradine, midodrine, fludrocortisone, clonidine, SSRI, desmopressin, pyridostigmine, octreotide

CBT - to help adjust to chronic illness

IV FLUIDS - in an emergency only

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