

A Newcastle perspective of Positional Orthostatic Tachycardia Syndrome (POTS)

Positional Orthostatic Tachycardia Syndrome (POTS) is a condition where sufferers experience an increase in heart rate (tachycardia) upon standing up. This can sometimes be so severe that it affects normal activities of life, such as bathing and housework. Even eating can sometimes be significantly limited. The severity of these symptoms and how they impact upon function are said to be similar to those seen in common conditions such as chronic obstructive pulmonary disease and congestive heart failure.

Historically, many patients with POTS were given a diagnosis of Chronic Fatigue Syndrome / ME, anxiety or panic disorder. A recent cross sectional study performed in Newcastle has confirmed that 27% of those with a diagnosis of CFS have POTS which is important when the public health implications of CFS/ME, and fatigue in its more general sense, is considered.

In the Falls and Syncope Service in Newcastle we have recently looked at the numbers of those with POTS that are being seen in our clinics. Over the last 10 years we have seen over 70 patients diagnosed with POTS. These are predominantly females and most have been unwell for several years before we have seen them. The numbers of patients we are seeing with the diagnosis of POTS seems to be increasing year on year which either suggests that the condition is becoming more common or more likely that it is being increasingly recognised as a diagnostic entity by clinicians.

POTS can affect any age group but the majority of the patients that we see are young or middle aged. However, the oldest person we have seen with POTS was 82 years of age, so it is important to consider the diagnosis even in older age groups.

One of the questions that I am frequently asked in clinic is – ‘Will I get better?’ Currently, there is only limited data available on the prognosis of patients with POTS, so it is difficult to be sure what are the chances that someone who presents with POTS tomorrow being better in 5 years. Although in the few studies that there are, outcome can seem fairly bleak, I think it is important to realise that these studies were performed before we understood POTS and before we had the range of medication options that we have today. I believe that

studies performed in cohorts today would suggest better outcomes.

There are currently no licensed medications for the treatment of POTS and to date there have been no randomised controlled trials. A recent retrospective case series of 152 patients with POTS from the Mayo clinic underlines the current dilemmas faced by clinicians when seeing patients presenting with POTS. This study (the biggest published to date) describes 11 different treatments including 8 medications. So at the moment, treatment needs to be managed on a case by case basis until there are suitably large randomized controlled trials to inform our practice as to the best treatment.

In our unit we aim to individualise treatment and to focus upon management of the symptoms that are causing the patient most distress. The first things we do are to discontinue potentially culprit medications if possible and identify and treat any conditions that could be causing POTS (e.g. amyloidosis or cancer).

In addition to using medication, we encourage all patients to begin a gradual program of physical reconditioning particularly focusing upon gentle resistance training of the lower extremities and abdomen in order to strengthen the skeletal muscle pump. We try to ensure that patients with POTS have adequate fluid intake of around 2 litres per day (this should only include a small (5 cups) proportion of caffeine). Also, elasticated compression stockings are sometimes helpful when they provide at least 30 mm Hg of ankle counter pressure.

In terms of the future, we have recently started using one of the newer heart rate controlling medications that have come onto the market (Ivabradine) and there are several new treatments that are on the horizon that have the potential to offer real improvements in the management of POTS. What is urgently needed are randomised controlled trials of new and more established treatments so that we can fully inform our clinical management of patients with POTS.

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