

This article has been written to help those STARS members who are struggling with managing this debilitating condition. Understanding what her body demands and needs in relation to diet, exercise and rest, has enabled this STARS member to run a family and continue working in a demanding and sometimes stressful profession.

## WORKING WITH POTS

I have PoTS and vasodepressor(vv) syncope due to Ehlers-Danlos Syndrome (EDS). I also manage a demanding and unpredictable job, often working 10 to 15 hours per day without formal breaks. I was asked to write an article describing how I manage this problem -so here goes.....

I sleep with a head-up tilt - 2 blocks of wood under the headboard as this increases blood volume in the morning. I no longer have central heating on in the bedroom. This helps stop dizziness and sweats when I get dressed but, as you can imagine, this move wasn't very popular! I wear layers of clothing so that if I overheat I can remove something and remain respectable!

Next, I load up with fluids. If I aim for 2 ½ litres it means I consume at least two (refilling a half litre sports bottle allows me to keep track). A huge mug of hot milk mixed with espresso works well – caffeine raises blood pressure slightly and I drink 2 or 3 cups a day. I often feel better for 2-3 hours. I have a glass of water with my medicines and set off for work.

My consulting room is full of food and drinks - the filing cabinet resembles a larder. I find if I eat too much or allow myself to get hungry, I feel unwell. Refined carbohydrates such as white bread and cake make symptoms worse. I eat a bowl of fibre cereal immediately before starting work -that keeps me going until mid morning.

Even before I learned my diagnosis, I found that I had to graze all day long - little and often. I bring high fibre sandwiches and cartons of soup, bananas etc. I keep breakfast-bars, oat-cakes, flapjacks and dried noodles for emergencies. Sports drinks are really helpful, especially when I am unable to take a break. The EDS causes abdominal pain after proper meals so I reserve them for evenings when I can lie down afterwards.

I try to avoid standing still. I don't find the usual counter-manoevres such as crossing legs and squeezing a fist very helpful. I find that going for a short walk or rocking up and down onto my toes when I have to stand still works better (actively using calf muscles). It looks a bit odd, but people are used to seeing me do this at work!

Meetings and lectures are difficult. I become just as dizzy with prolonged sitting as with standing. After an hour or so, I usually have a headache, sweats, palpitations, nausea and poor concentration. Disc problems in my back due to the EDS make meetings painful. I never sit still. I cross my legs or elevate them if possible - I am quite little and can curl them up on a chair. Support tights (class 3) may help. I buy the silverline ones as the silver prevents bacterial growth and keeps them fresh! The black tights look quite good. However, if the environment is hot, tights make the PoTS worse! I carry bottled water, high-fibre cereal bars and little sachets of salt from fast-food restaurants in my

handbag. If meals are provided at meetings, I take Slow Sodium salt tablets - it's more discrete than sprinkling salt on your sandwiches!

This may all sound like a lot to think about, but in fact I had already made many of these adjustments before I knew I had PoTS. I didn't understand why, but they made me feel better. The rest became part of the daily routine.

I am fortunate in that I only work three or four days a week. I know that PoTS/vasodepressor syncope will deteriorate if I don't keep fit. On my days off, I try to exercise four times a week but, if I am honest, I usually manage two or three sessions only. I used to play tennis and badminton, but found myself becoming dizzy and disorientated. I now swim (boring) and play table-tennis (badly)! I also have to fit in rest periods as I am usually exhausted if I have been working or exercising the previous day.

I won't pretend to have found all the answers. I have read that everyone's 'PoTS' is different and what helps one person may not help another. During investigations, I was off work for a while. Within days of commencing fludrocortisone, I was able to return to work reliably. However, I still regularly have days where I want to lie down, curl up and shut my eyes until it all goes away..... but I can't.

Fortunately, I have wonderful colleagues at work. They have always been supportive so it is important to keep them informed. Although I work within the NHS, no-one had heard of PoTS and knew little about EDS. Providing information, helps them to be aware of the tasks that I find difficult and so don't overload me. In return, I try to take on extra management tasks, especially on my days off, where I can work at my own pace.

Although my symptoms are not fully controlled, I am optimistic that future adjustments to my medication will improve things further - unfortunately, the wheels of the NHS turn very slowly. I am very much aware that, although I have a debilitating problem, it will not shorten my life and may confer some benefits such as reduced incidence of hypertension, stroke and heart problems. Many people are not so lucky.