

Living with postural orthostatic tachycardia syndrome

Lorna Busmer explains how this condition has affected her daily life, and outlines some of the frustrations involved in getting a diagnosis and reducing the severity of symptoms

I have always been an active person, enjoying all types of outdoor activities such as hill walking, biking, skiing—generally anything that gets me outside. During 2006, aged 34, I had the opportunity to spend a number of weeks working as a ski instructor in the Alps. At one point I developed a cold, but that did not stop me. I then had a fall—nothing dramatic, I just winded myself. After this I became emotionally unstable, having been fine the day before. During my next ski trip, a couple of weeks later, I found I was struggling to ski as I would normally; not rushing out of the door in the morning, instead enjoying long leisurely lunch breaks and always home in time for afternoon tea—very unlike me! I blamed this on the altitude and having already spent a number of weeks skiing.

Throughout the summer my low mood persisted so I did more exercise, taking up climbing and mountain biking, since I felt like I was losing my fitness. Eventually my mood lifted a little, but my exercise intolerance worsened. One day I could do what would be normal for me: a 20-mile bike ride (although at an increasingly slower pace and I struggled to keep up with my friends). The next, I was completely wiped out, fatigued and exhausted. The fatigue and extreme tiredness persisted as I was determined to maintain my normal level of activity. Looking back, I was exhausted, my body desperately telling me to stop.

Over Christmas 2006 I developed palpitations after drinking coffee and found my resting heart rate to be 120 beats per minute. I was referred to a cardiologist who carried out various tests including a 24-hour Holter monitor, 24-hour urine collection for catecholamines, and basic blood tests. Unfortunately, as no arrhythmia was found, and all other test results were normal, my symptoms were put down to depression and anxiety.



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Getting a diagnosis

I remained tachycardic with a high resting heart rate, which rapidly accelerated beyond 150 beats per minute on minimal exertion, causing shortness of breath and chest discomfort. By this point I was struggling with daily life, and even the few metres' walk to the shops was a challenge. The fatigue and tiredness were profound.

A number of months later I was referred to an electrophysiology cardiologist who diagnosed me with inappropriate sinus tachycardia. Unable to tolerate beta-blockers, I started on diltiazem (a calcium-channel blocker), which has helped to slow my heart rate down. I plodded along for a couple of years, until another cardiologist sent me for a tilt table test and autonomic function testing, which pointed to postural orthostatic tachycardia syndrome (POTS). My systemic symptoms, such as sleep disturbance, pre-syncope episodes, irritable

bowel syndrome and fatigue, contributed to this diagnosis. *Table 1* outlines the features of POTS and the management strategies that are used.

Sertraline (a selective serotonin reuptake inhibitor (SSRI)) was added, which has greatly improved my sleep, with some reduction in tachycardia, and overall improving symptoms a notch further. It is frustrating and time-consuming trying many different drug options before finding the right combination.

Unfortunately, awareness of POTS remains poor among medical professionals, with only a handful of specialist centres round the UK. It took me four years to get an explanation, and I know that's good compared to some.

Adjusting my life

Learning to manage POTS is an ongoing challenge. It's a hidden condition, so very few people fully appreciate what it is like to live with. I wish they could stand in my shoes for a while to find out. I often feel I am not believed as I look so well. Medication has reduced the tachycardia, but no day goes by without symptoms. Some days feel like I'm wading through mud with flat batteries, and just getting out of the house is too much effort. A slight virus, a bad night's sleep, a drop of stress, or too much exercise the day before all compound symptoms.

I have had to reduce my working hours and change my job as I could not manage the eight hours as a nurse in accident and emergency on my feet. Now I work as an advanced nurse practitioner in primary care, so I get my own seat!

I have regained some exercise tolerance; although I remain a long way from where I was before, muscle fatigue, and the effects of post-exercising fatigue limiting me the most. Medication has most certainly helped slow my heart rate, at least it puts a

cap on it, stopping it from going too high; but it does not control the rate of acceleration. I still don't need to do much for my heart rate to be over 100! As a result, I know my muscles do not get adequate oxygen and I get very tired.

I have had to reset my goals in life and accept my limited physical capacity, but also acknowledge I have done myself a favour by keeping myself as active as possible.

Cycling was my everyday norm, covering miles every week. Now it's an occasional treat as the post-exercising fatigue is profound.

Skiing is my passion, previously I'd been aiming to ski better and harder. I still struggle when I see my friends, who I used to ski with, doing run after run of high-intensity skiing, all day long ... then getting up the next and doing it all again. Now I focus on teaching other people to ski and remain thankful for what I can still achieve.

I have taken up new hobbies such as climbing and pilates as they have a greater emphasis on muscle strength rather than cardiovascular fitness.

Climbing is a great way to spend all day outside with wonderful people, hanging around on rock. Climbing has been described as 'an activity for people who do not do activity'. I never used to climb—too much sitting around for my liking—preferring a good stomp over the hills as I needed to expend my energy. Now I love it. I have learnt a new skill, have new friends and I'm thankful that I have found an activity that is achievable even with POTS.

With my determination and positive outlook, I continue to push myself through the fatigue and tachycardia to live life to the full. I have learnt to pace myself, to do things slowly. I have learnt when to push through symptoms, and when to stop and rest. I enjoy and appreciate everything in life and continue to be thankful for what I can do. POTS has opened up new opportunities such as meeting new people, developing new interests and spending more time with people, which would have never happened before.

Table 1
Postural orthostatic tachycardia syndrome: The basics

Postural orthostatic tachycardia syndrome (POTS) is a condition of the autonomic nervous system. It is characterized by symptoms of orthostatic intolerance such as headaches, fatigue, palpitations, sweating, nausea, syncope, near syncope and dizziness associated with an increase in heart rate from the supine to upright position of greater than 30 beats per minute, or a heart rate of greater than 120 beats per minute within 10 minutes of standing (Soliman et al, 2010). Diagnosis is usually based on a tilt table test. Other autonomic functions such as digestion, bladder control, temperature control, sweating, and stress responses can also be affected.

POTS has a significant impact on every aspect of life, with symptoms and limitations of daily activity varying from mild to severe (Johnson et al, 2010). Disability can be equivalent to that found in heart failure, with 25% of patients unable to work (Benrud-Larson et al, 2002) and some may be wheelchair-dependant.

Management

POTS cannot be cured, but with the correct medication and appropriate lifestyle changes can be managed, therefore improving quality of life. Non-pharmacological treatment options include increasing fluid and salt, compression stockings and light to moderate exercise (Grubb et al, 2006). Pharmacological treatment options include fludrocortisone to aid sodium retention and therefore elevate blood pressure; midodrine to constrict the peripheral blood vessels to aid venous return; beta-blockers, calcium-channel blockers and ivabradine to slow down heart rate. Selective serotonin reuptake inhibitors (SSRIs) such as sertraline have been used, as serotonin plays a part in the control of both heart rate and blood pressure (Thieben et al, 2007). Sertraline also has the benefit of improving sleep in some patients. Treatments must be highly individualized, as the same drug can have very different effects on different individuals. People with POTS tend to be drug-sensitive, therefore drugs need to be commenced in tiny doses and effects monitored very closely.

Further information can be obtained from

POTS UK: www.potsuk.org

STARS (Syncope Trust And Reflex anoxia Seizures): www.stars.org.uk

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