Exercise rehabilitation for PoTS – My experience

When I first read about exercise therapy I thought, “are the clinicians just saying that POTS patients are unfit?” I used to be very active as a teenager and in my early twenties, with lots of sports hobbies – horse riding, judo, gymnastics, dancing - but as my symptoms increased there was a continuous gradual reduction in activity. I think it is a fairly normal response to try to avoid triggers; and since I was regularly stumbling off the cross-trainer at the gym, lightheaded, or nearly collapsing at salsa dancing classes, I began to avoid these things over time. Even “gentle” activities like Pilates or yoga classes became difficult because of all the postural changes and stretching – at my worst period in 2007-8 looking upwards or stretching to yawn were enough to make me almost blackout, and I was having around 30 semi-conscious episodes or collapses per day. Consequently any formal exercise seemed out of the question at the time.

Perhaps if I knew then what I know now, I would have had the “tools” to try to maintain some muscle strength and reduce the deconditioning in a safe way. There has definitely been a pattern of long peaks and troughs over the last 18 years, and I certainly feel more geared up now to avoid a big spiral downhill, or at least reduce the severity of the spiral, if my condition does deteriorate again.

But back then I just felt safer avoiding exerting myself as it only seemed to make things worse. By the time I returned to work after maternity leave in 2010, I was better than in 2008 but still quite symptomatic each time I stood up, and I was really struggling pushing the pram home from nursery after a busy workday. I would stand up to get out of the taxi, nearly collapse, enter the nursery, nearly collapse again with the change from cold to hot, and then had a walk home to get through with a racing heart, legs like lead, and my vision going blurry when I stopped at the pedestrian crossing. I was grateful for a pram to lean on, but frightened of passing out whilst responsible for my child! The fatigue was overwhelming and my pre-syncope symptoms were quite severe, especially in the evenings.

Fortunately my symptoms began to improve throughout 2010-11 as I started on new medication, under the careful and expert guidance of the Autonomic Unit at the National Hospital for Neurology and Neurosurgery in London.

I was interested in the concept of exercise therapy, which I had read a little bit about online. I followed the rationale that the more cardiovascular fitness I had, the better my body could deal with the stresses and demands that POTS added. I also understood the logic that if the leg muscles and core tummy muscles were stronger they could push the blood back up to my brain more effectively with each muscle movement; and they could help to prevent the blood from pooling when standing up. It made sense, but I just didn’t know what to do, or how to do it. Climbing a flight of stairs was enough to make me almost pass out, so how could I exercise safely?

Furthermore, I had a dilemma: the Autonomic Specialist Nurse had advised me that I needed to conserve energy in order to manage my fatigue, and we had discussed some helpful, practical tips. But how do you conserve energy if you also need to expend it through exercise to try to improve your symptoms?

During summer 2011 I was fortunate to be referred by my GP to a Cardiac Rehab Highly Specialist Exercise...
Practitioner at a local hospital. I was not the usual kind of post-heart attack patient that the clinician generally saw, and he had not come across POTS previously. However, he contacted colleagues from the Autonomic Unit in London, spent some time researching and understanding my medical condition, and used his specialist experience with exercise rehabilitation to devise a programme for me.

It was individually tailored, because everyone’s starting point is different. Some syncope and POTS patients may still be very fit (but perhaps less so than they used to be); some people may be wheelchair-users due to the severity of their symptoms, and consequently the deconditioning in the leg muscles may be greater.

The manifestation of symptoms might also differ for people with POTS. For example I experience multiple lightheaded and near-blackout symptoms daily (with warning signs and specific triggers), whereas other people may have a more predominant symptom of nausea, chest pain or persistent tachycardia. I have cough syncope and also struggle with changing from cold to hot environments, so swimming can be difficult for me on both counts. But this might be an ideal method of building up cardiovascular fitness for someone else.

Therefore symptoms of the syndrome may present different challenges for each person, and this would need to be managed on an individual basis; consequently there is no “one size fits all” programme. However, there is a set of general principles for exercise rehabilitation, which Edward Caldow shared in his presentation at the STARS Patient’s Day in September 2012.

We heard from other patients at the conference that exercise does not work for everyone, since there may be other side-effects that are very difficult to manage, or it may not improve their symptoms sufficiently (perhaps when their starting level of fitness is higher). These are very valid points, and I fully accept that everyone is different, just as people respond to medications in diverse ways. I just wanted to share my personal experience here to show how exercise rehabilitation has helped my individual situation — in combination with good medical management and occupational therapy — in the hope that it could help someone else too.

It has been hard work — and it still is - if I am truthful, because this has to be a lifestyle change for the long term; so I had to make changes psychologically and practically, with help from my husband, to make it sustainable. However, this is the same principle as any other person who embarks on a long-term healthy eating or exercise plan — there is no quick fix and you have to change how you think and behave.

The added complexity for me was that I was starting out with overwhelming fatigue and symptoms that meant it frequently took 15 minutes to climb the stairs and multiple near-blackout episodes per day. I also had a little girl, Eva, who needed her mummy’s reserve energy after work — so I was often in bed by 8pm, not long after my 3 year old daughter.

I was also nervous of undertaking exercise: having spent so long trying to avoid the things that made me feel faint, it felt strange and risky to think I might actually cause myself more syncope problems by trying out this programme. I had also heard a cardiologist imply that POTS patients needed to get really fit by pushing themselves and their heart rates like marathon runners. This suggestion seemed so wildly unrealistic for me, with the symptoms I had, that I wasn’t confident I could improve my fitness at all, if that was what it would take to make my POTS better.
The Exercise Physiologist was very reassuring that we would take things really slowly and gently, and monitor symptoms closely to avoid making things worse. And we would not be aiming to run any marathons! After an assessment in clinic, I started using a foot-bike at home, so I could sit down to exercise on the sofa safely, and consequently there was no worry if I had pre-syncope episodes. I could manage around 7 minutes of seated foot-cycling around August/September 2011, before my heart was really pounding against my chest or I felt really fatigued. I was advised to slow down or stop if the effort increased too much, so that I didn’t push myself to the point of the near-blackouts that were a regular feature of my day.

I also started using a theraband – a stretchy piece of latex - with specific exercises to strengthen my leg muscles and core abdominal muscles. I also worked some arm muscles too, for variety and also to help with lifting activities (the washing basket or small child, for example!). These exercises can be done sitting down, using a very low resistance theraband, gradually building up the resistance or the number of repetitions - so I think many people would be able to try them. The theraband is also a very cheap and transportable way of exercising.

I was very motivated to try but also very overwhelmed with the tiredness and the difficulty of fitting a session in with work and family time. It may only be a few minutes on the foot bike or half an hour of theraband exercises, but there was a period of recovery time afterwards to factor in, and there was not a great window of opportunity to exercise when I needed to get in bed so early, in order to be able to function the next day at work.

It was (and still is) about trying to find the right balance. I do try to keep in mind that time invested in the exercise programme has lead to an improvement in symptoms over the last year, which ultimately gives me more time and energy to maintain and enjoy other activities with family and friends. However, I didn’t know this would be the case at the start, so it was hard at first to make myself follow the programme.

Sometimes I was so tired I would feel symptomatic at lower resistance levels or after a shorter session. So it could be de-motivating when the effort of exercising was exceptionally hard just to “achieve” less than the week before.

I often felt deflated following periods of illness, coughs and colds, when my POTS would worsen and I had the cough syncope to deal with; Similarly when my husband Eric had to work away overnight or if he or Eva were unwell and I had more to do at home, my energy was spent and it often felt a bit much, trying to fit the exercise in and prioritise it.

A conversation with the Autonomic Specialist Nurse in London at a review appointment really helped me, when she pointed out that neurological conditions are fraught with ups and downs and so exercise rehabilitation for POTS will never be linear – that is, I should not expect to achieve X fitness level after doing Y exercise Z times per week, it is more complex due to the fluctuations in the condition by the hour and by the day.

So gradually I started to accept this “peaks and troughs” cycle, and find ways to manage this, psychologically. I think I was frightened that if I missed a few days I would give it up all together, so I gave myself a really hard time if I had missed sessions, even if there were good reasons why. The Exercise
Physiologist suggested that I keep an exercise diary, which was a really valuable tool. We reviewed it at our monthly appointments and over time I started to have faith in myself that I was keeping it up, and that good days or bad days aside, the programme was having a good effect overall.

Using the exercise diary helped me to be aware of extra activity and the impact on symptoms or ability to exercise. The fatigue was still there but the diary helped me to understand and consider the cumulative effect of activities and triggers – for example whether I experienced increased fatigue or blackouts the next day because I had overdone the exercise the day before, or if in fact the symptoms were more likely to be due to the hot weather and a really busy couple of days at work.

Over time Eric and I also made some practical changes to adapt to the new routines, such as changing the spare room upstairs into a second lounge where I could exercise, so that I didn’t have to climb the stairs to get to bed after doing exercise. This reduced my symptoms post-exercise, and gave me no excuses on the bad days!

By January 2012 we bought an upright exercise bike – it was a kind of reward after a few months for having made the lifestyle changes to include exercise in some small capacity several times a week. And by then I felt confident enough with the foot-bike, sitting upright on the dining room chair instead of the sofa, that I felt I could manage the upright bike.

And this increased confidence was because I was using the “Rating of Perceived Effort (RPE) scale (or “Borg scale”). The RPE scale is an easy-to-use practical tool to ensure you don’t overdo things and bring on symptoms. I learned to stop or slow down before that point was reached. This meant I could gauge how much effort it was taking to do the current level of exercise and alter the programme or activity accordingly. So one night it might feel like RPE 15 (“difficult”) to do 20 minutes on level 5 of the exercise bike; yet it might feel like RPE 16 to do only 5 minutes on resistance level 3 the next night. Perhaps this was because I had a cold, or I’d done extra physical activity during the day like housework or a walk to the shop, or maybe Eva had inexplicably woken us up at 4am and I was more tired than usual! Using this scale takes into account how you are feeling at that moment in time and so you can adjust your exercise programme (perhaps by reducing the resistance level on the bike, or doing less repetitions of the theraband) and feel safe - instead of setting yourself unrealistic targets and pushing yourself until you pass out!

I honestly didn’t think that doing such small amounts of exercise could make such big changes, and particularly if I was reducing the length of time or the resistance when the going got tough. For exercise to make a difference, I thought that you really needed to get a sweat on, and keep pushing yourself to the maximum. I was wrong! You do need to push yourself a little in order to try to improve, but it can be done within safe limits. The goal is not to do 30 minutes of exercise, regardless of how it is making you feel at the time, and pay for it later! It’s a subtle difference but quite hard to accept when you are quite competitive by nature and just want to beat your last target!

I also had to get used to the fact that increasing the heart rate is a normal part of exercise. I get so many palpitations and I am so aware of my heart rate or rhythm that it took quite some time to get used to the fact that a rising heart rate is a normal response to exercise and did not necessarily mean I was going to collapse. I had to get used to exercise again, not panic, use the RPE scale and occasionally a pulse check to reassure myself, and adjust the exercise if necessary to keep within my safe limits.
Between January and March 2012 my calf and thigh muscles increased in circumference by an inch, as the muscle toned up. I moved from a yellow theraband to a higher resistance red band and by summer time, around 9 months later, I started using the green theraband. And I managed up to 40 minutes of cycling, or 30 minutes of interval training (going a bit faster or harder for short bursts). I started on level 1 (of 16 resistance levels on the exercise bike), and on a good day I can spend short blasts at level 7 now. Having said that, I still have my level 1 days!

Crucially, I also had to learn to put the increasing levels of fitness and energy conservation techniques in to practice in the real world (outside of my lounge!), to increase my independence. I was so fortunate to obtain help from a Highly Specialist Occupational Therapist, who works closely with the Exercise Physiologist on the Cardiac Rehab team. I think my improvement after the first few months of the programme also coincided with seeing the OT, who provided psychological support and helped me further with energy conservation.

For example, we talked about energy being like a bank balance, where you “deposit” some energy in order to save it up to “withdraw” or use later. So I planned better, for example to avoid making unnecessary extra trips up and down stairs. We made small adaptations to the home such as putting a tall stool in the bathroom so I can sit to brush my teeth, in addition to the one in the kitchen so I can sit to chop vegetables or stir dinner. I sit to put washing in the machine and I sit when I reach the top of the stairs. I used to resist sitting down as much as possible and push on through the lightheaded spell; but I realize now that sitting “preventatively” generally leads to less spells overall!

I began to understand that standing for long periods (for instance preparing food) was making my stretchy blood vessels fight against gravity all the time, and there was no functional gain from this (standing for longer wasn’t going to make me any better). By depositing some energy in “the bank” through avoiding some of these standing tasks or just sitting down to do them, I could withdraw some energy to spend on the types of activities that I needed to do in order to get better, like doing some theraband exercises, which would have functional benefit by increasing the muscle tone. Alternatively, I could withdraw that energy later to undertake necessary daily activities more safely – such as walking home from nursery with Eva - or to do things that would just improve my quality of life, such as taking Eva to the park on my own and standing to push her on the swings for longer.

This links in with the some CBT techniques I discussed with the OT. I used the confidence I was getting from the encouraging exercise results to plan and successfully achieve some practical steps forward in day-to-day life, like catching a train on my own with my little girl. The sense of freedom and independence was huge!

It’s not perfect. But there are now many more good days! I do truly believe that the exercise programme has had a strong impact on my quality of life. I have improved my standing tolerance, which means that on good days I feel more able to stand at a bus stop for a few minutes, or in a shop queue on my own, so I feel less dependent on other people all the time, and more able to do normal activities with my little girl. When I joined in with Eva and my nephews kicking around a football in the park, I realized how much I had felt unable to do before. It is so good to have a bit of “normality” back – and to feel more in control. This is something that I am able to do myself, to help myself, and I am not entirely at the mercy of whether a drug will work for me or not.
My core muscles are stronger so I have less joint and ligament pains (I have mild joint hypermobility and I had ligament problems post-pregnancy). Strengthening my core muscles means I seem to pass out less when I cough and sneeze, particularly if I tense those muscles if I get warning. I tense the large legs muscles and core muscles when queueing up or when I get in a lift, and there are less lightheaded spells because these muscles are more effective in stopping the blood pooling.

This helps to break the cycle, since the more I collapse, the more tired I get; and the more tired I am, the more I collapse. Being able to prevent some of these spells helps to reduce this recurrent effect for me. The reality of this is really important to me - less collapses in the office, less falls in the supermarket queue, more freedom and confidence to get out and about safely with my family. Eric can also relax a little more when leaving me anywhere on my own, now that I am safer and a bit more independent again – the importance of this cannot be underestimated either, since our families do spend a lot of time worrying about us.

I don’t think there is one thing on its own that will ever be “the answer” – POTS is a long-term, complex condition. Exercise therapy may not work for everyone, as all syncope treatments seem to be a matter of trial and error. I still have daily symptoms – but a lot less than this time last year. So all I can say is that my personal experience has shown me that exercise rehabilitation, alongside OT support, medical treatment and lifestyle changes, has made a big difference to me and my family, and I would encourage any one to give it a try.

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