



PoTS UK

welcome you to our
training event

Autonomic Dysfunction: Exercise and Activity

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Background



- Qualified in 2004
- 17 years working in exercise rehabilitation
- Nearly a year working with long covid patients
- Dysautonomia patients are regularly seen in the long covid service, with a return to exercise key
- Studies have found that 67% of long covid patients have dysautonomia (Larsen et al, 2022)
- POTS has doubled since the pandemic

Relevance



Studies have found that POTS can cause:

- A smaller heart , reduced stroke volume, reduced venous return, reduced blood volume, impaired vasoconstriction (Fu et al, 2010)
- Peripheral alterations (Blitshteyn, 2022)
- Reduced brain blood flow (Ocon et al, 2009)
- An exacerbation and heightened psychological burden/effort (Raj et al, 2018)
- Deconditioning (Joyner et al, 2008; Parsaik et al, 2012)
- Reduced aldosterone (Mustafa et al, 2011)

2 Approaches to Dysautonomia



Inactivity and Dysautonomia



- Lack of activity can prevent delay and hamper recovery for long covid/dysautonomia
- Exercise intolerance can lead to neuromuscular and central fatigue
- Cardiovascular deconditioning (cardiac atrophy and hypovolemia) may contribute significantly to POTS and its functional disability
- Venous pooling is one of the major causes of orthostatic intolerance

(Fu and Levine, 2018)

Why Exercise?



“Physical reconditioning with regular exercise is the cornerstone of treatment for POTS ([Sheldon et al. 2015](#)) especially in the chronic state when physical disability has been compounded by cardiovascular deconditioning”.

Why Exercise?



- Increased vascular function: venous return, LV mass, end-diastolic volume, stroke volume and blood volume (Fu and Levine, 2018)
- Increased VO2 max (Fu and Levine, 2015)
- Increased muscle changes: strength gains, peripheral recruitment, oxygen supply (Lee, 2022)
- Improved mental health (Raj et al, 2018)
- Improved renal function (Mustafa et al, 2011)
- Reduction in sympathetic response, prevents/reverses deconditioning, improves general function (Fu and Levine, 2015)

A Word of Caution



- Need to be managed carefully to avoid PEM
- Symptom-titrated
- Patients may not be able to tolerate some exercise
- HR and fatigue needs to be monitored
- Sometimes POTS symptoms can worsen with exercise
- Exercise won't cure POTS

Protocols



- Levine/Dallas and Children's Hospital of Philadelphia (CHOPS)
- CHOPS doesn't include pre-exercise
- 4 months of recumbent exercise: bike, rowing, swimming
- Month 4 upright bike
- Month 5 further upright training
- Alternating strength and CV training

Disadvantages



- Rigid
- Need equipment, such as HR monitor, rowing machine, etc
- Use of leisure centre, cost associated
- If needing to use leisure centre, too symptomatic
- Time intensive up to 7 days a week, needs commitment
- 8 month programme, many services can not accommodate this
- Patients who are severely affected might not access services so early

Relevance to Long Covid



- Much of our approach involves increasing parasympathetic activity and reducing sympathetic activity (polyvagal approach)
- Deconditioning is a problem in LC, deconditioning can lead to more fatigue and worsens symptoms of POTS/dysautonomia
- Exercise can have a positive impact on this and is key to recovery
- Exercise specialists agree with the benefits of exercise retraining
- Many patients get into a boom/bust pattern or one of inactivity which worsens symptoms

Where does exercise fit in our pathway?



- Fatigue is stable OR
- Very slow recovery and deconditioning is likely impacting on fatigue
- Breathlessness at rest has improved sufficiently
- Patient has a good knowledge of PESE to be able to self monitor with exercise
- Any concerns around chest pain/ palps/ dizziness/obs have been explored
- The decision to exercise is appropriate
- The patient is happy to exercise
- Often seen once dysautonomia is stable

Exercise Principles



- Reinforce breath control techniques during exercise
- Provide WHO booklet and introduce the BORG scale as a measure of exertion levels
- Explain that a degree of breathlessness is normal with exercise
- Introduce target heart rate – if this is appropriate
- Explain concept of symptom titrated exercise
- Explain PEM- affecting energy/ concentration/ memory/ sleep/myalgia/ Explain self monitoring between sessions- give fatigue diary
- Safety advice when doing exercises at home
- Bring any medication needed e.g inhalers to each session
- Manage patient expectations

Progression – symptom titrated approach



- Guidance based on WHO for long covid
- Emphasis on symptom monitoring/titration
- Pre exercise tests
- Monitoring during exercise
- Increase to next stage every 2-4 weeks
- If note a relapse , step back down a stage
- Start lower and slower
- Want to see a normal response to exercise – breath control/ HR

BORG Scale and WHO Phases



BORG CR-10		Phases				
Score	Level of exertion	1	2	3	4	5
0	Rest/no exertion at all					
1	Really easy/extremely light					
2	Easy/very light					
3	Moderate/light					
4	Somewhat hard					
5	Hard					
6						
7	Very hard					
8						
9	Extremely hard					
10	Maximal exertion					



Phases

Phase 1 (BORG 0/1)

- Prepare to return to exercise
- Activities include gentle walks, flexibility and balance, stretches, Thai Chi
- Could be recumbent based on symptoms

Phase 2 (BORG 2/3)

- Low Intensity Exercise
- Walking, light-household/garden tasks, pilates, yoga

Phase 3 (BORG 4/5)

- Moderate intensity exercise
- Adding Inclines to walks, stairs for exercise, light bands/weights, gentle swimming, cycling

Phase 4 (BORG 5-7)

- Moderate Intensity – aerobic and strengthening
- Brisk walking, jogging, cycling, dance classes, Zumba

Phase 5 (BORG 8-10)

- Return to normal baseline

Adapting to Dysautonomia



- Cautious approach that increases parasympathetic activity and reduces sympathetic activity to normalise sensory processing
- Physical reconditioning should start early (according to studies)
- Slow progression, may need to start with bed exercise or recumbent before progressing
- Pool or water submersion can help
- Exercise that doesn't cause orthostatic stress
- Leg and core strength to reduce orthostatic stress
- Body-based therapies can benefit dysregulated nervous system
- Increase frequency and duration then bring in upright exercise
- Lifestyle and symptom advice

Patients in Our Pathway



- Young, fit, patients of working age
- Marathon runners, soldiers, wanting to become more active
- Very rarely a linear progression
- Often take a step back in recovery
- Need flexibility
- Need to utilise skills in managing patient expectations, anxiety when regress
- Constant encouragement, measures of progress
- 100% of patients show improvement in 6MWT over 6-7 sessions

Specific Patient



Background

- 32 year old female
- Previously went to the gym and ran 10ks
- High levels of fatigue
- Floaters, dizziness and migraines
- Breathing pattern disorder
- Anxiety

Treatment

- Fatigue management
- Anxiety (CBT)
- Referral to GP for medication
- Vestibular rehab
- Breathing exercise
- Exercise pathway
- Lifestyle advice

Specific Patient



Currently

- Treadmill exercise, working to BORG 3
- Continuing to wear compression stockings
- Building leg strength
- No longer on medication
- Awaiting cardiology review

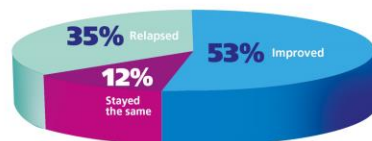
Our Results



Clinical outcome measures

(patient self-reported measures at discharge)

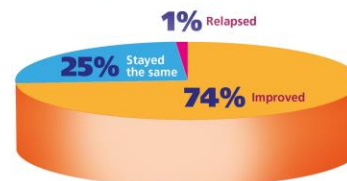
Chalder Fatigue Scale



Clinical outcome measures

(patient self-reported measures at discharge)

Medical Research Council Dyspnoea Scale



Conclusion



- Dysautonomia causes a number of debilitating symptoms
- If there is opportunity to exercise patients, an early approach is beneficial, providing fatigue is stabilised
- Exercise has a number of benefits to the patient with a dysregulated autonomic nervous system
- Exercise must be carefully managed to avoid a boom/bust pattern
- We will look to build in more early exercise

References



POTS versus deconditioning: the same or different? (Joyner and Musuki, 2008)

Decreased upright cerebral blood flow and cerebral autoregulation in normocapnic postural tachycardia syndrome (Ocon et al, 2009)

Cardiac Origins of the Postural Orthostatic Tachycardia Syndrome (Fu et al, 2010)

Abnormalities of Angiotensin Regulation in Postural Tachycardia Syndrome (Mustafa et al, 2011)

Deconditioning in patients with orthostatic intolerance (Parsaik et al, 2012)

2015 Heart Rhythm Society Expert Consensus Statement on the Diagnosis and Treatment of Postural Tachycardia Syndrome, Inappropriate Sinus Tachycardia, and Vasovagal Syncope (Sheldon et al, 2015)

Exercise in the postural orthostatic tachycardia syndrome (Fu and Levine, 2015)

Cognitive and Psychological Issues in Postural Tachycardia Syndrome (Raj et al, 2018)

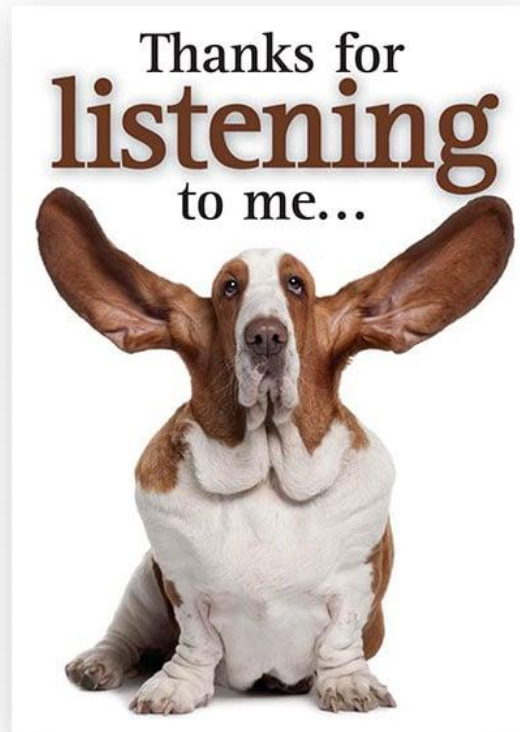
Exercise and Non-Pharmacological Treatment of POTS (Fu and Levine, 2018)

Characterization of Autonomic Symptom Burden in Long COVID: A Global Survey of 2,314 Adults
Larsen et al (2022)

Is postural orthostatic tachycardia syndrome (POTS) a central nervous system disorder? (Blitshteyn, 2022)

Strength training to manage POTS (Lee, 2022)

Thanks for listening



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