Rehabilitation for PoTS
PoTS UK Masterclass

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Plan

- Share an approach to rehabilitating people with PoTS
  - Integrating key PoTS exercise related research
  - Anecdotal experience
- Case studies
Acknowledgments

Patients
Dr Nelly Ninis
Professor Christopher Mathias
Professor Rodney Grahame
Dr Alan Hakim
Dr Hanadi Kazkaz
Dr Inge de Wandele
Dr David Low
Professor Peter Rowe
Interest started with complex referrals

- Joint laxity/ hypermobility / joint instability (hEDS/ HSD)
- Persistent widespread pain
- Persistent fatigue
- Pre syncope and sometimes fainting
- Temperature dysregulation
- Gastrointestinal symptoms - reflux, slow transit
- Bladder symptoms – irritable bladder, incontinence
- Allergies - rashes
Onset
GI manifestations

Cardiac Dysautonomia

Musculoskeletal

Pain

Fatigue

Bladder

Allergy/MAC

Mental Health

GI manifestations

systemic severity scale
Ninis, de Wandele & Simmonds 2015
Problem based approach - Explore expectations - Choice
Rehabilitation Principles

Education:

Reassurance

Pacing – fatigue and pain management

Agree and set realistic goals

Anxiety management

- Cognitive Behavioural Therapy, Relaxation, Mindfulness, Hypnosis
- Hyperventilation - Breathing Exercises

Sleep management

- Sleep routine
- Timing of food and exercise
- Screen time
- Sleepio App
Monitor medications: often complex cocktail

Advise on non pharmacological treatments

- Compression garments – aid venous return
- Fluids and salt – maintain blood volume
- Dietary advice – small meals, low carbohydrate, FODMAPS

Design and implement exercise reconditioning programme*

Evidence suggests that orthostatic intolerance and PoTS are related to deconditioning (Fu et al., 2010; Parsaik et al., 2012; Sheldon et al., 2016)

Cause or Effect?
Monitor medications: often complex cocktail
Advise on non pharmacological treatments
  • Compression garments – aid venous return
  • Fluids and salt – maintain blood volume
  • Dietary advice – small meals, low carbohydrate, FODMAPS
Design and implement exercise reconditioning programme*

Evidence suggests that orthostatic intolerance and PoTS are related to deconditioning (Fu et al., 2010; Parsaik et al., 2012; Sheldon et al., 2016)

Cause or Effect?
Regardless of the relationship – deconditioning negatively influences cardiovascular function
Premise: Long term benefits of improved physical fitness counteract orthostatic intolerance

- Increased blood volume
- Increased cardiac output
- Enhanced vascular compression due to increased muscle mass and tone
- Improved endothelial function
- Improved baro-reflex function
Case Control Study: 19 cases of PoTS and 16 healthy controls

3 month graduated exercise intervention

Results

• 10/19 cases no longer met the diagnosis of PoTS
• Significant reduction in upright heart rate
• All improved quality of life (SF36)
Growing evidence for exercise as alternative to medication

Published in final edited form as: 

Exercise Training versus Propranolol in the Treatment of the Postural Orthostatic Tachycardia Syndrome

Qi Fu¹,², Tiffany B. VanGundy¹, Shigeki Shibata¹,², Richard J. Auchos², Gordon H. Williams³, and Benjamin D. Levine¹,²

Side effects of medication – lead to cessation

- Beta blockers – fatigue
- Fludrocortizone – hypokalemia
- Alpha adrenergic agonists - hypertension

Galbreath et al., 2016 Clin Auton Res, 21, 73-80
Exercise Reconditioning Programme

Aims: improve cardiovascular fitness and lower limb strength

Cardiovascular exercise

Start with chair peddles, reclining bicycle, rowing and swimming
Progress to upright position

During exercise, people with PoTS have a low stroke volume response to exercise – leads to light headedness, dizziness, dyspnoea and weakness
Resistance / Strength Training

- Body weight
- Weights
- Elastic bands

Resistance training is more demanding on the circulatory system. Lead to changes in blood pressure. Avoid Static exercise and Valsalva hold breath – increase in BP, followed by a fall in BP.
### How Often and How Hard?

#### Frequency and Intensity of Exercise

**First month**
- 3-4 per week: Reclining exercise CV training (20 - 40 min)
- 1 x per week: Resistance training per week (15 – 20 mins)
- **RPE 6 - 16**

**Second month**
- 3-4 per week: Upright bike CV training (25 -34 mins)
- 2 x per week: Resistance training per week (20-25 mins)
- **RPE 6 - 18**

**Third month**
- 3-4 per week: Upright CV training (35-40 mins)
- Cross trainer/ walking
- 2 x per week: Resistance training (30 mins)
- **RPE 8 - 18**

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**Rate of Perceived Exertions**

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<th>RPE Scale</th>
<th>Description</th>
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<tr>
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<tr>
<td>8</td>
<td>Fairly Light</td>
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<td>9</td>
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</table>
My Reality - Frequency and Intensity of Exercise

First Month
4-5 per week: Reclining exercise CV training (2-10 mins)
4-5 x per week: Resistance & proprioception training per week (2-10 mins)

Second – Third Month
4-5 per week: Upright bike / Walking CV training (10 – 30 mins)
4-5 per week: Resistance & functional training per week (10 – 20 mins)

Fourth – Six Month
3-4 per week: Upright bike, Walking, Cross trainer (30-40 mins)
2 - 3 x per week: Resistance & functional training (20 mins)
RPE 9 - 18

George et al., 2016  Heart Rhythm, 13, 943 - 50
Pain

Fatigue

Musculoskeletal

Cardiac Dysautonomia

Bladder

Allergy/MAC

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Mental Health

Ninis, de Wandele & Simmonds 2015

systemic severity scale
Case Two

Management
Complex pharmacological management for PoTS and Mast Cell Activation
- Fluids and salt
- Dietary advice
- Schooling plan

Functional restoration programme
Normalise movement
Gait re education
Hydrotherapy
Graduated cardiovascular and resistance training
Bike, cross trainer, squats, weights arms and legs, leg press

Goals
Complete GCSE’s
Be able to go shopping on the high street
Stay over with friends and holiday
**Tips for Rehabilitation**

Give hope  
Holistic view  
Problem solving  
Find the base line  
Progress steady pace  
Drink before, during and after  
Psychology  
Graduate slowly  
Underlying HSD – likely to be very weak and deconditioned with poor proprioception. Need to incorporate stability training.