Hypermobility 104: Exercise Selection and Progression for HSD/hEDS and POTS

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Slide handouts and recording available at: https://webspace.clarkson.edu/~lrussek/hsd.html

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Who Am I?

- Professor Emeritus, Physical Therapy Department, Clarkson University
- Staff PT, St. Lawrence Health System, Potsdam NY
  - Clinical specialties: hypermobility, fibromyalgia, headaches, temporomandibular disorders
- Frequent presenter to professional and patient groups at national conferences
- Author of multiple review and research articles on hypermobility
- Author of "Chronic Pain" chapter in *Physical Rehabilitation* textbook for PT students
- Lrussek@Clarkson.edu
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I do not have any conflicts of interest to report

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Objectives

By the end of this presentations, participants should be able to

1. Describe several different goals for exercise in HSD
2. Identify potential risks for exercising with HSD
3. Describe how and when to progress (or regress) exercises with HSD
4. Outline approach to exercising with POTS

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Hypermobility Lecture Series

- HSD 101: Basics of HSD/hEDS and self-care
- HSD 102: POTS and POTS self-care, basics of MCAS
- HSD 103: Pain management in HSD/hEDS
- HSD 104: Safe exercise selection and progression with HSD/hEDS
- (HSD 105: HSD/hEDS in children)
- HSD 106: Gut issues in HSD/hEDS, POTS, MCAS
- HSD 107: Fatigue in HSD/hEDS and POTS
- HSD 108: Headaches, migraines, and TMJ pain in HSD, POTS and MCAS
- HSD 109: Breathing dysfunctions in HSD
- HSD 110: Lumbar instability (NEW!)

I will refer to these if you want more info

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DISCLAIMER

The information in this presentation is for general purposes, only, and may or may not apply to your situation. Check with your health care provider before starting any new exercise program to ensure that it is appropriate and safe for YOU.

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Benefits of Exercise/Activity

- Regular (appropriate) exercise/activity reduces pain
  - Protects against chronic pain onset
  - Sedentary lifestyle increases risk of chronic pain
- Protects against autonomic dysfunction (POTS)
- Improves function
- Improves sleep quality, decreases fatigue
- Mind-body practice, such as Pilates, yoga, Tai Chi enhance body awareness and relaxation
- Improves mood, decreases anxiety
- Decreases systemic inflammation

Lima et al, 2017
Sabharwal, 2016
Ambrose, 2015

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Goals of Exercise in HSD

Exercise in HSD may be to achieve various goals. To improve:

1. Body awareness, proprioception, balance
2. Motor control (accuracy of muscles)
3. Strength and stability of joints

Needed for stabilization

4. Muscle flexibility, so tight muscles don't stress loose joints
5. Cardiovascular function
6. Overall body awareness and relaxation
7. Not damaging anything along the way..

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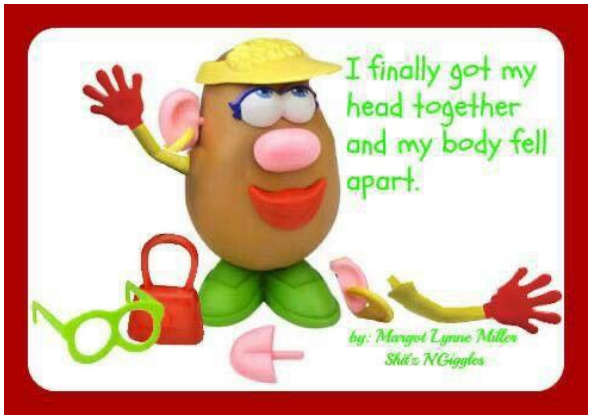
Body Awareness, Proprioception, Balance

If you don't know where your body is, you are more likely to damage it



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Body Awareness and Proprioception

- We need to know where our body (joints, muscles) is to accurately control it
  - Joints, muscles, and skin all contribute to body awareness
  - Joint position sense is called 'proprioception'
- People with HSD have poor body awareness/proprioception at joints
  - This leads to more instability, stress on joints, muscle spasm, injury
- Assessing body awareness/proprioception
  - Balance testing
  - Ability to return to a predetermined joint position
  - Ability to activate the correct muscles
  - Coordination, clumsiness

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Improving Body Awareness/Proprioception

- Access more sensory input:
  - Use visual input to see where your body is in space
    - Look in a mirror
  - Use skin contact to add skin sensory input:
    - Compression clothing,
    - Elastic braces, neoprene sleeves, etc.
    - Taping
  - Other sensory input may help, such as vibration or TENS

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Improving Body Awareness/Proprioception

- Improve body awareness/proprioception through exercise
  - External feedback is more effective than internal sensing of body position
  - Move mindfully – that is, move slowly and pay attention to your movement
  - Do balance/proprioception exercises that are challenging, but that you can do with control
  - Do mind-body movement, such as Tai Chi, Pilates, yoga, qigong..

Use External Feedback

- Look in a mirror (e.g., to make sure knees are not hyperextended, shoulder does not shift forward, etc.)
- Use a laser pointer attached to a body part
  - Motion Guidance™ (e.g.: https://youtu.be/SggmqmZhmDU) or SenMoCOR™
- Use biofeedback such as pressure biofeedback for the neck and low back (e.g.: https://youtu.be/mRyev39P0ZI)
- WII Fit balance™ (e.g.: https://youtu.be/PZMaadXFm7E)
- Virtual reality?

Questions?

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Motor Control

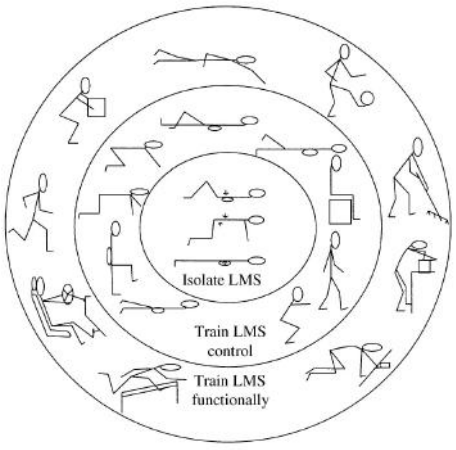

Fig. 12—Stages of rehabilitation based on a motor learning model (LMS – local muscle system). (Reproduced by kind permission of W.B. Saunders.)

- Motor control is the ability to accurately control your movement
  - You need body awareness to know where you are to begin with
  - You must be able to activate muscles selectively
  - Your muscles must have enough strength to do what they need to do
- If you don't move correctly during exercises and daily activities, you are more likely to injury yourself or overstress your tissues
- If you don't start in good alignment, you will place excessive stresses on your body/joints

Picture: O'Sullivan PB. Lumbar segmental 'instability': clinical presentation and specific stabilizing exercise management. *Man Ther.* Feb 2000;5(1):2-12.

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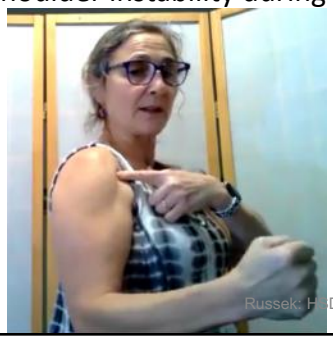
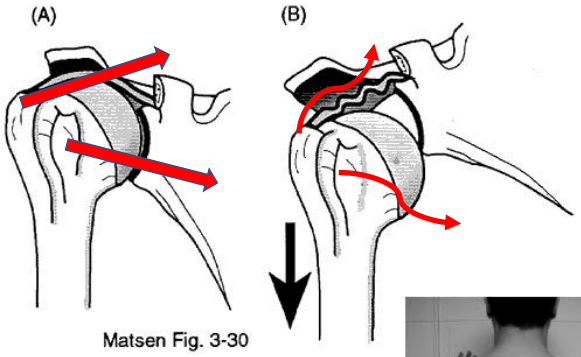
Example: Shoulder instability

- Joints must be properly aligned before movement
- It is critical that exercises are done correctly!
- Poor motor control during exercise
  - Anterior shoulder instability during strengthening exercise (video)
  - Anterior shoulder instability during stretching exercise (video)



Motor Control Example: Shoulder Girdle



Matsen Fig. 3-30

Picture from: https://orthop.washington.edu/patient-care/articles/shoulder/atraumatic-shoulder-instability.html

- If the shoulder is subluxed before moving, it will not move properly
- If the shoulder blade is not aligned correctly and does not move properly, the arm can't move properly

https://www.fysioterapeuterna.se/globalassets/_sektioner/fysisk-aktivitet-och-idrottmedicin/kongressarsmote/kongress-2016/shoulder-2016.pdf

Examples of Motor Control Exercises

- Shoulder 'drawing in' maneuver
- Shoulder blade glides
- Wall slides with elastic (https://youtu.be/gF-8XCHcbxc)
- Movements using laser feedback

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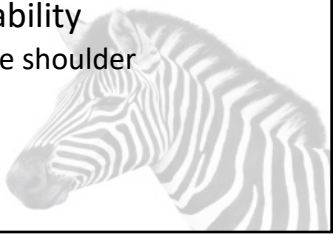
Strength and Joint Stability

- Not all strengthening exercises are good!
- Some exercises increase stability, while others increase instability
  - Exercises that encourage muscles to compress through joints increase stability
    - E.g., the shoulder wall slides described previously
  - Large, movement muscles sometimes increase instability
    - E.g., pectoral (chest) strengthening exercises can increase shoulder subluxation



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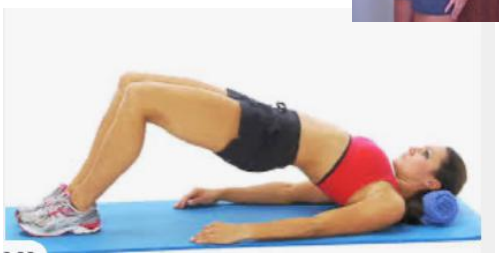
Stabilization Exercise Examples





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But Don't Stress Other Joints!

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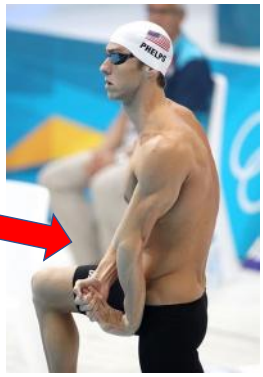
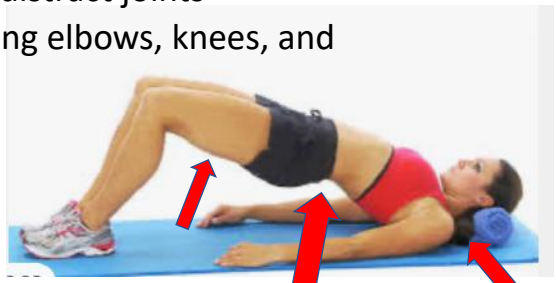
Don't Stress Other Joints!

- Be careful with:
  - Gripping weights or resistance bands
  - Weight on extended wrists
  - Weights that distract joints
  - Hyperextending elbows, knees, and spine





Russek: HSD [illegible]: Exercise

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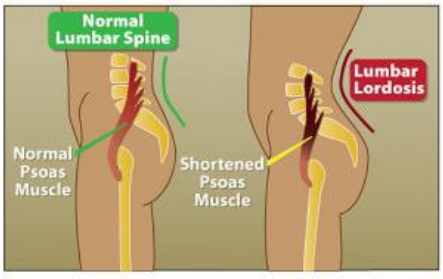
Muscle Flexibility Exercises

- Although your joints are loose, muscles may be tight
- Tight muscles can pull loose joints out of alignment



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Stretching Muscles Carefully

- Your body will always stretch first where you are already stretchiest!
- You need to carefully stabilize hypermobile joints to protect them
- You may need to start with 80% stretch for 5 seconds

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Overall Wellness Exercise/Activity

- Try to select life-long activities to remain fit
  - Low impact is better: walking, biking, rowing, swimming/water aerobics
  - Body-awareness activities are good choices: Tai Chi, Pilates, Yoga (caution for pretzel poses), qigong, many forms of dance
  - If you cannot tolerate weight bearing activities, find alternatives: water exercise, Pilates or sitting versions of other exercises, such as chair aerobics, sitting Tai Chi, etc..

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Exercise Progression

- People with HSD/EDS start 6 weeks more deconditioned than normal sedentary individuals.
- Tissues are weaker, and more vulnerable to overuse damage
- Muscles and connective tissue can be strengthened
- Sometimes people with HSD/EDS need more recovery time between exercise bouts
  - The "2-hour rule" – discomfort should be back to/below baseline within 2 hrs
- **"Start Low, Go Slow!"**

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Making Exercises More Challenging

- More proprioceptive feedback > less feedback
- More external support (e.g., exercise machines) > less stable weights
- Standing/sitting on solid surface > soft or unstable surface
- Focus on a single joint/movement > more complex movements
- Focusing on the exercise > exercising with distraction
- Mid range > full range
- Slow > faster
- Low impact > high impact (if tolerated)

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Questions?

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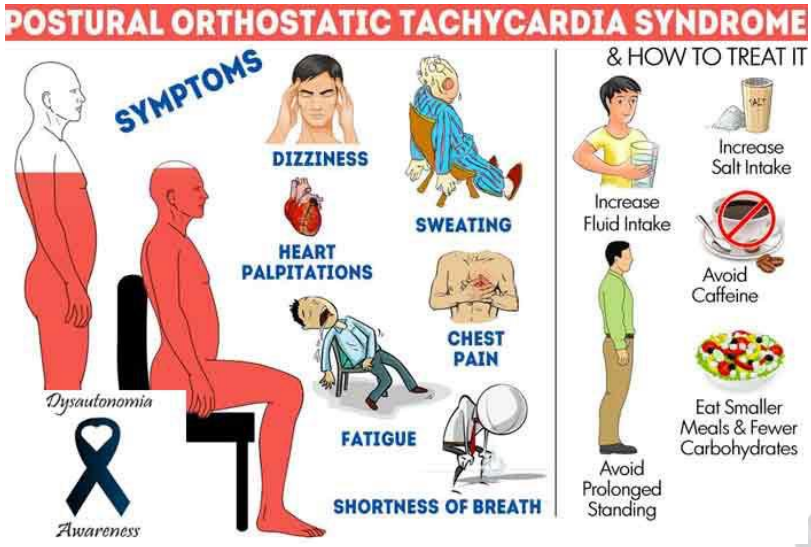
POTS

Great info at: www.potsuk.org

HSD 102: POTS and MCAS; HSD 107: Fatigue



https://zovon.com/latest-health-news/pots/

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POTS Progression

- Phase 1:
  - Gentle movements lying down, isometrics, antigravity movement, stretching
- Phase 2:
  - Recumbent cardio exercise: swimming, recumbent bike, rowing
  - Progress no more than 20%/week
- Phase 3:
  - "Normal" workouts – some people are able to manage their POTS and do "normal" workouts, while others need to be more cautious
  - http://www.dysautonomiainternational.org/page.php?ID=43
  - https://www.potsuk.org/exercise_examples

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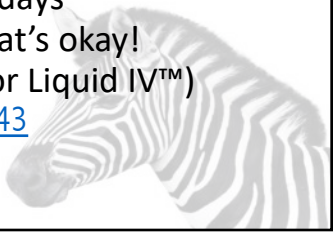
Exercise for Very POTSIE People

- Progress exercises VERY gradually
  - Start horizontal, progress to vertical
    - Exercise lying down or sitting at first, if necessary
  - Start with compression garments: full stockings best
  - Water exercise is particularly good due to hydrostatic pressure
  - Start with leg muscle 'setting' to pump blood to heart
  - Core exercises decrease fluid build-up in the abdominal area
  - Gradual progression of difficulty, allowing for recovery days
  - You might only be able to do a few minutes at first – that's okay!
  - Stay hydrated, supplement electrolytes (e.g., Propel™ or Liquid IV™)
- Resource: http://www.dysautonomiainternational.org/page.php?ID=43



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POTS Exercise "Protocol"

- Children's Hospital of Philadelphia (CHOP) protocol
  http://standinguptopots.org/fnuwifh289ry298fhijewf/misc/30-chop-modified-dallas-pots-exercise-program
  - Note that the CHOP protocol is not specifically for people with HSD/EDS, so some of the exercises might not be appropriate for HSD/EDS
- Exercise videos for "potsies":
  http://www.dysautonomiainternational.org/page.php?ID=209
  - Again, not specifically intended for people with HSD/EDS

Sample POTS Exercise Protocol (Fu & Levine, 2015)

Pre-Month 1

Sun	Mon	Tue	Wed	Thu	Fri
1	2 Training Mode 1: 5-10 min Warm Up, 3 min Base Pace, 2 min recovery, 3 min Base Pace, 5-10 min Cool Dwn	3 Weight Training	4 Training Mode 1: 5-10 min Warm Up, 3 min Base Pace, 2 min recovery, 3 min Base Pace, 5-10 min Cool Dwn	5 Weight Training	6 Training Mode 1: 5-10 min Warm Up, 3 min Base Pace, 2 min recovery, 3 min Base Pace, 5-10 min Cool Dwn
8	9 Training Mode 1: 5-10 min Warm Up, 4 min Base Pace, 3 min recovery, 4 min Base Pace, 5-10 min Cool Dwn	10 Weight Training	11 Training Mode 1: 5-10 min Warm Up, 4 min Base Pace, 3 min recovery, 4 min Base Pace, 5-10 min Cool Dwn	12 Weight Training	13 Training Mode 1: 5-10 min Warm Up, 5 min Base Pace, 3 min recovery, 5 min Base Pace, 5-10 min Cool Dwn
15	16 Training Mode 1: 5-10 min Warm Up, 5 min Base Pace, 3 min recovery, 5 min Base Pace, 5-10 min Cool Dwn	17 Weight Training	18 Training Mode 1: 5-10 min Warm Up, 6 min Base Pace, 3 min recovery, 6 min Base Pace, 5-10 min Cool Dwn	19 Weight Training	20 Training Mode 1: 5-10 min Warm Up, 6 min Base Pace, 3 min recovery, 6 min Base Pace, 5-10 min Cool Dwn
22	23 Training Mode 1: 5-10 min Warm Up, 6 min Base Pace, 3 min recovery, 5 min Base Pace, 5-10 min Cool Dwn	24 Weight Training	25 Training Mode 1: 5-10 min Warm Up, 7 min Base Pace, 3 min recovery, 5 min Base Pace, 5-10 min Cool Dwn	26 Weight Training	27 Training Mode 1: 5-10 min Warm Up, 7 min Base Pace, 3 min recovery, 5 min Base Pace, 5-10 min Cool Dwn

Training Mode 1 = any of: supine cycling, recumbent bike, swimming laps, swimming laps with a kick board, rowing (Concept II preferred) Recovery = slow down, reduce resistance, get a drink, but don't stop moving
--Warm Ups and Cool Downs are done starting very slowly with little (or no) resistance and leading up to and out of your Base Pace HR zone.
--Physical therapist can begin with **supine cycling** only if a patient is beginning program as wheel-chair bound/bedridden.
--Weight Training can be done on same days as cardio workouts if necessary.

Month 1

Sun	Mon	Tue	Wed	Thu	Fri
1	2 Training Mode 1: 5 min Warm-Up, 30 min Base Pace, 5 min Cool-down	3 Weight Training	4 Training Mode 1: 5 min Warm-Up, 30 min Base Pace, 5 min Cool-down	5 Weight Training	6 Training Mode 1: 5 min Warm-Up, 30 min Base Pace, 5 min Cool-down
8	9 Training Mode 1: 5 min Warm-Up, 30 min Base Pace, 5 min Cool-down	5 Weight Training	11 Training Mode 1: 5 min Warm-Up, 30 min Base Pace, 5 min Cool-down	12 Weight Training	13 Training Mode 1: 5 min Warm-Up, 20 min **MSS**, 5 min Cool-down
15	16 Training Mode 1: 5 min Warm-Up, 30 min Base Pace, 5 min Cool-down	17 Weight Training	18 Training Mode 1: 5 min Warm-Up, 30 min Base Pace, 5 min Cool-down	19 Weight Training	20 Training Mode 1: 5 min Warm-Up, 30 min Base Pace, 5 min Cool-down
22	23 Training Mode 1: 5 min Warm-Up, 30 min Base Pace, 5 min Cool-down	24 Weight Training	25 Training Mode 1: 5 min Warm-Up, 25 min **MSS**, 5 min Cool-down	26 Training Mode 1: 40 min Recovery	27 Weight Training

Training Mode 1 = Any of: Recumbent Biking, Swimming, Rowing (Concept II preferred)
Weight Training can be done on same days as Cardio workouts if necessary.

Sample Strength Training for POTS

- The following are suggested resistance exercises for POTS, but might not be appropriate for you.
- It is also important that you do them correctly, so you are advised to begin this program under supervision of a PT or trainer.
- You may need to modify these to accommodate issues related to your HSD
  - Seated leg press
  - Knee curls
  - Knee extensions
  - Calf raises
  - Chest press
  - Seated row
  - Abdominal strengthening
  - Back extensions
  - Planks
  - Pilates-based core strengthening

Fu, 2018

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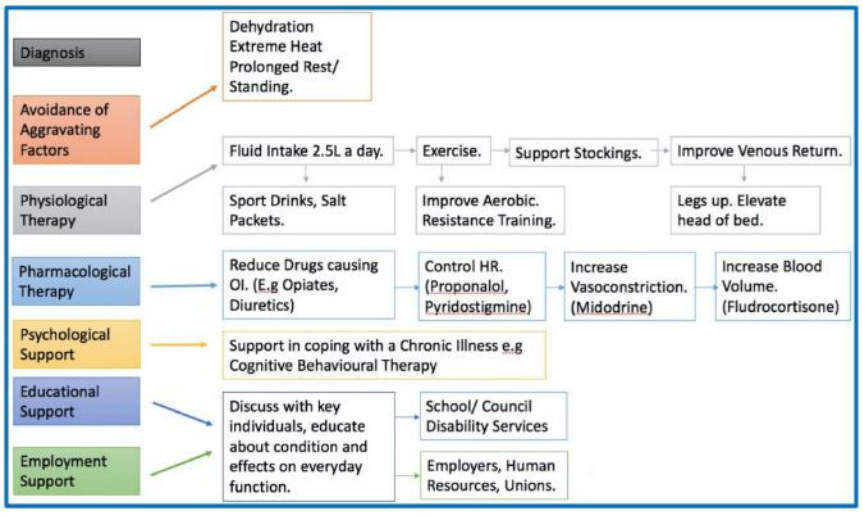
Managing POTS Fatigue

HSD 107: Fatigue Management



 Strassheim, 2018

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Summary:

- Not all exercises are appropriate for everyone
- For exercise to be helpful *and not harmful*, it must be:
  - The correct exercise (for you, now)
  - Done correctly (proper body awareness and motor control)
  - At the correct dose (intensity, time/reps)
  - Not overstressing other joints or muscles
  - Activating, strengthening, or stretching the correct tissues
- There is no protocol appropriate for everyone with EDS/HSD
- **Start low, go slow!**

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Not All Exercises Are Appropriate

- Avoid:
  - Positions that overstretch joints
  - High impact sports/activities
  - Excessive weight lifting/carrying, joint distraction
  - Poor posture or motor control
  - Exercises that aggravate POTS
    - Sudden head-up postural change
    - Upright cardio exercise until POTS is managed

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Resources

- For EDS in general: https://www.ehlers-danlos.org
- For exercise in EDS:
  - https://www.ehlers-danlos.org/information/exercise-and-movement-for-adults-with-hypermobile-ehlers-danlos-syndrome-and-hypermobility-spectrum-disorders/
- For POTS
  - http://www.dysautonomiainternational.org
  - https://www.potsuk.org

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Questions?

REMINDER:
The information in this presentation is for general purposes, only, and may or may not apply to *your* situation.
Check with your health care provider before starting any new program to ensure that it is appropriate and safe for YOU.

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