



Don't Do This!

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>



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
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**I do not have any
conflicts of interest to report**

Russek: HSD 104: Exercise

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 an approach to exercising with POTS



Hypermobility Lecture Series Schedule

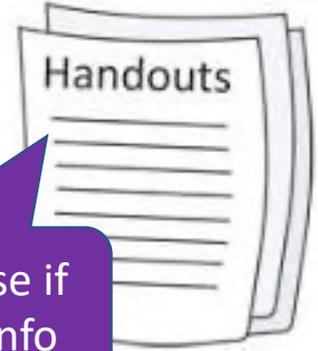
- HSD 101: Basics of HSD/hEDS and self-care
- HSD 102: POTS and POTS self-care, basics of MCAS
- HSD 103: Pain management in HSD/hEDS
- HSD 104: Safe exercise selection and progression with HSD/hEDS and POTS
- HSD 105: Body mechanics, posture and joint protection
- HSD 106: Gut issues in HSD/hEDS, POTS, MCAS
- HSD 107: Fatigue in HSD/hEDS and POTS
- HSD 108: Headaches, migraines, & TMJ pain in HSD, POTS and MCAS
- HSD 109: Breathing dysfunctions in HSD
- HSD 110: Lumbar instability
- HSD 111: Cervical instability
- HSD 112: The vagus nerve
- HSD 113: The importance of fascia



I will refer to these other lectures if you want more info



Relevant Handouts Available



I will refer to these if you want more info

- <https://webpace.clarkson.edu/~lrussek/research.html>

• Exercise

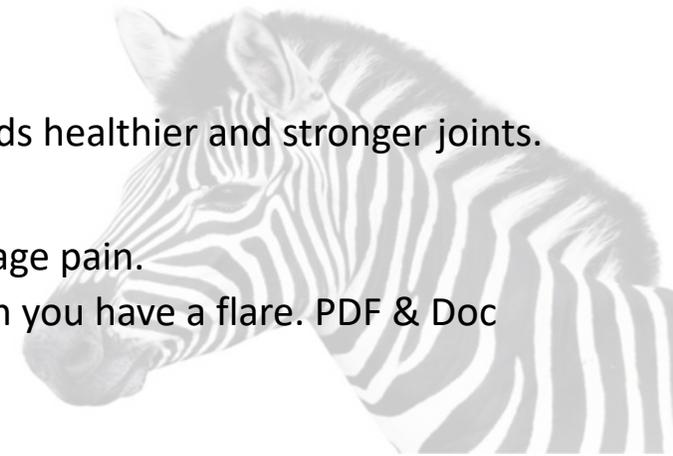
- [Breathing](#). Breathing incorrectly can increase pain sensitivity, headaches, jaw pain, and more.
- [Starting to Exercise Ideas](#). Some ideas to help you get started on exercise: how to deal with fatigue, pain, and fear of movement.
- [Starting to Exercise Worksheet](#). It can be difficult to exercise or be active when you have HSD. This worksheet helps people identify and overcome roadblocks to being more active. Written for teenagers, but appropriate for anyone.
- [Augmented Reality Activities for Fitness](#). Staying stable and strong doesn't need to be boring. Some augmented reality games, using free apps on your smartphone, tablet, or projected on your TV can be healthy and fun!
- [Ways to keep younger kids active while having fun](#). Games and make-believe to keep younger kids moving.

• Self-Care Strategies

- [Checklist for POTS self-care management](#).
- [Flow charts for POTS management, including fatigue and sleep](#).
- [Joint Protection Strategies](#) Learning to protect your joints and muscles is the first step towards healthier and stronger joints.

• Pain Management

- [Pain self-care plan](#). Create a flare management plan so you can identify what helps you manage pain.
- [Pain flare management plan](#). Create a flare management plan so you know what works when you have a flare. PDF & Doc versions.

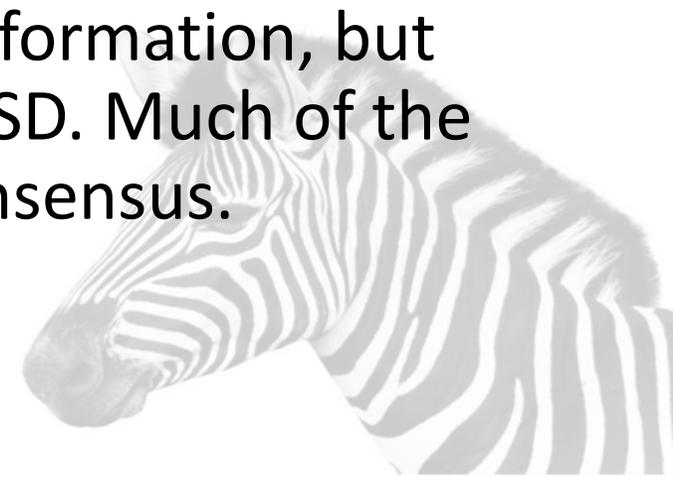


DISCLAIMER

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. I cannot provide individual diagnostic or treatment advice.

Also note that this lecture is based on best available information, but there is not much rigorous research about exercise in HSD. Much of the information presented is based upon expert consensus.



Approach to Management of HSD

Assist patient in identifying and managing systemic comorbidities: education, treatment and/or referral

Decrease central, peripheral, and autonomic pain sensitization

Educate for correct posture and joint alignment, body mechanics, joint protection, appropriate use of splints and braces

Proprioceptive and motor control training, with training to relax muscles that are guarding

Stabilization, strengthening, muscle flexibility, aerobic conditioning

Integration of proper alignment & movement into function

Education about flare management

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



Goals of Exercise in HSD

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

1. Pain management: range of motion, relaxation, trigger point, etc.
2. Body awareness, proprioception, balance
3. Motor control (accuracy of muscles)
4. Strength and stability of joints
5. Mobility: muscle stretch, nerve glide, fascial elongation
6. Cardiovascular function
7. Overall body awareness and relaxation
8. Not damaging anything along the way..

Needed for
stabilization



Body Awareness, Proprioception, & Motor Control

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



I finally got my head together and my body fell apart.

by: Margot Lynne Miller
Shit & N'Giggles

Hypermobility vs. Instability

- “Hypermobility” refers to having too much range of motion (movement that you can voluntarily control)
- “Instability” refers to the ability of your nerves and muscles to control motion at a joint
 - You need to sense joint/limb position and the forces on the joint: “proprioception”
 - You need to be able to activate the correct stabilizing muscles the correct amount at the correct time – this is “motor control”
- Appropriate exercise decreases instability by improving proprioception and motor control
 - Inactivity and being sedentary increases instability



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



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



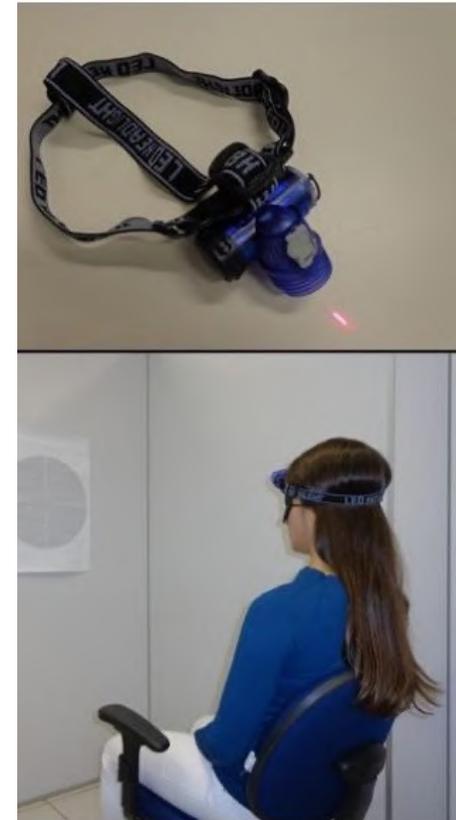
Improving Body Awareness and Proprioception

- Improve body awareness/proprioception through training
 - External feedback is more effective than internal sensing of body position (Lauber, 2014)
 - 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,
 - But be careful to avoid movements that place too much stress on joints..
- Treatments that address proprioception help decrease pain (Reychler, 2021)



Use External Feedback

- Other sensory input: pressure from the floor, a Pilates ball, a stick, resistance band (compression clothing)
- 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 or augmented reality





Questions?



Motor Control

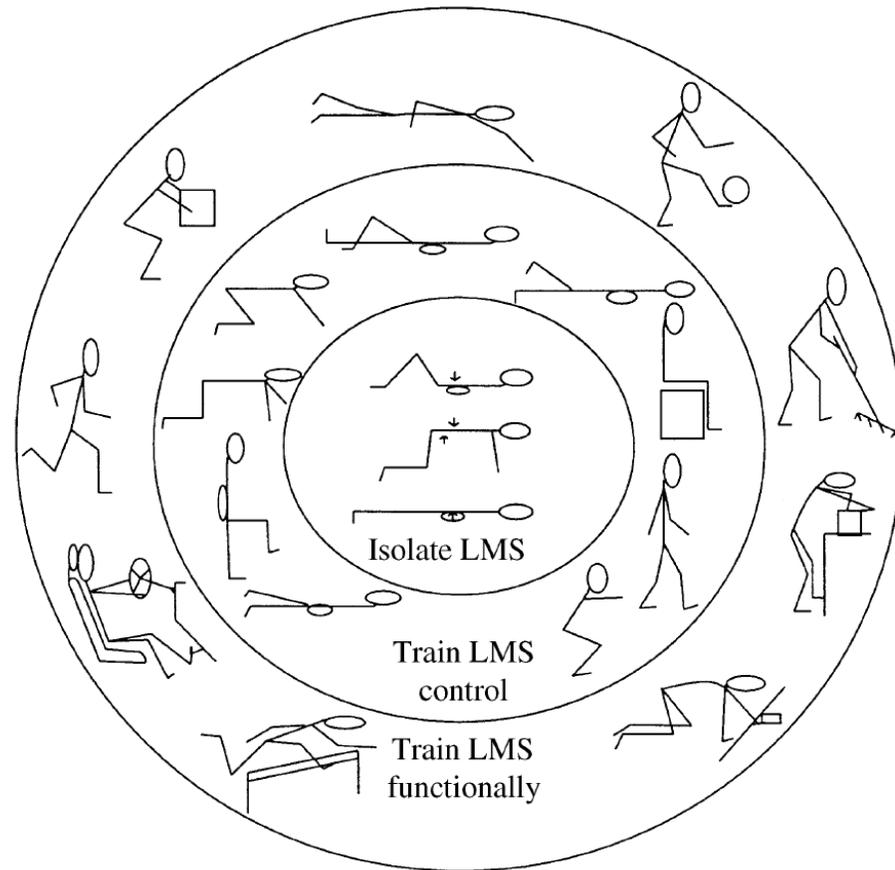


Fig. 12—Stages of rehabilitation based on a motor learning model (LMS – local muscle system). (Reproduced by kind permission of W.B. Saunders.)

- 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 injure yourself or overstress your tissues
- If you don't start in good alignment, you will place excessive stresses on your body/joints
- Treatments that address motor control help decrease pain.

(Reychler, 2021)

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

Mobilizer vs. Stabilizer Muscles

Function

- Local stabilizer
 - E.g., multifidi, TA, VMO
 - Increases segmental stiffness, proprioception
 - Tonic activity to provide stability
- Global stabilizer
 - E.g., IO, EO, gluteus medius
 - Controls ROM, often eccentrically
 - Phasic activity for stability with motion
- Global mobilizer
 - E.g., RA, iliocostalis, piriformis
 - Generates torque for movement
 - Phasic activity when moving

Dysfunction

- Local stabilizer
 - Inhibited by pain, subtle subluxation
 - Motor control deficit
 - Decreased stiffness, poor control
- Global stabilizer
 - Eccentric control deficit
 - Fails to stabilize with movement
 - Length-strength imbalance
- Global mobilizer
 - Responds to pain with spasm, myofascial shortening, and restricted movement
 - Generates myofascial pain
 - Activated by sympathetic state

HSD 110/111:
Lumbar/Cervical Instability



Example: Shoulder instability

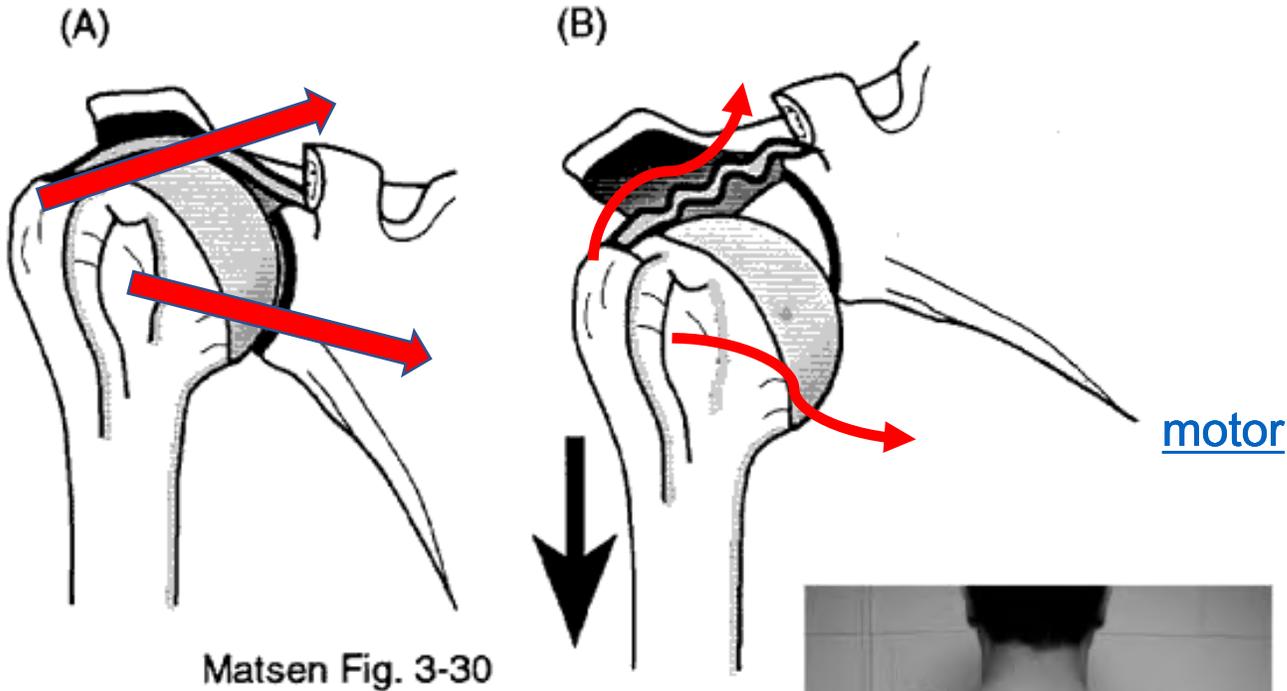
- Joints must be properly aligned before movement
- It is critical that exercises are done correctly!
- Poor motor control during exercise
 - Anterior shoulder instability during strengthening exercise (video)
 - Anterior shoulder instability during stretching exercise (video)



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Motor Control Example: Shoulder Girdle



- 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

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



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

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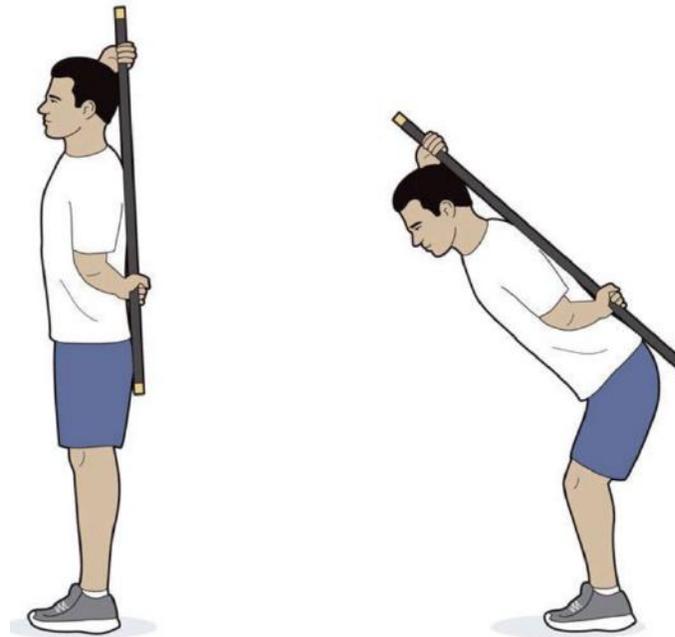
Examples of Motor Control Exercises



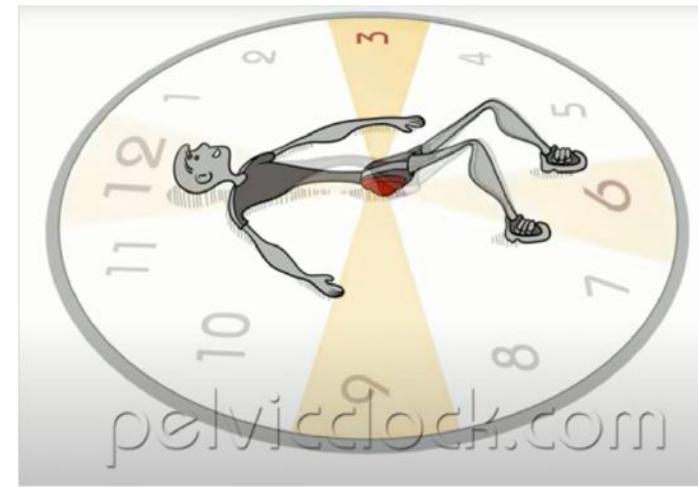
- Pelvic “clock”
- Hip hinge
- Shoulder ‘drawing in’ maneuver
- Movements using laser feedback



<https://www.themanualtherapist.com/2017/05/top-5-fridays-5-exercises-to-enhance.html>

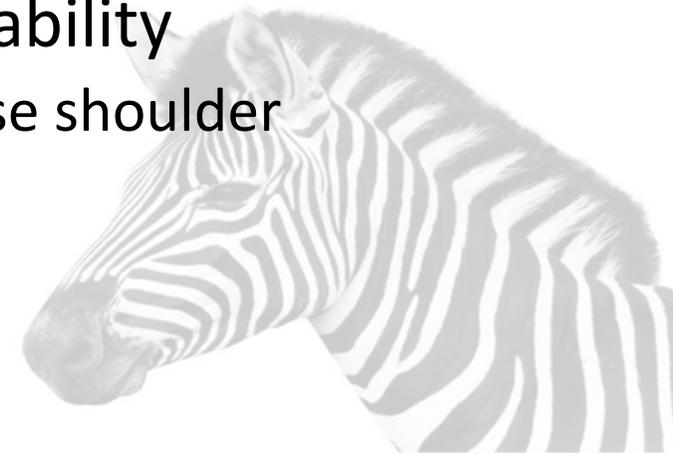


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Strength and Joint Stability

- 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



Stabilization Exercise Examples

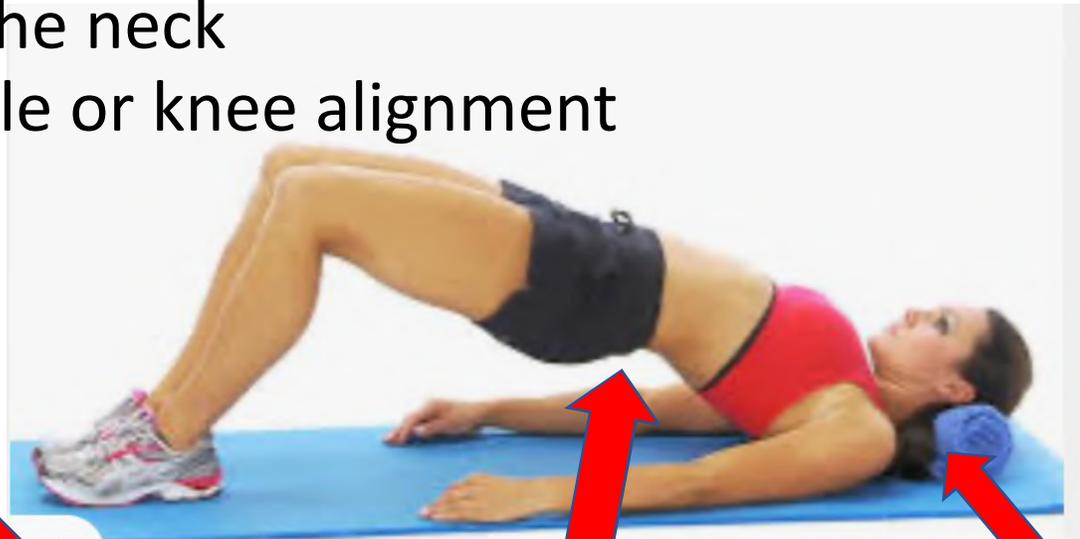
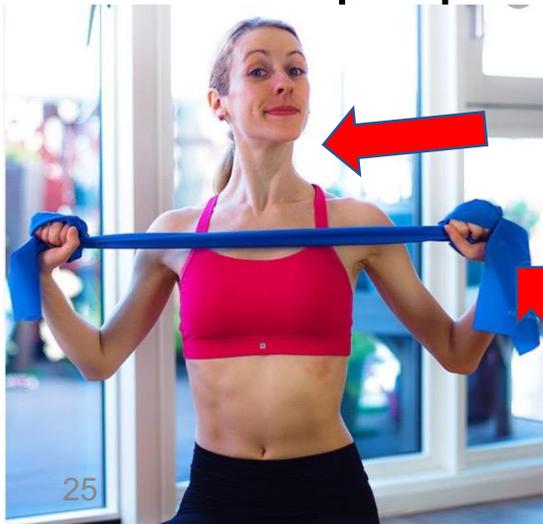


But Don't Stress Other Joints!



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
 - Over flexing the neck
 - Improper ankle or knee alignment



Russek: HSD Exercise



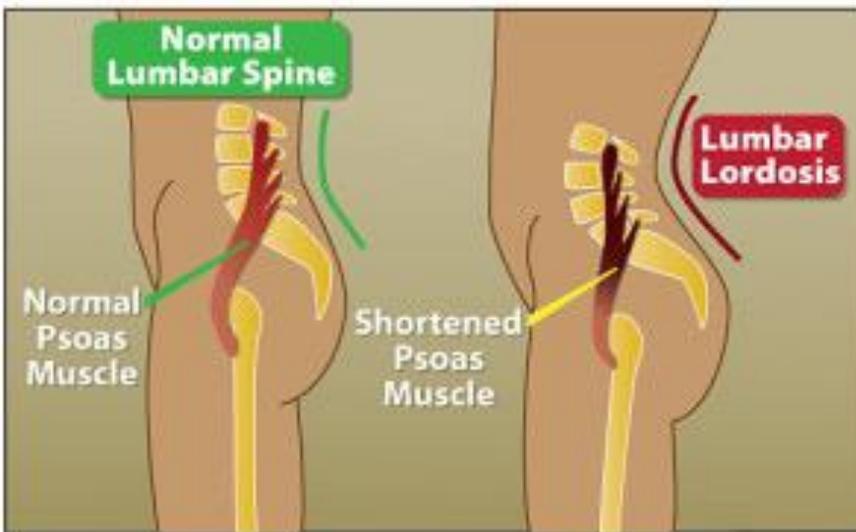
Other Types of Exercises

- Mobility
 - Range of motion: when acute, to decrease pain
 - Nerve glides
 - Fascial mobility
- Stretching
 - Muscles
 - Fascia
 - (Nerve)
- Other
 - Trigger point management
 - Relaxation, vagus nerve activation



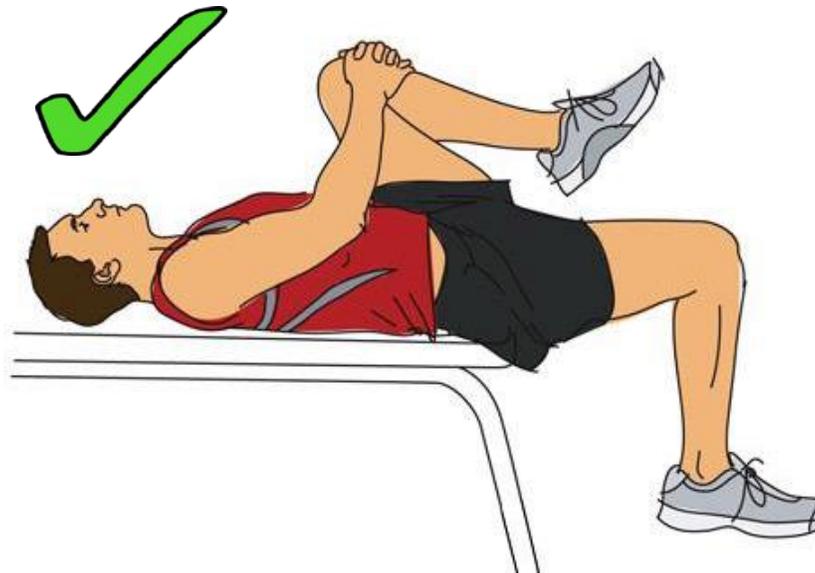
Muscle Flexibility/Elongation Exercises

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



Stretching/Elongating Muscles Carefully

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



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
 - The Zebra Club app provides a range of Pilates exercises specifically for people with HSD..



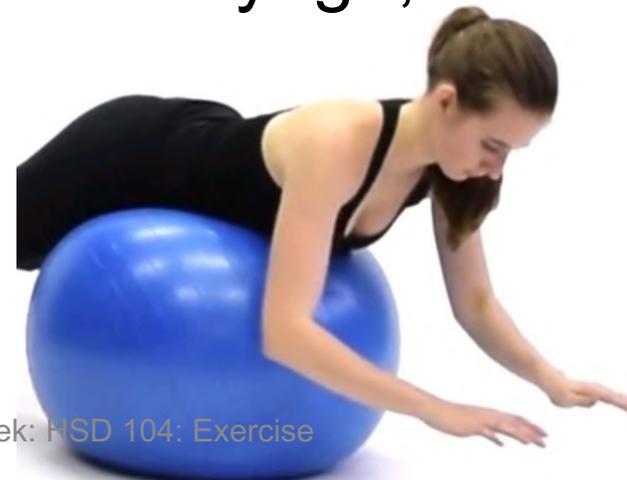
Starting to Exercise
Ideas



Modifying Exercises



- Use snorkel to protect neck swimming
- Use walking sticks to walk/hike, props to support you
- Do chair aerobics, sitting Tai Chi or yoga, etc.



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Exercise Can Be Fun

Augmented Reality
Activities for Fitness

- If you really don't like to exercise, consider movement-based games
- Augmented reality uses your phone camera to interact with the game
- Benefits:
 - Visual feedback might improve body awareness and proprioception
 - Aiming for targets might improve motor control
 - Side-to-side movements may improve stability
 - Many can be done with a friend/kid
- Games with free options
 - Active Arcade™: <https://www.activearcade.ai>
 - Entirely free
 - Plaicise™: <https://plaicise.com>
 - Has free options



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!”**



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)

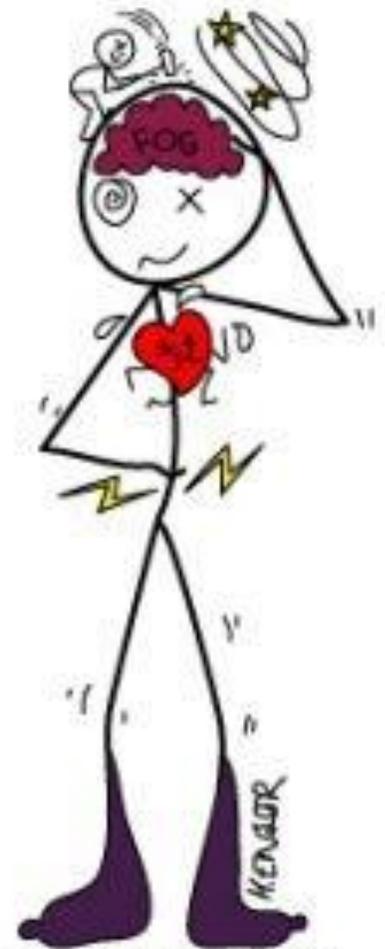




Questions?



Dysautonomia, POTS & Fatigue



stickmancommunications.co.uk

POTS

POSTURAL ORTHOSTATIC TACHYCARDIA SYNDROME

SYMPTOMS

- DIZZINESS
- SWEATING
- HEART PALPITATIONS
- CHEST PAIN
- FATIGUE
- SHORTNESS OF BREATH

& HOW TO TREAT IT

- Increase Fluid Intake
- Increase Salt Intake
- Avoid Caffeine
- Eat Smaller Meals & Fewer Carbohydrates
- Avoid Prolonged Standing

Dysautonomia Awareness

HSD 102: POTS and MCAS;
HSD 107: Fatigue

POTS Checklist



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



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
 - Unless the water is warm, which may cause a POTS or fatigue flare
 - 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>



Sample Exercises for Very POTSIE People

- 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.
- POTS “Pumps”
 - Supine ankle pumps, quad set, hamstring set, glute set
 - Deep belly breathing
 - Arm ‘pumps’ with arms elevated, pumping hands or squeezing a ball
- Gentle strengthening lying down
- Core strengthening lying down



Fu, 2018

POTS Exercise “Protocols”

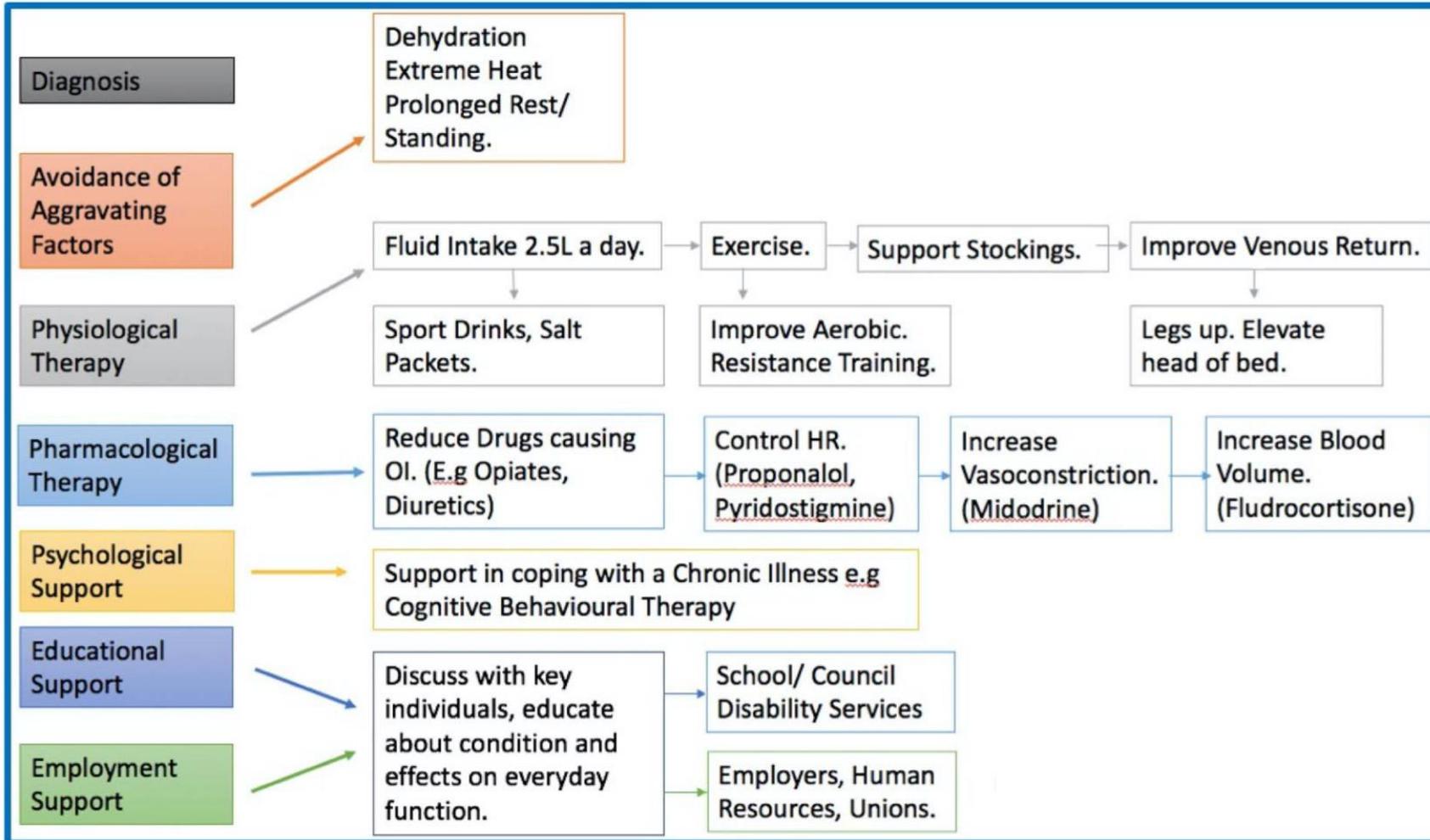
- New POTS protocols:
 - Autonomic Disorder adaptive Physical Therapy (ADaPT)
 - Children’s Hospital of Philadelphia Acquired Autonomic Dysfunction Program (CHOP AADP)
- Previous POTS programs:
 - Children’s Hospital of Philadelphia (CHOP) original protocol
 - Levine protocol
- Exercise videos for “potsies”:
<http://www.dysautonomiainternational.org/page.php?ID=209>
 - Again, not specifically intended for people with HSD/EDS



Managing POTS Fatigue

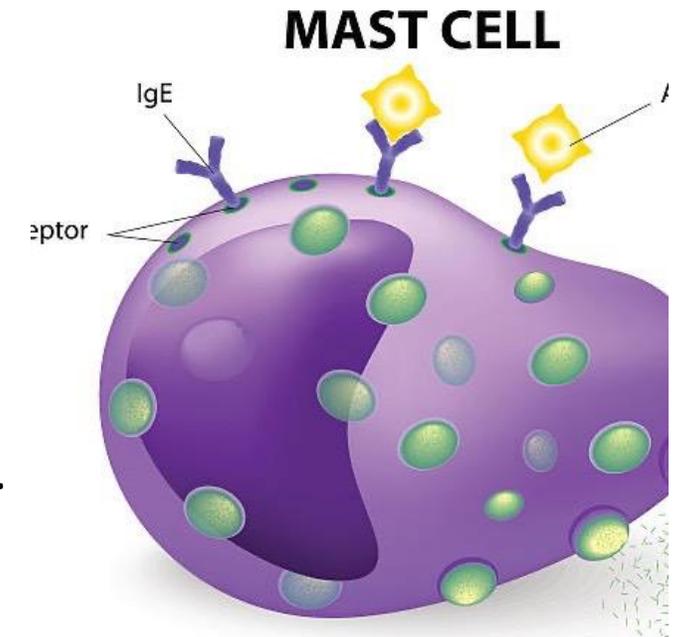
HSD 107: Fatigue Management

Flow Chart for POTS Management



MCAS Challenges with Exercise

- Increased body temperature during exercise activates mast cells
- This is a normal process that leads to tissue strengthening
 - But, if your mast cells are overactive, they may over-react
- I don't know of evidence showing how to avoid this, but ideas...
 - Exercise in a cool environment, such as air conditioning or with a fan. Cooler temperatures result in less mast cell activation
 - Do a relaxation practice at the end to activate your parasympathetic nervous system ("rest and digest"). Diaphragmatic breathing, meditation, etc.
 - Take a cool shower after you exercise to cool your body temperature.
 - Take an antihistamine medication (if safe for you) to calm mast cells



Common Reasons for Exercise “Failure”

POTS checklist, MCAS self-care

1. Starting when your overall condition is unstable (POTS, MCAS, GI, fatigue, etc)
2. Pain sensitization
3. Excessive sympathetic nervous system activity (“fight or flight” mode)
4. Starting exercises in poor alignment
5. Performing exercises incorrectly due to proprioceptive, motor control or strength deficits
6. Inappropriate exercises or intensity; trying to do too much
7. Being overwhelmed or giving up due to repeated failure
8. Fear of damaging yourself

Pain Handouts

HSD103, HSD109, HSD112

HSD102, HSD106, HSD107

HSD105



Using the “Rate of Perceived Exertion”

- A common problem is doing exercise that is too difficult for you now
- The Rate of Perceived Exertion (RPE) is a guide to exercise effort
- Exercises should start around 3/10
- Progress exercises when <3/10
- Regress exercises if >6/10 or increased pain >2 hrs after
- Mittal, 2021

Starting to Exercise Ideas

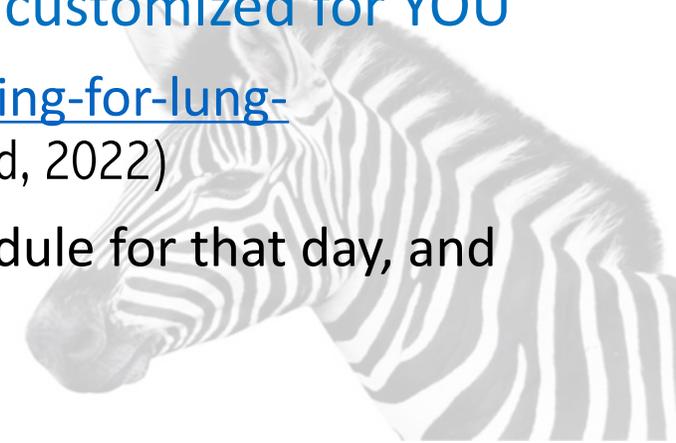
RPE SCALE	RATE OF PERCEIVED EXERTION
10 /	MAX EFFORT ACTIVITY Feels almost impossible to keep going. Completely out of breath, unable to talk. Cannot maintain for more than a very short time
9 /	VERY HARD ACTIVITY Very difficult to maintain exercise intensity. Can barely breathe and speak only a few words
7-8 /	VIGOROUS ACTIVITY Borderline uncomfortable. Short of breath, can speak a sentence
4-6 /	MODERATE ACTIVITY Breathing heavily, can hold a short conversation. Still somewhat comfortable, but becoming noticeably more challenging
2-3 /	LIGHT ACTIVITY Feels like you can maintain for hours. Easy to breathe and carry a conversation
1 /	VERY LIGHT ACTIVITY Hardly any exertion, but more than sleeping, watching TV, etc

“I Can’t Do Anything. How Can I Start?”*

Week	5 min	5 min	5 min
1	Diaphragmatic breathing Or Singing (2-3/10 RPE)	Diaphragmatic breathing Or Singing (2-3/10 RPE)	Diaphragmatic breathing Or Singing (2-3/10 RPE)
2	Diaphragmatic breathing Or Singing (2-3/10 RPE)	Diaphragmatic breathing Or Singing (2-3/10 RPE)	Postural/alignment correction, motor control (2/10 RPE)
3	Diaphragmatic breathing Or Singing (2-3/10 RPE)	Diaphragmatic breathing Or Singing (2-3/10 RPE)	Motor control, Posture strengthening (2-3/10 RPE)
4	Diaphragmatic breathing Or Singing (2-3/10 RPE)	Posture strengthening (3/10 RPE) Or gentle aerobic movement	Core control/strengthening (2-4/10 RPE)
5	Aerobic exercise (2-3/10 RPE)	Posture strengthening (3-4/10 RPE)	Core or other strength (3-4/10 RPE)
6	Aerobic exercise (2-4/10 RPE)	Aerobic exercise (3-5/10 RPE)	Strengthening (3-5/10 RPE)

* This is just a SAMPLE program; it would need to be modified or customized for YOU

- Singing for Lung Health: <https://www.blf.org.uk/support-for-you/singing-for-lung-health/what-happens-in-a-singing-for-lung-health-session> (Kaasgaard, 2022)
- Any day you don’t feel well enough, return to a previous week’s schedule for that day, and gradually work back up to your schedule



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)
 - You need to start and move in good alignment
 - At the correct dose (intensity, time/reps) and progression
 - 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!**



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



Resources

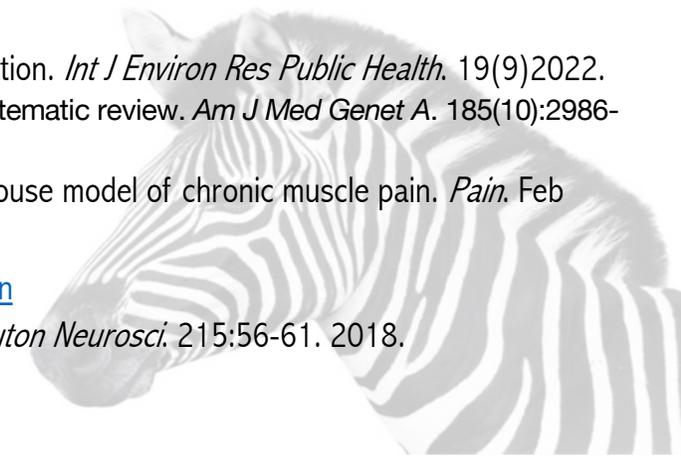
- For EDS in general: <https://www.ehlers-danlos.org>
- For exercise in EDS:
 - <https://www.ehlers-danlos.org/information/exercise-and-movement-for-adults-with-hypermobile-ehlers-danlos-syndrome-and-hypermobility-spectrum-disorders/>
- For POTS
 - <http://www.dysautonomiainternational.org>
 - <https://www.potsuk.org>
- The Zebra Club Pilates for people with HSD: <https://jeannedibon.com/products/>
- Augmented Reality: Active Arcade, Plaicise



**The
Zebra
Club**

Scientific References

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Questions?

