



Hypermobility 104, Part 2: How to Modify Exercises for HSD & POTS

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



Who Am I?

- Professor Emeritus, Physical Therapy Department, Clarkson University
- Retired 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
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**I do not have any
conflicts of interest to report**



I Know I Should Exercise.... BUT...



It always makes
me worse



Objectives

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

1. Identify potential challenges for exercising with HSD or POTS
2. Propose ways to select or modify exercises when you have HSD or 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 104 Part 2: Modifying exercise for HSD & POTS (NEW)**
- 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
- HSD 114: Hospitalization and surgery with the Trifecta
- HSD 115: Functional Neurological Disorder (FND)



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://webspaces.clarkson.edu/~lrussek/research.html> or use Scan Code
- **Exercise**
 - [Breathing](#). Breathing incorrectly can increase fatigue, exercise intolerance, and pain sensitivity.
 - [Starting to Exercise Ideas](#). Ideas to overcome fatigue, pain, and fear of movement.
 - [Starting to Exercise Worksheet](#). Overcoming obstacles. Written for teenagers, but ideas are good for anyone.
 - [Augmented Reality Activities for Teens](#). Staying stable and strong doesn't need to be boring.
 - ["Exergames" for Adults](#). Ideas to make staying active fun!
 - [Ways to keep younger kids active while having fun](#).
 - [The Zebra Club](#). a Pilates-based exercise app designed for people with HSD.
- **Self-Care Strategies**
 - [Self-Care Toolbox](#). A checklist to help you optimize your self-care toolbox.
 - [Checklist for POTS self-care management](#).
 - [Flow charts for POTS management, including fatigue and sleep](#).
 - [Joint Protection Strategies](#) Learn to protect your joints and muscles.
- **Pain Management**
 - [Pain self-care plan](#). Create a pain self-care plan so you can identify and remember what works for you.
 - [Pain flare management plan](#). Create a flare management plan to help manage flares.

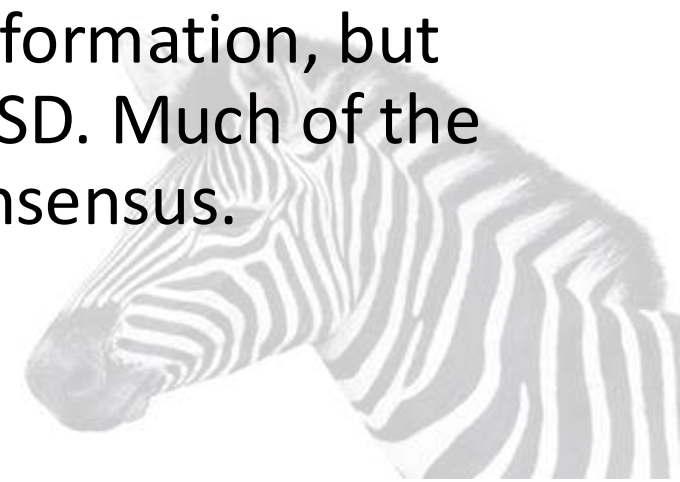


DISCLAIMER

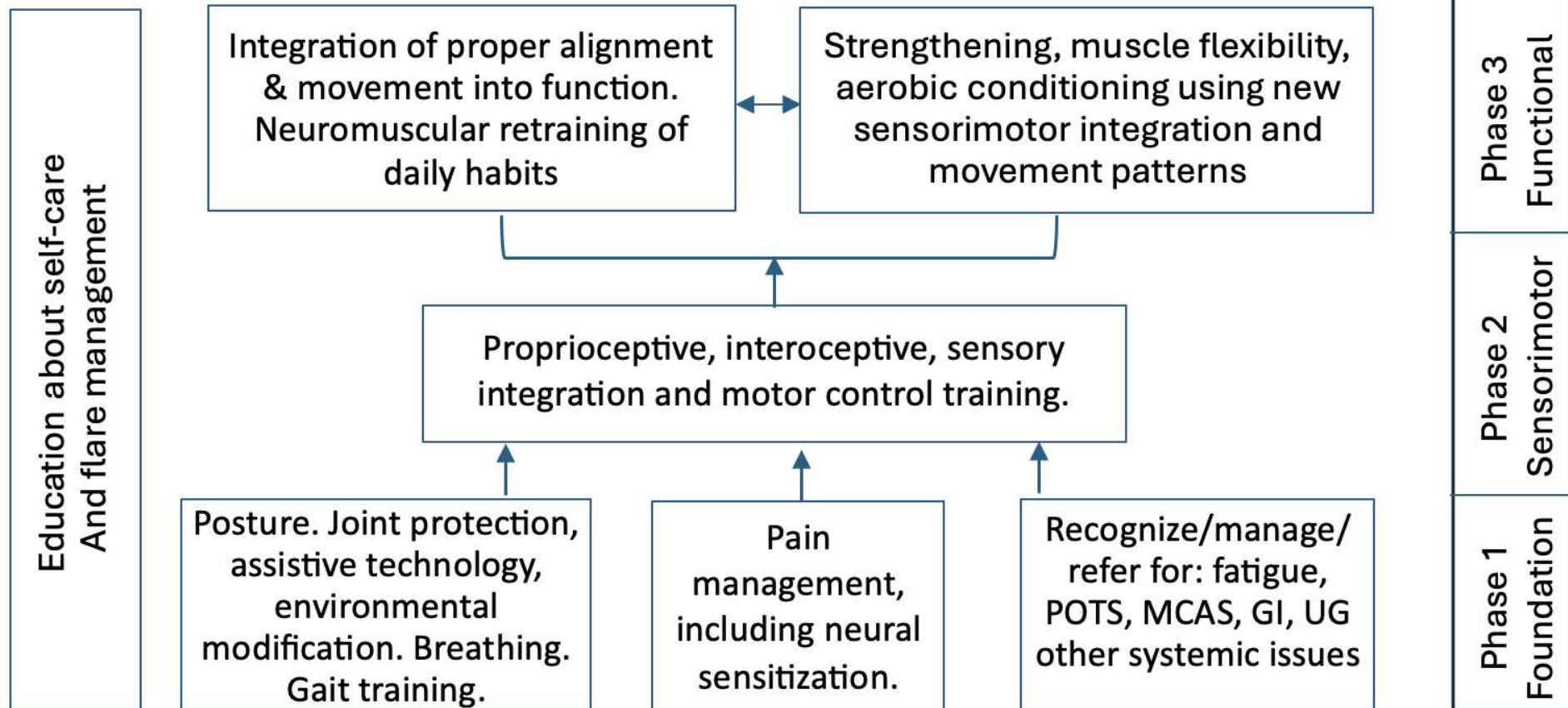
The information in this presentation is for general purposes, only, and may or may not apply to your situation.

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.



PT Approach to Managing HSD



Why Should You Exercise?

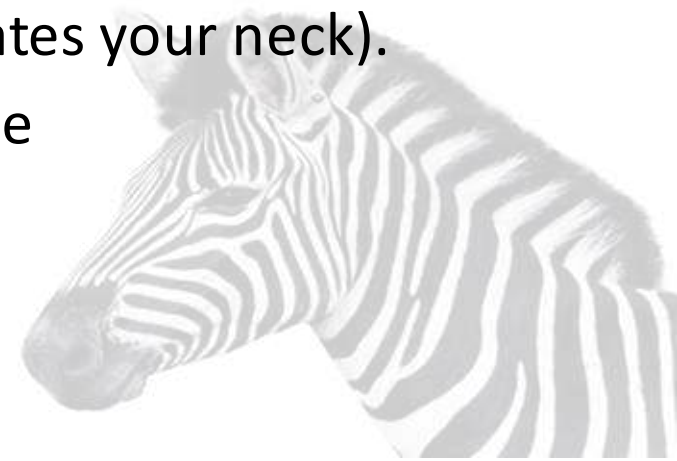
- To decrease pain and inflammation, improve immune & vagus function.
- To develop better body awareness.
- You have osteoporosis and need to strengthen my bones.
- You have POTS or fatigue and need to improve cardiovascular function.
- You had surgery and need to strengthen again afterwards.
- To decrease the chance of falling.
- To improve your ability to do functional activities.
- To reduce stress and improve sleep.
- To improve self-esteem.
- It can be a social activity.

Lima et al, 2017
Sabharwal, 2016
Ambrose, 2015



Potential Challenges for Exercise

- You are too fatigued to start, or you crash with fatigue for several days after exercise.
- It aggravates your cervical instability
- Resistance exercises (weights & resistance bands) hurt your wrists, shoulders, low back, hips, knees
- Standing or walking exercises increase leg pain.
- Part of the movement needed aggravates one of your problem areas (for example, you like to swim, but neck rotation to breathe aggravates your neck).
- Nothing specific, but exercises seem to always be uncomfortable
- Exercise is boring and/or stressful.
- Being upright aggravates your POTS



General Principles for Successful Exercise

- **Start Low, Go Slow!** It's easier to gradually increase exercise than to crash and start over again.
- Keep good posture and joint alignment throughout; if necessary, use braces or external support to maintain good alignment.
- Do a gentle warm-up with a pain-free, no resistance movement.
- Start movement exercises with no resistance, make sure your form is good.
- Start resistance exercises with no movement (isometric), gradually increase.
- If you have POTS or fatigue, select exercises in the optimal position.
- Increase sensory input: pressure from the floor, a Pilates ball, a stick, resistance band, compression clothing, Kinesiotape.
- Pace yourself with breaks during exercise.
- Do a gentle cool-down to relax mind and body at the end.



Challenges To Be Discussed

- Fatigue and post-exertional malaise: *“I can’t even start exercising!”*
- General pain, nerve sensitization: *“Everything hurts!”*
- Cervical instability: *“My neck always hurts during/after exercise.”*
- Low back pain: *You see the pattern, here*
- Upper extremity problems: shoulder, elbow, wrist, fingers
- Lower extremity problems: hips, knees, ankles, feet
- POTS & dizziness being upright: *“I’m too woozy!”*





Causes for Fatigue

Poor quality sleep

POTS

MCAS

Post-Exertional Malaise (PEM)

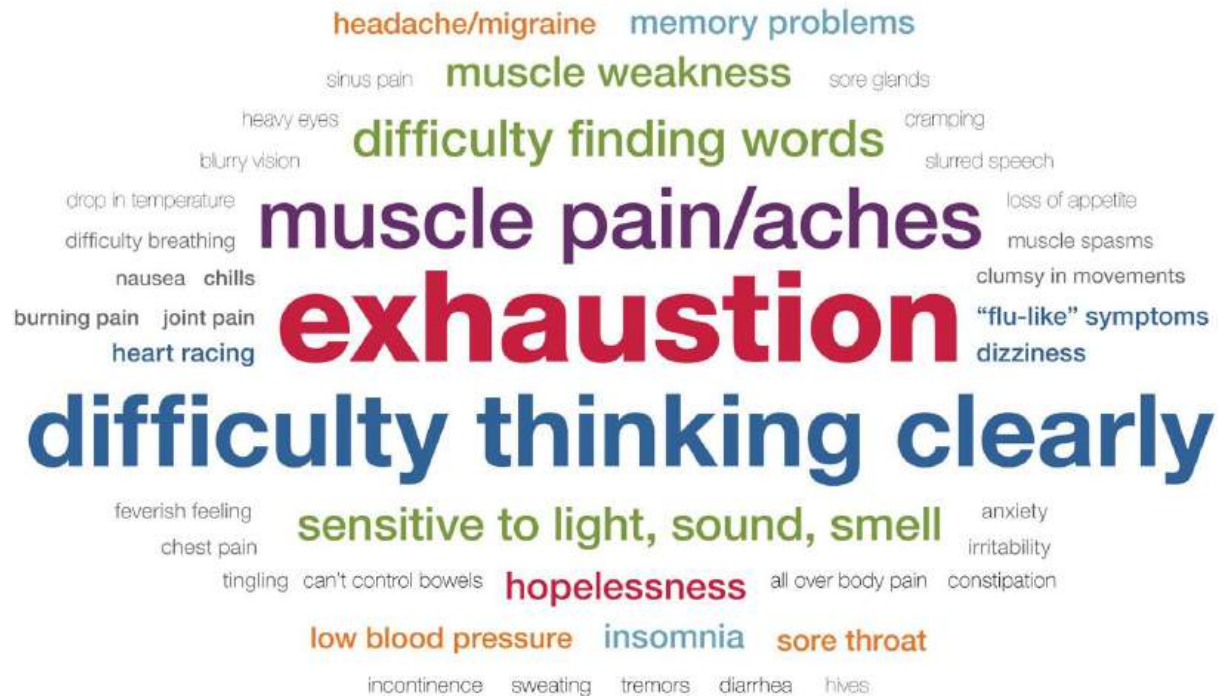
Deconditioning

HSD 102: POTS & MCAS

HSD 107: Fatigue & Sleep



Post-Exertional Malaise



- You feel like you have a flu for several days after exercise
- Typical of myalgic encephalomyelitis/chronic fatigue syndrome, long-COVID, and sometimes POTS
- Excellent information about ME/CFS at <https://workwellfoundation.org>

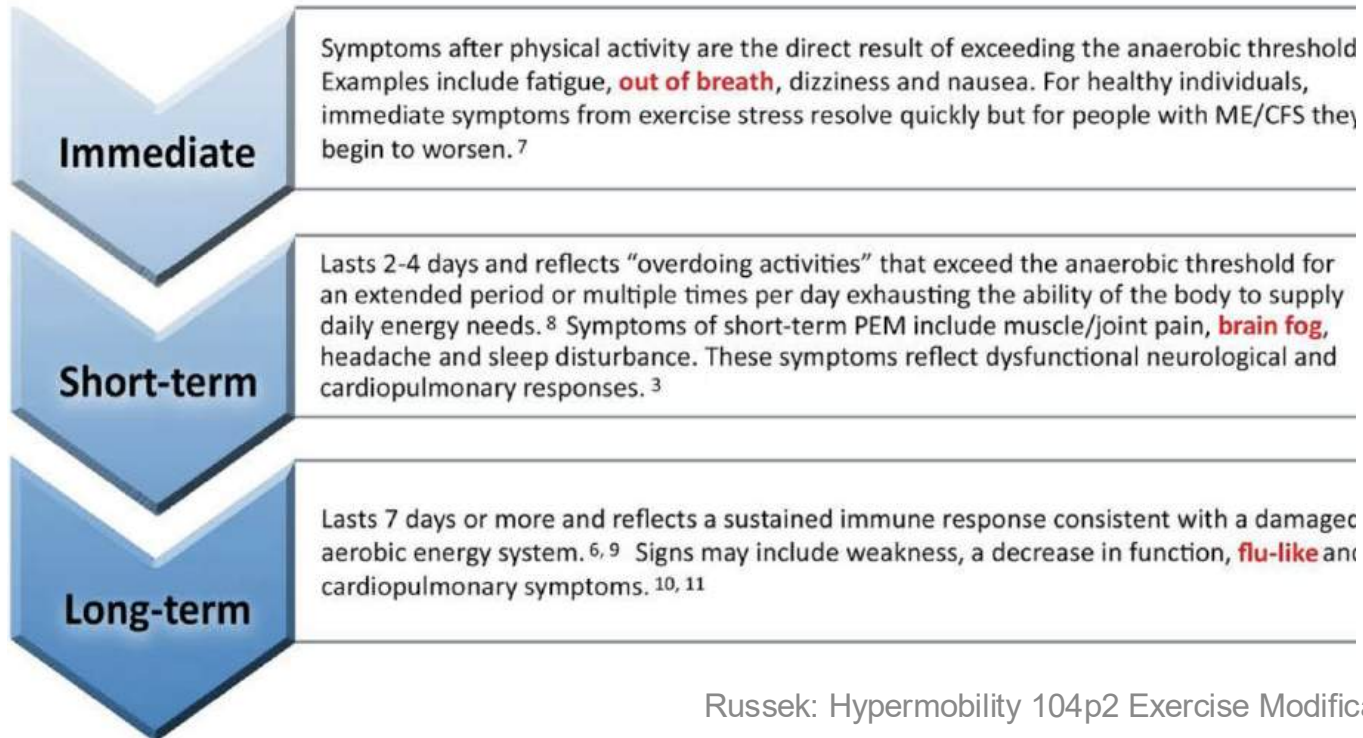


Post-exertional Malaise (PEM) Timecourse for ME/CFS

What is Post-exertional Malaise Following Physical Activity?

Post-exertional malaise (PEM) is considered the hallmark clinical feature of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). PEM is the worsening of symptoms and decreased function following physical, cognitive, or emotional effort. The onset may occur immediately after activity or be delayed.^{1, 2} Immediate, short-term and long-term PEM symptoms following physical activity can be explained in terms of the damaged energy systems found in ME/CFS.^{3, 4, 5} Overload in other areas (cognitive, emotional, sensory, upright posture, etc) can also cause immediate and longer-term symptoms, but responses to these stressors are less well documented in the literature.⁶

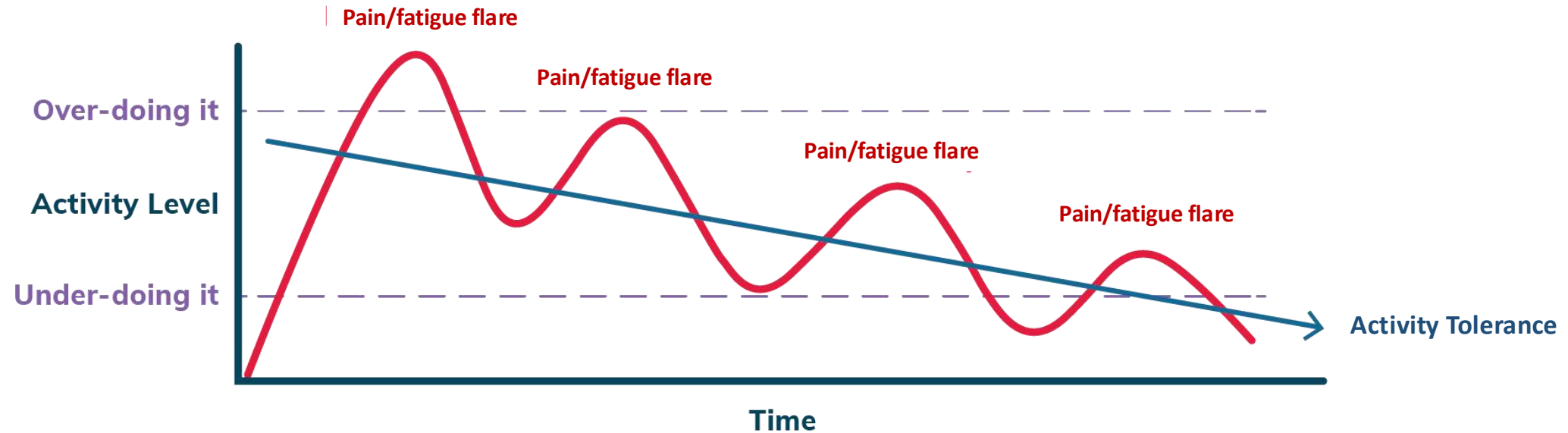
PEM Timecourse



<https://workwellfoundation.org/resources/>



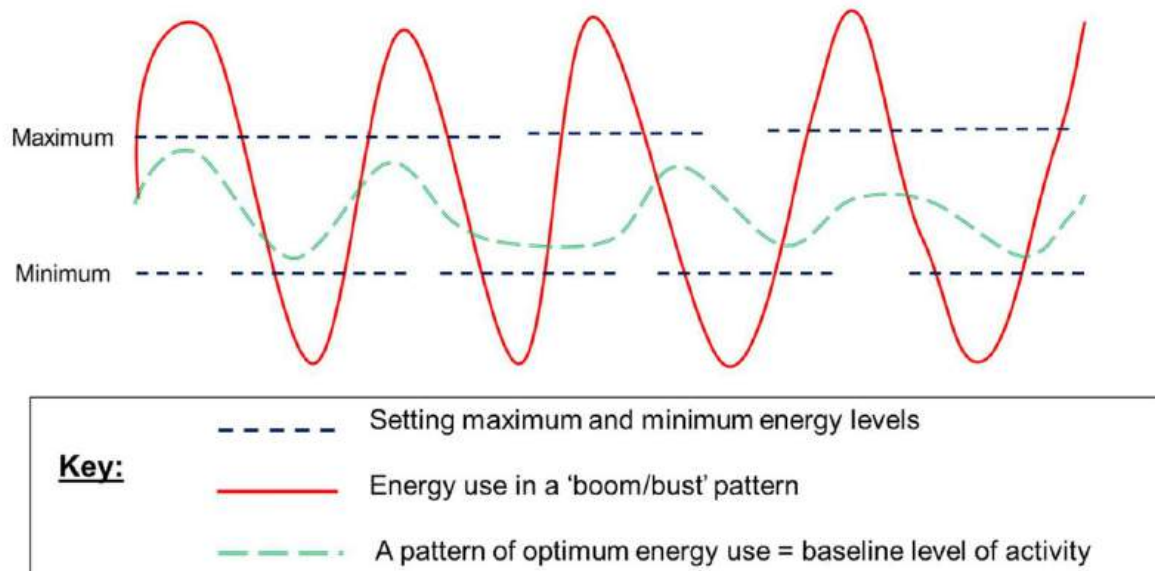
Boom-Bust Activity Cycles



- Exercise intolerance leads to a boom-bust cycle where you try to exercise, crash for several days due to pain and/or fatigue, then you try to exercise, crash, etc.
- Over time, your energy limit decreases.
- Trying to exercise this way may DECREASE your fitness rather than increase it.
- https://me-pedia.org/wiki/Boom_and_bust_activity_cycle



Avoiding Boom-Bust Cycles



- National Health Service “Fundamentals of Fatigue Management” at <https://www.royaldevon.nhs.uk/media/eargcx0r/4-session-1-fundamentals-of-fatigue-management.pdf>

- Avoid overdrawing your energy ‘bank account’ (and paying overdraft fees).
- Learn to recognize signs that your energy bank account is almost empty.
- Identify your PEM ‘overdraft’ symptoms, rest if you start to feel these symptoms.
- Common PEM symptoms:
 - Immediate: difficulty breathing, dizziness, nausea
 - Short term: pain, brain fog, headache, sleep disturbance
 - Long term: weakness, flu-like symptoms, decreased function
- Identify things that drain your energy account
- Schedule rest and rejuvenating activities to replenish your account



Activity Pacing with HR Monitor or RPE

Rate of Perceived Exertion (RPE)

Score	Effort
10	Maximal Effort
9	Very, Very Hard
8	Very Hard
7	Hard
6	Somewhat Hard
5	Moderate Activity
4	Light
3	Easy
2	Very Easy
1	Very, Very Easy
0	No Exertion

- Pacing using HR or Rate of Perceived Exertion (RPE) can avoid Boom-Bust cycles
- Determine resting HR in your exercise position (e.g., lying down, sitting, or standing)
- Limit activity to HR increase of 15 beats/min (BPM) or RPE of 2/10
- Identify your PEM symptoms that you are doing too much, stop activity if you start to feel these symptoms or if they get worse
- **This is similar to POTS protocols!**
- <https://workwellfoundation.org/wp-content/uploads/2023/01/HRM-Factsheet.pdf>



Other Ideas to Avoid PEM

- Change your exercise program to one that doesn't cause a crash.
 - Start very slow and very easy. Monitor HR and/or RPE.
 - Exercise in a POTS-preferred position: recumbent or lying down.
- Make sure you are breathing properly.
- Try doing intervals, e.g., 30 seconds on, 30 seconds rest.
- Do a gentle cooldown afterwards to re-activate your parasympathetic nervous system: gentle movement or deep breathing.
 - Or try the POTS "Recovery Position", lying on your back with legs propped up
- Stay well hydrated.
- Pace yourself during the rest of the day: daily activity is 'exercise' too!



Visible App



- “Visible is designed to help you understand your energy-limiting illness including Long Covid, ME and Chronic Fatigue Syndrome (CFS).

“Unlike fitness trackers, Visible is designed for rest and pacing, not workouts and exercise. Track your activity levels, symptoms, fatigue, medication, crashes, heart rate, HRV, and more”

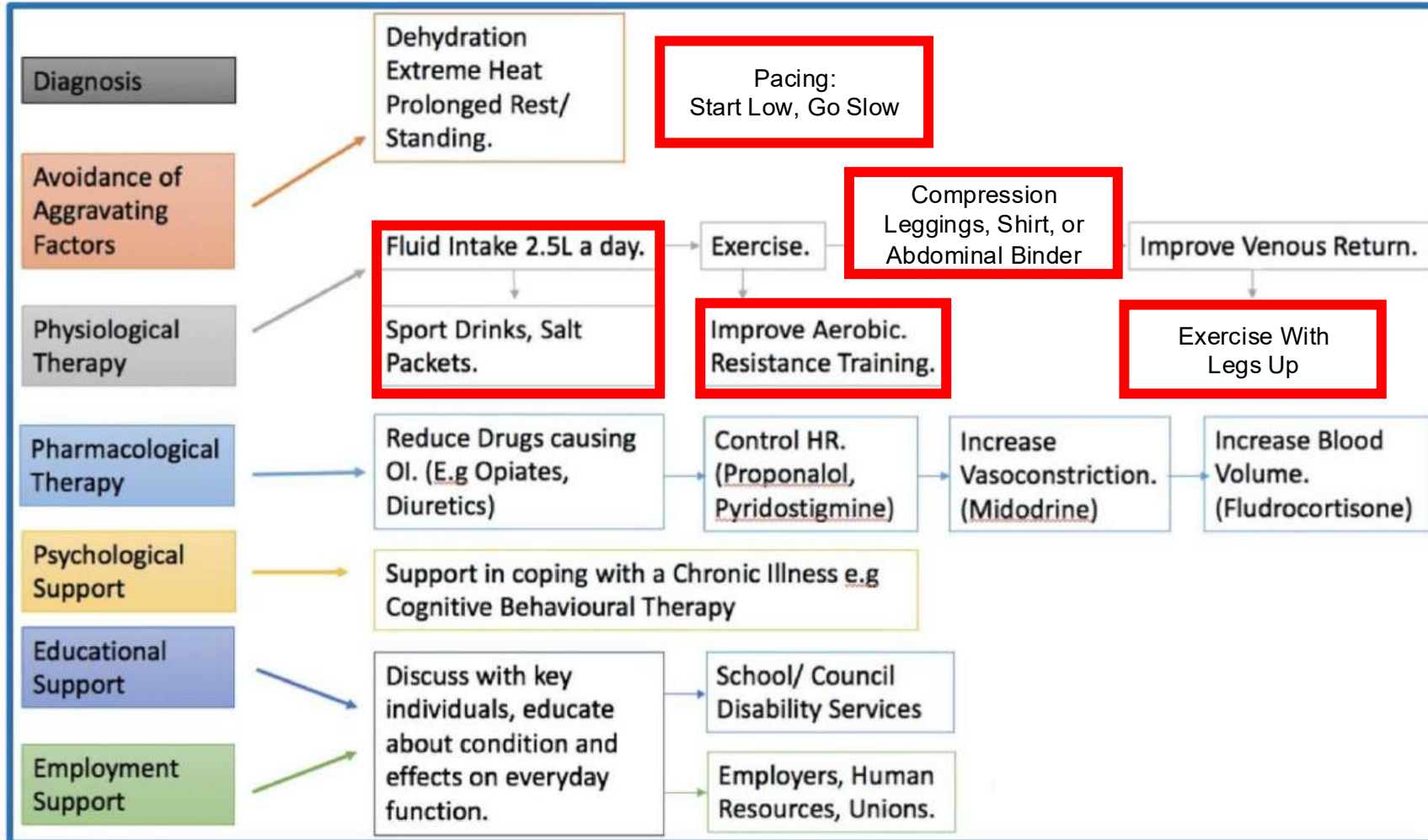
I have no personal experience with this app, but colleagues and patients tell me it is helpful.



Managing POTS Fatigue

HSD 107: Fatigue Management

Flow Chart for POTS Management



Deconditioned? Start Slow and Easy

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

Nervous System Sensitization

HSD 103: Pain Management

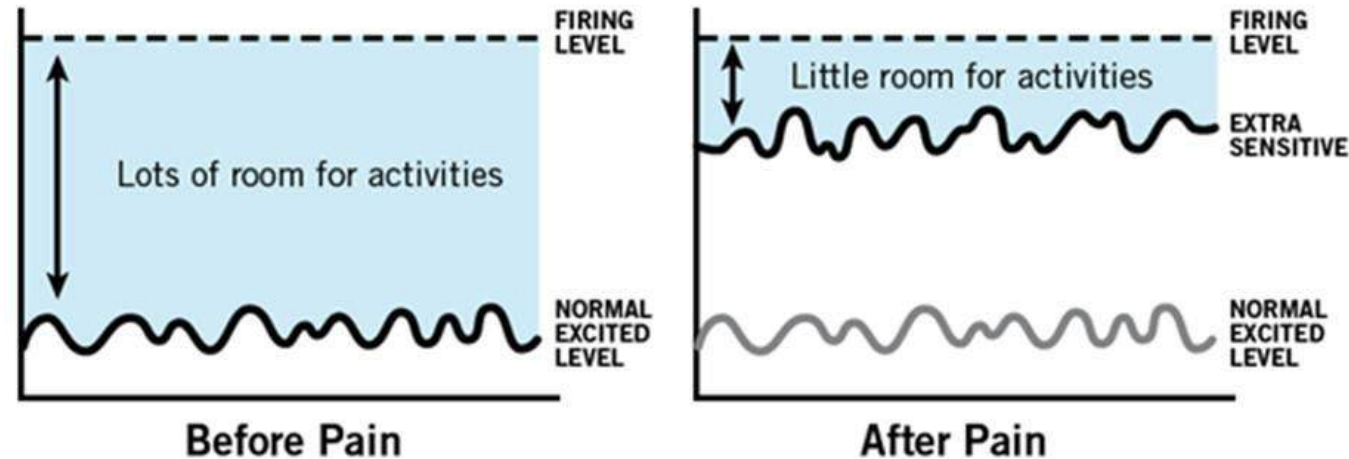


“Messed up volume control”



Nervous System Sensitization

- Nociceptive (pain) nerves become more sensitive, react more easily and more strongly.
- Caused by inflammatory chemicals, tissue damage, or neuroplasticity.



Why Do I Hurt?; Louw 2013 OPTP

- When your nervous system is sensitive, you might not tolerate any exercise, even 'good' exercise
- You may need to calm your nervous system before exercising.
- Appropriate exercise can help reprogram the nervous system (Zou, 2024)



The Pain Sensitivity “Bucket”

Pain sensitivity results from the gap between inputs and outputs for the “pain sensitivity bucket”

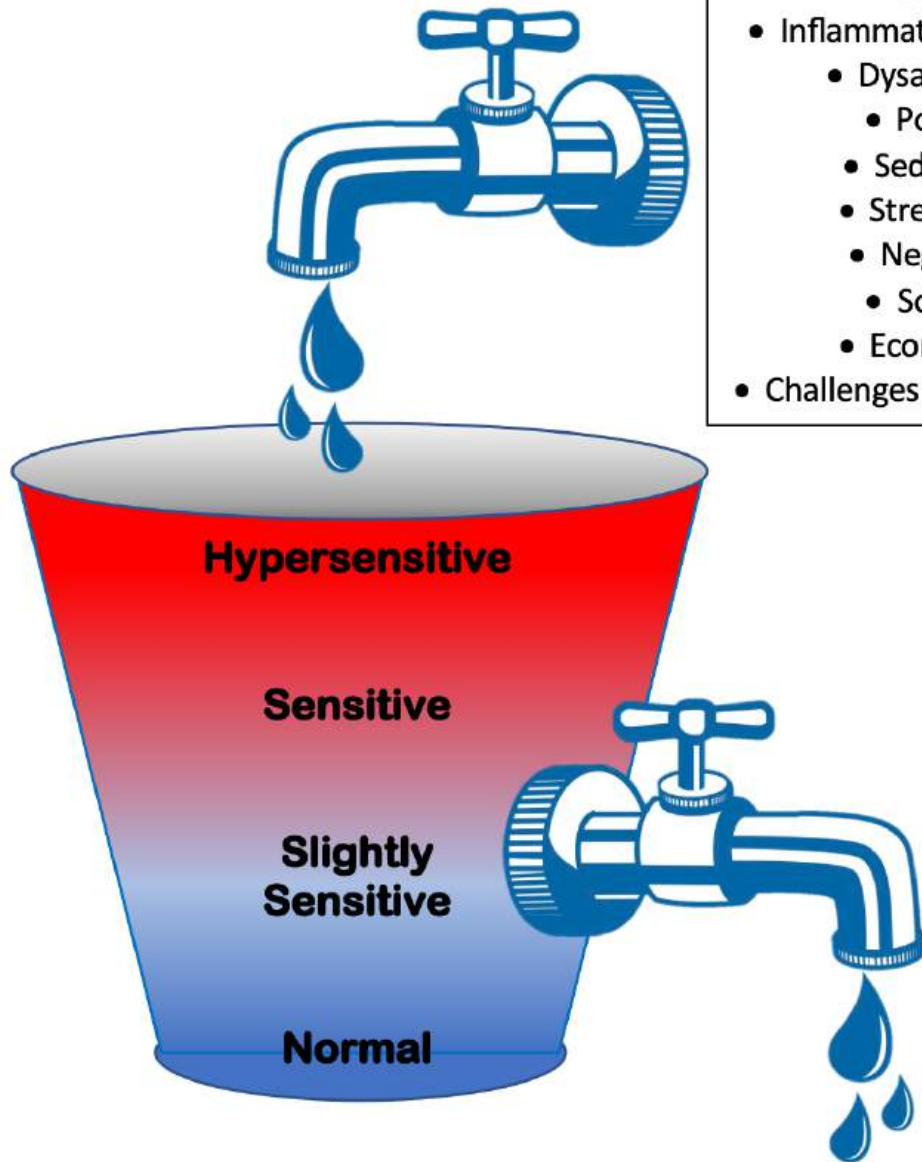


Things Filling the Pain Sensitivity Bucket

- Tissue stress/injury
- Inflammation (including MCAD)
 - Dysautonomia/POTS
 - Poor sleep/diet
 - Sedentary lifestyle
 - Stress/anxiety/fear
 - Negative thinking
 - Social stressors
 - Economic stressors
- Challenges of health care system

Things Draining the Pain Sensitivity Bucket

- Good sleep/diet
- Positive coping skills
- Therapeutic alliance
- Relaxation/stress management
- Self-care strategies
- Appropriate exercise
- Social support



Managing Pain Sensitivity

Nociplastic Pain

- Sensitive nervous systems benefit from reprogramming/calming
 - Quality sleep
 - Pain Neuroscience Education (PNE) to learn that not all pain indicates tissue damage, that stress may cause/amplify pain, and it may be safe to move
 - Calming the nervous system: mindfulness, meditation, deep breathing, biofeedback, vagus nerve activation, mindful movement such as (modified) Tai Chi, yoga, Pilates, qigong.
 - Cognitive behavioral strategies
 - (Zou, 2024)

HSD 103: Pain Management





Questions?





Minimize Stress to Your Body



Principles for Strengthening Exercises

- Make sure your alignment is perfect.
- Start with light isometrics, where you don't move your body.
- Start movement exercises without any resistance.
- Support your body better. Use floor, wall, or chair for support.
- Keep joints in mid-range, or use braces for support.
- If it still hurts, it isn't a good exercise for you.

- *(Definition: isometric – an exercise where muscle length does not change when the muscle is activated)*



Joint-Specific Concerns: Neck

Common problems:

- High impact exercises: running, field sports (e.g. soccer) jumping, contact martial arts.
- Awkward neck positions: 10-speed bicycling, swimming. Even just holding your head against gravity.
- Rapid or extreme neck movements: tennis, volleyball, field sports.
- Bumpy activities: horseback riding, mountain biking.
- Excessive tension held in neck muscles, due to stress, poor body awareness, or inappropriate form.

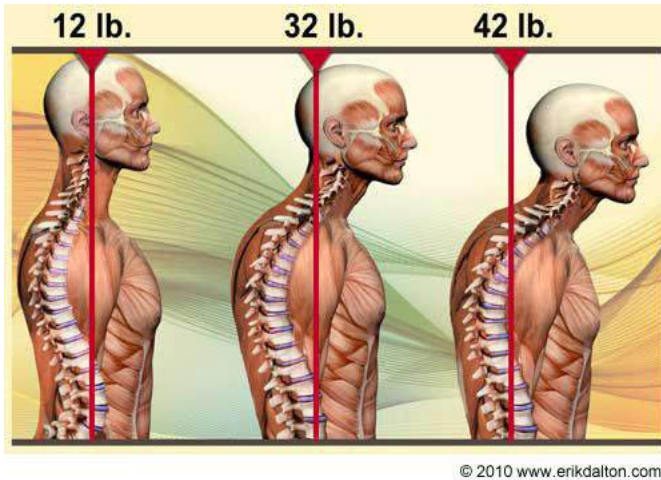


Neck: Keep Your Neck Aligned

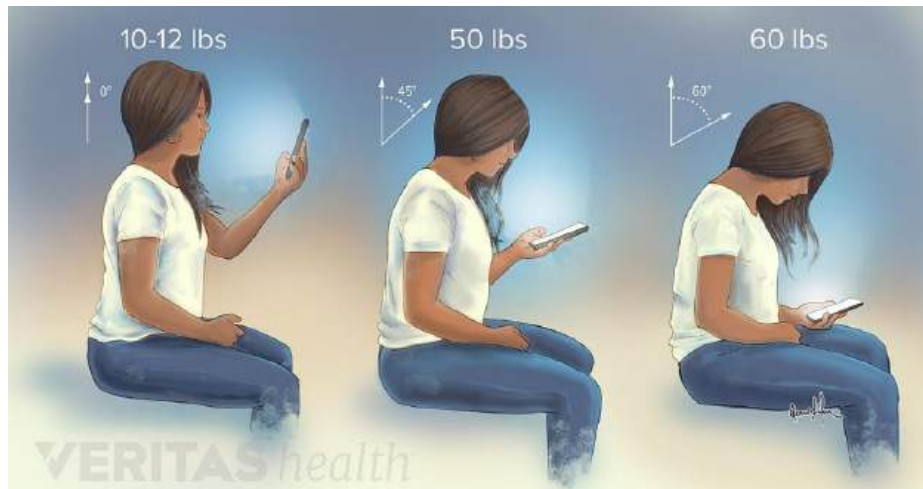
- Make sure the neck is properly aligned at all times. If you are unable to keep it aligned, don't do that exercise.
- Do exercises lying down where your head and neck are supported in good alignment
- Wear a neck brace to keep the neck in good alignment
- Use a snorkel when swimming to keep the neck in neutral
- Some people need a folded towel under their head when lying down to prevent the head from tipping backwards



Neck: Your Head Weighs 12 Pounds Plus...



- Because your head weighs 12 pounds, your neck does a lot of work just holding your head in place.
 - Poor posture increases the work your neck must do just to hold your head still.
 - Holding your head horizontally places significant strain on your neck.
- Solution: Don't use these positions!
 - Quadruped can be good once you can do pain-free.



Neck: Use (Only) the Correct Muscles

- People with HSD tend to activate muscles in an All-Or-None pattern.
 - i.e. throw everything you have at a task and hope it's enough.
- This activates muscles that should NOT be active.
- The deep stabilizing muscles are preferentially activated at LOW LOADS.
- Strenuous activity preferentially activates power muscles that destabilize joints and go into spasm
- Stress also activates power muscles that destabilize joints and go into spasm



HSD 111: Cervical Instability



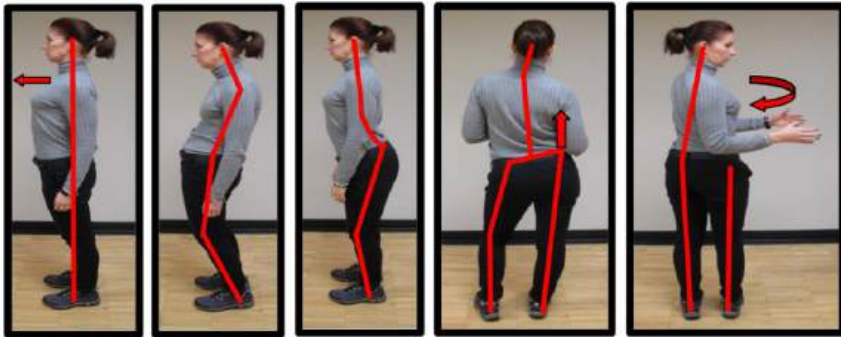
Neck: Use (Only) the Correct Muscles

- Suggestions:
 - Exercises should begin at low loads, 1/10 effort, even if that means there is no movement or minimal resistance. "Start Low. Go Slow!"
 - Engage muscles slowly, such as over a count of 5.
 - Learn to fully relax muscles slowly once activation is done.
 - Exercises should isolate ONLY those muscles that should be active.
 - You might need to do low back or leg exercise lying down with head and neck stabilized so you don't need to activate neck muscles.
 - You may need to relax your mobilizer muscles before you exercise.

The Zebra Club™



Joint-Specific Concerns: **Low Back**



- If your back is sensitive, try to keep it in neutral, not arched, flexed, or twisted
 - Controlled movement can be healthy, once asymptomatic
- Avoid high impact activities, including tennis or golf, where impact transmits to the back
- Exercises for power muscles (e.g., crunches) can destabilize the spine



Joint-Specific Suggestions: Low Back

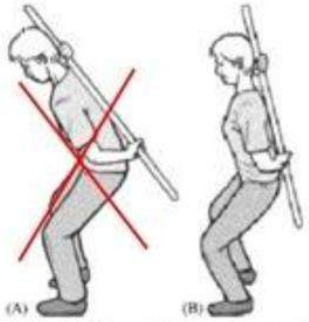


Figure 1 The hip hinge: (A) incorrect—stooping and (B) correct—squatting.

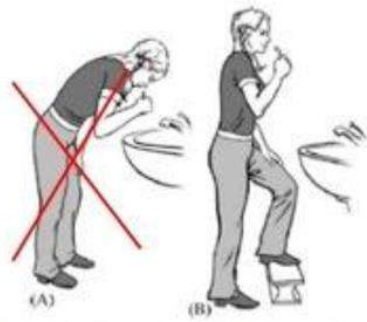


Figure 3 Brushing teeth: (A) incorrect and (B) correct.



Figure 5 Picking up a bag from the floor: (A) incorrect and (B) correct.



Figure 2 Getting out of chair: (A) correct and (B) incorrect.

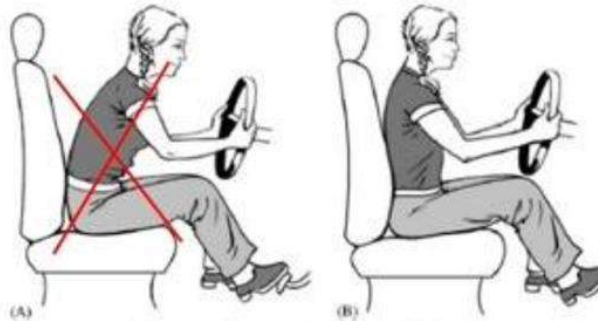


Figure 4 Driving: (A) incorrect and (B) correct.



Figure 7 Changing a baby: (A) incorrect and (B) correct.



Figure 8 Lifting: (A) incorrect and (B) correct.

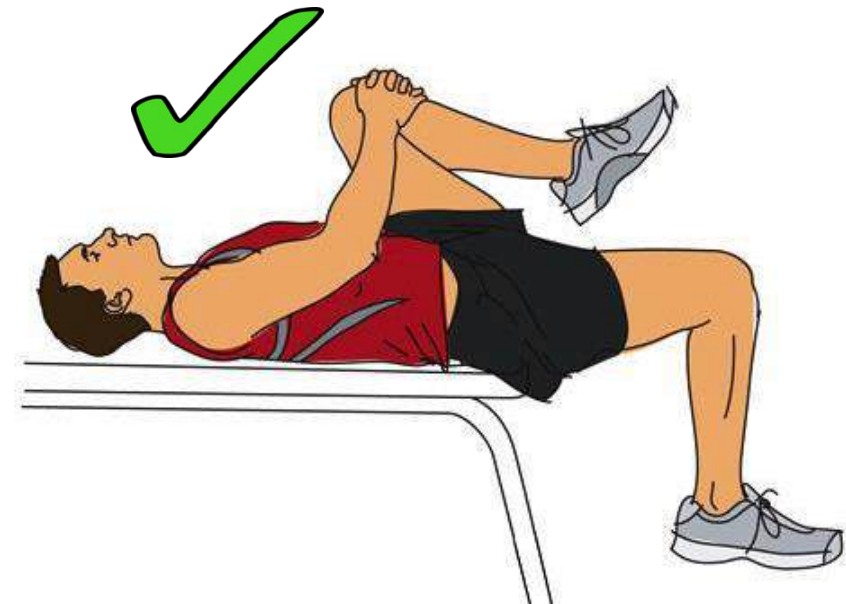


- Maintain neutral
- Use hip hinge.
- Add proprioception and support by lying on the floor.
- Start with stabilization training.
- Start with low loads to ensure you activate only the correct muscles.
- Activate muscles slowly (5 count, and relax slowly).



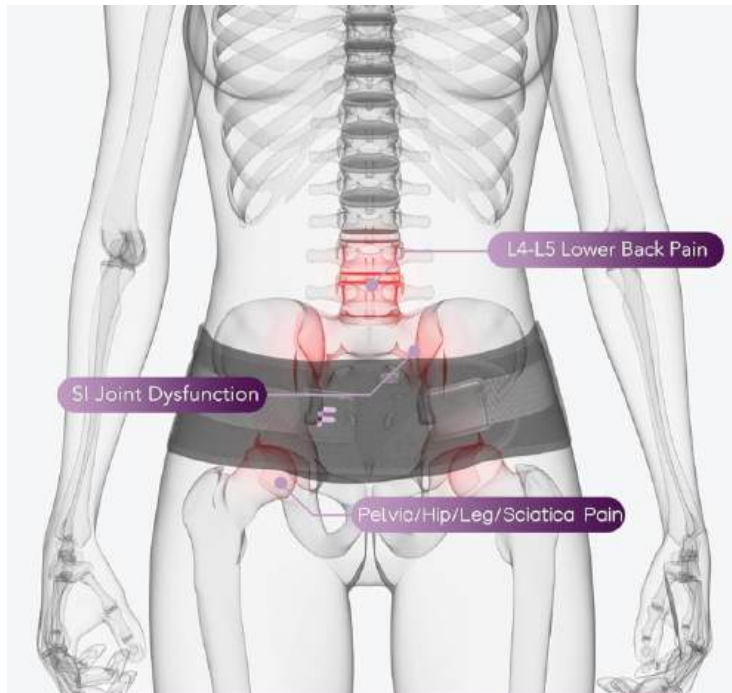
Stretching/Elongating Muscles Carefully

- Tight hip muscles pull the low back out of alignment
- Stretch carefully!
 - Your body will always stretch first where you are already stretchiest!
- You need to carefully stabilize a hypermobile lumbar spine
 - Elongation requires/teaches motor control for stabilization



Low Back: Other Strategies

- Wearing a back brace, sacroiliac brace, or Kinesiotape may help provide support and/or proprioceptive feedback
- Exercise in positions where low back is supported



Russek: Hypermobility 104p2 Exercise Modifications

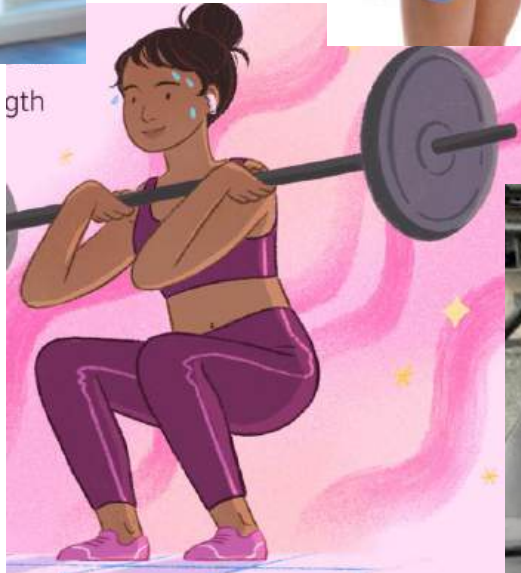
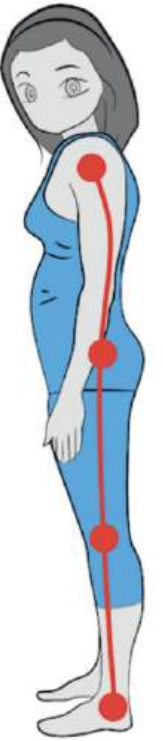


Joint-Specific Concerns: **Upper Limb**



- Common Problems:

- Weight on extended wrists or pushing
- Hyperextending elbows
- Forceful gripping
- Holding free weights
- Excessive shoulder movement
- Tight chest muscles pulling shoulders forward



Russe



Joint-Specific Suggestions: Shoulders

- Start with shoulders in good alignment (not forward, not drooping, not shrugged)
- Shoulders: Start with stabilization exercises (e.g., “drawing in”), then isometrics.
- Avoid heavy free weights or even light weights for prolonged time
- Closed chain (hands on wall or floor) can increase stability
- Make sure you strengthen and stabilize shoulder blades



Prone I, T, W, Ys



Joint-Specific Suggestions: Wrists

- Keep wrists in neutral (with or without wrist brace)
- Place resistance bands around forearms rather than gripping
- Avoid holding dumbbell weights
- Avoid weight on extended wrists:
 - Do planks on forearms
 - Use push-up bars/yoga blocks
- Use wrist brace/support



Joint-Specific Suggestions: Fingers

- Avoid forceful gripping
- Use a "C" or lobster-claw grip
- Use handles on resistance bands or place bands around wrists
- Use braces or splints

Push MetaGrip



Oval-8 Finger Splints

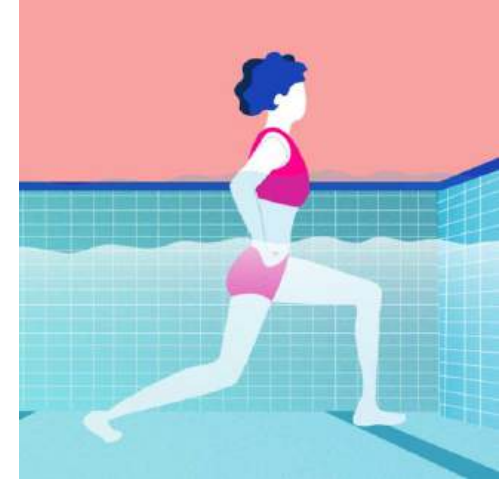


Joint-Specific Concerns: Lower Extremity

- Common problems
 - Anterior knee pain with knee flexion movements
 - Hip instability or lateral hip pain when walking/standing
 - Ankle instability



Standing or Walking Causes Leg Pain



Modify your standing/walking exercise

- Make sure you have good shoes with orthotics if you need them.
- Use walking poles to decrease stress to legs
- Wear knee, hip, or ankle braces to support the painful joint
- Wear compression clothing to improve body awareness

Choose different exercises/positions

- Exercise sitting down.
- Exercise lying down.
- Exercise in the pool.

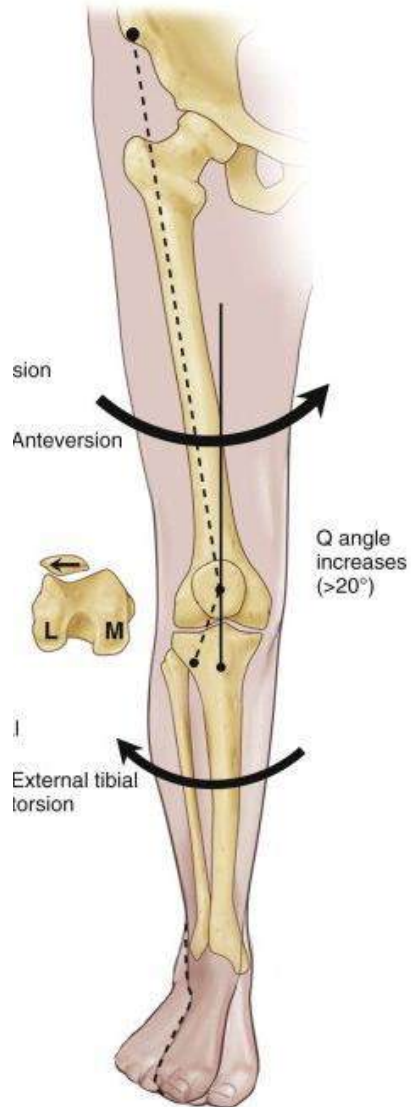


Joint-Specific Suggestions: Hips

- Hips: Start with stabilization exercises (e.g., “drawing in”), then isometrics.
- Manage tight muscles pulling on loose hip joints (carefully so you support lumbar spine).
- Lateral hip pain is often trochanteric pain syndrome
 - Minimize standing and walking until pain decreases
 - Strengthen hip abductors (outside of thigh)
 - Keep your pelvis level when you walk or stand on one leg



Anterior Knee Pain (Patellofemoral Pain)



- Stretch tight quadriceps muscles (carefully!).
- Wear orthotics if you have flat feet; don't go barefoot.
- Strengthen hip muscles (glutes and external rotators)
- Avoid deep knee bends
- Keep knee tracking over foot when bending it
- Never let knees go forward of toes
- Patellar stabilization brace or KT tape



Ankle Instability



- Wear an ankle brace while doing activities that feel unstable, especially when on uneven ground
- Strengthen the ankle, especially the outside muscles (eversion)
- Work on single leg balance and ankle proprioception



Flat Feet Compromise Leg Alignment

FOOT ARCH TYPES



FLAT



NORMAL

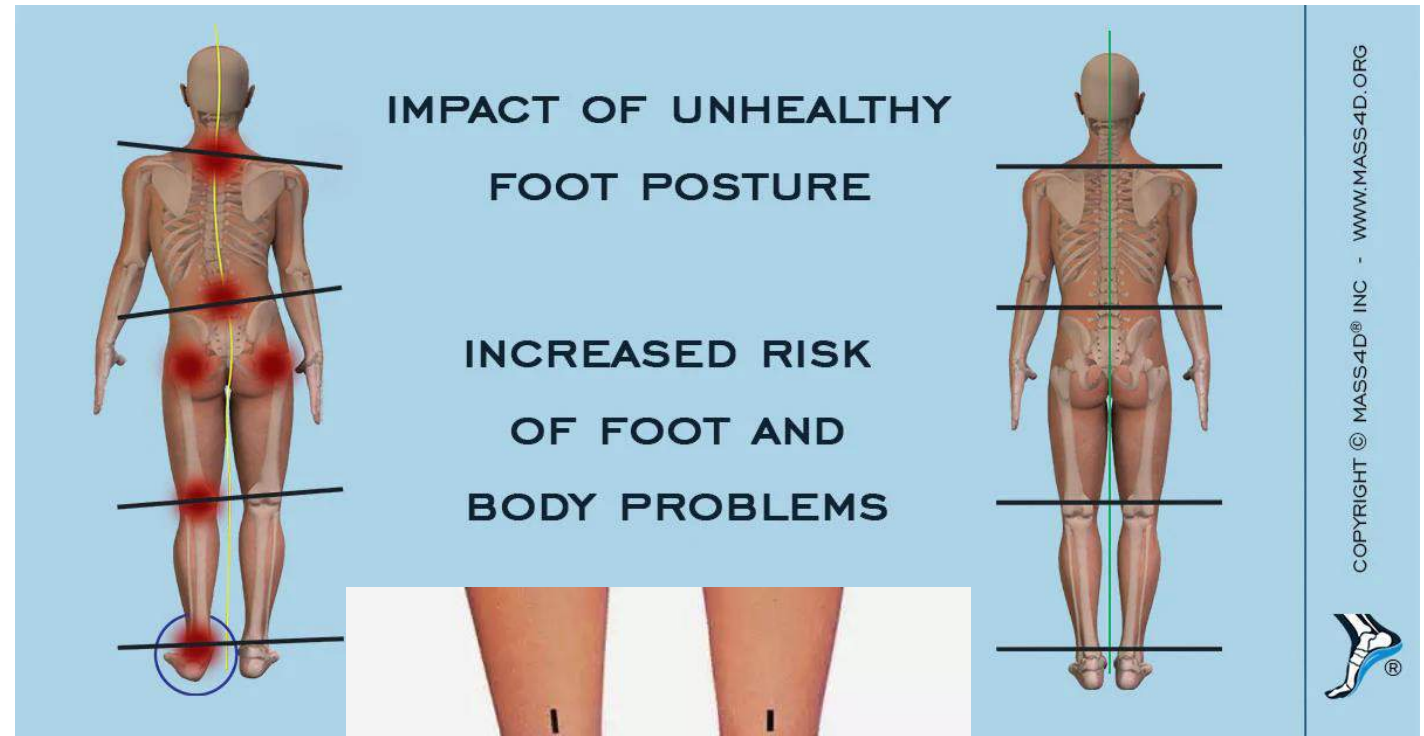


HIGH



VERY HIGH

- The “paper towel” test: place a dry paper towel over a damp paper towel and step on them.
- Over-the-counter orthotics are often sufficient. If you have flat feet, look for an arch support and heel cup.



Lower Extremity Supports & Braces

- Taping or bracing a vulnerable joint can protect it and improve proprioception.
 - Also provide reminder to not move into extreme positions
- Orthotics keep legs aligned.

KT: For those with skin sensitivity: Pretreat the skin with Benadryl cream, Pepto Bismol or Imodium for 10 minutes, then wipe off any remaining.
Or use Cavilon pre-tape spray.



Making Exercises Less → 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)



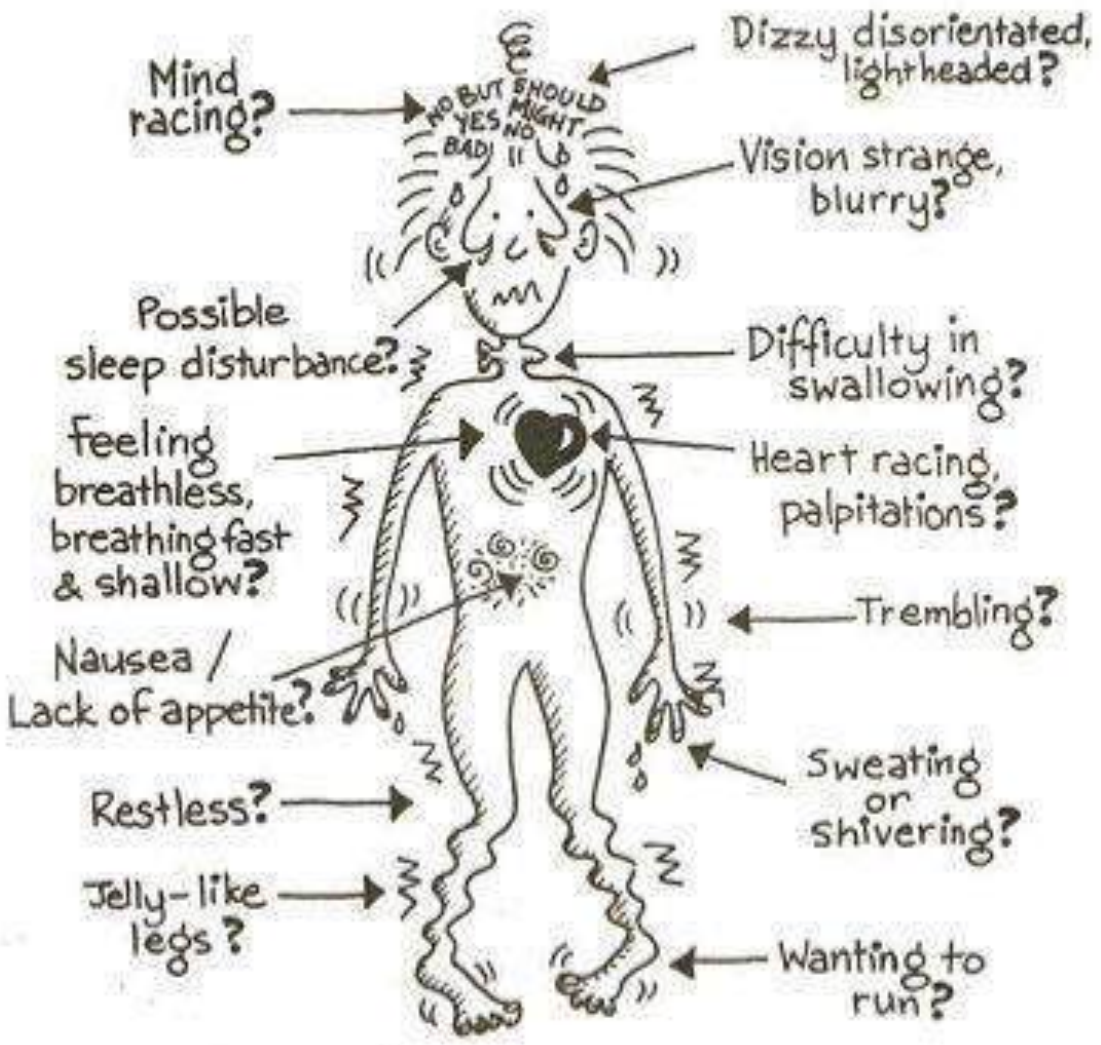


Questions?



DOES THIS LOOK FAMILIAR?

POTS Symptoms



“Being Upright Aggravates My POTS”

- Do aerobic exercise sitting or lying down.
 - For example: POTS “wall slide” done lying down.
- Strength exercises sitting or lying down: antigravity, isometrics, or resistance bands
- Drink plenty of fluids with electrolytes.
- Wear waist-high compression leggings when exercising.
- Exercise in the pool. (NOT a warm, therapeutic pool)
- Keep cool: exercise in cool locations, use a fan, spritz with water.



For Very POTSIE People

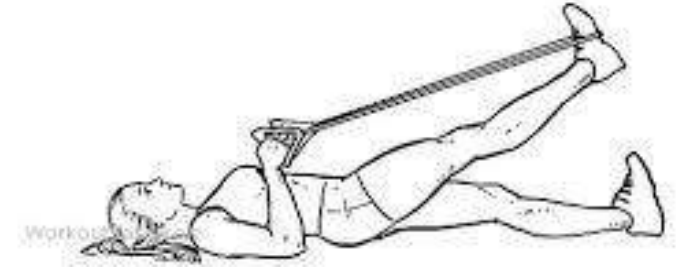


- Start with lying down exercises
- POTS “Pumps” are a ‘recovery’ exercise: Lie down with legs elevated: ankle pumps, quad set, hamstring set, glute set (isometric), deep belly breathing
- Gentle leg/arm strengthening using body weight or resistance bands
- Core strengthening
- Wall slides (shown here) for aerobic exercise if you cannot do aerobics upright

• Fu, 2018



Exercising Lying Down



U



Sitting Exercise Options

There are many other good sitting exercise YouTubes available. They are typically developed for seniors, but are perfect for people who need to be careful about how they exercise

These are just a couple I know about.

Chair yoga:

<https://www.youtube.com/channel/UCcsQamTnd7SujVLeIXywZ7g>

Sitting Tai Chi (breathing-based movement):

https://youtu.be/_V29hE0_oBE

Sitting qigong (breathing-based movement):

<https://youtu.be/ppM9FRRX-Uo>



Exercise is BORING!



Make Exercise Fun: Exergames

- Dance or movement-based games may be more engaging
- 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

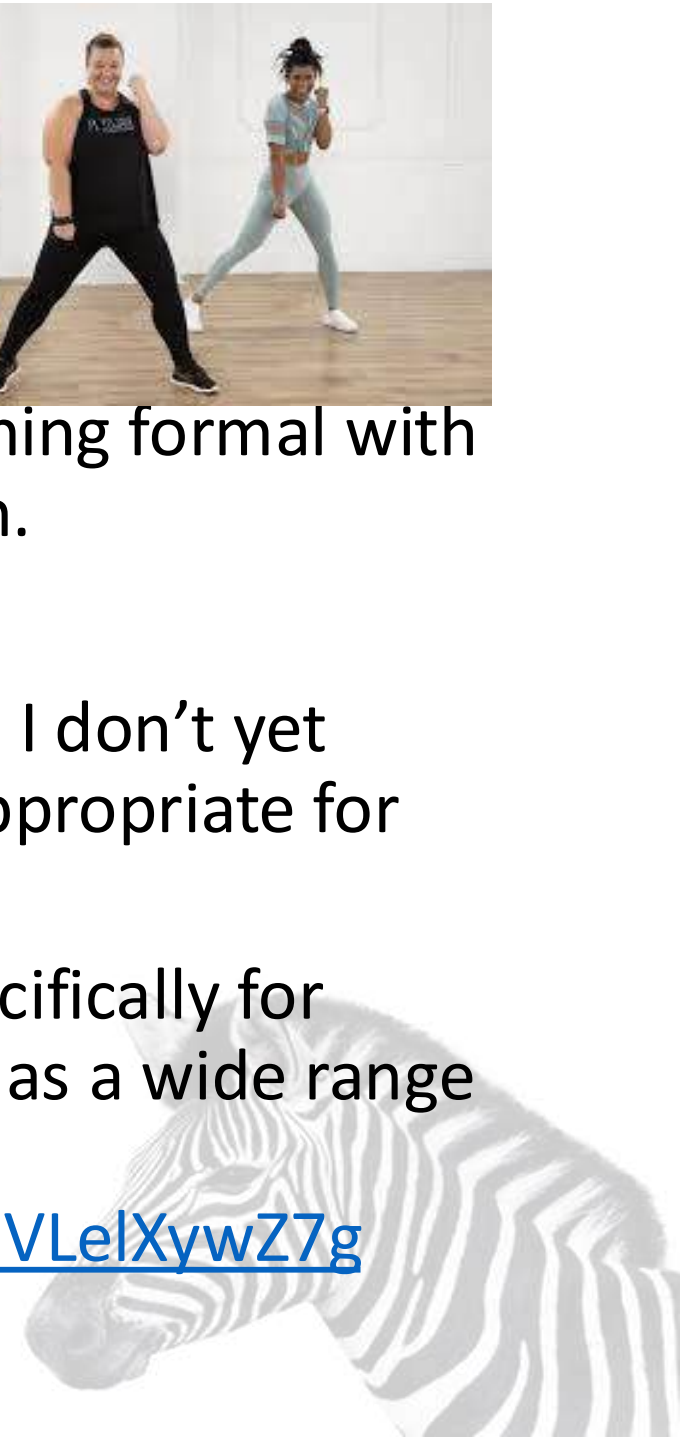


Make Exercise Fun: Dance



- Dance can be a great exercise, whether you do something formal with a partner, or you just groove to the music on your own.
- Music is motivating
- Be sure that the dance app/routine is not too difficult. I don't yet know enough about dance apps to recommend any appropriate for EDS.
- YouTubes of chair yoga with Sherry Zak Morris are specifically for older people or people with physical limitations. She has a wide range of musical genres.

<https://www.youtube.com/channel/UCcsQamTnd7SujVLeIXywZ7g>



Exercises Designed for Zebras



- The Zebra Club (TZC) Pilates app for people with HSD is developed by an HSD specialist, Jeannie Di Bon. The app has many types of exercises, ranging from breathing and pain reduction to strengthening and cardio. It also has lectures, discussion groups, live ‘meet-ups’ where you can ask questions.
- Disclosure: I am a scientific advisor for TZC, and a friend of Jeannie’s, but I don’t get anything for recommending the app.
- It is somewhat expensive, but when you compare to medical co-pays or traveling for care, it may be cost-effective for you.
- <https://www.thezebra.club/>





Questions?



Common Reasons for Exercise “Failure”

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

POTS checklist, MCAS self-care

Pain Handouts

HSD103, HSD109, HSD112

HSD102, HSD106, HSD107

HSD105



Summary:

- Not all exercises are appropriate for everyone
- But many exercises can be modified to be more appropriate
 - What do you like about this exercise?
 - What can you modify, to minimize the stressful parts while keeping what you like
 - Can you find another exercise that achieves similar goals, with less stress to your body?
- **Start low, go slow!**
- **Don't Give Up!**



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, Party Fowl



**The
Zebra
Club**

A Few More Exercise Links

Fibromyalgia has many similarities to the Trifecta, so suggestions are helpful

- A resource on Fibro-friendly exercise:
- <https://www.fibromyalgiafund.org/fibro-friendly-exercises/>
- Tips for modifying exercises when you have fibro, but similar for HSD/EDS
- <https://www.issaonline.com/blog/post/exercise-improves-symptoms-for-clients-with-fibromyalgia>
- The following link has some general suggestions for modifying exercises when you have a disability, though not specific to HSD or FMS.
- <https://www.helpguide.org/wellness/fitness/chair-exercises-and-limited-mobility-fitness>



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Questions?

