Hypermobility 107: Managing Fatigue in HSD/hEDS and POTS

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Slide handouts and recordings are 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
- On national and international EDS related committees
- 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

“HSD 101” Lecture Series Schedule

I will refer to these if you want more info

- 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 and teens
- HSD 106: Gut issues in HSD/hEDS, POTS, MCAS
- HSD 107: Fatigue in HSD/hEDS and POTS
- HSD 108: Headaches, migraines, and TMJ pain associated with HSD, POTS and MCAS
- HSD 109: Breathing dysfunctions in HSD
- HSD 110: Lumbar instability
- HSD 111: Cervical Instability, (Part 1, anatomy on-line) Part 2, diagnosis and PT
- HSD 112: Vagus nerve
- HSD 113: The importance of fascia

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Relevant Handouts Available

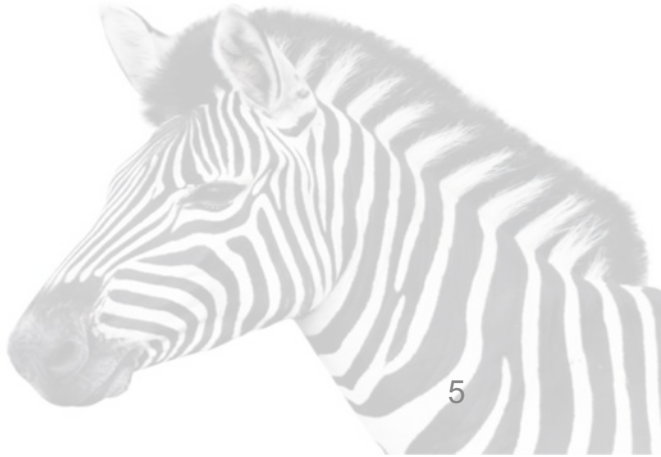
I will refer to these if you want more info

- https://webspace.clarkson.edu/~lrussek/research.html

- **Self-Care Strategies**
  - Sleep Hygiene and Positioning. Sleep posture and sleep hygiene strategies.
  - Sleep Checklist. A checklist to make sure you haven't forgotten any options.
  - Checklist for POTS self-care management.
  - Flow charts for POTS management, including fatigue and sleep.
  - Suggestions for managing MCAS.
- **Exercise**
  - Breathing. Breathing incorrectly can increase pain sensitivity and fatigue.
  - Starting to Exercise Ideas. Ideas to help start to 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!
- **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.

Objectives

1. Identify factors contributing to fatigue in patients with HSD/EDS
2. Outline the role of dysautonomia/POTS in fatigue
3. Propose non-pharmacological strategies for managing fatigue
   - Improving sleep
   - Appropriate exercise
   - Pacing and behavioral approaches



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 treatment approach
to ensure that it is appropriate and safe for YOU.

I cannot provide any individual diagnostic or treatment advice.

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

↓

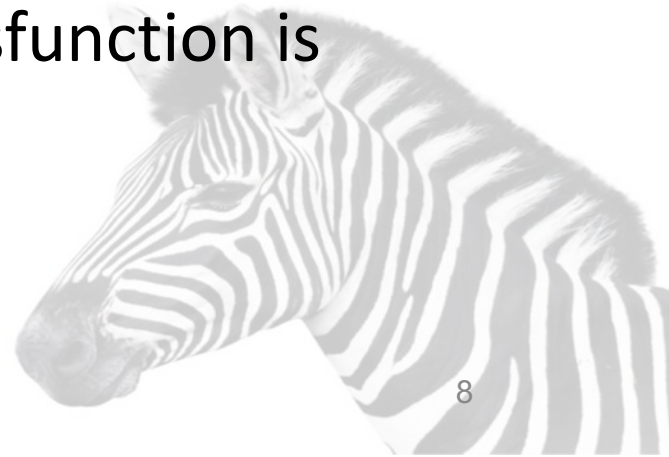
Integration of proper alignment & movement into function

↓

Education about flare management

Prevalence of Fatigue in hEDS/HSD

- 79.5% of people with EDS report severe fatigue (Krahe, 2017)
- 91% of people with POTS report fatigue; 40% report brain fog or trouble concentrating (Kavi, 2016)
- 64% of people with chronic pain (any reason) report severe fatigue
- 80% of patients with fibromyalgia and chronic fatigue syndrome have HSD (Eccles, 2021)
- Fibromyalgia, Anxiety, Hypermobility & Autonomic Dysfunction is called FAHA syndrome. (Eccles, 2021)



Factors Contributing to Fatigue

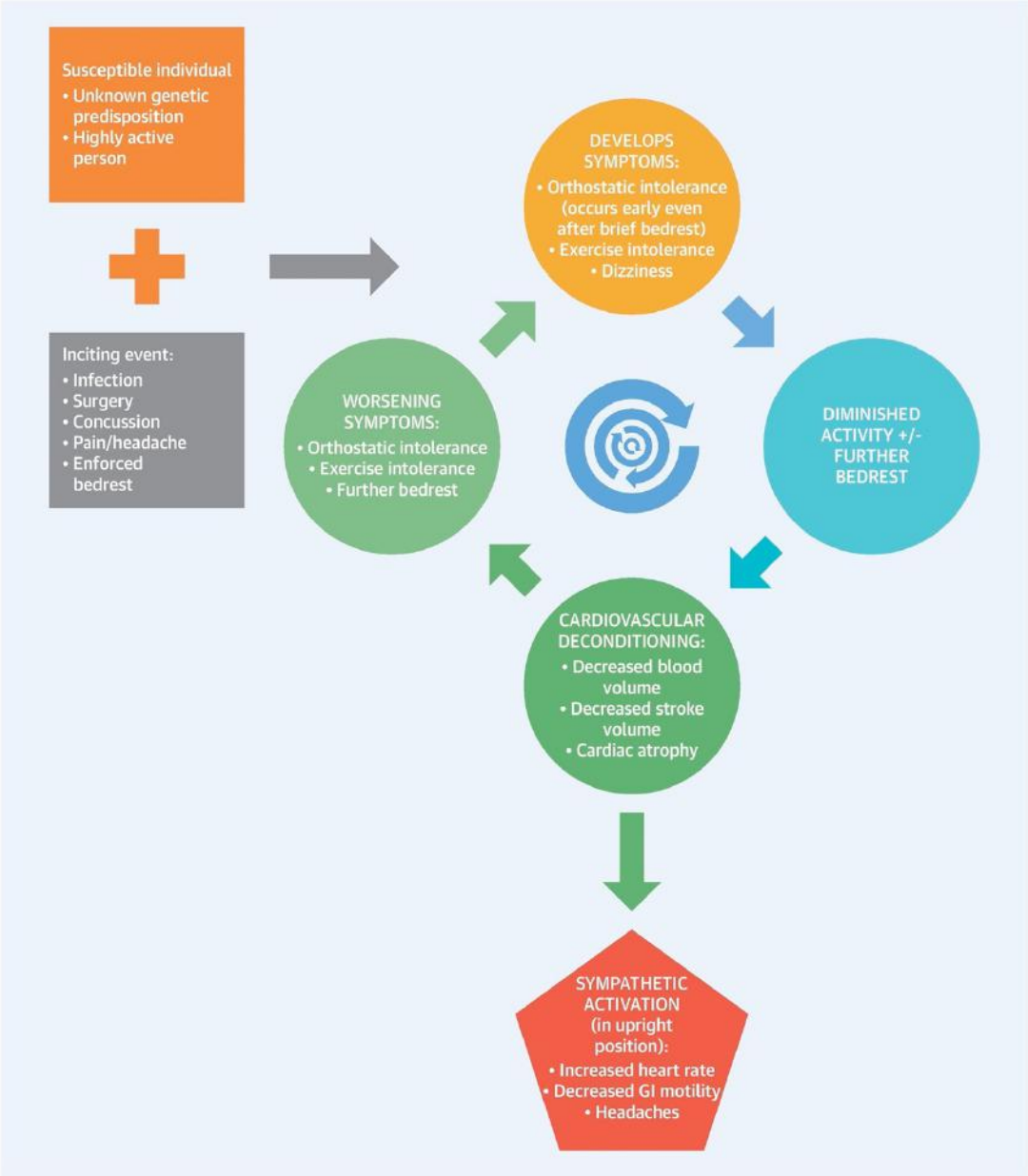
1. Poor quality sleep
2. Chronic pain
3. Orthostatic intolerance and dysautonomia, including POTS
4. Deconditioning
5. Disordered breathing
6. Inadequate pacing and/or prioritization
7. Stress of managing a chronic illness

Additional important contributing factors I will not discuss today

- Anxiety and/or depression
- Poor nutrition (EDS nutritionist Bonnie Nasar, https://nasarnutrition.com)
- Neurological issues causing fatigue in HSD

Hakim, 2017; Strassheim, 2018; Baeza-Veasco, 2018

CENTRAL ILLUSTRATION: Postural Orthostatic Tachycardia Syndrome: Downward Spiral



Bryarly, M. et al. J Am Coll Cardiol. 2019;73(10):1207-28.

The Downward Spiral

- A triggering event decreases activity
- Decreased activity leads to deconditioning
- Deconditioning worsens symptoms/fatigue
- Worse symptoms and fatigue lead to further decreased activity

Bryarly, 2019

Managing Fatigue

1. Fix problems contributing to fatigue
   - Especially poor quality sleep
2. Manage energy available
3. Do things to gradually increase energy/function

NOTE: even once you are doing all the right things, fatigue management can take months to years. Be patient.

SLEEP

Why Is Sleep Important?

- Sleep improves:
  - Brain function, learning, memory
  - Emotional well-being
  - Pain management (sleep deprivation increases pain sensitivity)
  - Physical health: decreased risk of heart disease, kidney disease, high blood pressure, diabetes, stroke
  - Body's ability to heal from injury or illness, and immune function
  - Weight control by regulating hunger hormones & insulin (decreases obesity)
  - Energy levels
  - Function and safety during the day

https://www.nhlbi.nih.gov/health-topics/sleep-deprivation-and-deficiency

Walker, M. *Why We Sleep*. *Scribner*, 2018.

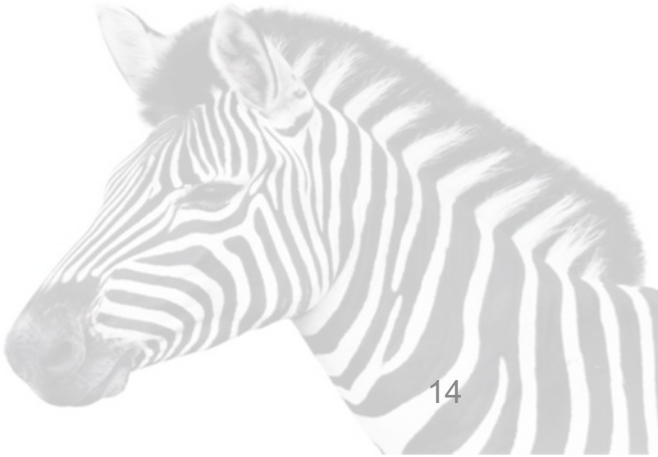
Sleep Checklist

Reasons for Poor Quality Sleep

A. Poor sleep hygiene
B. Pain, in general and specific to being in bed
C. Postural orthostatic tachycardia syndrome (POTS)
D. Stress, anxiety, racing mind
E. Sleep disordered breathing
F. Waking to urinate
G. Medications

Hakim, 2017; Sedky, 2019

Note that poor quality sleep also amplifies pain.
(Simpson, 2018)



Sleep Hygiene

Sleep Hygiene and Positioning

- **Do:**
  - Use bedroom only for sleep and intimacy
  - Regular sleep schedule and bedtime routine
  - Exercise on most days
  - Increase exposure to bright light during the day
  - Quiet, cool, dark room; bed supportive but soft
  - Have a wind-down routine; consider meditations, breathing, etc.
- **Avoid:**
  - Caffeine, nicotine, alcohol, sweets before bedtime
  - Heavy meals or fluids 2-3 hrs before bedtime
  - Late afternoon naps
  - Computers, phones, tablets, blue light before bedtime
  - Lying in bed awake (get up, do something boring)..

https://sleep.org

Managing Night-Time Pain

HSD 103: Pain Management

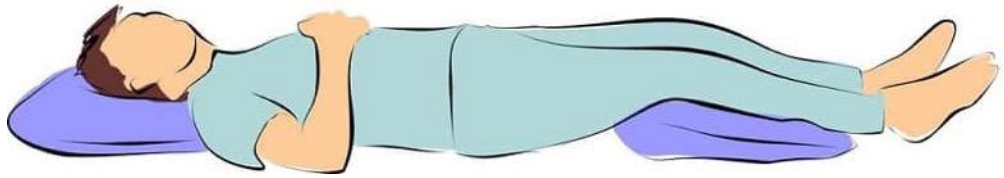
Pain Self-Care Plan

- Manage day-time pain: posture, exercises, body mechanics, etc.
- Bath, heat, ice, topical rubs, TENS (aka, electromassager) before bed
- Do relaxation exercises, such as gentle movements or muscle stretches
- Physiological quieting at bedtime, (to decrease nerve sensitization)
- Cognitive behavioral pain management
  - Curable™ app offers 6 weeks free access if referred by a clinician*
- Use optimal body positioning, support, and padding
  - Minimize subluxations
- *Pain medications, if necessary*

**email me if you would like to try the Curable app*

Ideal Bed Support

Sleep Hygiene and Positioning



- Spine should be aligned
- Pressure should be distributed across whole body
- Bed too soft allows sagging → poor spinal alignment
- Bed too hard → too much pressure on shoulders and hips

https://www.europeanbedding.sg/blogs/articles/the-influence-of-sleeping-on-a-hard-or-soft-bed-why-a-firm-mattress-won-t-relieve-you-from-back-pain
https://www.terrycralle.com/best-sleeping-positions-for-lower-back-pain/

If Your Bed Is Not Ideal…

- Consider a bed "topper" or pillows to provide necessary support
  - Bed toppers can distribute body weight more evenly
  - Options: memory foam, down, fleece, egg crate, etc.
- Best topper *for you* depends on:
  - Your sleep position(s)
  - Your body size/type
  - What your complaints are due to (e.g., excessive pressure or poor alignment)
- Reviews of toppers:
  - https://buyersguide.org/mattress-topper/t/best
  - https://www.sleepadvisor.org/best-mattress-topper-for-back-pain/

Neck Pillows

Sleep Hygiene and Positioning

https://www.comfycentre.com/best-pillow-for-neck-pain/

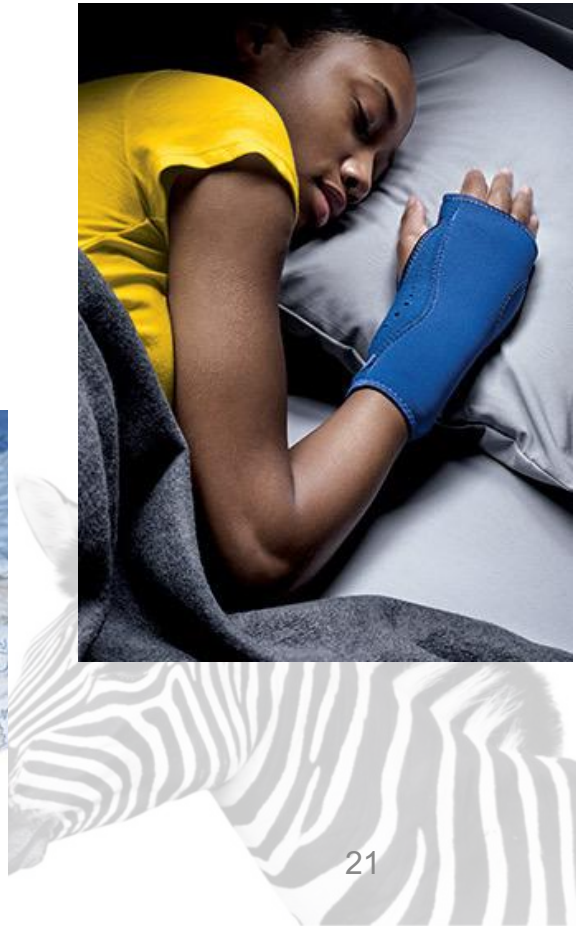
- There is no universal 'best' pillow for everyone
- The best pillow for you depends on:
  - Your body type
  - How you sleep
    - Back sleepers need soft/low pillow
    - Side sleepers need firmer/thicker pillow
    - Stomach sleepers….
- Your neck should be aligned with your spine

Supporting Your Body in Bed

- Decrease tissue compression by distributing body weight using pillows
  - Shoulder relief pillow to decrease shoulder compression side-sleeping
  - Waist pillow to decrease pressure on both shoulder and hip in side-sleeping, or to align the spine
  - Knee pillow to align hips in side sleeping
  - Body pillow for overall support, especially for belly-sleepers

Night-Time Subluxations

- It is possible for joints to slip out of place at night, when muscles relax
- Prevention before bed: strengthen stabilizing muscles, stretch tight muscles, improve posture
- Prevention in bed:
  - Use pillows to support limbs
  - Position joints in mid-range; don’t stretch joints
  - Decrease the weight of blankets on joints
  - Consider sleeping with braces



Questions?

Cognitive-Behavioral Therapy - Insomnia

- CBT-i should be the first Rx approach
- CBT-i (in general, not just this app) is at least as effective as medication
- CBT-i is a completely free app that teaches sleep hygiene
  - Has a self-assessment tool
  - "Sleep 101" education
  - Tools for relaxation
    - Meditations
    - Relaxation activities
    - Etc.
- Review of best insomnia apps: https://www.healthline.com/health/healthy-sleep/top-insomnia-iphone-android-apps

Physiological Quieting

- Sleep meditations, such as HeadSpace™, Calm™, Daily Habit™
- Deep breathing, slow breathing, yoga breathing
- Yoga, Tai Chi, qigong, biofeedback
- CBT-i has a selection of relaxation tools
- Binaural music designed for sleep
  - Stimulates slow waves in the brain, facilitating sleep
  - Review: https://www.psychologytoday.com/us/blog/sleep-newzzz/201810/how-can-binaural-beats-help-you-sleep-better
- Weighted blankets, especially for people with anxiety or depression (Ekholm, 2020)

Managing POTS & Sleep Disturbance

HSD 102:
POTS & MCAS

POTS Checklist

- Night-time POTS episodes disrupt deep sleep…
  - May wake you up during the night
- Management ideas
  - General POTS self-management
  - Relaxation activities at bedtime, to calm sympathetic nervous system: breathing, yoga, meditation, music, etc.
  - Elevating head of bed may decrease need to toilet at night (helps to retain fluids overnight)

Managing MCAS & Sleep Disturbance

HSD 102:
POTS & MCAS

MCAS Self-Care

- Mast cells in the brain regulate sleep-wake cycles
  - As well as other neurobehavioral traits (Nishino, 2022)
- The body releases the most histamine at about 3 am
  - Histamine levels gradually increase during the day and 'overflow' at night
  - Histamine stimulates the brain, causing wakefulness
- Management strategies:
  - Decrease histamine-containing foods and inflammatory foods
  - Consider sleep enhancing supplements, such as melatonin
  - Avoiding mold and toxins, including skin care products
  - Make sure none of your medications have dyes or alcohols
    - Check your medications at https://dailymed.nlm.nih.gov/dailymed/
  - Calm your nervous system: meditation, breathing, sleep yoga, etc.
  - https://mastcell360.com/fixing-sleep-challenges-in-mast-cell-activation-syndrome-and-histamine-intolerance/

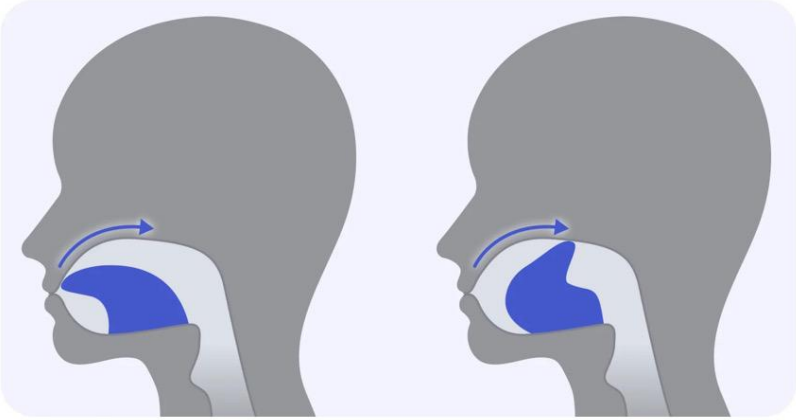
Sleep Disordered Breathing

- Sleep disordered breathing (obstructive & central sleep apnea)
  - 6x more common in HSD/EDS than general population (Sedky, 2019)
- Management:
  - Alter sleep position
    - 50% of sleep apnea is due to sleeping on your back https://www.sleepassociation.org/sleep-apnea/positional-sleep-apnea/
  - Mouth & tongue ("myofunctional") exercises:
    - https://www.sleepfoundation.org/snoring/mouth-exercises-to-stop-snoring
  - Improve breathing overall
  - CPAP (Continuous Positive Airway Pressure) is the traditional approach

HSD109 Breathing

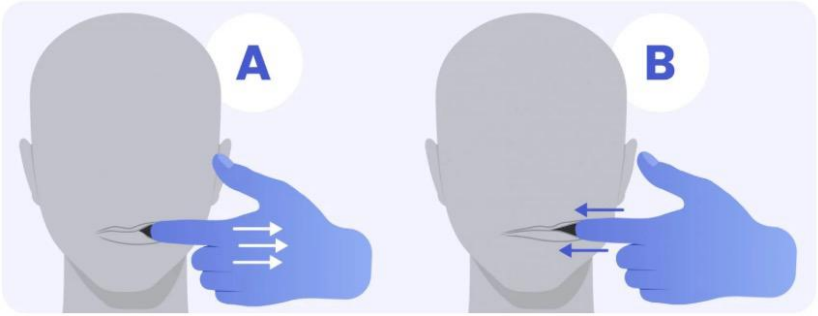
Breathing

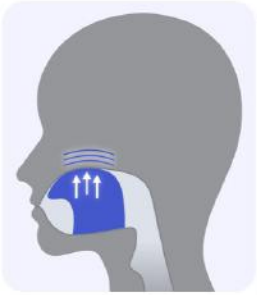
Myofunctional (Mouth) Exercises



Tongue Exercise #2: Tongue Stretch

- Stick out your tongue as far as you can. Try to touch your chin with your tongue while looking at the ceiling. Hold for 10 – 15 seconds and increase the duration gradually. Repeat 5 times.
- Purpose of Exercise: Increase tongue strength

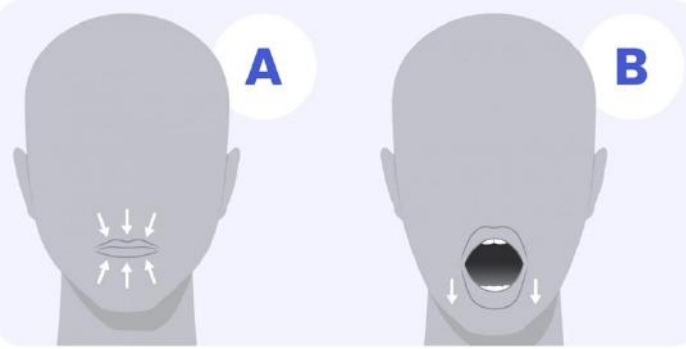


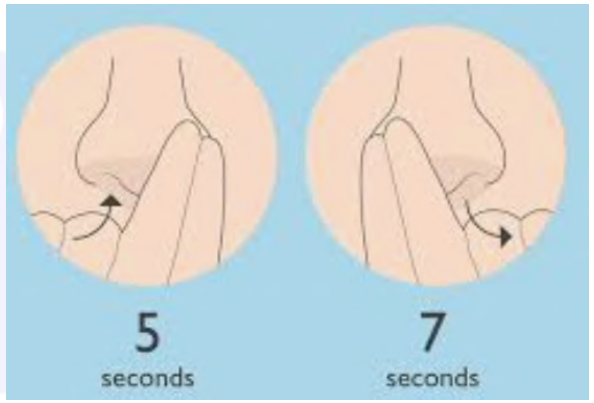


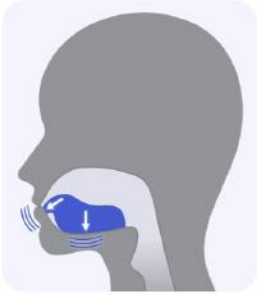
Tongue Exercise #3: Tongue Push Up

- Stick your tongue upward against the roof of your mouth and press your entire tongue against it. Hold this position for 10 seconds. Repeat 5 times.
- Purpose: Improve tongue and soft palate tone and strength

https://www.sleepfoundation.org/snoring/mouth-exercises-to-stop-snoring







Tongue Exercise #4: Tongue Push Down

- Put the tip of your tongue against your lower front teeth and then push the back of your tongue flat against the floor of your mouth. Hold this position for 10 seconds. Repeat 5 times.
- Purpose: Improve tongue and soft palate tone and strength

Medications that Disrupt Sleep

- Some cause insomnia, others compromise sleep quality
  - **Alpha-blockers** (for HTN, Raynaud's): e.g., Flomax, Minipress, Cardura
  - **Beta-blockers** (for POTS, HTN, migraines): e.g., carvedilol, atenolol, metoprolol, propranolol and other -olol drugs
  - **H1 antagonists** (allergies): e.g., Zyrtec, Claritin, Allegra, Astelin, etc.
  - **Antidepressants** (for depression, pain, HA): e.g., SSRI, Prozac, Paxil, Zoloft, Celexa, etc.
  - **Corticosteroids** (for inflammation, RA, lupus, Sjogren's, allergies)
  - Statins (high cholesterol): e.g., Lipitor, Crestor, Zocor, Mevacor
  - Angiotensin eceptor blockers (coronary disease, heart failure): e.g., Diovan, Cozaar
  - ACE inhibitors (HTN, heart failure): e.g., Monopril, Vasotec, Lotensin, et.c
  - Cholinesterase inhibitors (Alzheimers, memory loss)
  - Glucosamine & chondroitin (arthritis)
  - Thyroid replacement: e.g., levothyroxine (Synthroid)

https://www.aarp.org/health/drugs-supplements/info-04-2013/medications-that-can-cause-insomnia.html
https://www.goodrx.com/blog/could-your-medication-be-causing-insomnia/

Avoid "Sleeping Pills"

- Sleep medications (e.g., Ambien, Lunesta, etc.)
  - Do not produce the normal, rejuvenating sleep
  - Are habit-forming (addictive)
  - Can cause daytime drowsiness and fatigue
  - Can cause rebound insomnia when discontinued
- There is evidence these medications increase risk of illness

(Kripke, 2018)

www.DarkSideOfSleepingPills.com

Sleep Supplements

- **Melatonin:**
  - Decreases insomnia and improves sleep quality (good research) (Fatemeh, 2021)
  - However, long term safety is still not known. (It is probably safer than 'sleeping pills')
  - Optimal dose unknown. Dosing recommendations vary between 0.1 mg – 10 mg
  - Actual amount in specific brands varies from dose listed because it is not regulated
    - content ranged from -83% to +478% of the labeled content.

Savage, 2020. Available at https://www.ncbi.nlm.nih.gov/books/NBK534823/

- **Magnesium** also has good research support
  - Oral (Mg glycinate) or topical (creams or Epsom salts)
  - Helps fall asleep faster and sleep longer, improving sleep efficiency
  - Benefits other conditions: osteoporosis, HTN, type 2 diabetes, migraines
  - May cause irregular heartbeats. Mg Citrate may cause diarrhea. Taking with food decreases these risks. https://www.sleepfoundation.org/magnesium
- **Valarian and lavender** supplements might be helpful for improving sleep
  - Research is less consistent (Guadagna, 2020)
- **Aromatherapy for sleep:** limited research. https://www.sleepfoundation.org/best-essential-oils-for-sleep

Resources for Sleep Management

- CBT-i app, created by Veteran's Administration and Stanford University
- Overall information: https://www.sleepfoundation.org
- Review of best insomnia apps: https://www.healthline.com/health/healthy-sleep/top-insomnia-iphone-android-apps
- Newcastle Sleeping Problems guide: https://www.newcastle-hospitals.org.uk/downloads/Therapy%20Services/Sleeping_Problems_2016.pdf
- Good information at https://sleep.org
- Best Guided Meditations for Sleep: https://www.nestmaven.com/sleep/aids/best-guided-sleep-meditation/
- Walker, M. Why We Sleep. *Scribner*, 2018. How to sleep effectively.

Questions?

FATIGUE

The Newcastle upon Tyne Hospitals
NHS Foundation Trust

CRESTA
Fatigue Clinic

Managing your Energy

https://www.newcastle-hospitals.nhs.uk/content/uploads/2021/02/CRESTA-booklet-060720-contents-revised_sr.pdf

Russek: Hypermobilit

Table of Contents

Pain Self-Care

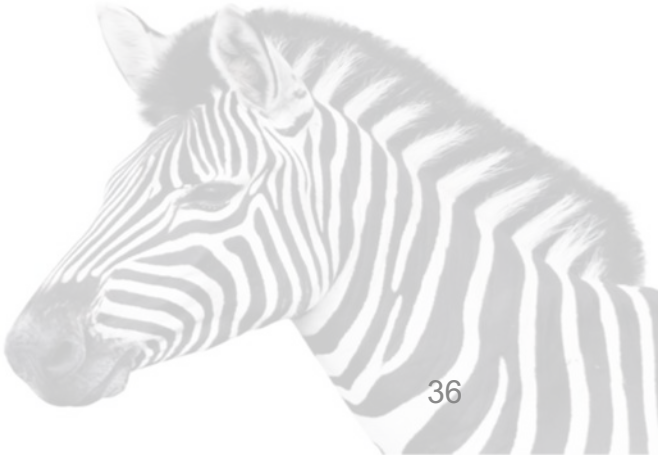
Managing Pain to Decrease Fatigue

HSD 103: Pain Management

- Pain is physically and emotionally draining
  - Treatments to manage pain are often fatiguing

(Van Damme, 2018)

- Inflammation uses energy, causing fatigue
- Some approaches address both pain and fatigue:
  - Breathing exercises/yoga
  - Relaxation/meditations
  - Sufficient, high quality sleep

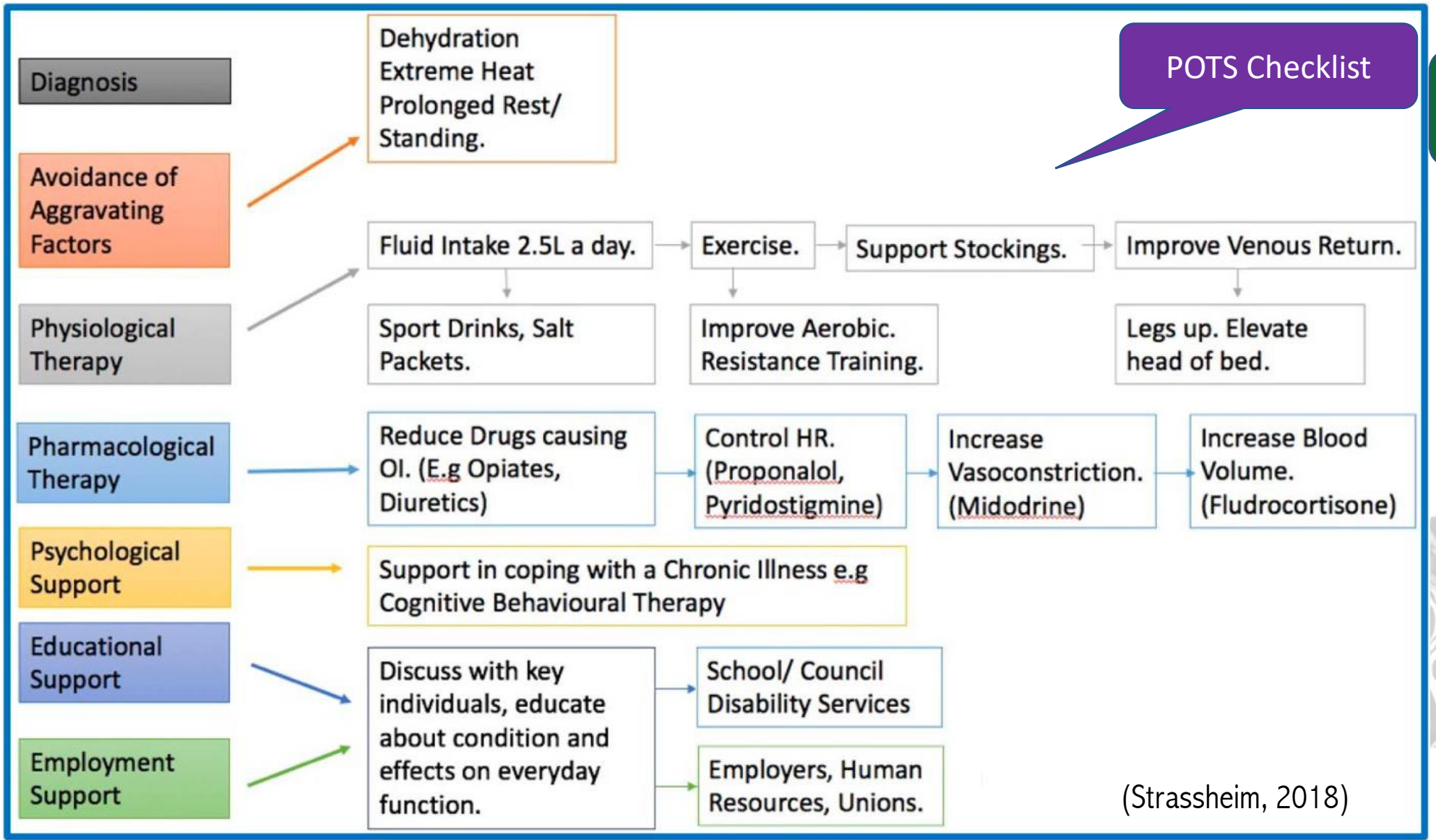


POTS and Fatigue

HSD 102:
POTS & MCAS

- 91% of people with POTS report fatigue as a primary complaint
- Dysautonomia causes fatigue, especially when upright
- POTS limits exercise tolerance, leading to deconditioning, which increases fatigue

Newcastle Approach to Fatigue in POTS



POTS Checklist

HSD 102: POTS & MCAS

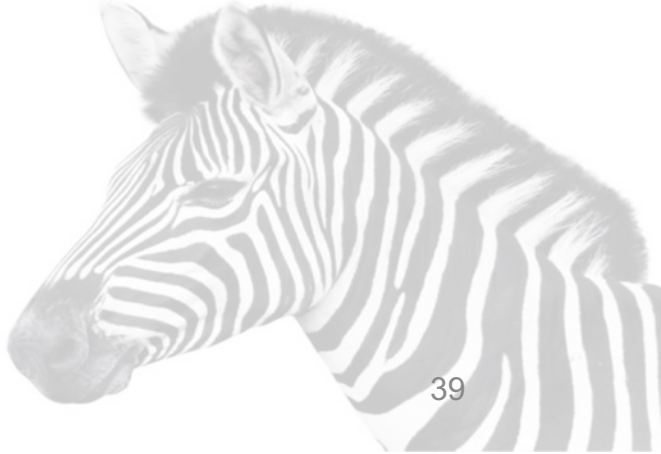
(Strassheim, 2018)

Post-Exertional Malaise (PEM)

headache/migraine memory problems
sinus pain muscle weakness sore glands
heavy eyes difficulty finding words cramping
blurry vision slurred speech
drop in temperature muscle pain/aches loss of appetite
difficulty breathing muscle spasms
nausea chills clumsy in movements
burning pain joint pain exhaustion "flu-like" symptoms
heart racing dizziness
difficulty thinking clearly
feverish feeling sensitive to light, sound, smell anxiety
chest pain irritability
tingling can't control bowels hopelessness all over body pain constipation
low blood pressure insomnia sore throat
incontinence sweating tremors diarrhea hives

- These are common symptoms of PEM.
- PEM often co-exists with dysautonomia.

(Natelson, 2022; Gandasequi, 2021)



Post-Exertional Malaise (PEM)

- Definition: the worsening of symptoms following even minor physical or mental exertion, with symptoms typically worsening 12 to 48 hours after activity and lasting for days or even weeks.
- PEM is a key symptom of myalgic encephalitis/chronic fatigue syndrome (ME/CFS)
  - ME/CFS diagnostic criteria: 1) profound fatigue, 2) PEM, 3) unrefreshing sleep, and either 4a) trouble thinking clearly or 4b) orthostatic intolerance
  - The parasympathetic nervous system does not re-activate after exercise

(Van Oosterwijck, 2021)

https://www.cdc.gov/me-cfs/healthcare-providers/clinical-care-patients-mecfs/treating-most-disruptive-symptoms.html

Managing Post-Exertional Malaise

- PEM can be minimized by:
  - Activity management (pacing) to avoid PEM flare-ups by balancing rest and activity
    - Newcastle fatigue booklet: (https://www.newcastle-hospitals.nhs.uk/content/uploads/2021/02/CRESTA-booklet-060720-contents-revised_sr.pdf)
  - Monitoring your body's stress state using heart rate variability (HRV)
  - Stress management.
  - Doing a cool-down (gentle, easy movement) at the end of exercise.
    - Activating vagus nerve after exercise might decrease PEM (not evidence based)
- Exercise should done be VERY cautiously in patients experiencing PEM.

Cognitive Fatigue & “Brain Fog”

- Cognitive fatigue is being mentally or emotionally tired or exhausted
- Difficult to concentrate, remember, learn new things, find words
- Feeling overwhelmed
- Forgetfulness
- Feeling “cloudy”, “slow”, “spacey”

Ross, 2013

- https://metro.co.uk/2019/02/09/feeling-irritated-stressed-finding-hard-get-stuff-done-might-cognitive-fatigue-8469750/

Brain Fog in POTS

- Aggravating factors:
  - Lack of sleep, hot showers, exercise (±), walking, caffeine (±)
- Interventions:
  - Manage POTS
    - Water 'bolus': drink ½ liter of water in 5 minutes (Rodriguez, 2022)
  - Non-pharmacological: lying down, avoiding heat, high fluid intake, high salt diet, regular exercise
    - Fluid 'bolus'
  - Strategies: planning, prioritizing, scheduling rest, etc.
  - Medications: IV saline, stimulants, salt tablets, B-12 injections, midodrine
    - Avoid meds that make it worse: SNRI, tricyclics, some beta antagonists, fludrocortisone

Ross, 2013

Brain Fog in MCAS

- Neuroinflammation from mast cells may contribute to brain fog
  - Activates microglia in the brain
- Appears to occur in Long-COVID related MCAS
- Diet and supplements to manage MCAS may help

Theoharides, 2021

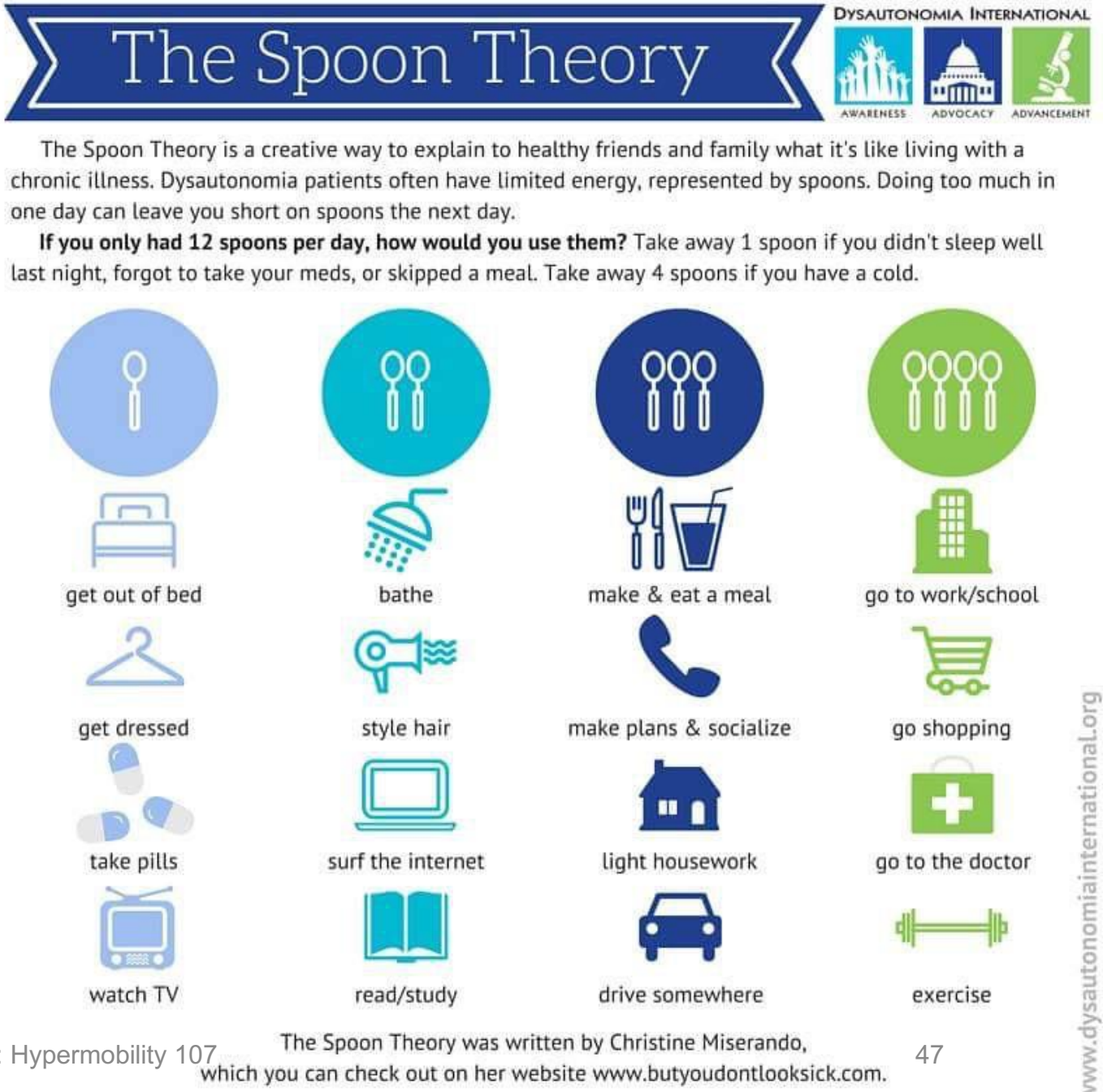
Manage the energy you have

Managing Your Energy

- Prioritize so you do what is most important to you
- Pacing: stop BEFORE you are exhausted or in too much pain
  - Don't "Boom and Bust"
  - You may need to use a timer to make sure you stop
- Change positions or activities -
  - E.g., use different muscles or do a resting task for a while
- Schedule recovery time
- Use assistive devices as needed
- Ehlers-Danlos Society has guidelines: https://www.ehlers-danlos.com/wp-content/uploads/Parry-Practical-Pacing-and-Fatigue-Management-S.pdf

Energy Management

- Plan your energy usage
- Plan time/strategies to re-energize
- Communicate with family and friends
- Use assistive devices if necessary to allow function..



Create an Energy Plan

NHS
University College London Hospitals
NHS Foundation Trust

	Mon	Tues	Wed	Thurs	Fri	Sat	Sun
7-8am	Breakfast	Breakfast	Breakfast	Breakfast	Sleep	Sleep	Sleep
8-9am	Getting ready	Getting ready	Getting ready	Getting ready	Sleep	Sleep	Sleep
9-10am	Work	Work	Work	Shopping	Sleep	Sleep	Sleep
10-11am	Work	Work	Work	Shopping	Sleep	Sleep	Breakfast
11-12am	Work	Work	Work	Shopping	Sleep	Sleep	TV
12-1pm	Lunch	Lunch	Lunch	Lunch	Breakfast	Breakfast	Lunch
1-2pm	Work	Work	Work	Cleaning	TV	TV	Family
2-3pm	Work	Work	Work	Cleaning	Lunch	Lunch	Family
3-4pm	Work	Work	Work	Cleaning	TV	TV	Family
4-5pm	TV	TV	TV	TV	TV	TV	Family
5-6pm	Cooks	Cooks	Cooks	Cooks	Cooks	Cooks	Cooks
6-7pm	Speaks to sister	Speaks to sister	Speaks to sister	Speaks to sister	Speaks to sister	Speaks to sister	Speaks to sister
7-8pm	Emails	Emails	Bills, etc	TV	TV	TV	TV
8-9pm	TV	TV	TV	TV	TV	TV	TV
9-10pm	Bed	Bed	Bed	Bed	Bed	Bed	Bed

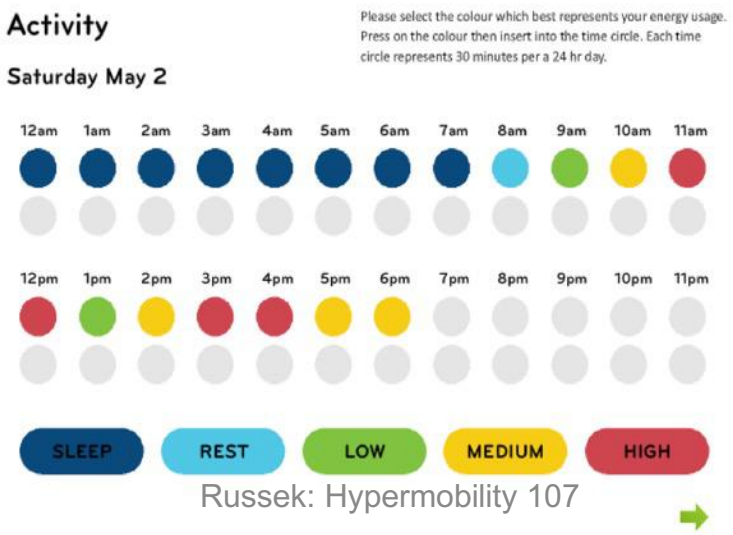
NHS
University College London Hospitals
NHS Foundation Trust

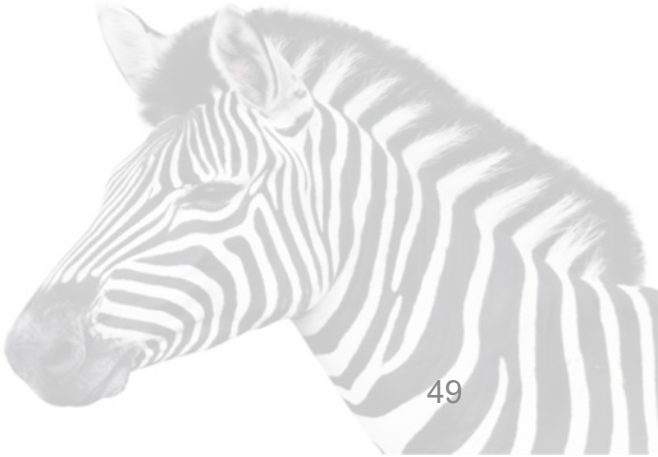
	Mon	Tues	Wed	Thurs	Fri	Sat	Sun
7-8am	Breakfast	Breakfast	Breakfast	Breakfast	Breakfast	Sleep	Sleep
8-9am	Getting ready	Getting ready	Getting ready	Getting ready	Getting ready	Sleep	Sleep
9-10am	Work	Outdoor walk	Work	Outdoor walk	Work	Stretches Breakfast	Stretches Breakfast
10-11am	Work Break	Cleaning	Work Break	Cleaning	Work Break	Family	Cleaning
11-12am	Work	Relaxation	Work	Relaxation	Work	Family	Relaxation
12-1pm	Lunch	Prepare food Lunch	Lunch	Prepare food Lunch	Lunch	Relax Prep food	Computer work
1-2pm	Work	Clearing up Rest	Work	Shopping		Lunch	Lunch
2-3pm	Work Break	Vacuuming Rest	Work Break	Reading	Work Break	Shopping	Family
3-4pm	Work	Exercises	Work	Exercises	Work	TV	Family
4-5pm	Exercises	TV	Exercises	TV	TV	TV	Family
5-6pm	TV	Cooks	TV	Cooks	Get ready to go out	Cooks	Relax
6-7pm	Put kids to bed	Speak to sister	Put kids to bed	Speak to sister	Socialising	Speak to sister	Put kids to bed
7-8pm	Dinner Wash up	TV/Dinner	Bills, etc	TV/Dinner	Socialising	TV/Dinner	TV/Dinner
8-9pm	TV Stretches	Emails Stretches	TV Stretches	Emails Stretches	TV Stretches	TV Stretches	TV Stretches
9-10pm	Bed	Bed	Bed	Bed	Bed	Bed	Bed

https://www.ehlers-danlos.com/resource/jason-parry-practical-pacing-and-fatigue-management/

“Pacing Up”

- Once you have stabilized your energy, gradually increase what you do, similar to Graded Exercise
  - Don’t increase activity more than 10-20%
  - Give your body time to stabilize at each level before increasing
- Chronic Fatigue Syndrome Diary app can help with planning and pacing





Do things to gradually increase energy/function

Treatments to Increase Energy

- Breathing exercises
- Graded exercise
- Stress management, cognitive behavioral therapy (CBT)
- *Dietary adjustments*
- *Ideas with little/no evidence*
  - *Self- acupressure*
  - *Wearable devices, such as Apollo Neuro (https://apolloneuro.com)*

Breathing Matters!

HSD 109 – Breathing & HSD

Breathing

- There are breathing exercises specifically for energizing:
  - Slow breathing: 5 seconds in, 5 seconds out
  - Some yoga breathing exercises (e.g., Breath of Fire or Skull-Shining Breath)
  - Right nostril breathing or alternate nostril breathing
    - https://www.spiritrisingyoga.org/kundalini-info/left-right-nostril-breathing
- André, C. Better Breathing Brings Better Health. Scientific American. Available at: https://www.scientificamerican.com/article/proper-breathing-brings-better-health/ . Downloaded 11/12/20
- Forceful singing may also provide aerobic exercise equivalent to brisk treadmill walking

(Philip, 2021)

- Acupressure for energy: https://www.prevention.com/health/a20478518/acupressure-for-energy/

POTS-Specific Exercise

HSD 104: Exercise in HSD & POTS

- Start horizontal if you are very fatigued
- Start with gentle muscle stretching and lower extremity isometrics, using pumping principles
- Dysautonomia International has videos of appropriate exercises: http://www.dysautonomiainternational.org/page.php?ID=43
- You may see old exercise recommendations that have been replaced
  - Levine Protocol
  - Modified Levine Protocol: CHOP (Children's Hospital of Philadelphia)
- New recommendation ADaPT: Autonomic Disorder adaptive Physical Therapy
- Other general videos
  - Restorative Yoga for "Potsies": https://youtu.be/CVMDHlVjJvA

Gradually Progressed Exercise

- Set personal goals
- Stabilize energy level
- Start at level you can do reliably without flare
- Increase no more than 10-20% per week if current level tolerated
- Don’t stop entirely in flare, back up 1-2 weeks
- Graded exercise therapy (GET) protocols can be helpful:
  - https://www.racgp.org.au/FSDEDEV/media/documents/Clinical%20Resources/HANDI/Graded-exercise-therapy-chronic-fatigue-syndrome.pdf
  - Also from Newcastle ”Managing Your Energy”

Exercise Cautions

- HSD:
  - Select activities/movements that do not aggravate your problem joints
  - Consider aquatic exercise (be careful about water resistance)
- ME/CFS (myalgic encephalitis/chronic fatigue syndrome)
  - CAUTION
  - *Current practice guidelines for myalgic encephalitis/ chronic fatigue syndrome (ME/CFS) caution about using graded exercise, as it may worsen fatigue in these patients.* (Larun, 2019, Cochrane Review)
  - *However, these flares may be due to inappropriate exercise.* (https://www.racgp.org.au/FSDEDEV/media/documents/Clinical%20Resources/HANDI/Graded-exercise-therapy-chronic-fatigue-syndrome.pdf)

Using HRV To Track Exercise Capacity

- You can use heart rate variability (HRV) to track your body's resilience
  - Wearables such as FitBit and AppleWatch can track HRV
- Create a baseline, by measuring HRV daily for 2 weeks
  - Be consistent: sleeping HRV or waking HRV are best
- If your HRV is lower than usual, your body is already stressed and shouldn't be further stressed by demanding exercises
  - Recharge your batteries through relaxation practice or gentle movement
- If your HRV is normal or higher than usual, your body is more resilient
  - You can push a bit harder
- https://ouraring.com/blog/train-better-using-hrv/

Rate of Perceived Exertion (RPE)

RPE SCALE	RATE OF PRECEIVED 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

- Heart rate is not always a good measure of exercise intensity
  - Especially if you take heart medication
- RPE is a good tool
- When starting a new exercise, target a difficulty of 2-3/10 on the RPE scale.
- When the exercise is consistently below 3/10, you can make it a bit more challenging (e.g., more time, more effort).
- If RPE is 6/10 or greater and you have increased discomfort, decrease the challenge.

*"I Can't Do Anything. How Can I Start?"**

Wk	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, (2-3/10 RPE) Posture strengthening
4	Diaphragmatic breathing Or Singing (2-3/10 RPE)	Posture strengthening Or gentle aerobics (3/10 RPE)	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

Make Movement Fun!

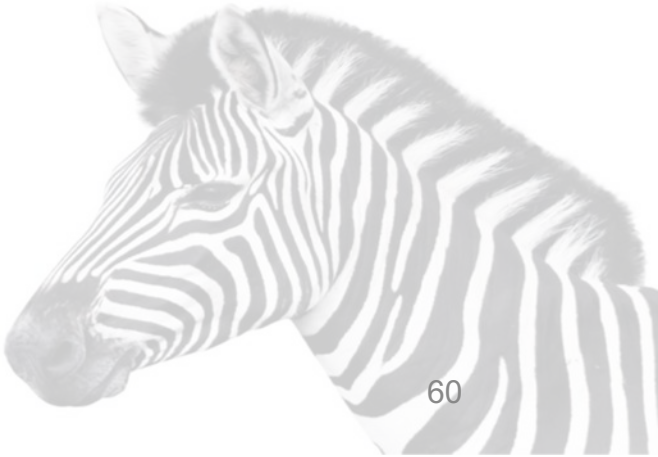
Starting to Exercise Ideas

Active Arcade ™ Whack-a-Mole

Augmented Reality Activities

Chair yoga: https://youtu.be/I3SZa5aGj20

Questions?



Summary

- Fatigue is COMPLICATED!
- You need to look for multiple contributing factors
- Addressing each factor might help 5-15%, but together it can add up
- Be patient! Managing fatigue takes time, even once you are doing the correct things

Resources

- Canadian guidelines on management of insomnia (content both for patients and providers, with lots of resources): https://tools.cep.health/tool/management-of-chronic-insomnia/#non-pharmacological-options
- André, C. Better Breathing Brings Better Health. *Scientific American.* Available at: https://www.scientificamerican.com/article/proper-breathing-brings-better-health/ . Proper breathing for better energy.
- Walker, M. Why We Sleep. *Scribner*, 2018. How to sleep effectively. (Note that there is a Summary version of this book)
- Ehlers-Danlos Society guidelines for fatigue management: https://www.ehlers-danlos.com/resource/jason-parry-practical-pacing-and-fatigue-management/
- https://mysleepwell.ca has guidelines for sleeping better without medications
- https://sleepcouncil.org.uk/advice-support/sleep-advice/ More sleep advice
- https://bedadvice.co.uk general advice about selecting a bed
- These and other "HSD 101" slide handouts and recordings are available at: https://webspace.clarkson.edu/~lrussek/hsd.html
- CRESTA Fatigue Clinic: Managing your Energy. https://www.newcastle-hospitals.nhs.uk/content/uploads/2021/02/CRESTA-booklet-060720-contents-revised_sr.pdf

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Thank You!

Questions?