Hypermobility 107:
Managing Fatigue in HSD/hEDS, POTS & MCAS

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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
- Retired PT, St. Lawrence Health System, Potsdam NY
  - Clinical specialties: hypermobility, fibromyalgia, headaches, temporomandibular disorders
- Member: Ehlers-Danlos Society Medical and Scientific Board
- Chair: The Allied Health Working Group of the International Consortium of Ehlers-Danlos Syndromes and Hypermobility Spectrum Disorders
- Frequent presenter to professional and patient groups at national and international conferences
- Author of multiple review and research articles on hypermobility
- Author: “Pain Mechanisms in HSD” in Di Bon, *The Integral Movement Method for Hypermobility Management*
- Author: “Chronic Pain” chapter in *Physical Rehabilitation* textbook for PT students
- Lrussek@Clarkson.edu
- https://webspace.clarkson.edu/~lrussek/

I do not have any conflicts of interest to report

“HSD 101” Lecture Series Schedule

Slide handouts and recordings are available at: https://webspace.clarkson.edu/~lrussek/hsd...

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 104 Part 2: Modifying exercise for HSD & POTS (NEW)
- 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
- HSD 114: Hospitalization with HSD, POTS, MCAS
- HSD 115: Functional Neurological Disorder

Relevant Handouts Available

I will refer to these if you want more info

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

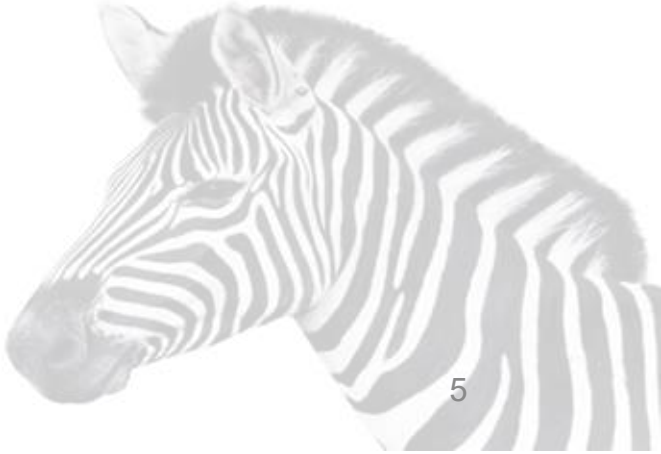
- **Self-Care Strategies**
  - Self-Care Toolbox. A checklist to help you optimize your self-care toolbox.
  - Sleep Hygiene and Positioning. Sleep posture and sleep hygiene strategies.
  - Sleep Checklist. A checklist to make sure you haven't forgotten any options.
  - Checklist for POTS self-care management.
  - 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. Identify and overcome roadblocks to being more active.
  - Augmented Reality Activities for Fitness. Move with games using free apps on your smartphone.
- **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 and MCAS in fatigue
3. Propose non-pharmacological strategies for managing fatigue
   - Improving sleep
   - Appropriate exercise
   - Pacing and behavioral approaches

POTS: Postural Orthostatic Tachycardia Syndrome

MCAS: Mast Cell Activation Syndrome

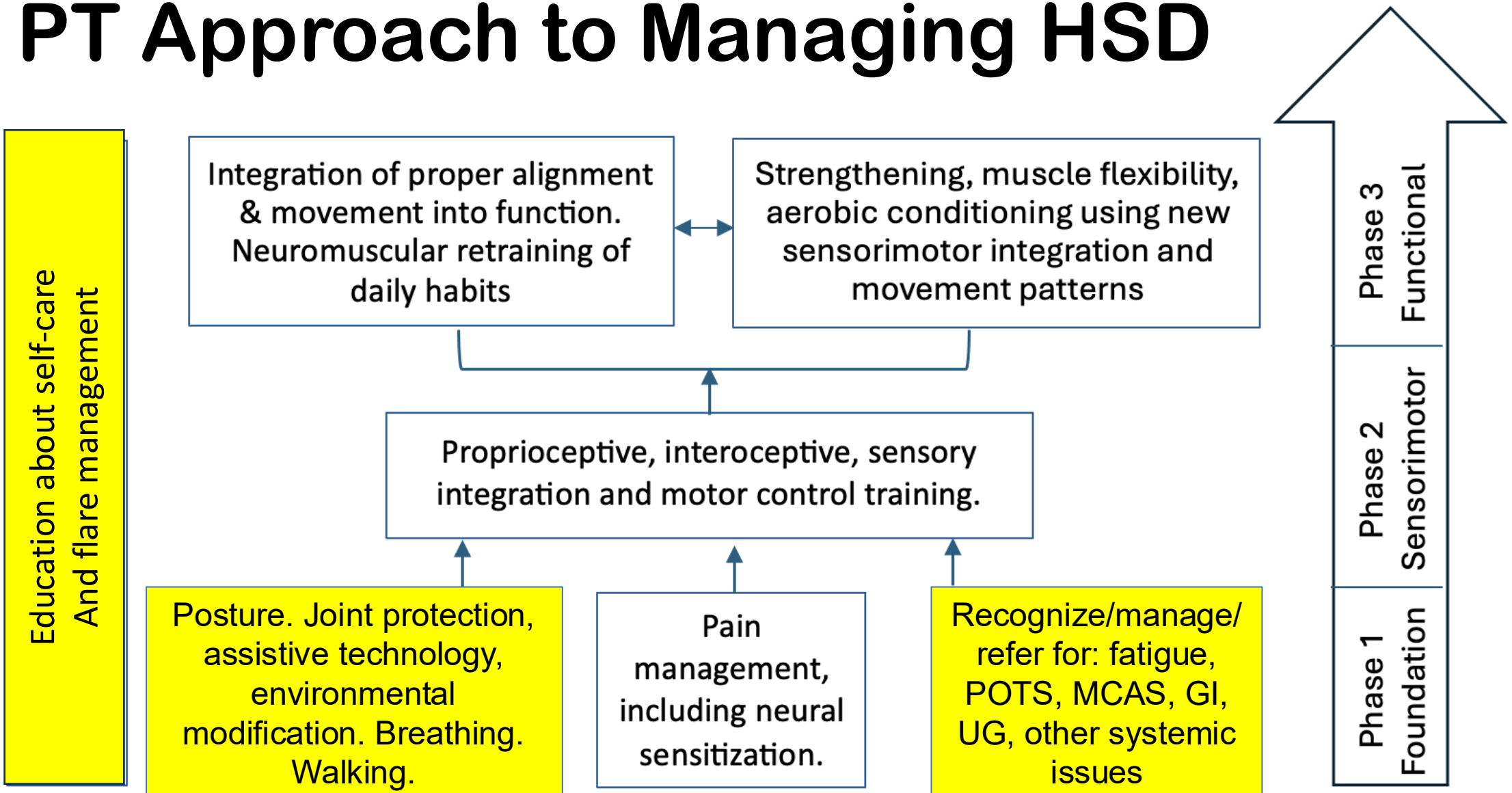


Disclaimer

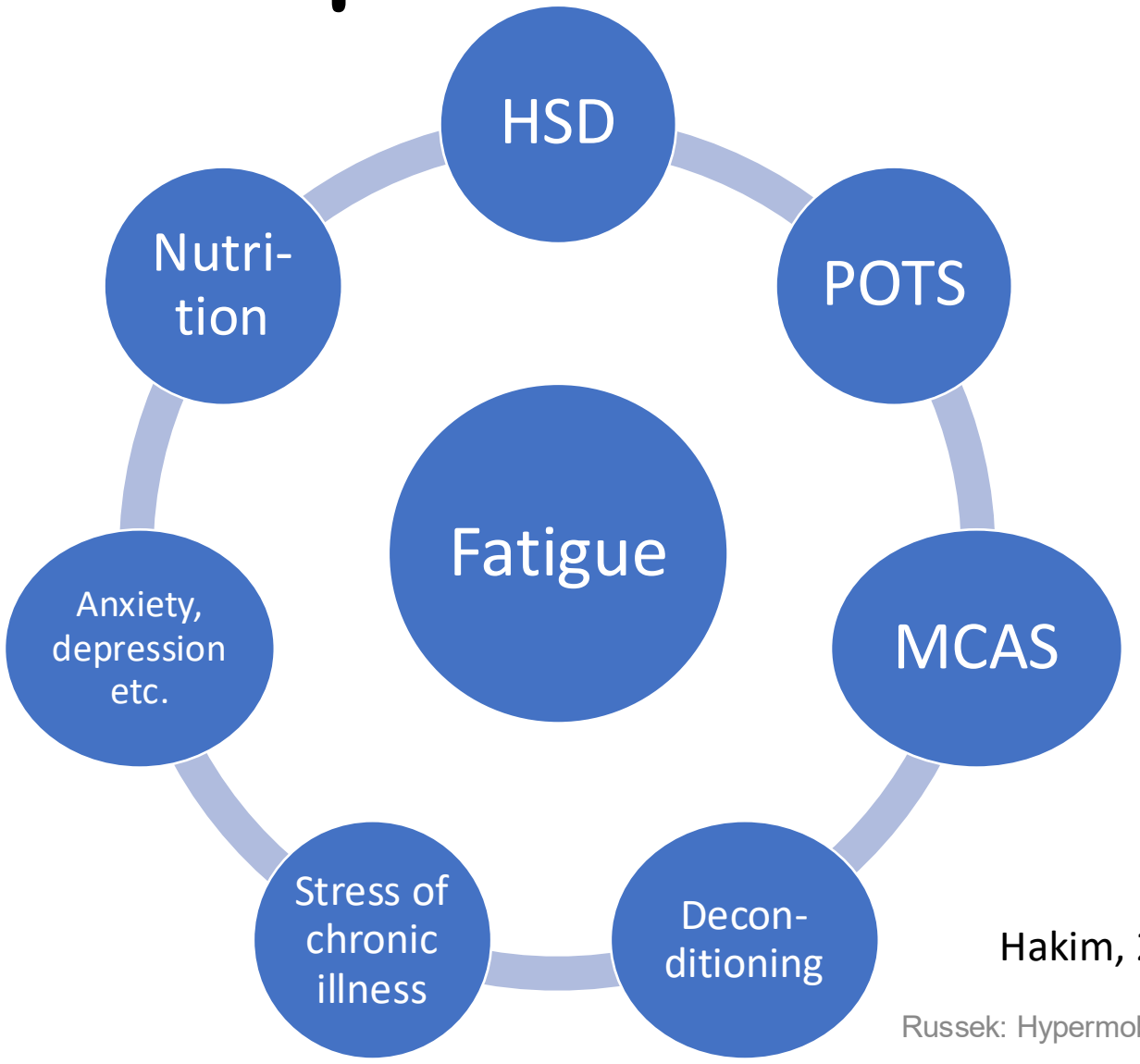
The information in this presentation is for general purposes, only, and may or may not apply to your situation.
Check with your health care provider
before starting any new treatment approach
to ensure that it is appropriate and safe for YOU.

I cannot provide any individual diagnostic or treatment advice.

PT Approach to Managing HSD



Multiple Causes of Fatigue

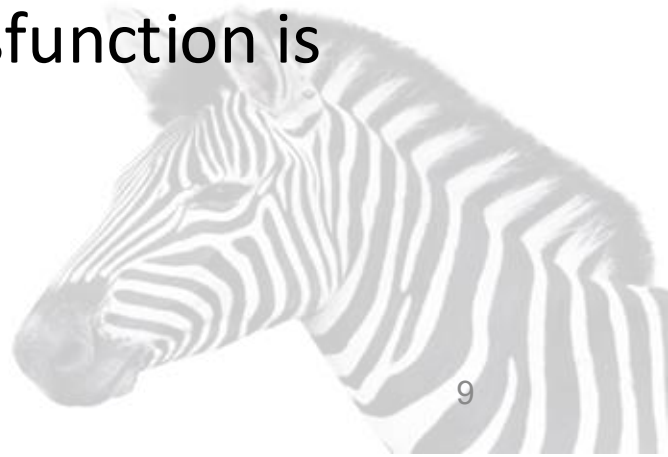


- HSD: sleep dysfunction, extra effort to hold yourself together. May include neurological conditions that directly cause fatigue.
- POTS: directly causes fatigue and exercise intolerance
- MCAS: directly causes fatigue and possibly ME/CFS
- Deconditioning: due to exercise intolerance, pain, etc.
- Stress of dealing with a chronic illness and dealing with health care
- Nutrition may be compromised by MCAS, HSD, POTS intolerances

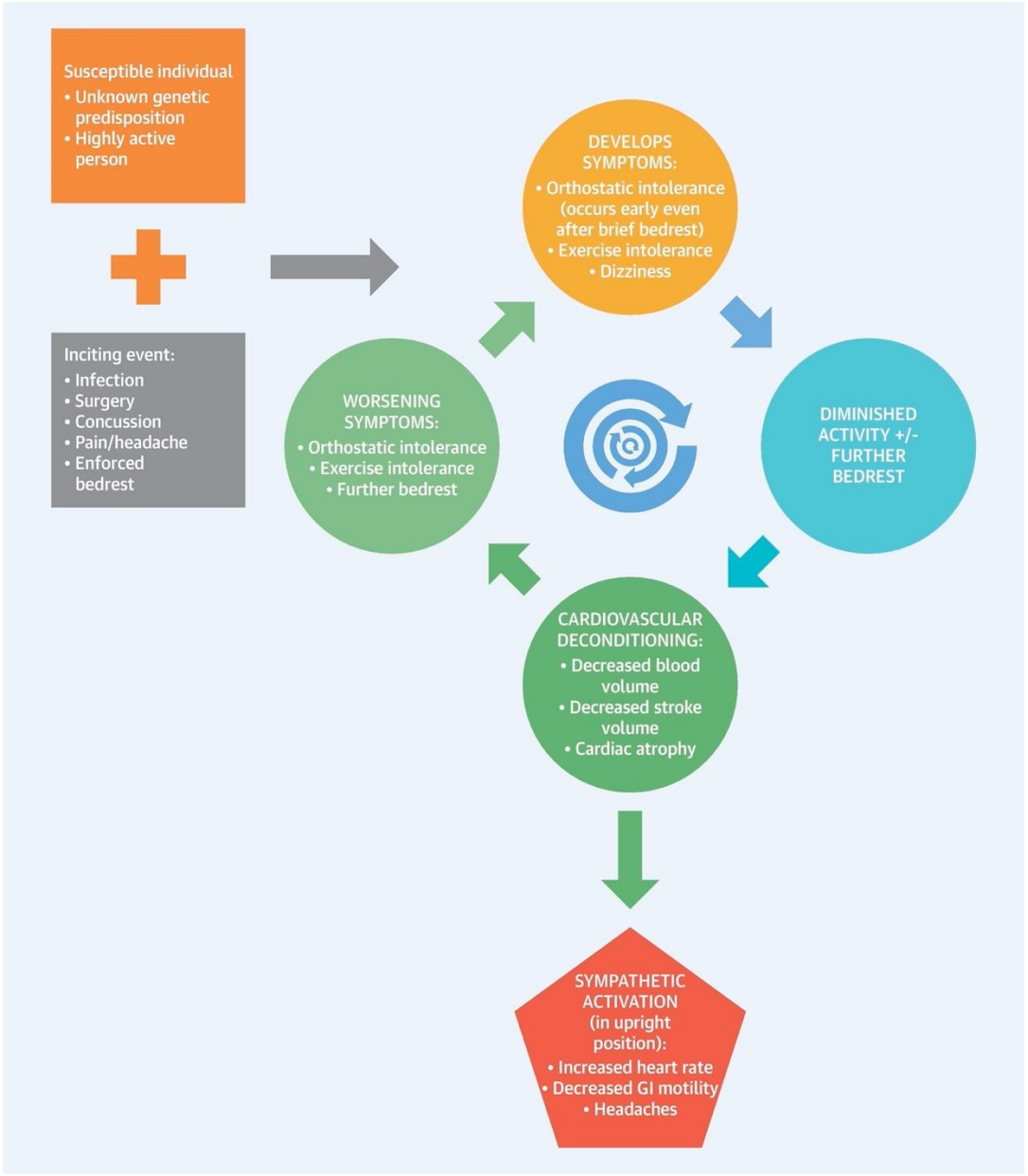
Hakim, 2017; Strassheim, 2018; Baeza-Veasco, 2018; Crews-Stowe, 2025

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)



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

Russek: Hypermobility 107

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.

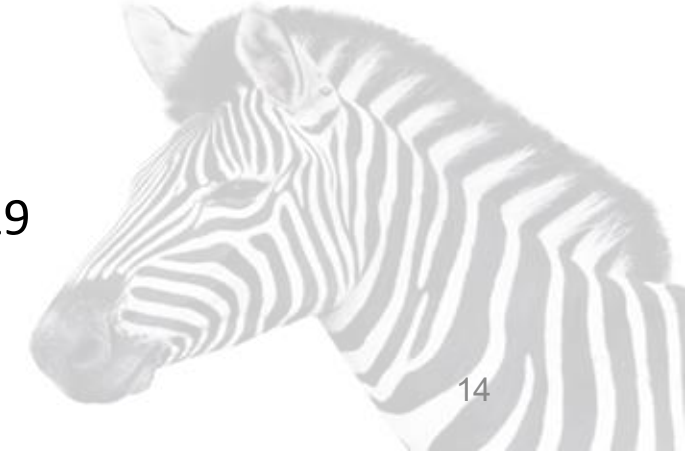
Sleep Checklist

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. Mast cell activation syndrome (MCAS)
E. Stress, anxiety, racing mind
F. Sleep disordered breathing
G. Waking to urinate
H. Medications

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

Hakim, 2017; Sedky, 2019



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

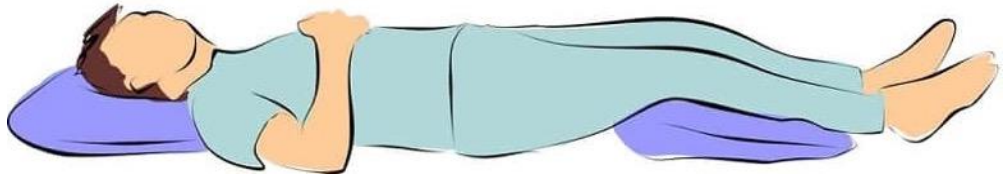
Pain Self-Care Plan

- 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/

Sleep Hygiene and Positioning

Neck Pillows

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

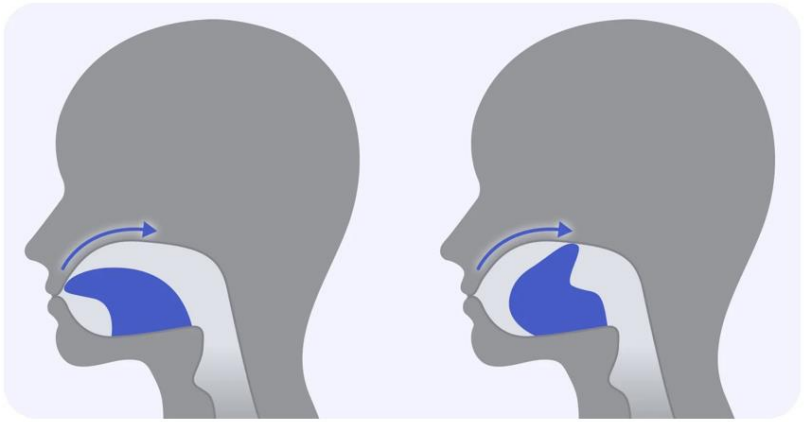
MCAS Self-Care

- 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

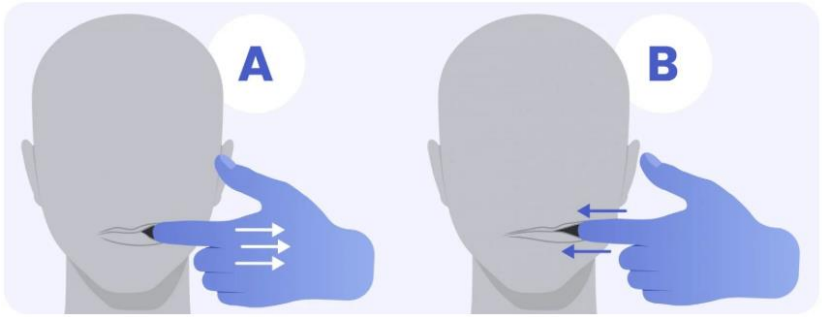
- Sleep disordered breathing (obstructive & central sleep apnea)
  - 6x more common in HSD/EDS than general population (Sedky, 2019)
- Management:
  - Alter sleep position
    - 50% of sleep apnea is due to sleeping on your back https://www.sleepassociation.org/sleep-apnea/positional-sleep-apnea/
  - 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

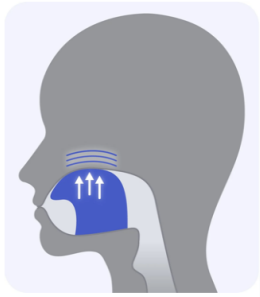
Myofunctional (Mouth) Exercises



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

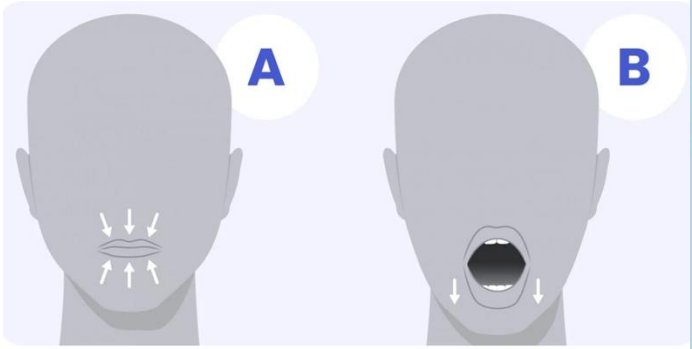


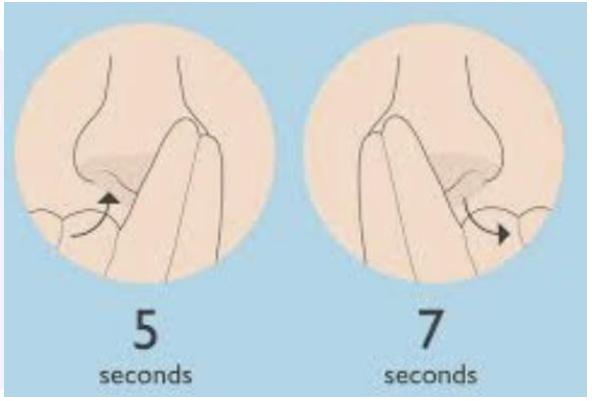


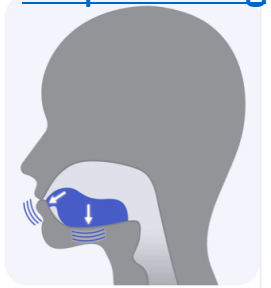
Tongue Exercise #3: Tongue Push Up

- 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

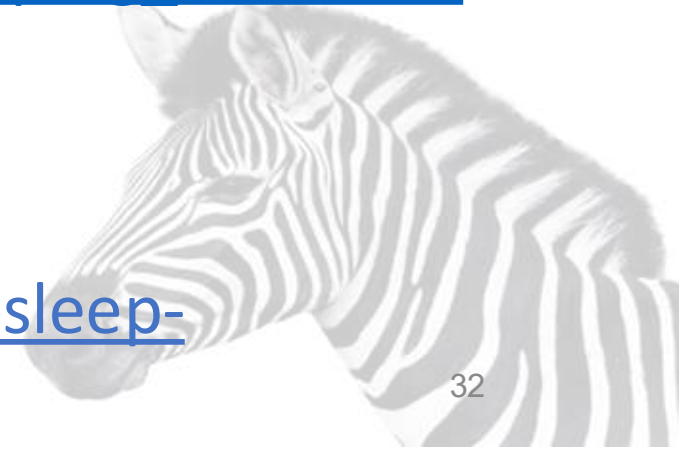
Sleep Supplements

- **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.

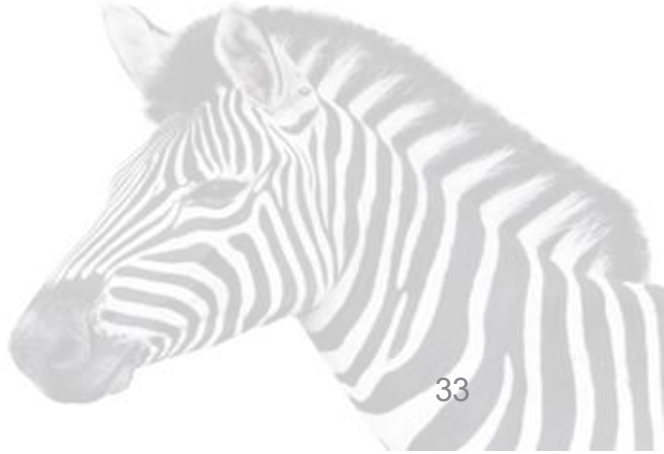
    Savage, 2020. Available at https://www.ncbi.nlm.nih.gov/books/NBK534823/
- **Magnesium** also has good research support
  - Oral (Mg glycinate) or topical (creams or Epsom salts)
  - Helps fall asleep faster and sleep longer, improving sleep efficiency
  - Benefits other conditions: osteoporosis, HTN, 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/



Questions?



FATIGUE

NHS

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

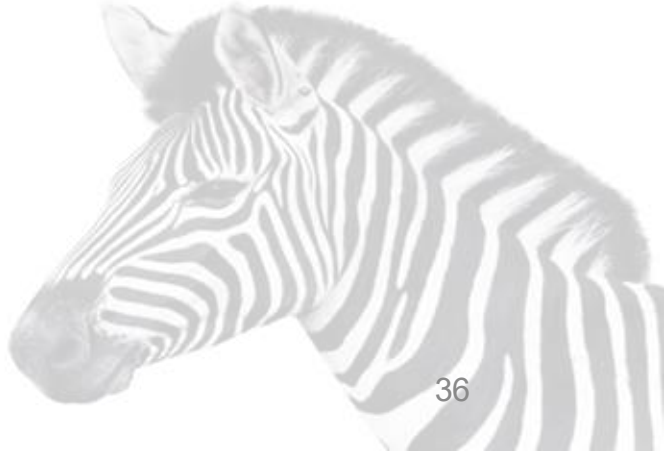
HSD 103: Pain Management

Managing Pain to Decrease Fatigue

- 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



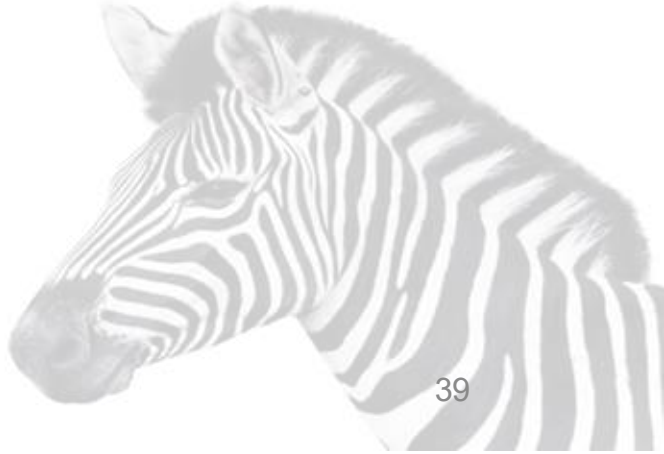
POTS and Fatigue

- 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

Mast Cell Activation and Fatigue

- Activated MC contribute to POTS, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), and Long-COVID syndrome – all are linked to chronic fatigue
- MC are everywhere in the body, including regions of the brain and endocrine organs that regulate ‘homeostasis’, or the body’s regulation

Theoharides, 2024



Myalgic encephalomyelitis/ chronic fatigue syndrome (ME/CFS)

DIAGNOSIS

Diagnosis relies on a detailed medical and social history, physical exams, laboratory tests, and evaluation of other conditions that may resemble ME/CFS or be present as comorbidities.

ME/CFS diagnosis requires **all three symptoms occur at least half of the time with moderate, substantial, or severe intensity:**

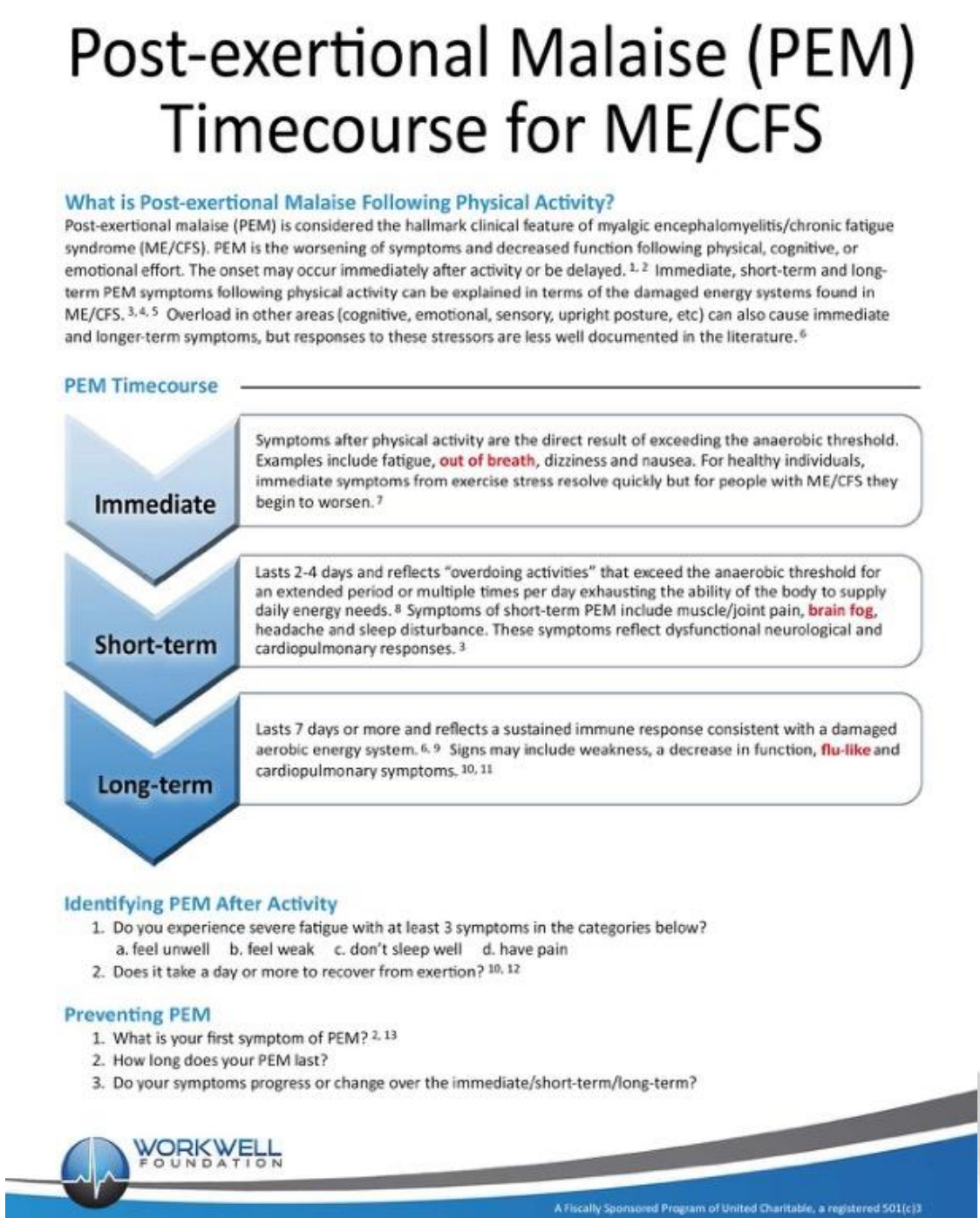
- **Profound fatigue and impairment** that lasts more than six months
- **Post-exertional malaise (PEM)**
- **Unrefreshing sleep**

In addition, **at least one** of the following symptoms must be present:

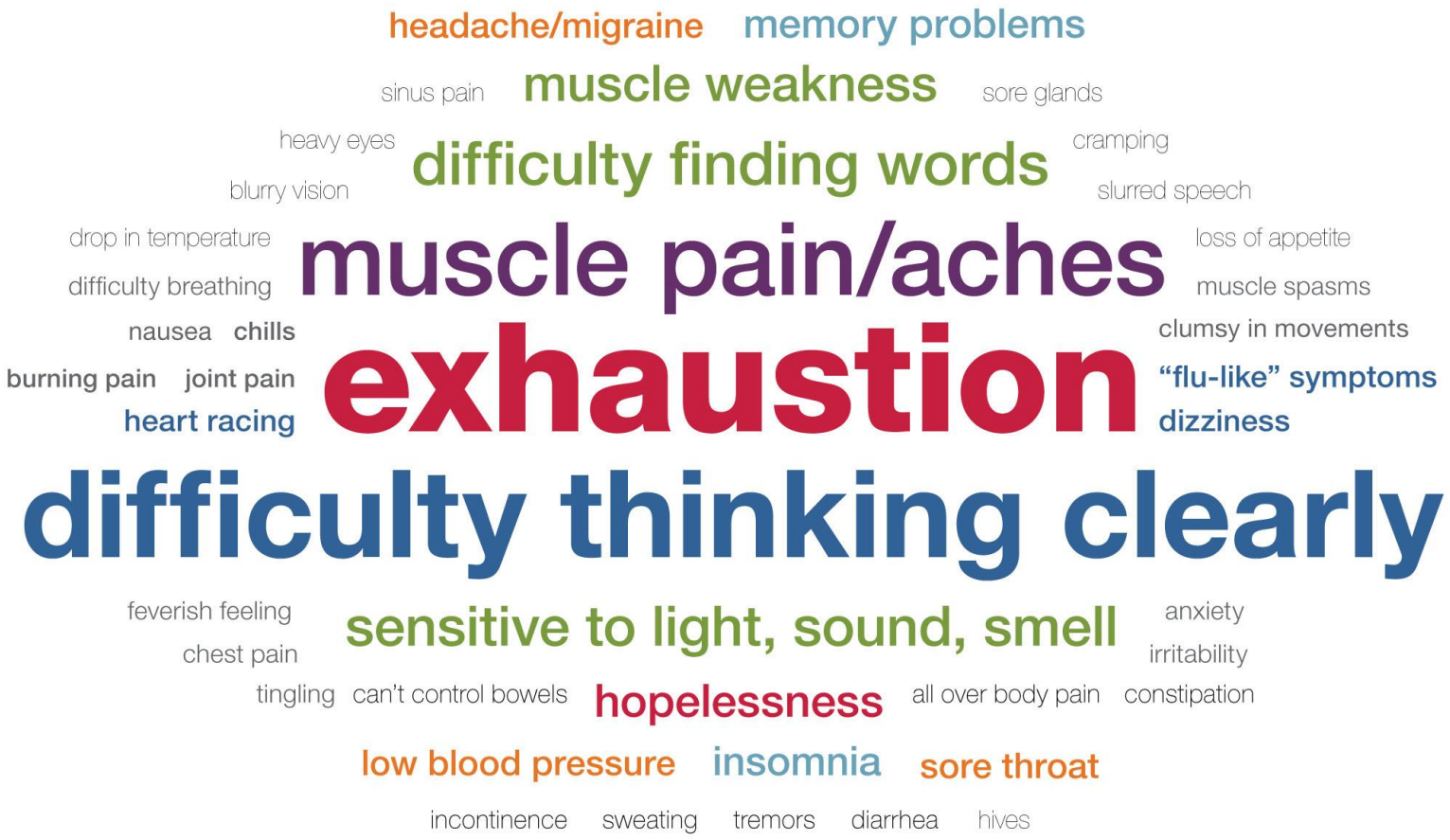
- Impaired memory or ability to concentrate
- Orthostatic intolerance

Workwell Foundation: www.WorkwellFoundation.org

Russek: Inspira

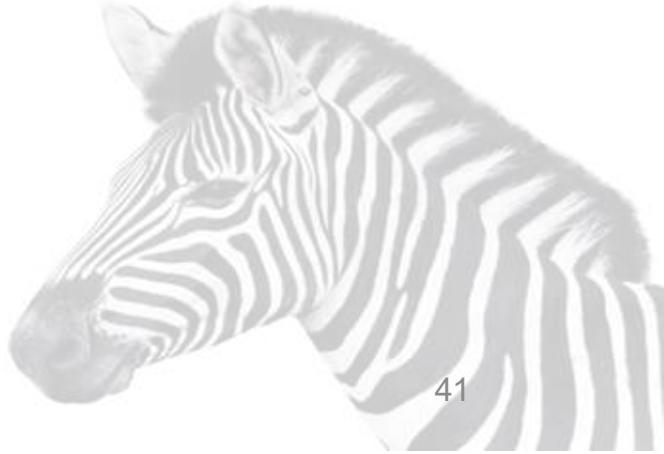


Post-Exertional Malaise (PEM)



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

(Natelson, 2022; Gandasequi, 2021)



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. Overwhelming the nervous system causes it to 'crash'

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

HSD 102:
POTS & MCAS

- 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

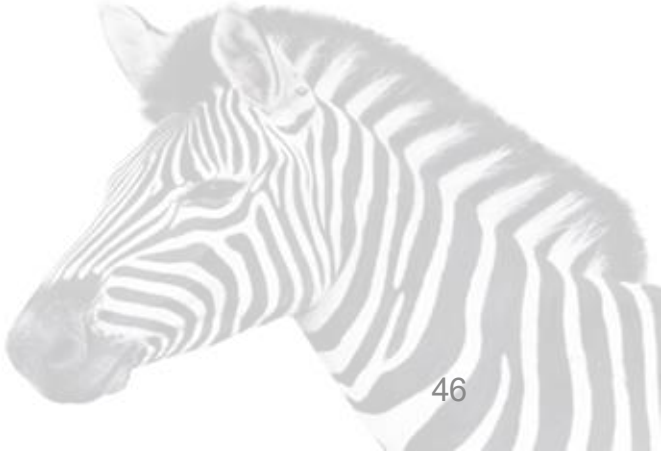
Ross, 2013

Brain Fog in MCAS

HSD 102:
POTS & MCAS

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

Theoharides, 2021



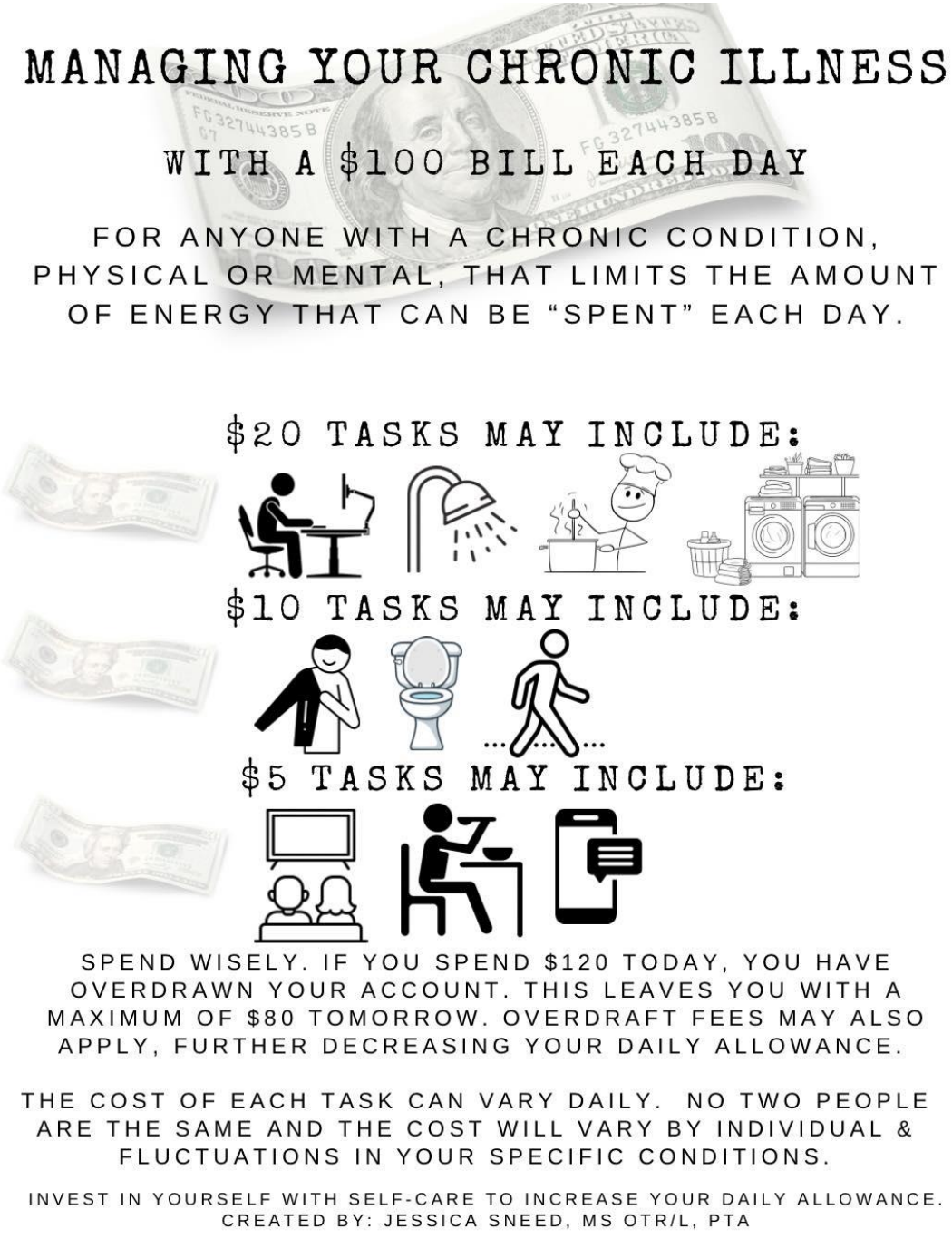
Manage the energy you have

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

- (Replacing the Spoon Theory)
- Plan your energy usage – you have $100/day to spend
- Don’t borrow on tomorrow!
- Plan time/strategies to re-energize – earn back $
- Communicate with family and friends
- Use assistive and energy saving devices if necessary to improve efficiency.

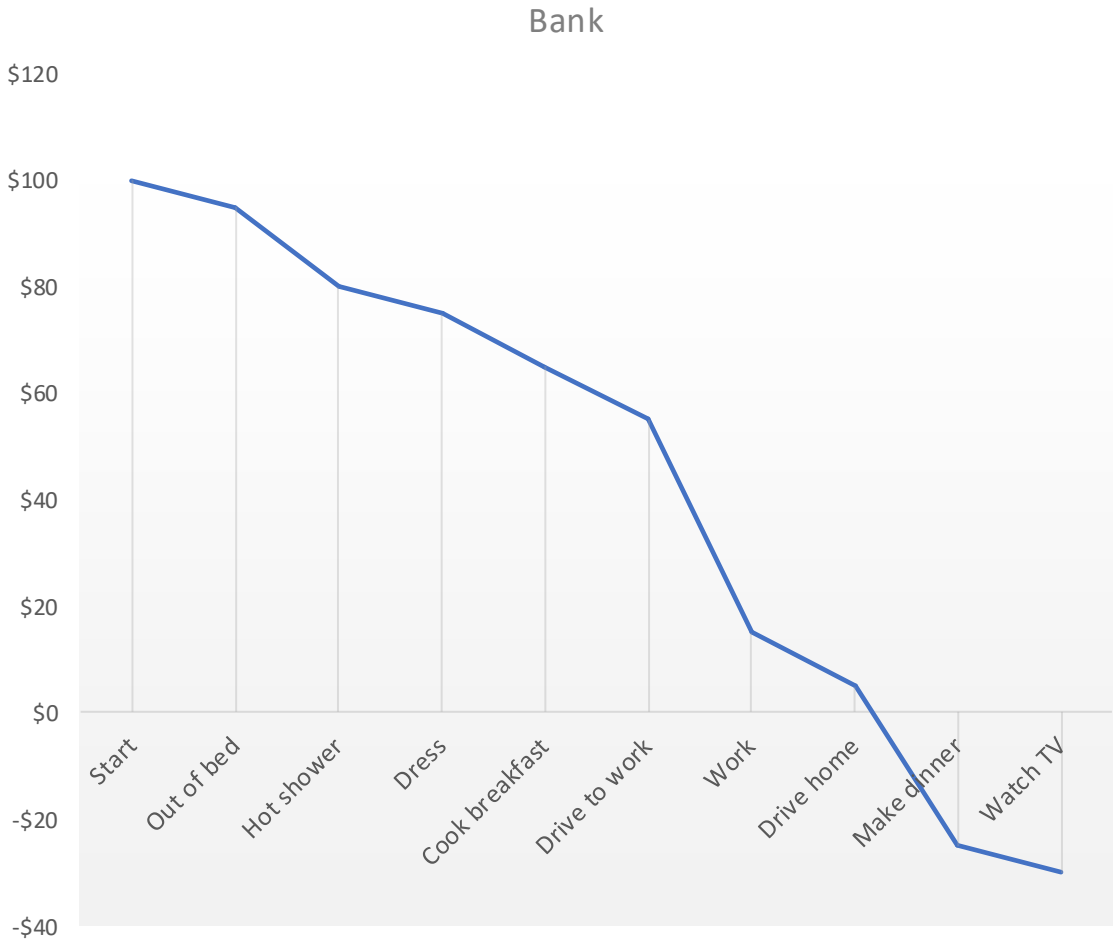


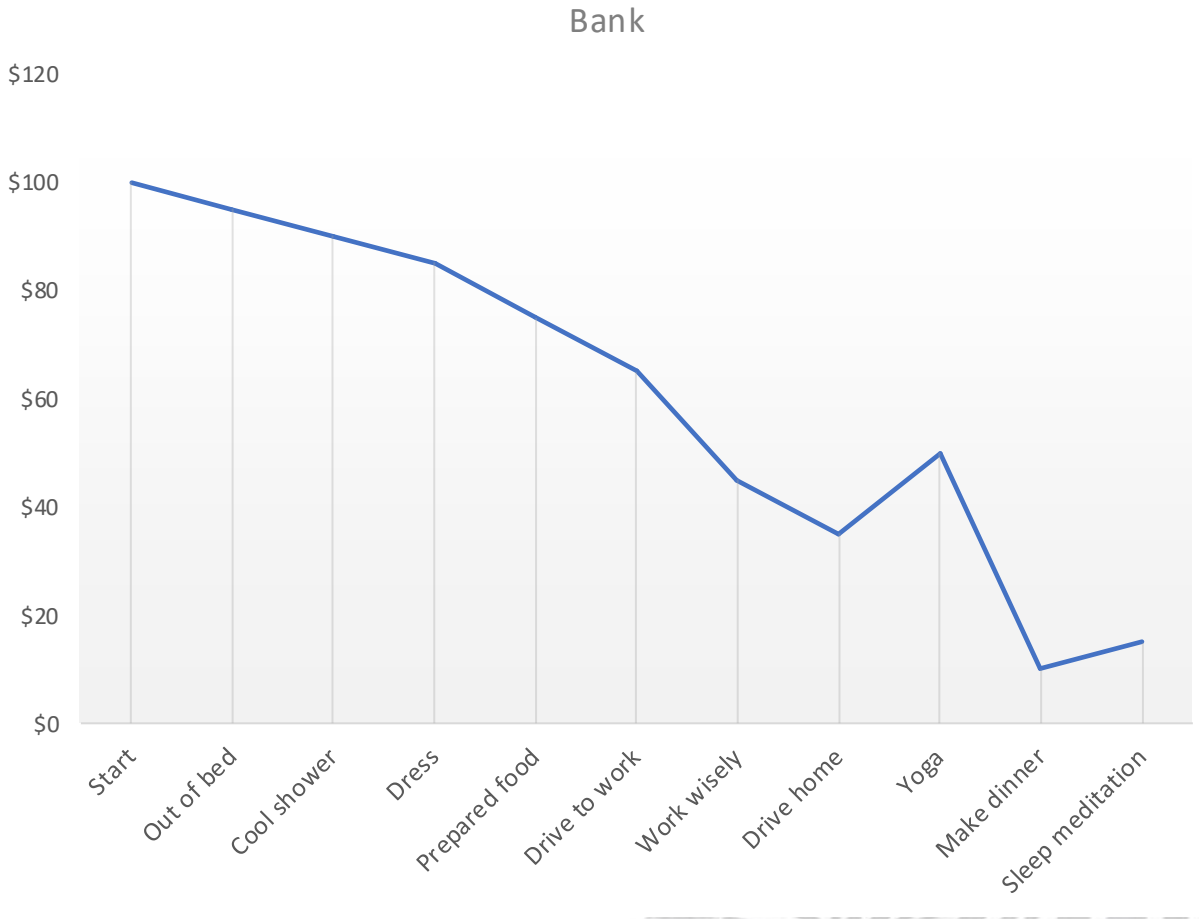
Russek: Hypermobili

How to Build the Bank Account

- Identify what activities cost the most
- Determine whether you can modify them to cost less. E.g.:
  - A cool shower costs less than a hot shower.
  - Have food prepared for breakfast rather than preparing each morning.
  - Make sure posture at work is good. Take microbreaks to relax. Prioritize.
- Avoid things that drain your energy and are unimportant to you.
  - E.g., listening to your co-worker complain, watching the nightly news.
- Invest in yourself with restorative activities.
  - Yoga, breathing practice, meditation, art, activities you enjoy.
- Once you have spare money, invest it wisely.
  - Take a 5-minute walk at lunch break, do 10 minutes of Pilates, etc.

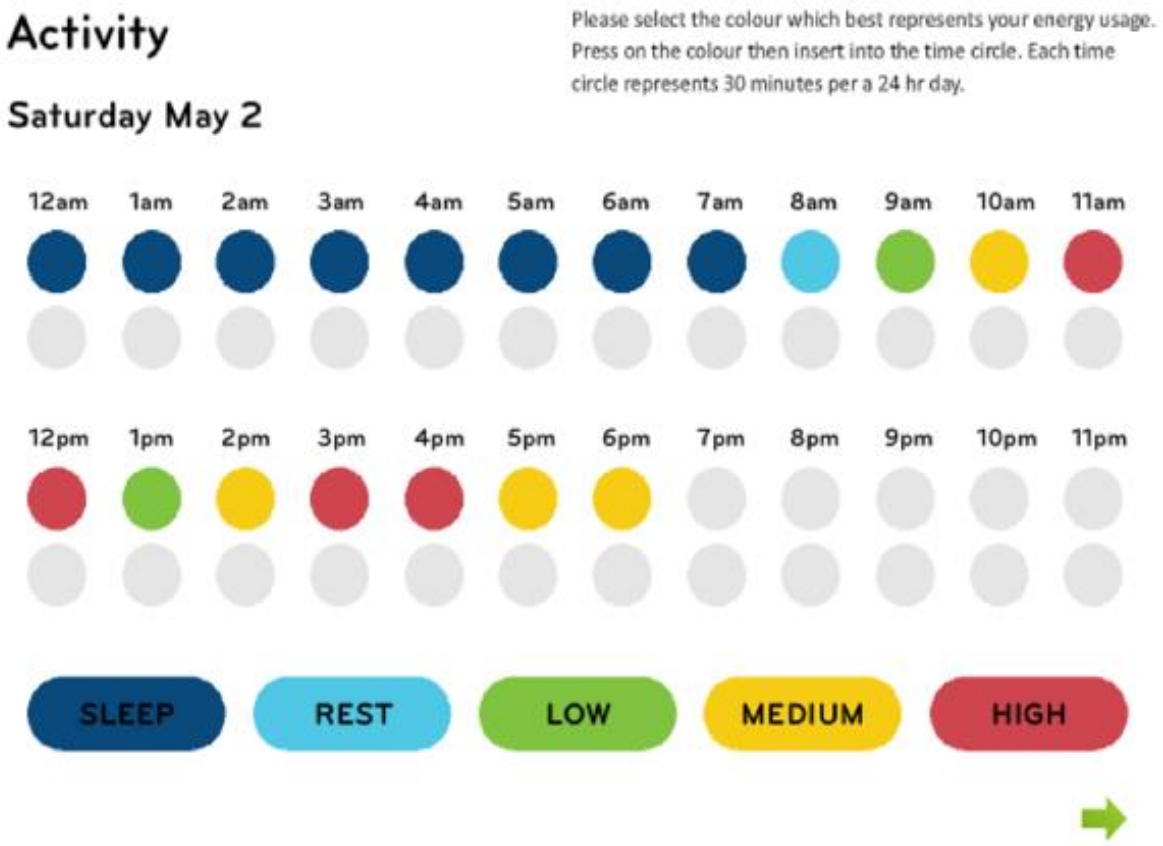
How to Manage the Energy Account





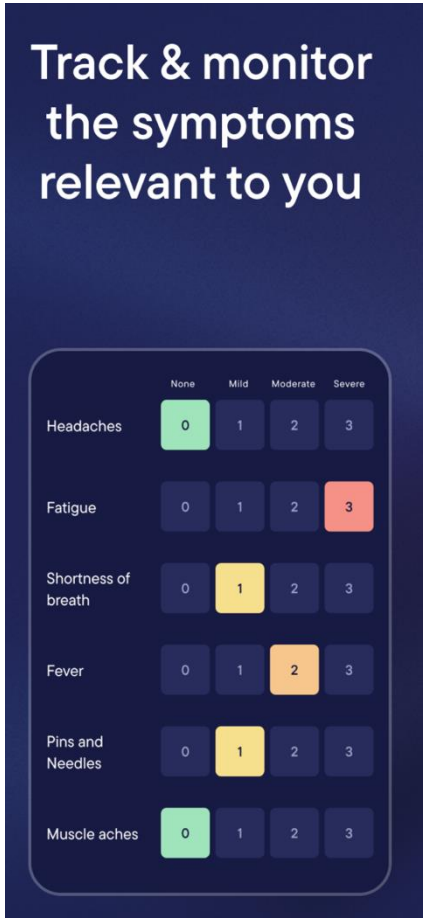
“Pacing Up”

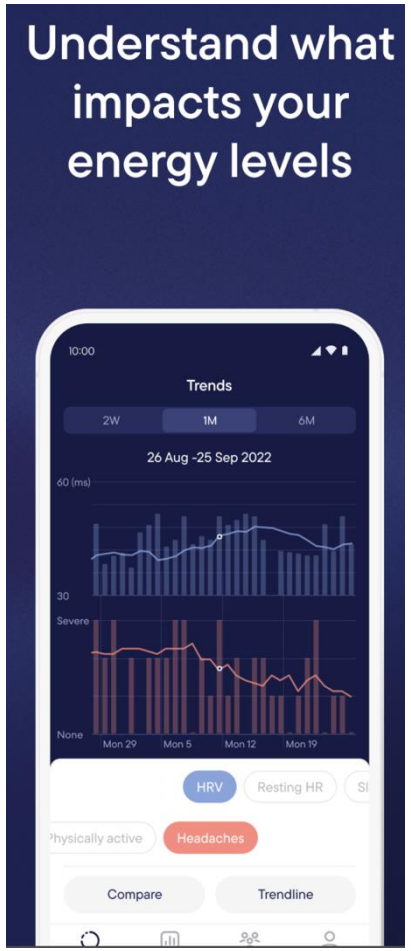
Don’t over do it and cause “Boom and Bust” cycles



- 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
- The Chronic Fatigue Syndrome Diary app can help with planning and pacing

Visible App

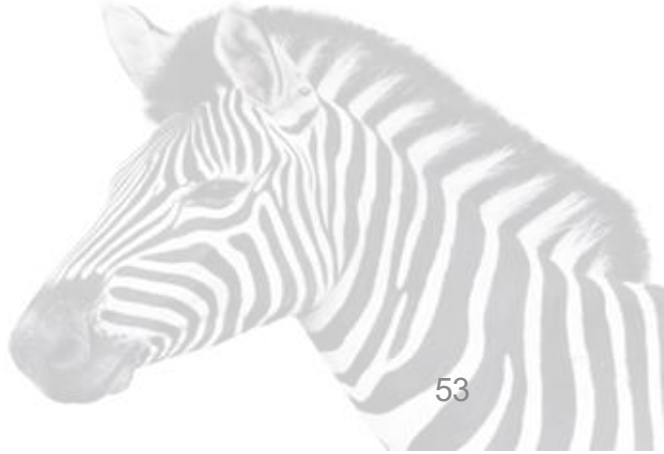




- "Visible is designed to help you understand your energy-limiting illness including Long Covid, ME and Chronic Fatigue Syndrome (CFS).

  "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.



Do things to gradually increase energy/function

Treatments to Increase Energy

- Managing pain, anxiety & depression (Clark, 2024)
- Breathing exercises
- Graded exercise
- Stress management, cognitive behavioral therapy (CBT)
- Red Light Therapy? Evidence is promising, but not yet strong
- *Dietary adjustments*
- *Ideas with little/no evidence, but low risk*
  - *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: 4 seconds in, 6 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/

Red Light Therapy

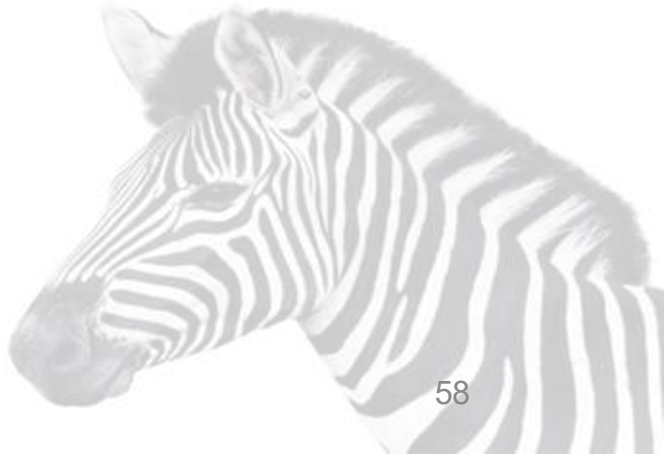
- Red light: wavelength 660 nm
- Near infrared light: 850 nm
- Also called ‘low-level laser light,’ ‘low-power laser,’ ‘non-thermal LED light,’ ‘cold laser,’ ‘biostimulation,’ ‘photobiomodulation’
- Provides the healthful benefits of sunlight without the UV
- Counteracts negative effects of blue LEDs
- Science is still evolving
  - Evidence good for skin, depression, anxiety, TMJ pain, some chronic pain (Farazi, 2024)
- https://my.clevelandclinic.org/health/articles/22114-red-light-therapy

POTS-Specific Exercise

HSD 102: POTS & MCAS

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
- CHOP AADP:
  - Acquired Autonomic Dysfunction Program
- 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
- Don’t exercise at an intensity that increases HR more than 15-20 bpm
- 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
- Visible App™ tracks HRV and advises you about appropriate activity
- https://ouraring.com/blog/train-better-using-hrv/

Rate of Perceived Exertion (RPE)

- 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!

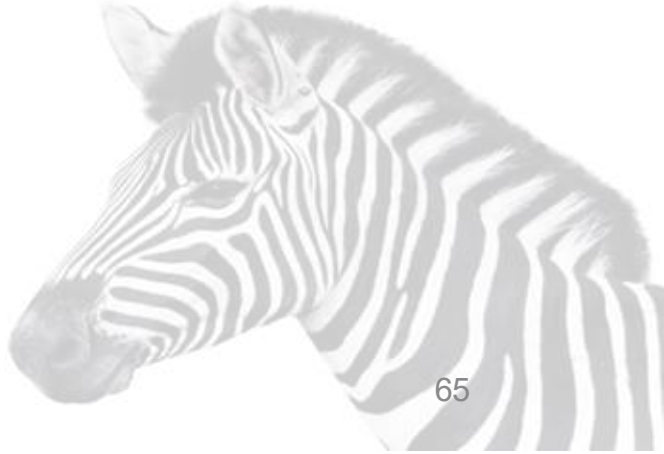
Starting to Exercise Ideas

Active Arcade ™ Whack-a-Mole

Augmented Reality Activities

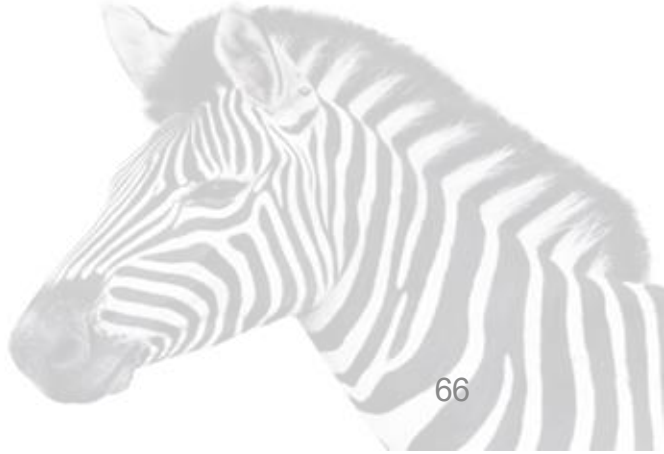
Chair yoga: https://youtu.be/I3SZa5aGj20

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?