



# LIFESTYLE STRATEGIES AND COPING SKILLS IN DYSAUTONOMIA

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Occupational Therapist

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I have no conflicts of interest to disclose.

# Road Map

- "The big 5" lifestyle management strategies
- Therapies
- Additional strategies for management
- Questions



# What are Lifestyle Interventions?

- Modifications to our lives and the various contexts or environments in which we live:
  - physical, social, cultural, spiritual, and virtual
- The world is dynamic and always changing
- Everything *happens: everything has a beginning and an end*







# 5 PRIMARY LIFESTYLE MEASURES

5 most recognized in non-Medication treatment of POTS

# 5 Primary Lifestyle Measures



Fluid



Sodium



Compression



Exercise



Head of bed  
elevation

*The Big*

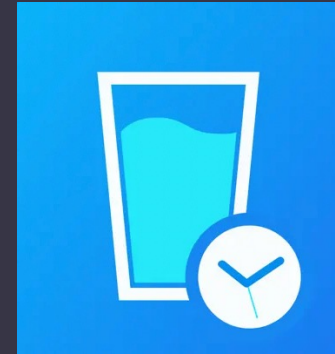
5

# Fluid

- Recommendations range 2-4 liters (100+ ounces)
  - Void bladder 5-6x/day light-colored urine after morning void; 20 second stream
- Typically limit or avoid caffeine
  - Exception is headache-related needs
  - A portion of patients do tolerate
- Increase success:
  - Bottles and apps with reminders
  - Naturally infuse with fruits, herbs

Mechanism:

- Blood volume expansion



Apps “water reminder”



Track consumption & glow reminders



Time-marked bottles

# Sodium

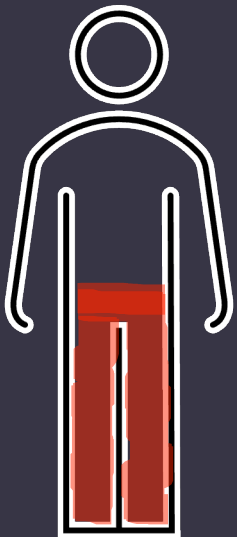
- Maximize benefit of fluid
- Recommendations range
  - 8-12 grams of salt (3,000-4,600 mg sodium)
  - Typical American diet gets 3-4 g salt
- Options:
  - Dietary increase
  - Electrolyte drinks
  - Tablets or capsules
  - Homemade recipes
    - Oral rehydration solutions
- Typically, best achieved with combination of approaches

Mechanism:  
▪ Blood volume expansion



# Fluid + Sodium

Baseline



Water + Salt



Mechanism:

- Increase blood volume
- Decrease norepinephrine
- Decrease heart rate

Homemade recipe:

-6 tsp sugar

- $\frac{1}{2}$  tsp salt

-1 L (about 4.5 cups)  
warm water

*Stir until salt and sugar  
dissolve and store in  
refrigerator*

Homemade popsicles,  
Jello, smoothies



# Fluid + Sodium

- Is this only important in hypovolemic POTS?



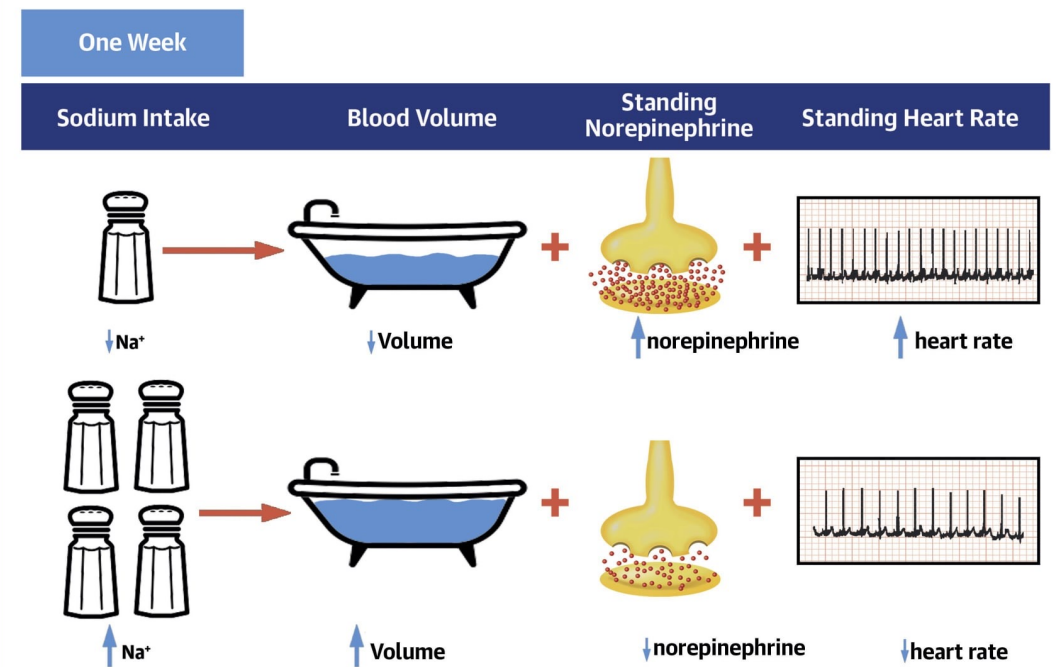
No

- According to a 2021 study (Garland et al.), high sodium diet salt in POTS →
  - increase in blood volume
  - decrease in norepinephrine
  - decrease in heart rate
- Relevance for hyperadrenergic and neuropathic POTS**

Mechanism:

- Increase blood volume
- Decrease norepinephrine
- Decrease heart rate

**CENTRAL ILLUSTRATION:** Effects of Low and High Sodium Diets in Postural Tachycardia Syndrome



Garland, E.M. et al. J Am Coll Cardiol. 2021;77(17):2174-84.

# Compression

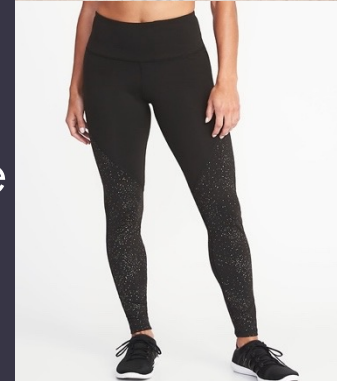
- Counteracts blood pooling
  - especially legs and abdomen
- How tight?
  - at least 20-30 mmhg
  - 15-20 mmhg is not ideal but may be only option for people without assistance and significant pain, fatigue, or sensory sensitivities
- Compression sleeves may aid cooling & temperature regulation
- Abdominal binder, even if no leggings

Mechanism:  
▪ Increase circulation; reduce pooling



★★★  
Good

6 bpm  
change



★★★  
Better

12 bpm  
change



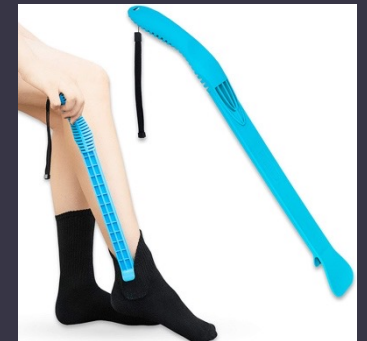
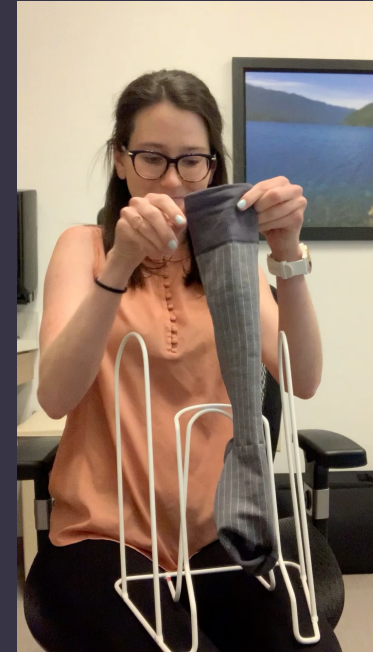
★★★  
Best

17 bpm  
change

# Compression: assistive devices

## Tips for Saving Energy:

- Donning (“On”) devices
- Doffing (“Off”) devices
- “Plastic/ garbage bag” method (open-toe only)
- Rubber kitchen gloves
- Partial fold method (turn inside out at heel)
- Non-slip grip on floor (e.g., dycem)
- Silicon lotion or powder (heel and ankle)
- Zipper or Velcro compression garments



# Movement

- Strengthening & cardiovascular... eventually
- Start laying down or reclined position
  - Equipment such as rowing machine or recumbent cycling
  - Swimming (gravity minimized, compression added)
  - Pilates
  - Horseback riding
  - Strengthening “in bed”
  - Daily activities
- ... as guided by a professional (OT, PT, personal trainer, cardiac rehab, etc.)
- Slow is the way to go

## Mechanisms:

- Blood volume expansion
- Improved circulation
- Increase red blood cells



# Movement Barriers

- Tolerance
  - Need to start at lower intensity than many have experienced
- Professional support and guidance
  - Specific, individualized approach needed
- Access to equipment and appropriate educational materials
  - More virtual programs (handouts, videos) becoming available
- Motivation
  - Uncomfortable post-exertional symptoms; affects daily life
    - Monitor for post-exertional symptoms and adjust accordingly

## Mechanisms:

- Blood volume expansion
- Improved circulation
- Increase red blood cells



# Post-Exertional Malaise (PEM)

- A reduction in functioning and a severe worsening of symptoms after what may be minimal physical, cognitive, or emotional exertion
  - The “hallmark” symptom of ME/CFS

## How is this different from other fatigue?

### Delayed

- often delayed 24-72 hours or more after the activity/exertion

### Prolonged

- lasting days, sometimes even weeks or months

### Symptoms

- immune-related: flu-like (sore throat, fever, swollen lymph nodes, malaise, pain, brain fog, muscle ache, sensitivities, dizziness)

Treatment will look different than those with fatigue without PEM.

# Movement Resources from DI

**DYSAUTONOMIA INTERNATIONAL** Select Language ▼

 **AWARENESS**  **ADVOCACY**  **ADVANCEMENT**

Interactive Global Dysautonomia Map  
Be Counted  
Get Connected  
Find a Doctor

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### Exercises for Dysautonomia Patients

**RECLINED EXERCISES** **CHAIR EXERCISES** **POOL EXERCISES**

Now available for download... [CHOP Modified Dallas Protocol](#)



# Movement: Rate of Perceived Exertion

RPE Scale	Rate of Perceived Exertion
10	<b>Max Effort Activity</b> Feels almost impossible to keep going. Completely out of breath, unable to talk. Cannot maintain for more than a very short time.
9	<b>Very Hard Activity</b> Very difficult to maintain exercise intensity. <u>Can barely breath and speak only a few words</u>
7-8	<b>Vigorous Activity</b> Borderline uncomfortable. Short of breath, can speak a sentence.
4-6	<b>Moderate Activity</b> Breathing heavily, can hold short conversation. Still somewhat comfortable, but becoming noticeably more challenging.
2-3	<b>Light Activity</b> Feels like you can maintain for hours. Easy to breathe and carry a conversation
1	<b>Very Light Activity</b> Hardly any exertion, but more than sleeping, watching TV, etc

Preliminary window of tolerance

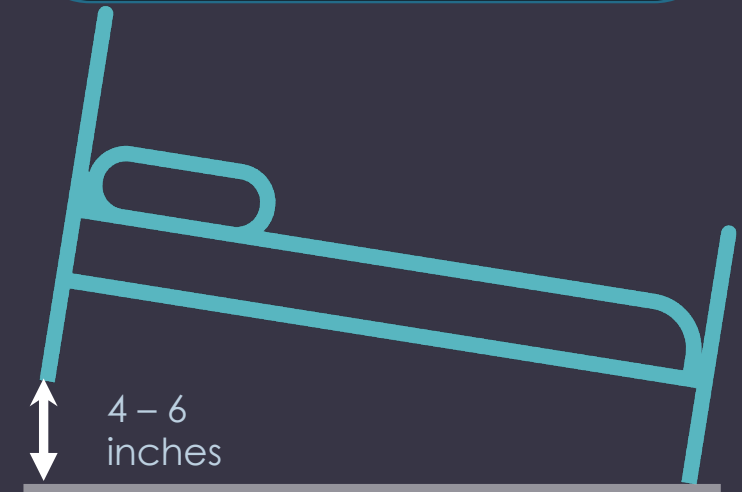
Eventual window of tolerance

# Elevating Head of Bed

- Full body at an angle
- 4-6 inches at head of bed
- Mechanisms
  - reduce autonomic instability
  - decrease nocturnal enuresis
  - may improve orthostatic tolerance
- Options:
  - elevate bed frame using bed risers, cinderblocks, wood
  - electric bed frame may work as well
  - full-body wedge



- Mechanisms:
- Volume expansion; reduced PM urination
  - Condition to orthostatic stress; less blood pooling



Ensure safety  
at footboard  
to sustain  
weight



BUT WAIT... THERE IS  
(SO MUCH) MORE





# Self-Management

- Daily management of your condition
  - Empowerment
  - Autonomy
  - Control
  - Confidence
  - Safety
  - Opportunity
  - Individualized
- Not: "you have to figure this all out yourself"

# You don't have to do this alone

- Allied health provider
- Health coach
- Family member or friend
- Peer with health challenges
- Community organization, peer mentoring



# Therapies

Occupational  
Therapy

Physical  
Therapy

Speech  
Therapy

Dietary and  
nutrition

Psychology

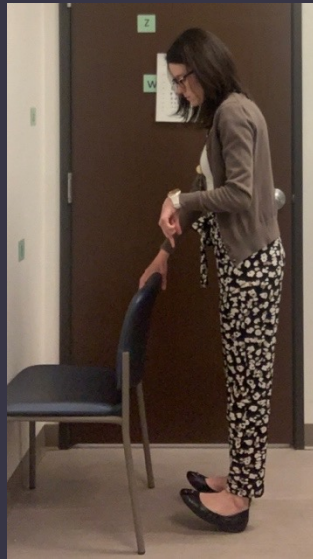
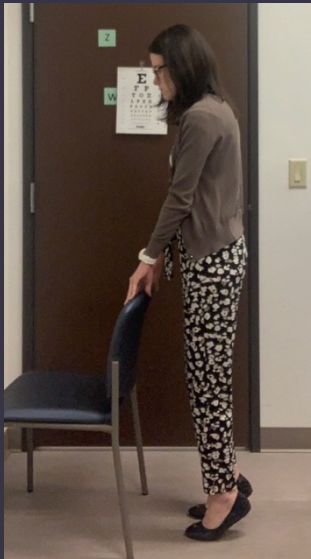
Social work

Somatic  
modalities  
(e.g., SE)



# Counterpressure Maneuvers

Mechanism:  
▪ circulate blood



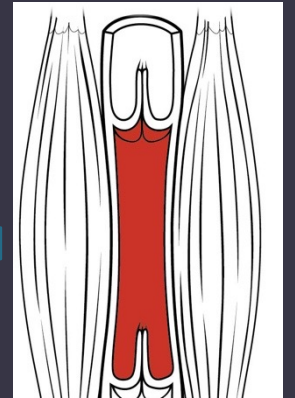
Calf raise with rock back



Crossing legs and squeeze



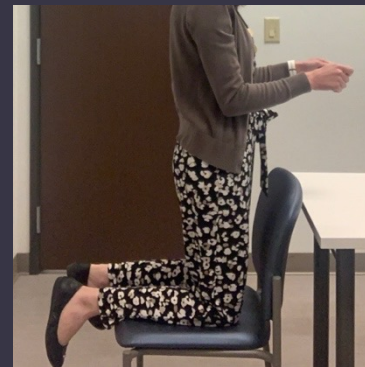
Glute squeezes



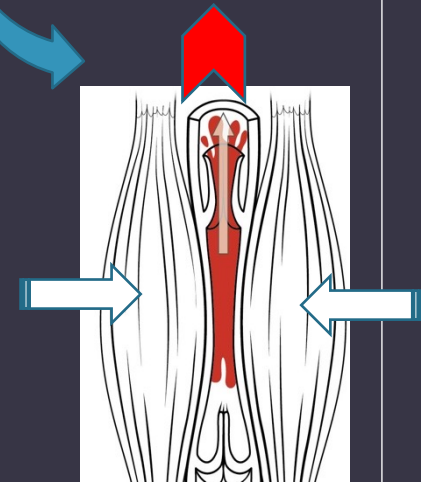
Shifting weight to stand on one leg



Shifting weight to stand on one leg (w/ other leg elevated)



Tall kneeling



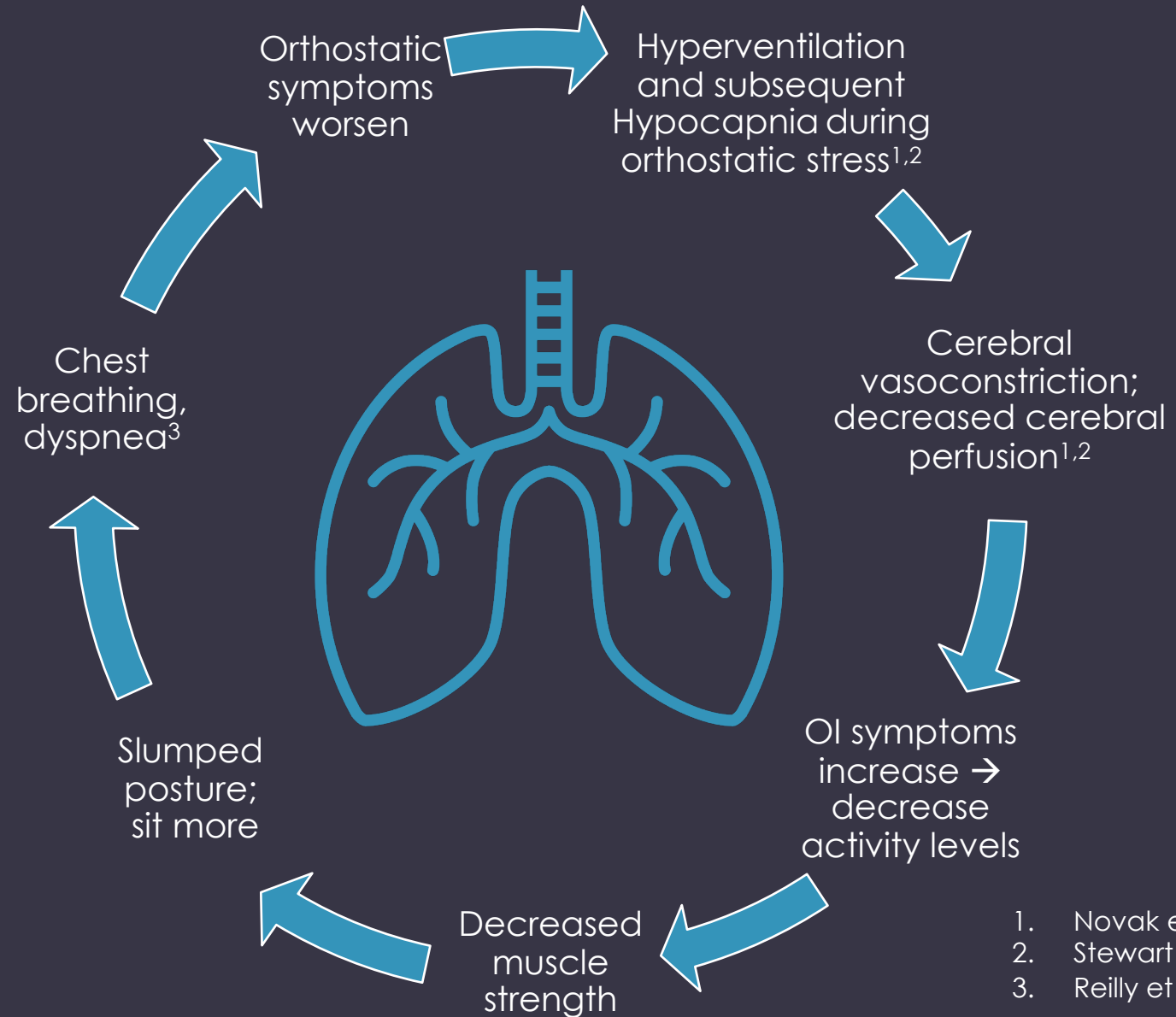
# Challenges with Breathing

- More than 70% of people with POTS experiences breathlessness.<sup>1</sup> Patients often complain of “air hunger.”
- Causes may include low blood volume, overactivity in sympathetic state, changes to breathing pattern, quality or frequency of breathing, symptoms of tachycardia and palpitations, exertion, stressors, or certain positions/ positional changes.<sup>2-3</sup>
- Reduction in cerebral blood flow, cardiac output, and BP, upon standing, can be associated with hyperventilation in some POTS patients, which can worsen tachycardia.<sup>4</sup>
  - This may be improved with adding CO<sub>2</sub><sup>4</sup>
  - This is different than panic disorders as tachypnea (fast breathing) is absent<sup>5</sup>
  - Potential link to interoception and feeling the need to breath more

1. Boris & Bernadzikowski, 2018
2. Novak et al, 1998
3. Reilly et al., 2020
4. Stewart et al., 2018 a
5. Stewart et al., 2018 b



# Potential model for the multiple effects of breathing on POTS function



1. Novak et al, 1998
2. Stewart et al., 2018
3. Reilly et al., 2020



# Breathing + Dysautonomia

- Should we be teaching a different way to breathe?
- Slow changes over time and going at the pace your body and nervous system will tolerate
- Where can you start?
- Diaphragmatic breathing through nostrils is one recommendation
- Considerations for intentional breath holding
- Individualize
- Many options for apps to guide and pace breath

# Dysfunctional Breathing

- Reilly 2020 study; 66 patients with POTS in the UK
- Intervention: respiratory physical therapy

**Table 2: Change in outcome measures pre – post physiotherapy intervention. Values reported as median (range).**

	<b>Pre-Physiotherapy</b> Median (range)	<b>Post Physiotherapy</b> Median (range)	<b>Median of differences</b>	<b>P Value</b>
Nijmegen score	37 (23 -51)	26 (6-46)	-11	P<0.001
Respiratory rate	22 (12 - 32)	18 (12 -24)	-5	P<0.001
Breath hold time	18 (4-33)	21 (6-70)	+3	P<0.001

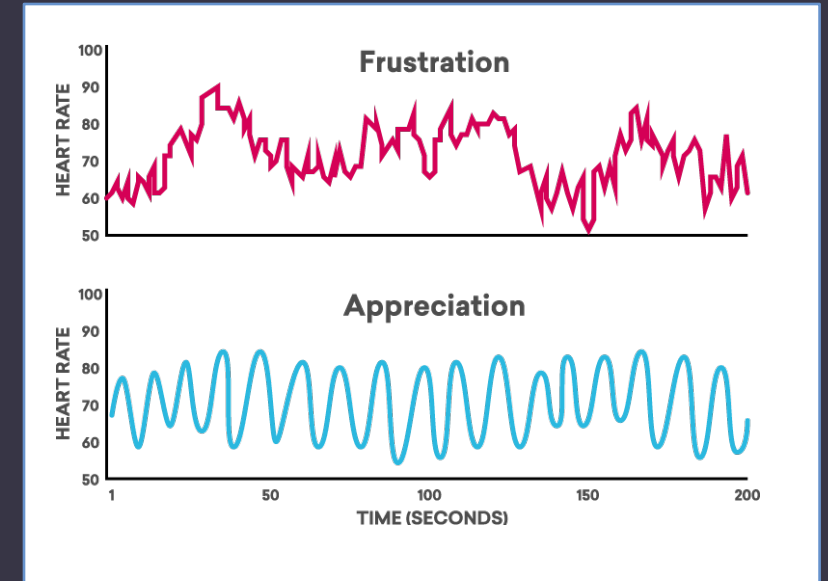
- Outcome: Significant improvement in symptoms and breathing patterns
- Authors discuss potential that an overactive sympathetic nervous system leads to routinely breathing too fast. This may reduce blood flow to the head and cause lightheadedness and cognitive impairment.

# Biofeedback

“Feedback about the body”

Many different forms:

- Heart rate variability and respiratory training
- Thermal or peripheral temperature
- Surface electromyography (EMG)
- Galvanic skin response
- Goal: independence in self-regulating nervous system throughout the day *without* need for feedback
- Free apps for tracking HRV using phone:
  - Juva Health (Apple only)
  - Welltory







# Self-Compassion

- A person doesn't need to have clinical anxiety to experience psychological distress
- Emotional challenges are normal with a significant change to functioning, especially in chronic illness
- Self-compassion includes:
  - Mindfulness
  - Common humanity
  - Self-kindness
- Online resources: including self-assessment and interventions
  - Kristin Neff ([self-compassion.org](http://self-compassion.org))
  - Center for Clinical Interventions – Australia
- "This is really hard right now. Struggling is a part of life. May I be kind to myself."

# Fatigue: Overview

## Primary Fatigue

A result of the medical condition

Shortness of breath  
Post-exertional malaise (PEM) or post-exertional symptom exacerbation (PESE)  
Cardiac-related  
Autonomic dysfunction  
Oxygen desaturation

## Secondary Fatigue

Indirect association

Changes in:  
Sleep  
Nutrition  
Routine  
Activity level and exertion  
Mood (anxiety, depression)  
Stress



# Energy



Physical

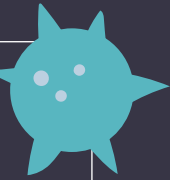


Cognitive



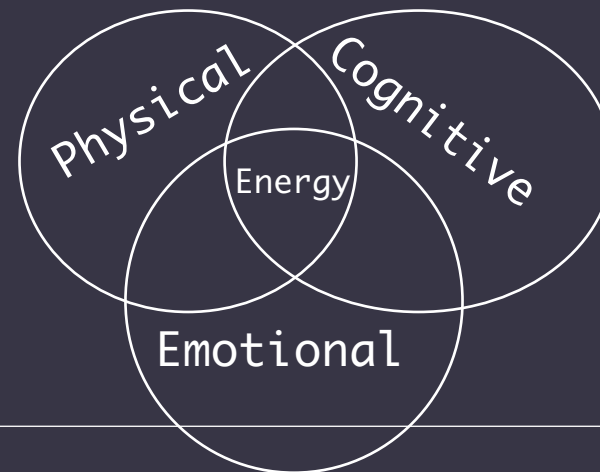
Emotional

# How do I Prevent Fatigue?



- Learn and avoid your triggers
- Pace yourself
- Conserve energy and simplify tasks
- Consider impact of physical, emotional, and cognitive energy expenditure

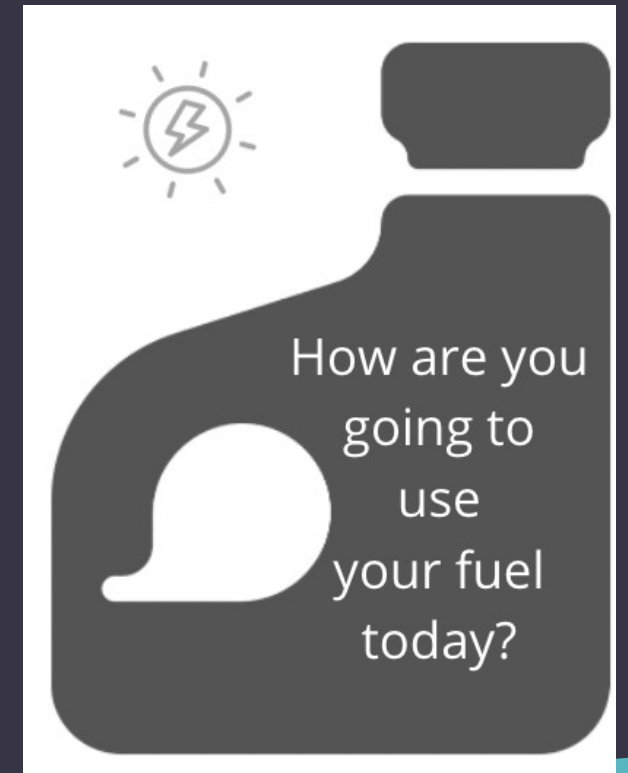
*Work smarter,  
not harder!*



# What do I do to Manage Fatigue?



- Learn strategies for rejuvenating and restoring energy. These may include:
  - Achieving restful sleep & balancing with time awake
  - Regulating stress levels
  - Consistent, appropriate movement
  - Spending time in nature and/or getting natural sunlight
  - Nourish body with appropriate nutrition & hydration
    - consider small, frequent meals
  - Self-compassion, breathing, heart-rate variability
- Plan, prioritize, pace
  - Pacing will, over time, expand the amount of energy you have at the start of each day



# Adaptive Equipment

Percentage of participants reporting use of adaptive tools (either one or multiple tools) in managing symptoms of POTS (n = 958).



Adaptive tools	<i>n</i>	%
Chair to sit while getting ready	623	68.8
Compression	609	67.3
Shower chair/tub bench	372	41.4
Cooling devices	174	19.2
Manual wheelchair	133	14.7
None	58	10.5
Cane	91	10.1
Long-handled brush/sponge	86	9.5
Electric cart or scooter	77	8.5
Service dog	57	6.3
Reacher	52	5.7
Rollator	42	4.6
Walker	39	4.3
Power wheelchair	30	3.3
Crutches	18	2.0
Long-handled shoe horn	16	1.8

These do not sum to 100% because “check all that apply” was asked for this question.

(Rich et al., 2021)

# Assistive Tools

Noise-lowering  
Ear buds



Tub bench/  
Shower chair



Weighted  
Lap pad



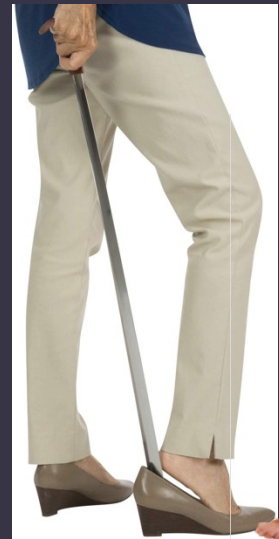
Standing stool



Cooling neck fan  
and towel



Zero gravity chair



Long-handled  
Shoe horn



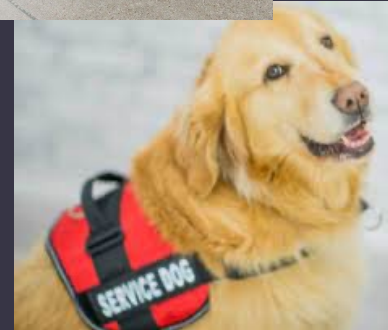
Razor



Long-handled  
sponge



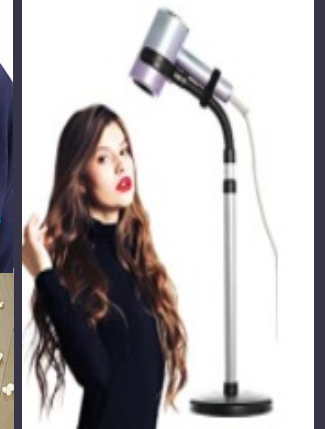
Long-handled  
cleaner



Service animals



Robotic  
Vacuum



Blow-  
Dryer  
On  
stand



# Nutrition

- Small, frequent meals are advised; finish at least 4 hours before bed
  - abdominal blood pooling may result from larger meals and lead to symptoms after eating
- Alcohol tends to aggravate symptoms and is best avoided
- Dietary changes?
  - Some emerging evidence
- Referral to a knowledgeable registered dietitian is often helpful





# Autonomic Regulation

"Toning" of the parasympathetic nervous system to increase activation of the "rest and digest"/ "feed and breed" system + limit overactivation of the "fight or flight" system

- Vagus nerve activation decreases HR, increases digestion, allows slow, deep breathing, and helps decrease inflammation

Opportunities (just a few):

- Breathwork
- Relaxation
- Vagus nerve toning/ stimulating exercises<sup>1</sup>
  - There are a variety of resources; evidence is emerging but limited specific to dysautonomia
  - E.g., humming, singing, splashes or swims in cold water, movement, salivation/ eating in relaxed environment, laughing, massage



# Acupuncture

- A branch of traditional Chinese medicine
- Goal: restore and sustain balance in the individual
- No studies to-date in dysautonomias
- Relatively low-risk; cost can be prohibitive
- Good evidence safe and effective in children and adults including chronic pain and headaches/migraines. Effects have been shown to be long-lasting (> 6 months).

# Additional Integrative Medicine Opportunities

- Mind-Body Modalities
  - Mindfulness-Based Stress Reduction (MBSR)
    - promising research evidence in POTS and other chronic conditions
  - Clinical hypnosis
    - research evidence in many chronic conditions and in teaching skills of self-hypnosis
  - Guided imagery
  - Progressive muscle relaxation
- Manual Therapies
  - Physical therapy
  - Massage
  - Chiropractic care
  - Osteopathic Manipulative Treatment (OMT)
  - Cranial-Sacral
  - Strain/Counterstrain
  - Visceral technique
  - Myofascial release

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# Connect + Questions

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- Instagram: [EmilyRichOT](https://www.instagram.com/EmilyRichOT)
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- Twitter: [EmilyRichOT](https://twitter.com/EmilyRichOT)
- Spotify: [Oh The pOTsabilities](https://open.spotify.com/album/OhThepOTsabilities)

