



 AOTA Specialty Conference:
Adult Rehabilitation

Long COVID & Dysautonomia
evidence-based rehabilitation strategies

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Objectives

- Know common signs and symptoms of long COVID.
- Identify post-exertional malaise symptoms and triggers
- Understand the importance of screening process for frequently found comorbidities related to long COVID including MCAS, sleep and breathing disorders, and hypermobility
- Learn how to stabilize long COVID patients for safe rehabilitation

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Names of Long COVID:

Long COVID can also be called
PASC (post-acute sequelae of COVID-19)
Post COVID Conditions
Long-haul COVID
Chronic COVID

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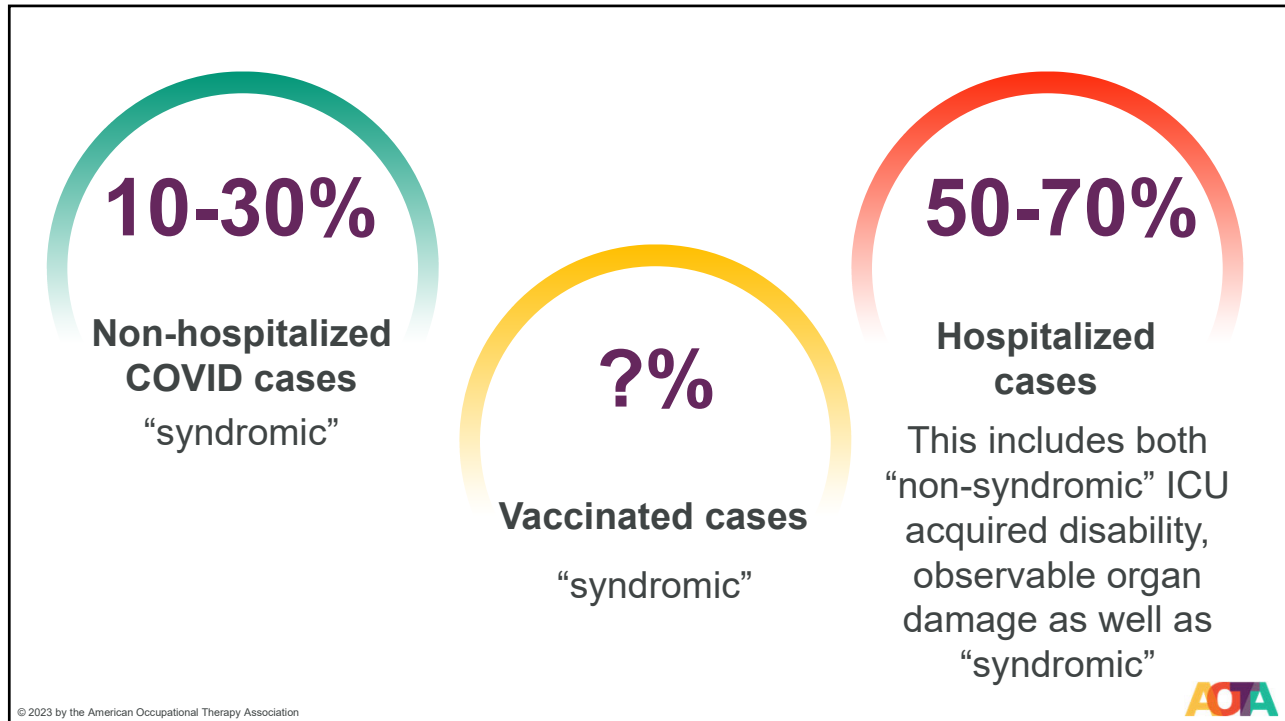
World Health Organization Definition:

“The continuation or development of new symptoms 3 months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least 2 months with no other explanation. While common symptoms of long COVID can include fatigue, shortness of breath and cognitive dysfunction over 200 different symptoms have been reported that can have an impact on everyday functioning.”

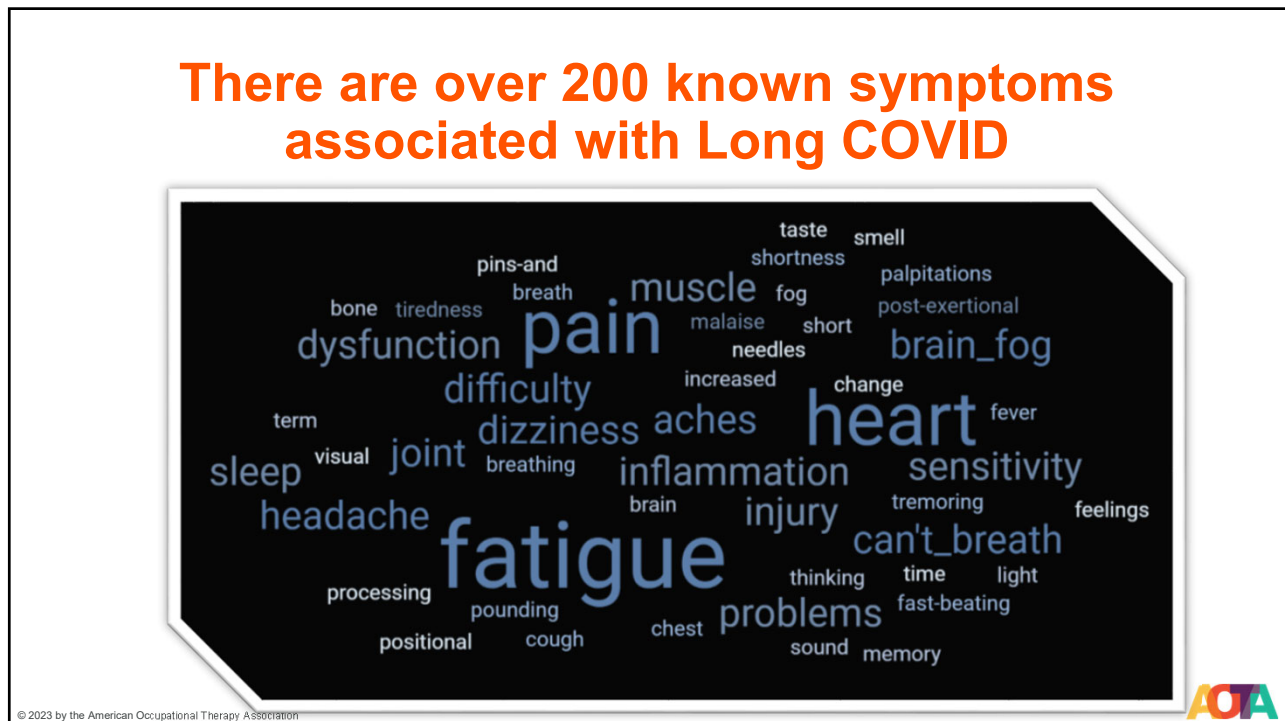
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Strategies to avoid Long COVID

1. Avoid COVID infection: mask, HEPA filters, small social circle, nasal rinses/sprays, hand hygiene, eyewear, get vaccinated.
2. Make sure you can breath well, sleep well, eat well & cultivate a solid gut (probiotics). Take a high quality multi-vitamin.
3. Have a check-up: vitamin D, iron/ferritin, folate, B12 levels.
4. Anti-inflammatories: Diet, tea, Melatonin, Quercetin, consider H1/H2 antihistamines and a B-complex (with drs permission)
5. Take your BP, resting heart rate or HRV regularly to note changes.
6. Rest and avoid stressors (including high intensity exercise) ~6 weeks post-COVID
7. Cultivate a practice that helps your ANS/vagus nerve
8. Know the warning signs and act immediately...

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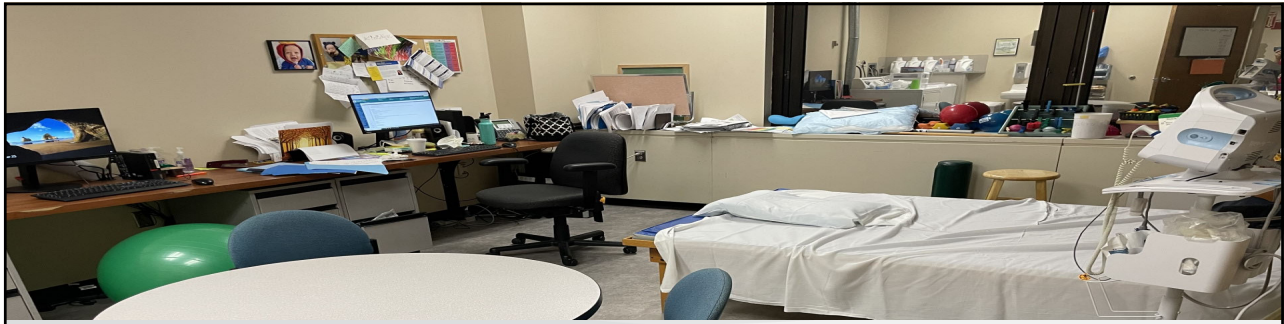
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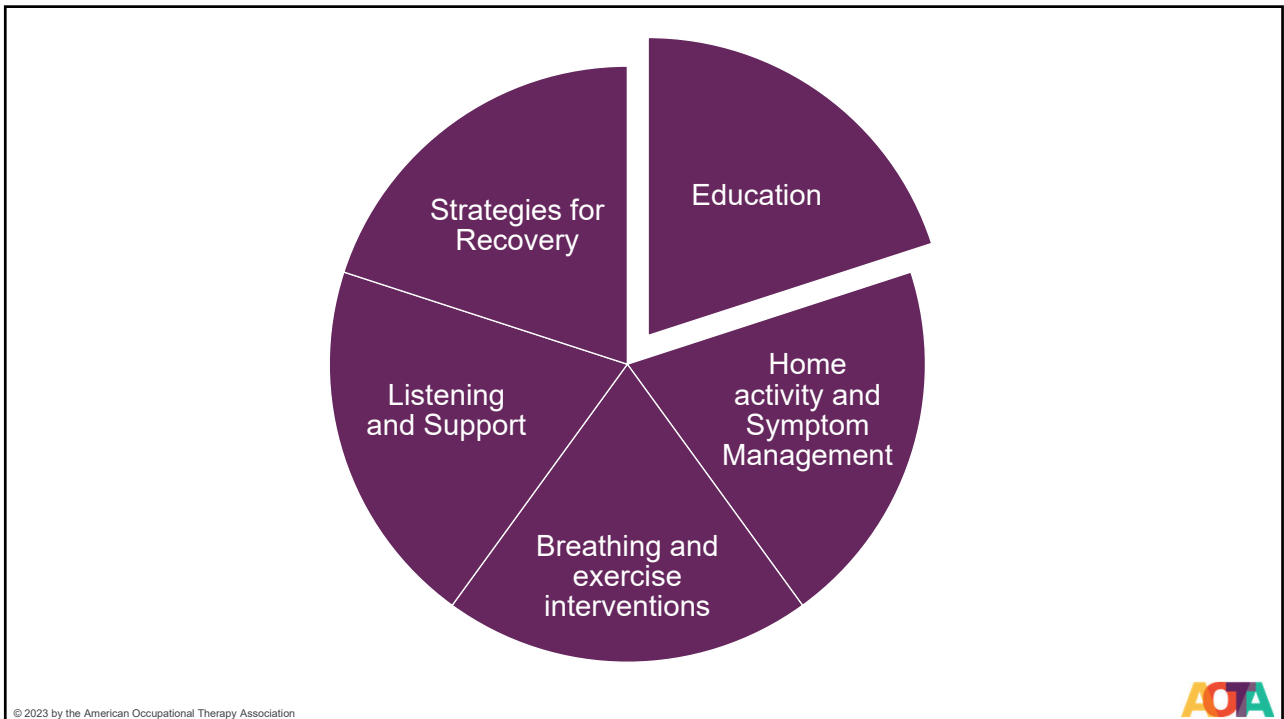


“Long COVID Persists as a Mass Disabling Event”

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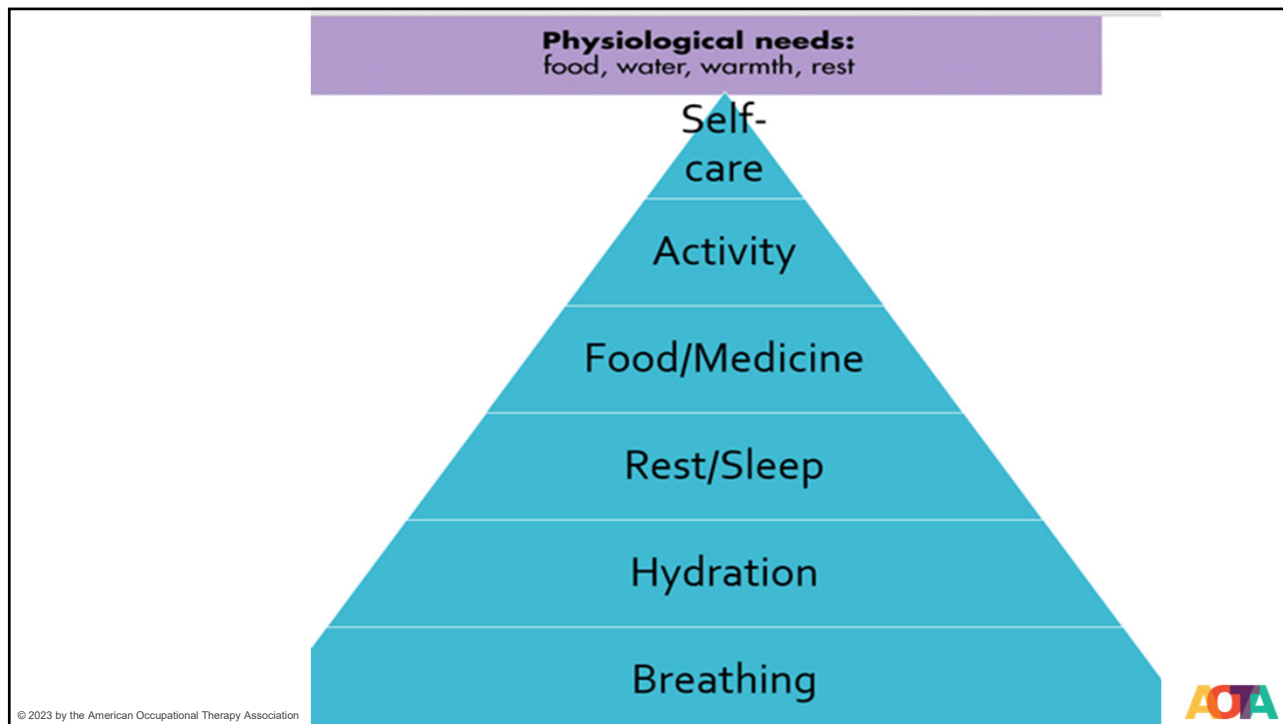
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Websites and Hotlines	Blogs/Articles/Podcasts/Books
<p>Rights as a Person with Long COVID: National Employment Lawyers Association Job Accommodations Network (JAN) askjan.org How to Get On: easy-to-understand explanations of disability benefits and financial survival</p> <p>Mental Health Resources: Substance Abuse and Mental Health: can help you find services in your area. 1-800-662-HELP Mental Health America mhanational.org National Alliance on Mental Health nami.org 988 Suicide and Crises Hotline</p> <p>ME/CFS & Activity Intolerance Unrest: documentary on YouTube about ME/CFS The Rest Room: podcast A Physiotherapist’s Guide to ME/CFS Solvecfs.org</p> <p>Adrenal Support Adrenal Transformation Protocol</p>	<p>Long COVID and Dysautonomia Long COVID Physio Ed Yong’s Long COVID Series in The Atlantic Gez Mendinger’s YouTube Videos TLC Sessions: podcast Long COVID Solution Book by Carla Kuon The Dysautonomia Project by Freeman The Long COVID Handbook by Gez Mendinger The Long COVID Survival Guide by Lowenstein Dysautonomiainternational.org Nature Magazine Long COVID Articles</p> <p>Hypermobility Ehlers-Danlos Resources Too Flexible to Feel Good by Pereira Living Life to the Fullest with EDS by Muldowney Disjointed by Diana Jovin Ehlers-danlos.com</p> <p>Air Hunger/Breathlessness Books by McKeown or Youtube @justbuteyko</p>

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16 to 34 million Americans may have Long COVID

up to four million Americans are unable to work due to the severity of their Long COVID symptoms

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Important to Understand Concepts

- Mast Cell Disorders
- Post Exertional Malaise
- Breathing and Sleeping Disorders
- Hyper-mobile Spectrum Disorders
- Dysautonomia

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Important to Understand Concepts

Mast Cell Disorders Post Exertional Malaise **75%** Breathing and Sleeping Disorders Hyper-mobile Spectrum Disorders Dysautonomia **60%**

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Assessments: WHODAS

QEESI or Mast Cell Mediator Symptom Questionnaire
Not in our scope of practice Mallampatti Nijmegen Epworth SS COMPASS-31 Active Stand Test

Mast Cell Disorders Post Exertional Malaise Breathing and Sleeping Disorders Hyper-mobile Spectrum Disorders Dysautonomia

Fatigue Severity Scale DSQ Beighton Pelvic floor & Cervical Screen

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Mast Cell Disorders

Best discussed with a specialist: allergist or immunologist

Labs: plasma histamine and tryptase

Mast cell stabilizers: cromolyn, hydroxyurea

Mast Cell inhibitors: montelukast (Singulair), zafirlukast (Accolate), zileuton (Zyflo)

Antibody neutralizer: omalizumab (Xolair)

Mast Cell Disorders



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Mast Cell Disorder: Home Treatment

Recommend treatment of everyone with persistent COVID symptoms on antihistamines for a trial period of 6 weeks to see if there are symptom improvements:

Treatment:

1. Pepcid/famotidine (or other H2 antihistamine)
- Zyrtec/cetirizine (or other H1 antihistamine)
2. Antihistamine Probiotic
3. Quercetin+Bromelain+Vitamin C
4. Avoid fermented/aged food or take a DAO Enzyme with high histamine foods

Mast Cell Disorders



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Important to Understand Concepts

Post-
exertional
Malaise

Dysauto-
nomia

Hyper-
mobile
Spectrum
Disorder

Breathing
and
Sleeping
Disorders



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Post-Exertional Malaise

When symptoms such as disabling fatigue or exhaustion, difficulty thinking, pain, exercise intolerance, and other symptoms are made worse by exertion, this is called post-exertional malaise (PEM). Exertion includes physical, cognitive, emotional social and sensory. **People are unable to produce sufficient energy on demand. It is NOT deconditioning and graded exercise should NOT be used as it is harmful to recovery.** PEM is characteristic among those with Myalgic Encephalomyelitis /Chronic Fatigue Syndrome (ME/CFS).

Symptoms: extreme fatigue not alleviated by rest, worsening symptoms after exertion

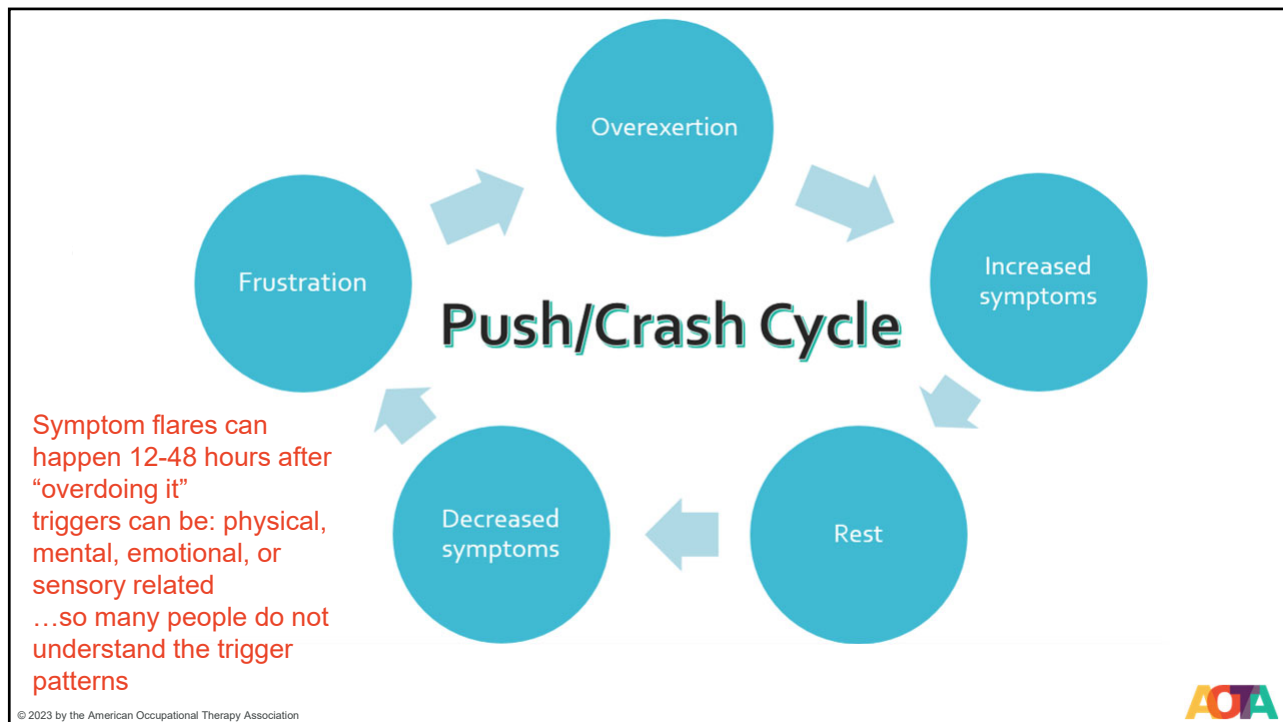
Assessments: *DePaul Symptom Questionnaire, Fatigue Severity Scale*

Post
Exertional
Malaise

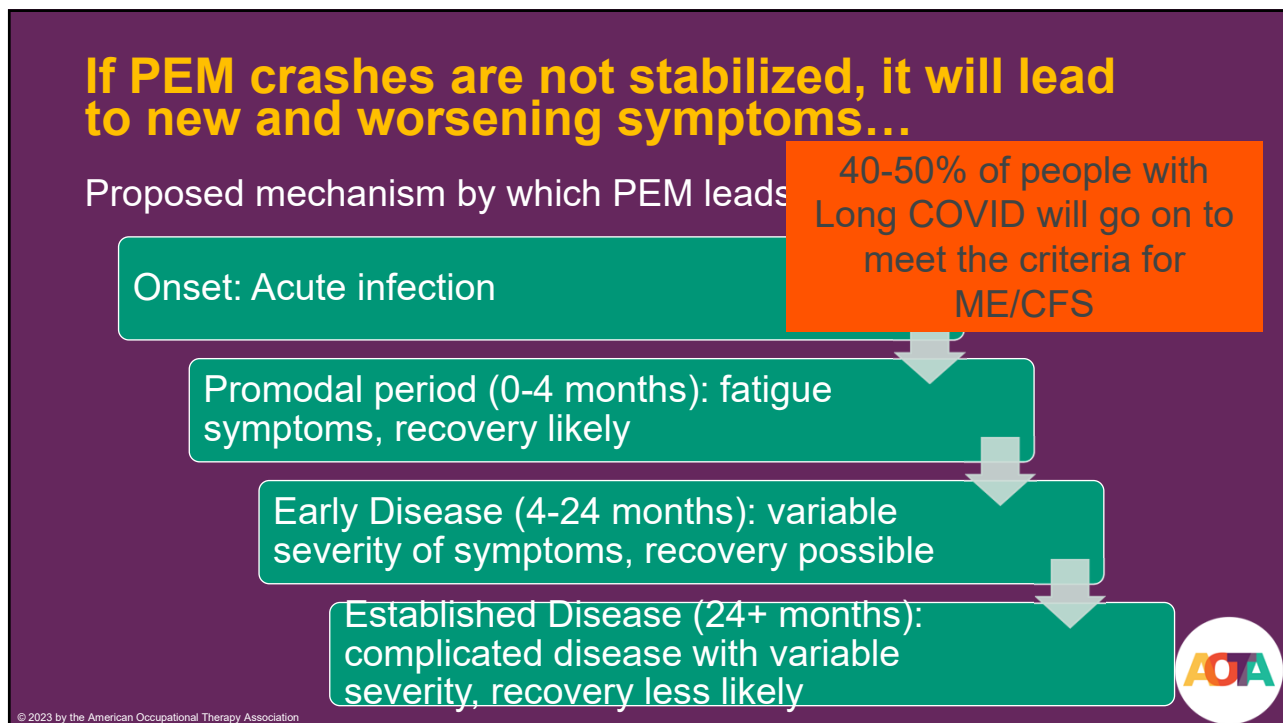


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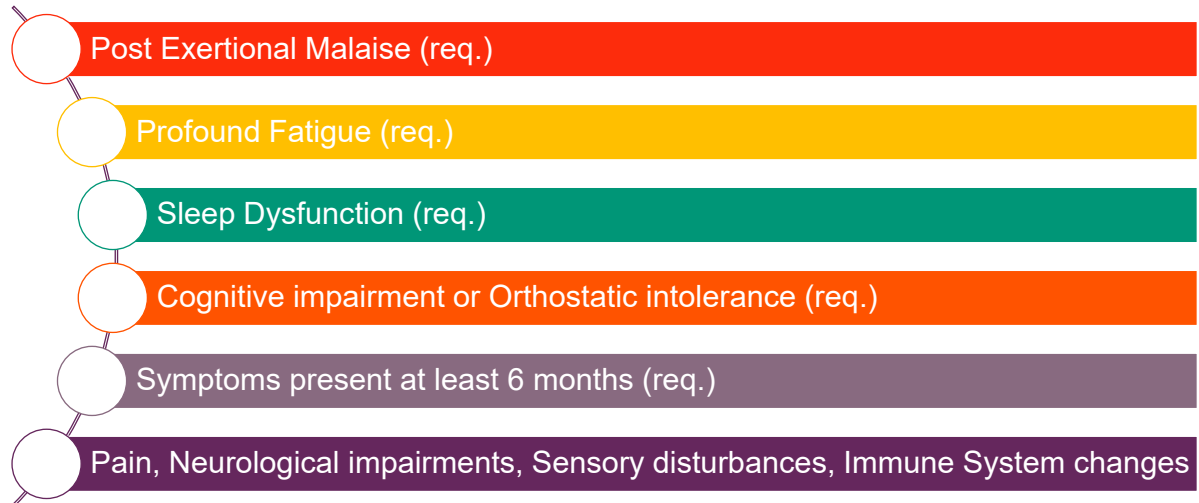


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ME/CFS Diagnostic Criteria (2015 IOM)



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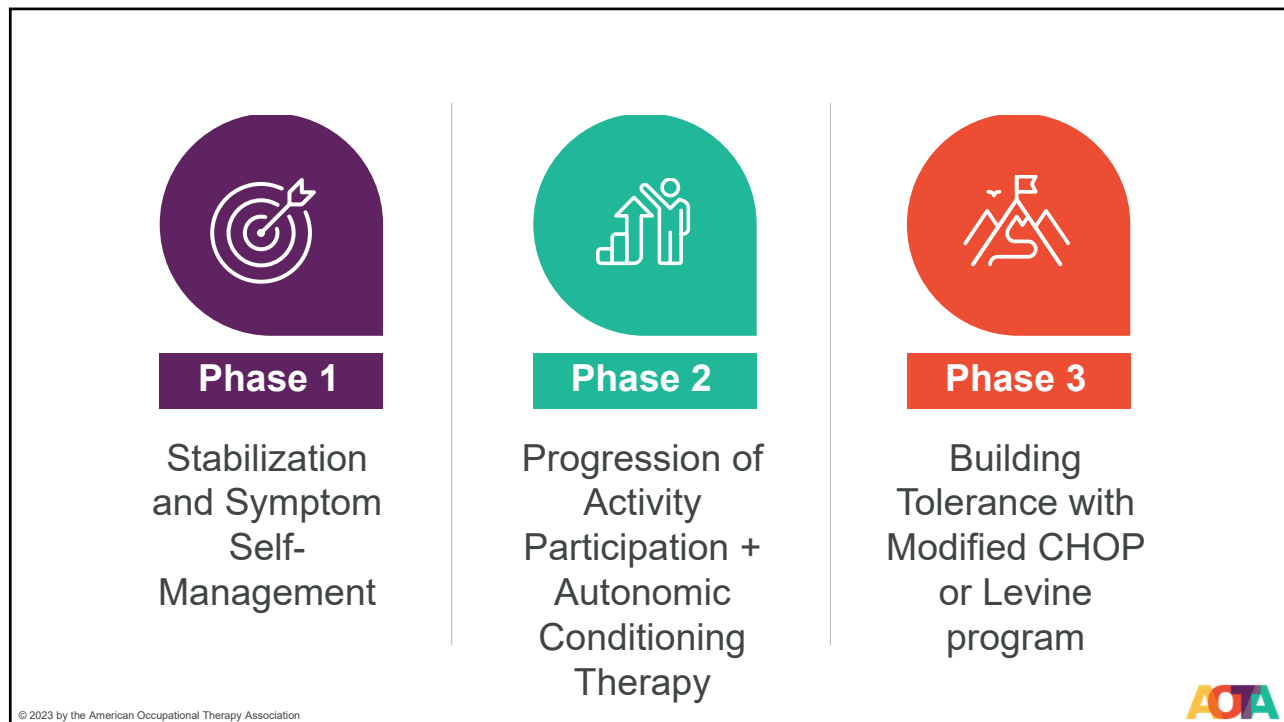
DePaul Symptom Questionnaire

Anyone who experiences an unexplained decrease in function should be screened for post-viral fatigue syndrome

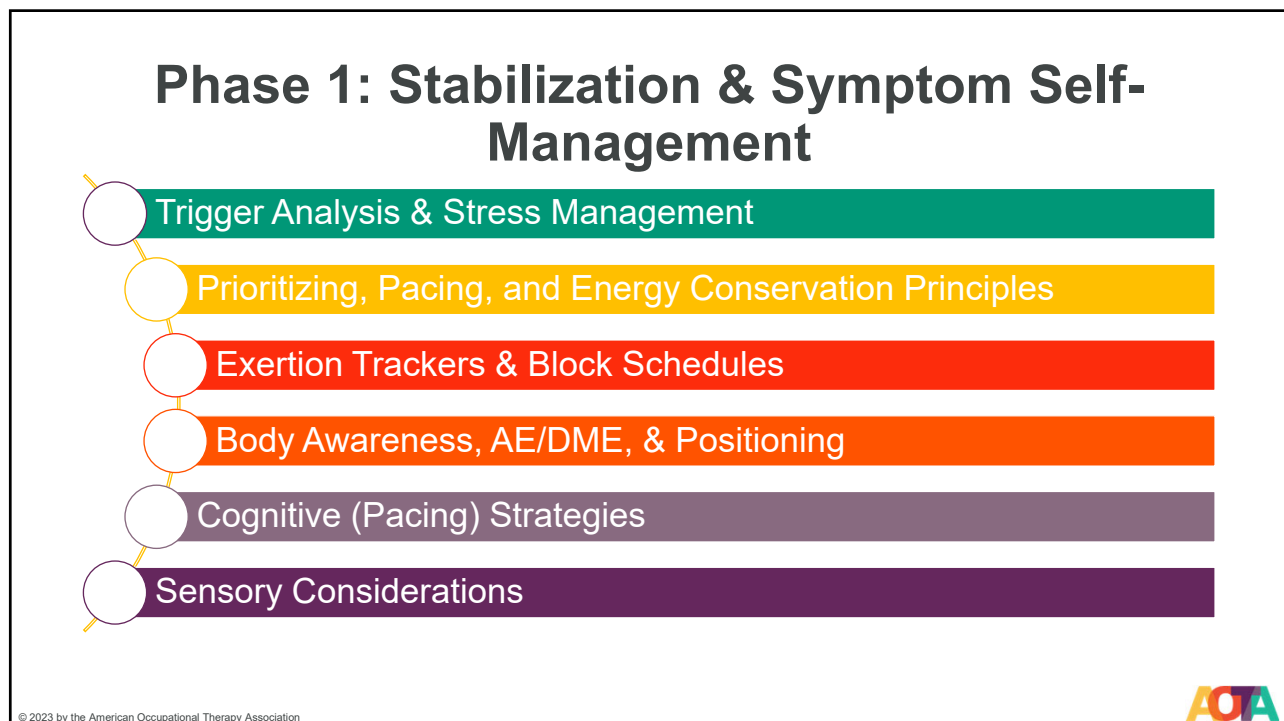
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Triggers and Helpers:

- Triggers may be related to physical, cognitive, sensory and emotional exertion:
- Stress and anxiety
- Poor sleep
- Dehydration or insufficient electrolytes
- Weather changes and allergies
- Premenstrual or menstrual cycle
- Sensory overload (i.e., loud noises, crowded spaces)
- Environmental exposures to mold, harsh cleaning products, chemicals, fragrances
- A new accidents, injuries or illness
- Starting a new medication or supplement
- Dietary changes or intolerances such as alcohol

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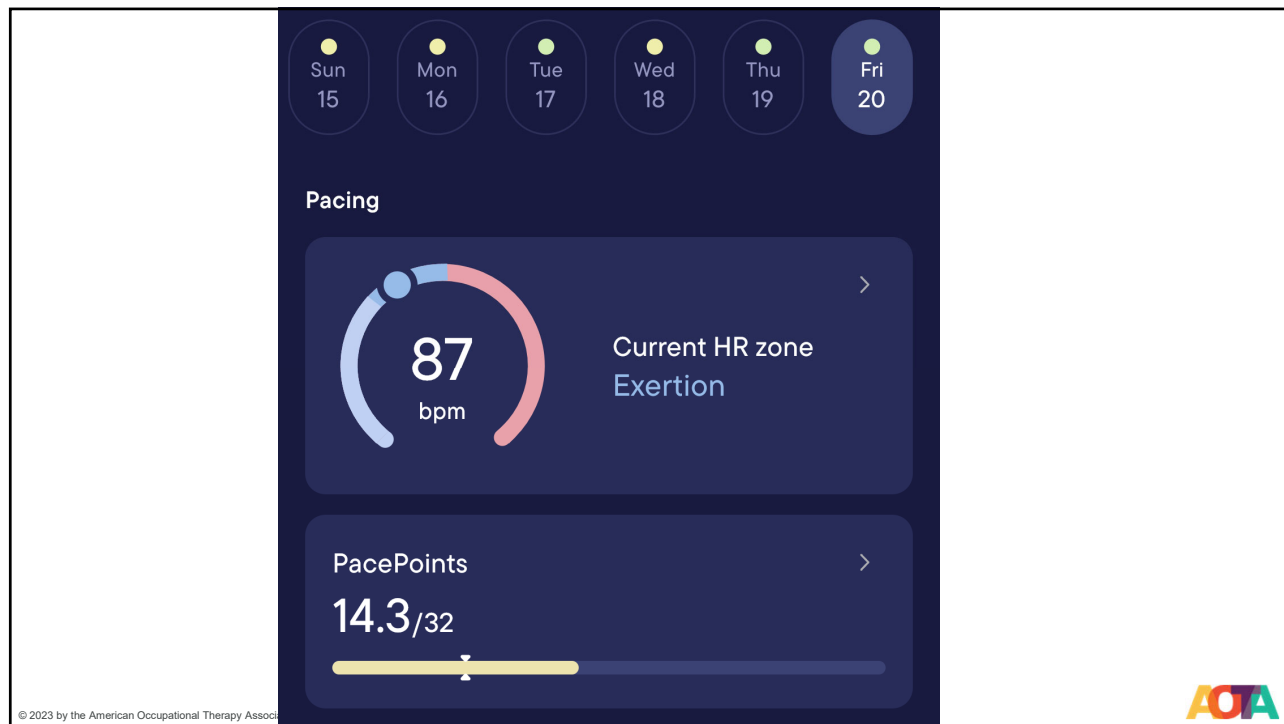
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The screenshot shows the website for the 'visible' app. The main heading reads 'Invisible illness. In plain sight.' Below this, it states 'The activity tracking platform for illness, not fitness.' There are buttons for 'Long Covid' and 'ME/CFS', and a prominent 'Download now' button. On the right side, there is a graphic showing health metrics: 'Resting HR' at 58 (with a red downward arrow) and 'HR Variability' at 58 (with a green upward arrow). The background features a woman in an orange shirt looking at her phone. The website URL 'makevisible.com' is visible in the browser's address bar.

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Fitness Trackers/Pedometers:

Step counters (pedometers): maintaining a consistent activity level day-to-day will help to demonstrate that you have found a “just right” level of activity with physical exertion.

Can also set up apps to monitor Heart Rate, activity levels, step counts with alerts

Recommend keep activities at <55% of max HR


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Touch Tree COVID Longhauers Model:

physical
cognitive
social
emotional
&
sensory
exertions



Danger

Avoid

- Mouth breathing or rapid breathing
- Feelings of frustration or irritation
- Brain "shuts off" and sensations feel overwhelming
- Longhauers symptoms increase

Challenge

Intervals

- 4 or 5/10 or 50% max heart rate
- Challenging to breathe through nose
- Some physical discomfort
- Have to focus cognitively
- Sensations mildly uncomfortable

Easy

Most time

- 2 or 3/10 or 20% max heart rate
- Breathe easily through nose
- Physically comfortable
- Feels automatic
- Sensations are pleasant

Rest

Consistent


- Breathe easily through nose and engaging diaphragm
- Purposefully relaxing muscles
- Utilize calm smells and music
- Focusing attention on bodily sensations
- Shutting down eyes

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Pacing: YouTube TouchTree Life

PEM & COVID Longhauers

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Longhaul COVID Post Exertional Malaise

Touch Tree Life - 1 / 4

▶

1

Covid Longhauers and Post Exertional Malaise

Touch Tree Life

12:07

▶

2

Covid Longhauers: Part 1 Planning, Pacing, Prioritizing

Touch Tree Life

14:32

▶

3

COVID Longhauers: Part 2 Planning, Pacing, Prioritizing

Touch Tree Life

14:55

▶

4

COVID Longhauers: Part 3 Planning, Pacing, Prioritizing

Touch Tree Life

13:52

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Prioritizing

Scheduled and Important	Flexible Time and Important
Scheduled time, less important	Flexible Time, less important

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Activity Analysis and Metabolic Equivalent of Task (METs)

<p>Light exercise</p> <ul style="list-style-type: none"> Light gardening 2.3 General cleaning & straightening up 2.5 Washing dishes, clearing the table 2.5 Putting away groceries 2.5 Walking 2.0 mph (strolling) 2.8 	<ul style="list-style-type: none"> Cleaning mirrors, windows 3.2 Sweeping, vacuuming 3.3 Stationary bike <50 watts 3.5 Resistance exercises 3.5 Walking 3.0 mph 3.5 Gardening, weeding 4.0 Multiple household tasks at once with vigorous effort 4.3 	<ul style="list-style-type: none"> Walking 4.0 mph* 5.0 Walking with a light (15 lb) load 5.0 Walking 3.0 mph at 3-5% grade (uphill) 5.3 Mowing the lawn 5.5 <p><small>*Energy ratings are based on METs (metabolic equivalent). Light exercise is less than 3.0 METs. Moderate exercise is 3.0-5.9 METs. Vigorous exercise is 6.0 METs and above.</small></p> <p style="text-align: right;"><small>whyexercise.com</small></p>
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- People often have worsening symptoms with static standing, lifting or maintaining an “arms up” position.
- All activities will be worsened with stress, temperature, dehydration and other “triggers”

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Sample Time Blocking Sheet

Time blocks or daily checklists:

8 AM	
9 AM	
10 AM	
11 AM	
12 PM	
1 PM	
2 PM	
3 PM	
4 PM	
5 PM	
6 PM	
7 PM	
8 PM	
9 PM	
10 PM	

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Cognitive (Pacing) Strategies



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Environmental & Sensory Considerations

...new onset
auditory,
visual
vestibular
sensitivities



<https://www.livescience.com/9728-monkey-drumming-suggests-origin-music.html>

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Stability is always the goal

Aim for at least two weeks of stability before adding...

Signs of a stable system include the following:

1. No “big” crashes: recovery from activity by the next day
2. Stable HRV and resting HR at your morning check-in
3. Consistent eating patterns, sleep patterns and water consumed to support your healing
4. Able to notice and correct for breathlessness and symptom flares in real time.
5. Consistent movement patterns using scheduled activities or step count.

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Putrino D, Tabacof L, Tosto-Mancuso J, et al. Autonomic conditioning therapy reduces fatigue and improves global impression of change in individuals with post-acute COVID-19 syndrome. Research Square; 2021. DOI: 10.21203/rs.3.rs-440909/v1.



Phase 1

Stabilization
and Symptom
Self-
Management
Prehab



Phase 2

Progression of
Activity
Participation +
Autonomic
Conditioning
Therapy /
Muldowney



Phase 3

Building
Tolerance with
Modified
LEVINE or
CHOP
Protocol

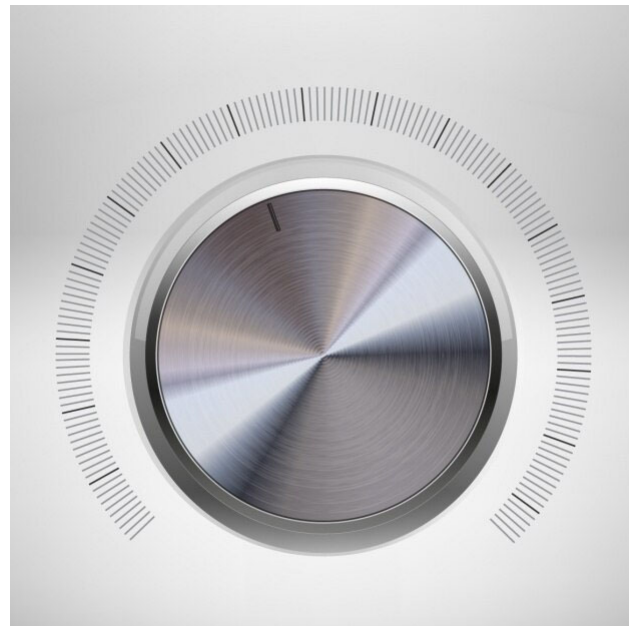
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Exercise Intensity

1. What are your starting symptoms
“background noise”
2. Do you know how to quiet your symptoms?
3. Should you provoke your symptoms?
4. Find the answer and determine how active to be.



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Important to Understand Concepts

Breathing and
Sleep Disorders

Hypermobile
Spectrum
Disorder

Dysautonomia



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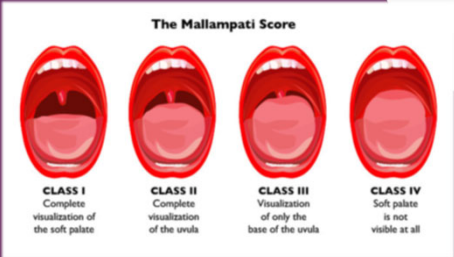
Breathing and Sleep Disorders

Often make sleep study referrals, ENT and airway focused dentists/orthodontists


Screens: Mallampatti, Nijmegen/breath hold time, Epworth Sleepiness Scale, Sleep Hygiene Index,

Treatment: Sleep Hygiene, posture and positioning, airway exercises, coherent breathing, respiratory support, TMJ treatment

Breathing
and Sleep
Disorders



<https://www.clinicaladvisor.com/home/the-waiting-room/understanding-the-mallampati-score/>



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Just Breathe...



<https://www.freepik.com>




<https://www.freepik.com/free-photos-vectors/respiratory-system>

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Just Breathe...

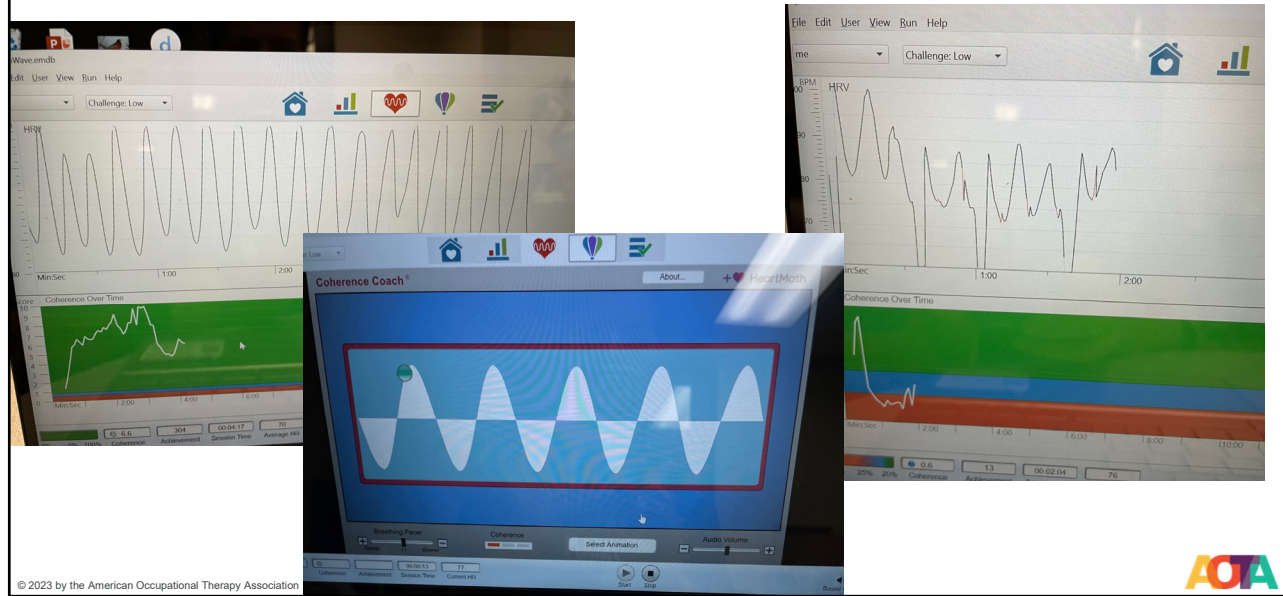
- **Coherent or resonant breathing:** slow down your breath and have your inhale and your exhale be approximately the same. You can use an app or YouTube video help you slow down your breathing to 5-7 breaths per minute.
- **Prone diaphragm breathing:** lay down on your tummy on a firm surface and get comfortable. Notice your diaphragm pressing against the floor when you inhale. Slow down your breath and stay mindful to your breathing; consciously relax your muscles.
- **Singing, humming, or reading out loud:** lay on your back or sit tall with good posture. To make it harder, sit on an exercise ball. Practice reading/singing or humming with attention to your breath and nose breathing. Make sure you have your back breath before continuing.

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Coherent Breathing Biofeedback: HeartMath



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Important to Understand Concepts

Dysautonomia

Hypermobility
Spectrum
Disorders



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Hypermobile Spectrum Disorder

Hypermobility Spectrum Disorder (HSD) and Hypermobile Ehlers-Danlos (hEDS) are connective tissue disorders. This group of people are especially prone to gut issues, MCAS, CFS, and POTS. You can use the *Beighton Scale* to help determine if you have hypermobility spectrum disorder. There is additional criteria required for an hEDS diagnosis. It is recommended you are aware of MCAS & POTS triggers and follow MCAS & POTS protocols even prior to developing POTS symptoms.

Best discussed with EDS aware OT/PT; geneticist

Labs: genetic screen for EDS (13 types of EDS, 12 of which have genetic mutations; hEDS does not have an identified mutation).

Treatment: EDS aware OT/PT, optimizing health management, nutritionist and GI specialist




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Hypermobile Spectrum Disorder

“Initial findings of the study found that generalized joint hypermobility (GJH) was more common than might be expected in people with Long COVID.

Among the complications of Long COVID, people with GJH were more likely to report significant joint, muscle, and nerve pain, and brain fog compared to people who were not hypermobile. Joint hypermobility may be a risk for neuromuscular symptoms in Long COVID.”

Hypermobile
Spectrum
Disorder



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Hypermobile Spectrum Disorder

People with HSD/hEDS are the most likely group to need ergonomics & positioning, slow and gentle supine corework such as Muldowney Protocol, proprioceptive work, breathing, and joint protection principles.

Russek LN, Block NP, Byrne E, Chalela S, Chan C, Comerford M, Frost N, Hennessey S, McCarthy A, Nicholson LL, Parry J, Simmonds J, Stott PJ, Thomas L, Treleaven J, Wagner W and Hakim A (2023) **Presentation and physical therapy management of upper cervical instability in patients with symptomatic generalized joint hypermobility: International expert consensus recommendations.** *Front. Med.* 9:1072764.

Hypermobile
Spectrum
Disorder



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Muldowney Protocol



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Important to Understand Concepts

Dysautonomia

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DYS-AUTONOMIA

Dysfunction of the Autonomic Nervous System

Dysautonomia is an umbrella term used to describe conditions that involve dysfunction of the autonomic nervous system. There are at least 15 types.

If is NOT rare—it impacts an estimated 70+ million people worldwide.

POTS: Postural Orthostatic Tachycardia Syndrome

OH: Orthostatic Hypotension

BF: Baroreflex Failure

NCS: Neurocardiogenic Syncope

IST: Inappropriate Sinus Tachycardia

PAF: Pure Autonomic Failure

AD: Autonomic Dysreflexia

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Dysautonomia

Dysautonomia is autonomic nervous system dysfunction. The sympathetic (fight or flight) and parasympathetic (rest and digest) systems are no longer working appropriately. This can cause multi-system symptoms.

Best discussed with POTS cardiologist or Dysautonomia Neurologist

An estimated 60% of people with Long COVID are estimated to have dysautonomia. COVID is now known to trigger POTS in up to 30% of Long COVID patients.

The COMPASS-31 and to help determine to what degree patients have dysautonomia. A healthcare professional can help with positional vitals assessments or a tilt table test.

Dysautonomia

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Guidelines


Lay down flat, legs uncrossed and rest 5-10 minutes prior to starting, record pt self-reported symptoms at each interval, no other speaking throughout test.

Orthostatics

Supine BP/HR, Sit up, feet on floor. Avoid moving or supporting weight with hands. Sit 2 minutes then BP/HR. Stand still 2 minutes then BP/HR.

Active Stand Test


Supine BP/HR. Stand still. Take BP/HR immediately upon standing then at 2, 5, 10 minute mark. Record symptoms.



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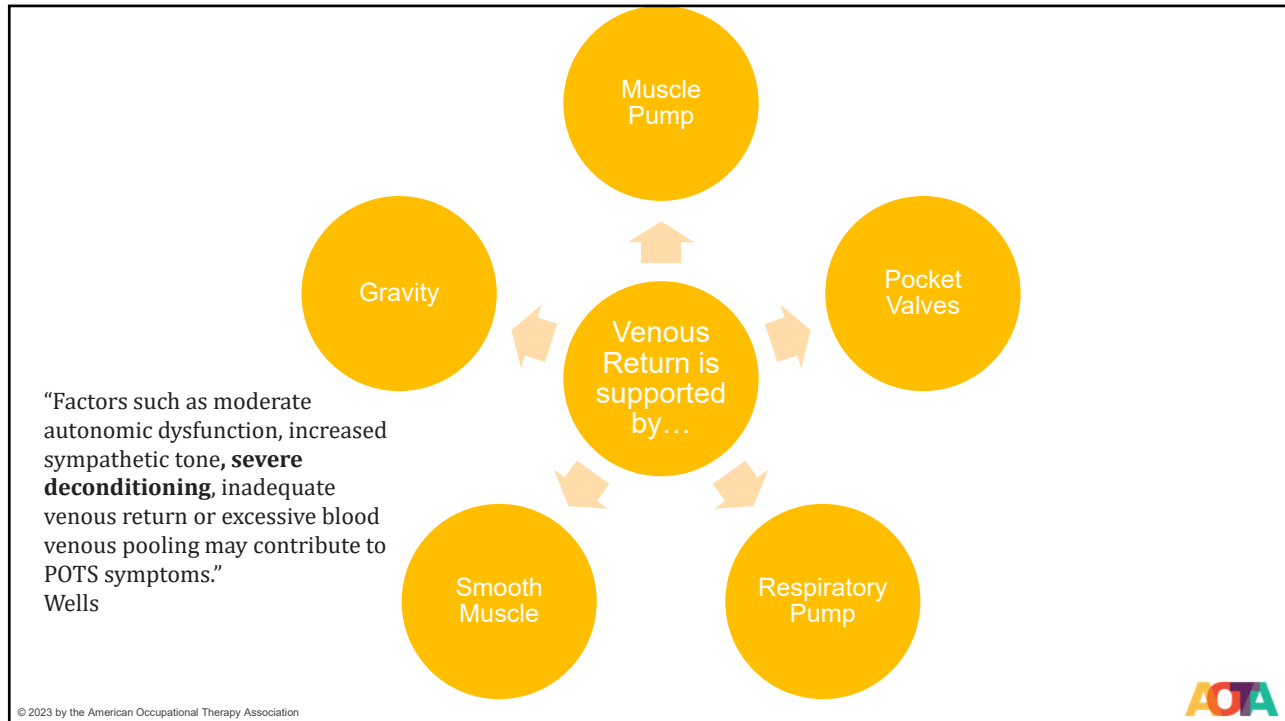
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Multiple Triggers of Dysautonomia		
Infectious	Activity	Endocrine
<ul style="list-style-type: none"> • COVID (SARS-COV-2) • EBV, CMV, HSV6 • Breathing disorders such as asthma and pneumonia amongst others 	<ul style="list-style-type: none"> • Excessive exercise (overtraining syndrome) • Prolonged bed rest • Sleep disorders 	<ul style="list-style-type: none"> • Thyroid disorders • Diabetes • HPA axis dysregulation • Estrogen/progesterone imbalance • Pregnancy
Autoimmune Illnesses	Nutritional	Anatomy
<ul style="list-style-type: none"> • Autoimmune conditions • Mast Cell Activation Syndrome 	<ul style="list-style-type: none"> • Nutritional deficiencies • Leaky gut • SIBO: Small intestinal Bacterial Overgrowth 	<ul style="list-style-type: none"> • TMJ/Mandibular instability • Craniocervical instability • Chiari malformation • Nutcracker syndrome • Nephroptosis
Trauma	Developmental	Drug/Toxin Exposure
<ul style="list-style-type: none"> • Vagus Nerve injury • Concussion/whiplash • Sinus Surgery • Intracranial hyper or hypotension 	<ul style="list-style-type: none"> • Growth spurt • Menarche • Inadequate airway growth 	<ul style="list-style-type: none"> • Mold toxins • Anticholinergics/Quinines • Vaccinations • Excessive energy drinks • Heavy metal toxicity



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YouTube Video: Can Microdosing Adrenaline be a primary cause of Long COVID, Dysautonomia, and POTS?

Help your Body Help you
Avoiding Adrenaline

Jenna Hopkins, MOT, M.Ed.
Touch Tree Integrated Living




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touchtreelife.com
@touchtreelife

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Hydration

Drink 2-3 liters of water daily with salt/electrolytes added. Autonomic dysfunction can often result in a low blood volume.




Salt




Sodium chloride supplements “Salt tabs” or add Celtic sea salt dissolved in water to all H2O
If you have high bp or kidney disease talk to your dr.

Compression



Wear compression during the day. High-waisted compression leggings, abdominal binders, Spanx or compression stockings can all be helpful.




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Avoid Heat

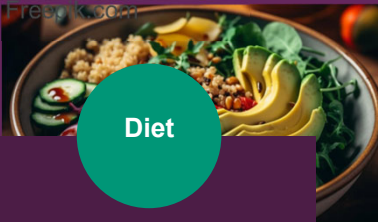
Avoid excessive heat This may include hot showers or baths, saunas, hot yoga, and warmer climates. Use cooler showers & a shower chair.




Positioning

Avoid standing still for prolonged periods of time. Avoid arms up positions. Find ways to sit and elevate your legs. “Pushing through” or ignoring your symptoms may cause you to fall or pass out.

Diet



Eat smaller, more frequent meals with salty snacks. Symptoms can worsen after a large meal. Refined carbs/ sugary foods can aggravate symptoms. Alcohol, coffee and caffeinated drinks may worsen symptoms.



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Autonomic Management: Exercise

The gold standard treatments have focused on protocols that may be harmful for those with PEM. This includes the Levine and CHOP programs.



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Managing daily activities and carefully titrated activity in supine with emphasis on breathing, core, and returning to baseline status (HR, breathing and exertion level) between reps is recommended prior to beginning any standardized program.

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Exercise: NOS

• High intensity exercise is **NOT** recommended for people with dysautonomia. HR monitors/BP cuffs/pulse ox can be helpful.



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• Do NOT progress too quickly. Increase the frequency and duration of exercise gradually over weeks and month only as body is able to respond appropriately with return to baseline status as evidenced by biometrics.

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Autonomic Conditioning Therapy

Take Vitals baseline, analog of fatigue complaint on 1-10 scale

LOW EFFORT: Pt should be a 2-4/10 on BORG for activities

STOP PROTOCOL: STOP if needing more than 5 minutes of rest or request to stop or greater than 3 point change on analog scale

RECOVERY BREATHWORK between sets (4 second inhale, 6 seconds exhale nasal breathing)---at every level

Pt can progress to next stage when they are able to perform without STOP protocol x 1 week.

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Autonomic Conditioning Therapy (ACT)

PREHAB: breathing exercises, pelvic floor & TA engagement, voicing, ergonomics

Stage 1A: SUPINE (at least 2 weeks)

- 5 supine exercises: 30 second intervals with recovery breaks
- deep neck flexor strengthening, hemi-bridge and adduction squeezes, heel slides or alternating marching, hip abduction, straight leg raise, glute squeezes

Stage 1B: SEATED ISOMETRICS (at least 2 weeks)

- 6 seated exercises: ~1 minute exercise or 2 sets of 10 reps with recovery breaks
- "Building phase" exercises or Hip adduction ball squeeze, hip flexion marches, LAQ, clamshells, high kneeling plank (plank 2 sets of 10 second holds), straight leg raise, alternate leg touches

Stage 2A: WALKING INTERVALS (at least 2 weeks)

- Week 1: 5 sets of 1 minute intervals---Week 4: 5 sets of 90 seconds intervals

Stage 2B: WALKING INTERVALS (at least 2 weeks)

- Week 1: 3 sets of 2 minute intervals to week 4: 6 sets of 2 minutes intervals
- complete 6 minute walk test at end of stage 2a.

Stage 3: Modified LEVINE PROTOCOL

- Modify Levine Protocol, continue with STOP protocol and only progress as able.

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