

EXCLUSIVE LIVE WEBINAR

An Interprofessional Approach to the Non-Pharmacologic Management of Postural Orthostatic Tachycardia Syndrome (POTS)

PRESENTED BY

Cheryl Harris
MPH, RDN, LD

March 29, 2023
2-3:30pm ET

EARN
1.5 CEUs



Disclosures

- **Cheryl Iny Harris**, faculty for this event, has no relevant financial relationship(s) with ineligible companies to disclose.
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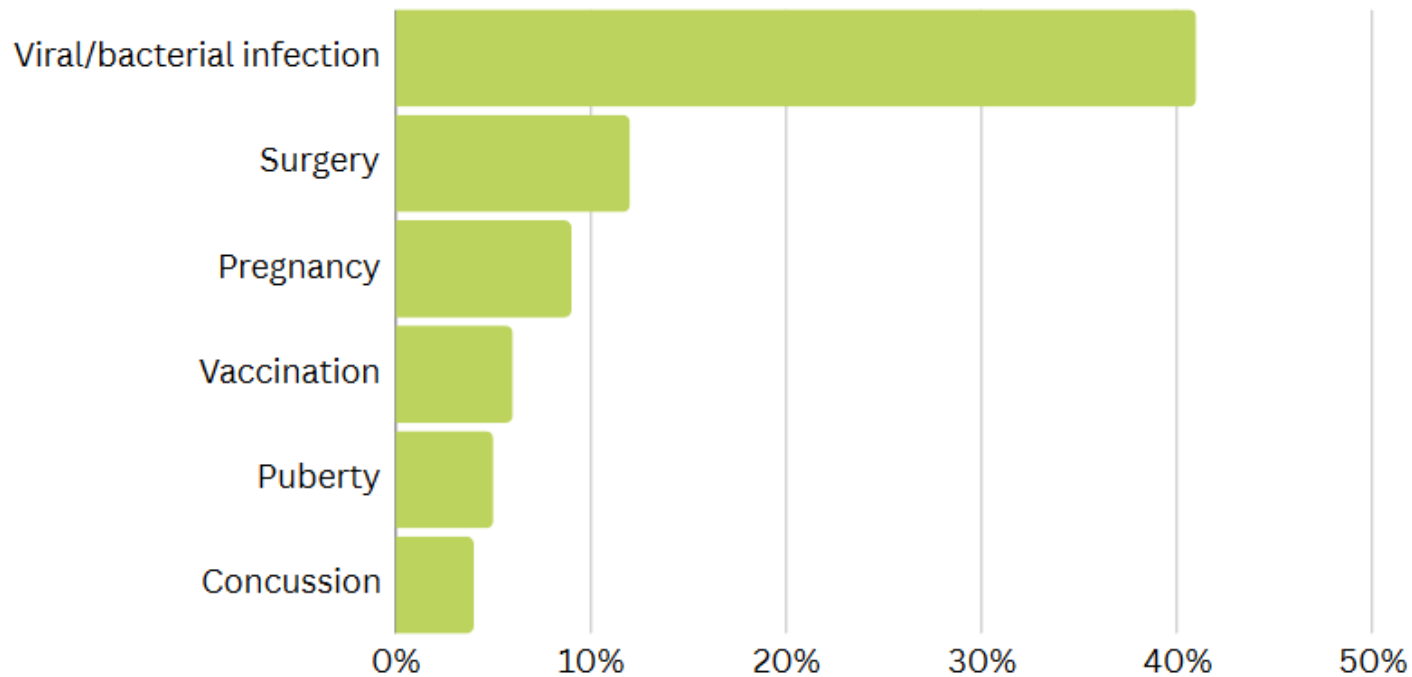
This activity will also award credit for dietetics (CDR CPEU).

Learner Objectives

1. Define POTS and its etiology and explain how symptoms may affect eating behaviors.
2. Outline the typical dietary guidance to treat POTS, including adaptations for common comorbidities and when to refer patients to specialists.
3. Describe lifestyle and movement guidelines for both POTS and Long COVID POTS, including adaptations for common comorbidities and when to refer patients to specialists.
4. Strategize collaboration techniques that engage the entire interdisciplinary health care team to support patients with POTS.



Known Triggers for POTS



Data adapted from: Blitshteyn, S. The risks of POTS after COVID-19 vaccination and SARS-CoV-2 infection. Nat Cardiovasc Res. 2022.

Poll

When was the 1st time you were aware of working with a patient with POTS?

- A. Last few months
- B. A year ago
- C. A few years ago, or more
- D. Haven't seen any yet



POTS:

Definitions, Diagnosis, Symptoms, Demographics

Definitions

Postural

Orthostatic

Tachycardia

Syndrome

- Dysautonomia
- ANS
- Post acute sequelae of SARS-CoV-2 infection (PASC)

Diagnosis of POTS

- Increase in heart rate by more than 30 beats min when going from recumbent to standing, in the absence of 20 point or more drop in systolic blood pressure, or an absolute HR of 120+
- Range of symptoms for 3+ months
- Sometimes involves tilt table or other testing



Who Diagnoses POTS?

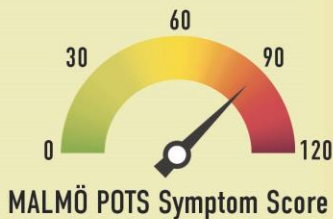
- Pediatrician
- Primary Care Physician
- Cardiologist
- Neurologist
- Autonomic specialist
- Gastroenterologist (occasionally!)

Symptoms

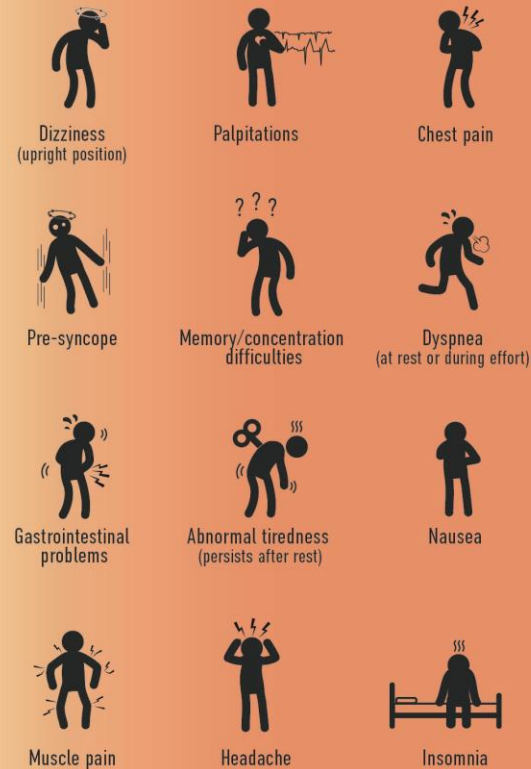
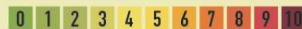
- Dizziness
- Palpitations ★
- Chest pain
- Pre-syncope
- Memory/concentration difficulties ★
- Dyspnea
- Gastrointestinal problems
- Abnormal tiredness ★
- Nausea
- Muscle pain
- Headache
- Insomnia

Spahic JM., et al. Malmö POTS symptom score. J Intern Med. 2023.

Malmö POTS Symptom Score: Assessing Symptom Burden in Postural Orthostatic Tachycardia Syndrome

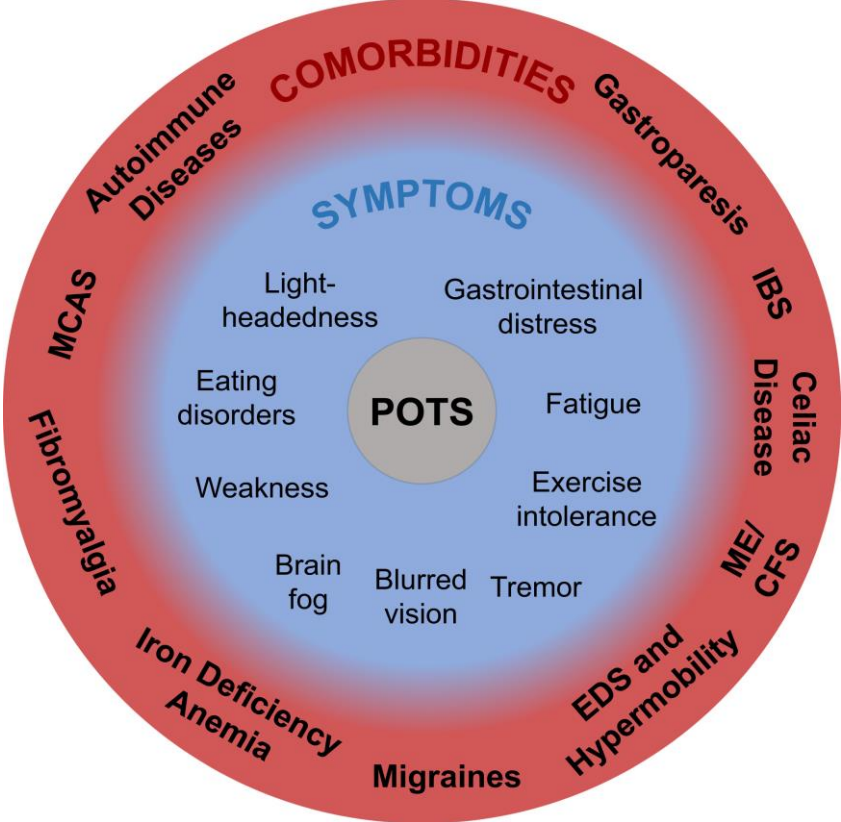


Self-rating scale for assessment of
12 POTS-related symptoms graded
from 0 (no symptoms) to 10 (pronounced)

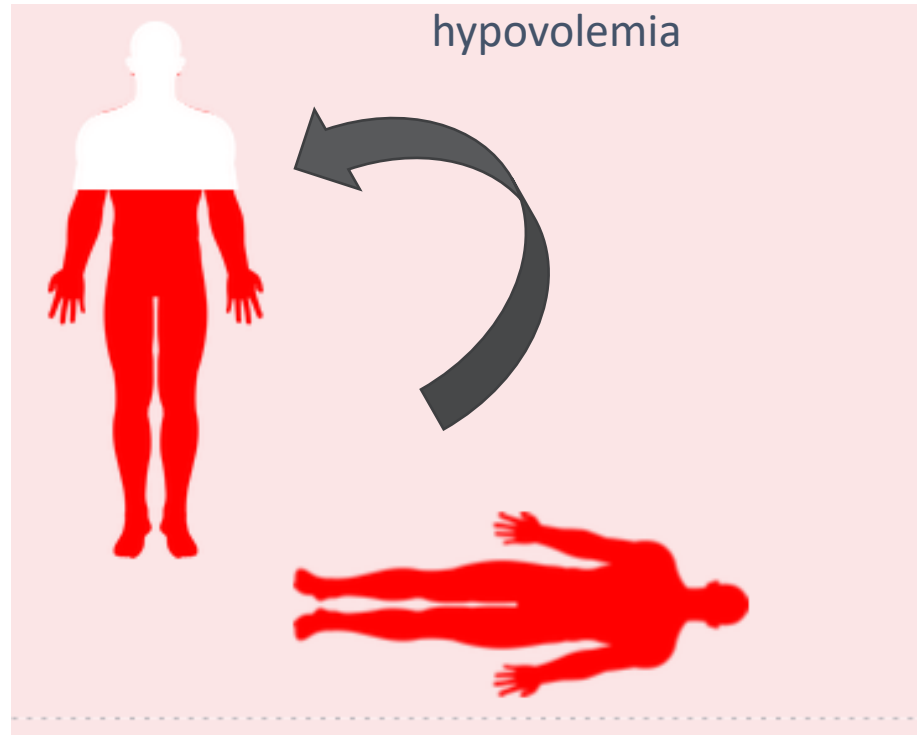


JIM Journal of
Internal Medicine
Founded in 1863

Symptoms



Physiology of POTS



Demographics

Prior to COVID

- White
- Female
- Childbearing age
- Pain conditions/co-morbidities

Harris CI. COVID-19 Increases the Prevalence of Postural Orthostatic Tachycardia Syndrome. *J Acad Nutr Diet.* 2022.

Khullar D, et al. Racial/Ethnic Disparities in Post-acute Sequelae of SARS-CoV-2 Infection in New York. *J Gen Intern Med.* 2023.



BMJ Case Reports

Postural orthostatic tachycardia syndrome in primary care: diagnosis, treatment and a case of African-American man presenting with POTS

2019 Sep 18;12(9):e229824

Andrew T Del Pozzi, Michael Enechukwu, Svetlana Blitshteyn

“African-American patients with POTS are particularly vulnerable to misdiagnoses or a lack of diagnosis we suspect that other non-white patients with POTS are likely undiagnosed or misdiagnosed with other medical or psychiatric conditions.” – Del Pozzi et al.

“Overwhelmingly, POTS affects young Caucasian women, which can lead physicians to miss the diagnosis in men or non-white patients”
- Del Pozzi et. al.

“We also emphasize that POTS should be considered as a differential diagnosis in any patient presenting with typical clinical features, who may not be in the usual demographics of the disorder”
- Del Pozzi et. al.

Long COVID POTS

Huge variance in numbers right now

- 30% of “highly symptomatic” patients with long COVID have POTS¹
- 25% of long COVID patients have dysautonomia²
- 2-14% have POTS^{2,3}
- 19-61% of people with long COVID have POTS-like symptoms³

¹Fedorowski A, et al. Autonomic dysfunction and postural orthostatic tachycardia syndrome in post-acute COVID-19 syndrome. *Nat Rev Cardiol.* 2023. ²Espinosa-Gonzalez AB, et al. Orthostatic tachycardia after covid-19. *BMJ.* 2023. ³Ormiston CK, et al. Postural orthostatic tachycardia syndrome as a sequela of COVID-19. *Heart Rhythm.* 2022.





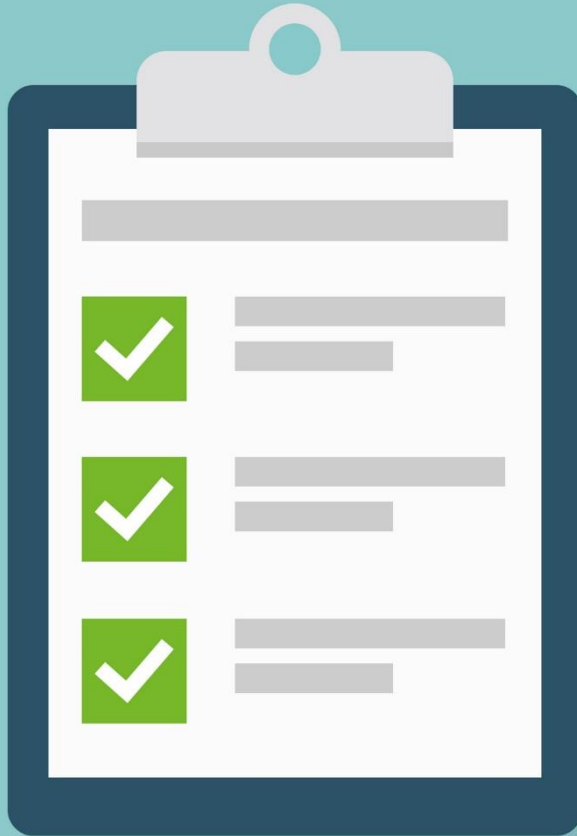
Dietary Assessment for Patients with POTS

Nutritional Assessment

Diet diary if appropriate or diet recall

Assess:

- Caloric and nutritional adequacy
- Fluids
- Sodium
- Caffeine
- Alcohol
- Timing of food
- Food restrictions/avoidance
- Movement





Supplements

No studies on POTS

Often patients use salt supplements

- Must get details re: dose, brand

Many patients use a wide range of supplements according to the EDS literature and the long COVID literature

- Patients may not disclose

Suggested question to ask patients:

- “How else do you seek relief from your symptoms?”



Journal of
& **Developmental
Behavioral Pediatrics**

Postural Orthostatic Tachycardia Syndrome and Disordered Eating: Clarifying the Overlap

2021 May 1;42(4):291-298

Julia Benjamin, Leslie Sim, Michele Tsai Owens, Andrea Schwichtenberg, Tracy Harrison, Cindy Harbeck-Weber

“Results: Nearly $\frac{3}{4}$ of participants described engaging in restrictive eating, and more than $\frac{1}{2}$ of them described experiencing weight loss”
- Benjamin et. al.

“ $\frac{1}{5}$ of the sample had experienced invasive interventions to correct for nutritional imbalances, such as having a feeding tube”
- Benjamin et. al.

POTS and Disordered Eating

	Pts w/ POTS
Any reported amount of weight loss	51%
Wt change of 10+ pounds	56%
Any restrictive diet	73.9%
Elimination diet	49.0%
Symptom-based restriction	37.5%
Multiple forms of diet restriction	16.7%

Medical change in diet recommended

Reduce specific foods	19.8%
Increase intake	16.7%

Food restriction

	POTS	General pop
Food allergy	26.0%	6.7%
Celiac disease	9.4%	~1%
Gluten sensitivity	25.0%	~6%
Lactose sensitivity	25.0%	
Eating disorder	10.4%	2.7%

Eating Disorders

One potential cause is because there is established link between eating disorders (orthorexia, ARFID) and disorders of gut-brain interaction (DGBI)

Screeners:

- SCOFF
- EAT-26
- Nine item Avoidant Restrictive Food Intake Disorder Screen

Nutrient Deficiencies?

- Small studies has suggested that people with POTS have more nutritional deficiencies
- 2023 study showed that blood levels of iron, ferritin, folic acid, B12, magnesium, and vitamin D were similar between people with POTS and controls
- Higher sodium levels
- C-Reactive protein higher in POTS patients
- Exercise levels lower
- Lower education, more often working part-time or on sick leave



Dietary Guidance



Fluids

Salt &

Everything else



Fluids

- 2-3 Liters/day
- 8.5 cups-12.7 cups/day

- Caution on alcohol and caffeine

Ways to Get Fluid

- ✓ Water before getting out of bed
- ✓ Drink at every meal
- ✓ Smart water bottles
- ✓ Apps with water trackers
- ✓ Reminders on phone, computer, etc.
- ✓ Keeping water bottle visible
- ✓ Starting the day with tea
- ✓ Water with fruit or mint
- ✓ Sparkling water
- ✓ Herbal tea
- ✓ Soups, broth, stews, etc.
- ✓ Coconut water
- ✓ Smoothies, shakes
- ✓ Melons, squash, cucumbers, lettuce, and other hydrating produce
- ✓ Jell-O, popsicles, etc.

What About IV Hydration?

RISKS:

- Raised blood pressure
- Site infection
- Sepsis
- Endocarditis
- Deep vein thrombosis
- Pulmonary embolism
- Catheter embolism
- Death

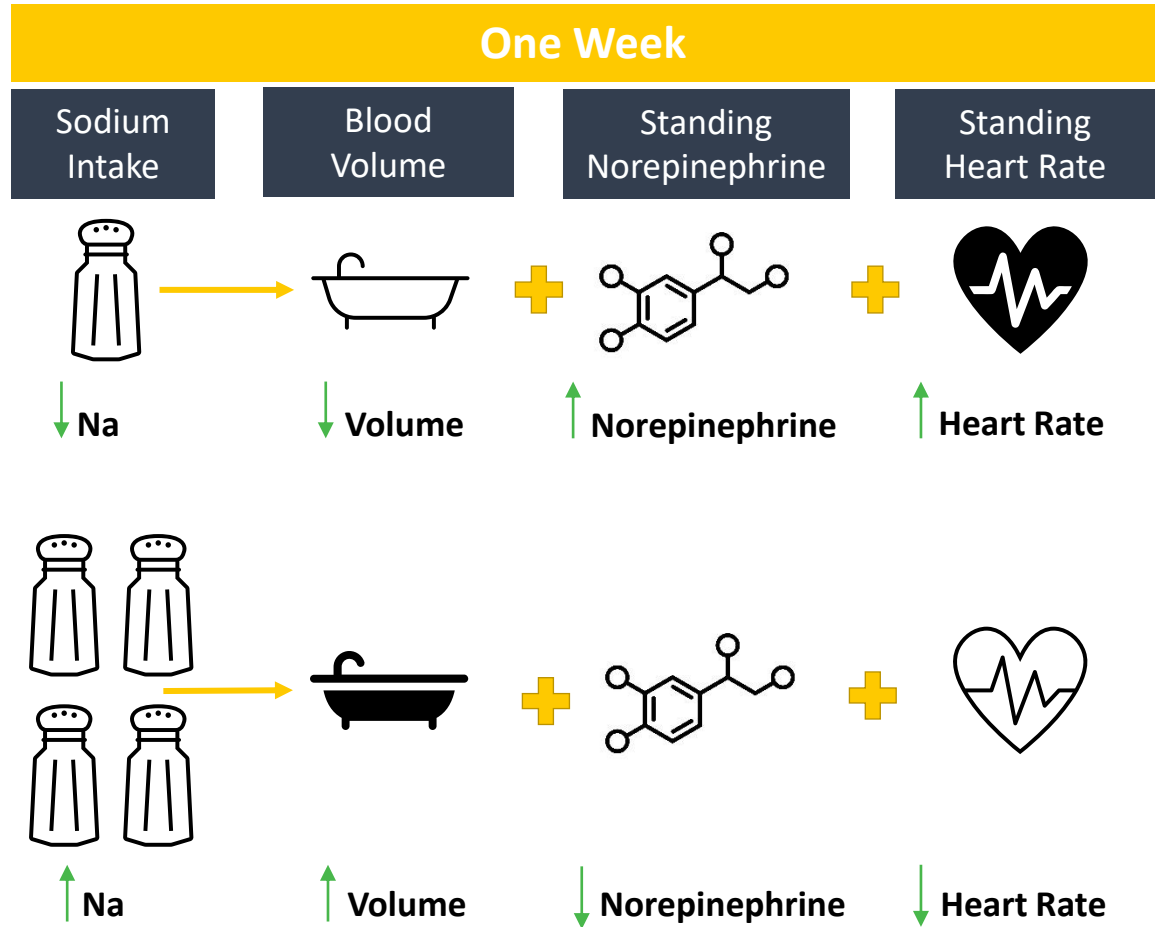


Poll

Do patients with POTS respond best to:

- A. Plain salt
- B. Salt with sucrose
- C. Salt, sucrose, and other electrolytes
- D. No research to date

Sodium Intake





Salt

~10 grams a day in addition to usual intake

- Coordinate with physician to get salt or sodium goal
- 1 tsp salt ~ 5 grams
- Sodium is NOT the same as salt



Ways to Add Salt?

Electrolytes

Ideal type will depend on

- Cost
- Glycemic needs
- Tolerance
- Taste preference



A D A P T

Making Adaptations

How Do Your POTS Symptoms Affect Eating?

- 29.3% of people with POTS report disabilities that interfere with work
- 55.8% of people reported POTS affected eating and feeding, with 75.1% reporting impact on meal prep and cleanup
- In a separate study, 55% of people with POTS reported that ability to cook was affected



Rich, E., et al. Functional status in postural tachycardia syndrome. Br J Occup Ther. 2021.
Rich, E., et. al. Postural Tachycardia Syndrome. Arch Phys Med Rehabil. 2018.

How to Adapt?

Depends on the problem, common concerns:

- Fatigue & brain fog
- Difficulty shopping
- Inability to stand
- Intolerance to heat

May refer to Occupational therapist & Social workers



How to Adapt to Physical Limitations?

If pain in hands, fingers and/or wrists
(common w/EDS and other autoimmune conditions)

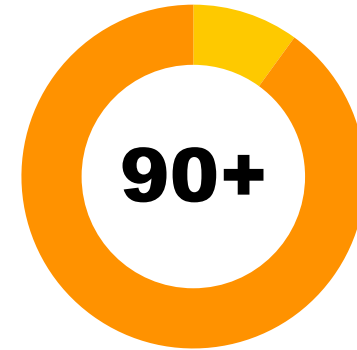
- ✓ Pre-chopped fruit
 - ✓ Pre-chopped veggies
 - ✓ Frozen fruit
 - ✓ Frozen chopped veggies
 - ✓ Canned veggies
 - ✓ Food processor
 - ✓ Blender
 - ✓ Electric can opener
-
- ✓ Cushy mats for standing

Consult with
PT & OT for
bracing,
exercises,
tools, and
other ideas

Gastro-intestinal Disorders

POTS and digestive symptoms

- Nausea
- Abdominal pain
- Bloating



% of patients

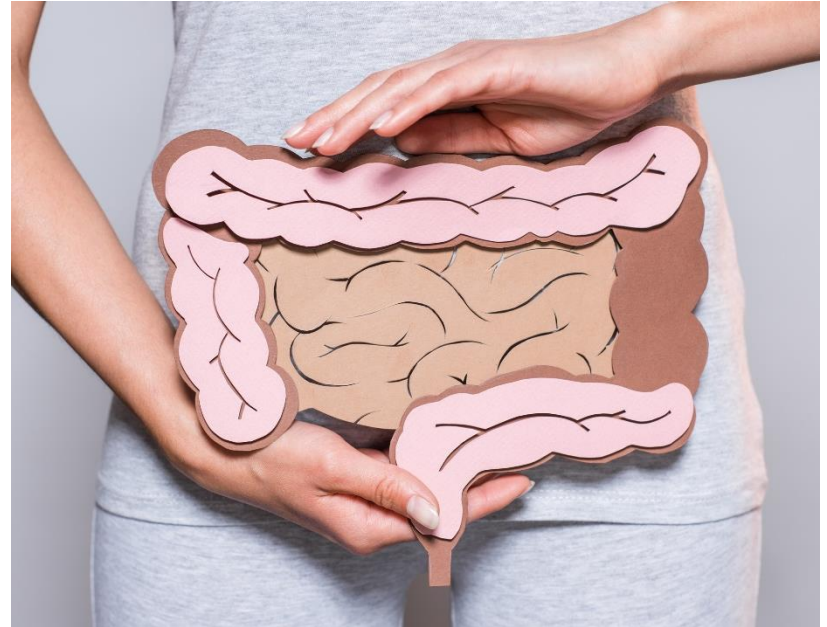
Patients with POTS and EDS have a higher GI symptom burden

Tu Y. Mechanisms and management of gastrointestinal symptoms in postural orthostatic tachycardia. *Neurogastroenterol Motil.* 2020.

Tai FWD, Functional gastrointestinal disorders are increased in joint hypermobility-related disorders with concomitant postural orthostatic tachycardia syndrome. *Neurogastroenterol Motil.* 2020.

Gastro Psychology

- GI hypnotherapy or cognitive behavioral therapy
- If a therapist is not available, a range of apps
- Can help with
 - Disorders of gut-brain interactions
 - Visceral hypersensitivity



Gluten-free?



- One study showing potential benefit
- No control group
 - Gluten?
 - Fructans/FODMAPs/ATI
 - Placebo?
- MUST test for Celiac first

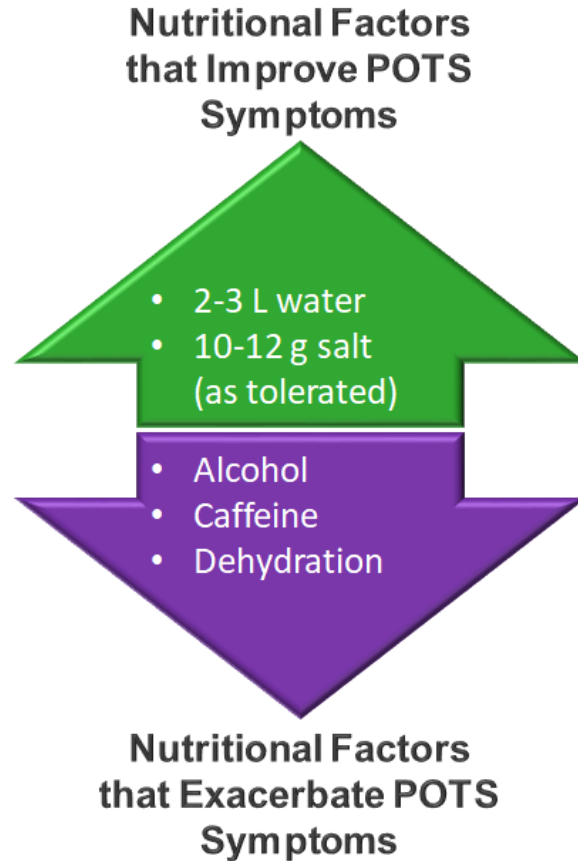


Glycemic Load

Breier, N.C., et. al. Worsening Postural Tachycardia syndrome. *Hypertension*. 2022;79:e89–e99.

Miglis, M.G., et. al. Mechanisms of post-prandial symptoms in postural tachycardia syndrome. *Clin Auton Res*. 2022.

Nutritional Factors



Factors that Stabilize POTS Symptoms

- Small frequent meals
- Start fluids early in the AM
- Screen for eating disorders
- Refer to therapy/social work as needed
- Lower glycemic meals
- Simplify meal prep
 - Refer to occupational therapy when appropriate
- Manage digestive symptoms
- Refer for celiac screening, when appropriate
- When appropriate, encourage paced recumbent activity
 - Refer to physical therapist when appropriate
- Coordinate with health care team

Pediatric Guidelines

- Increase in heart rate by more than 40 beats min when going from recumbent to standing, in the absence of 20 point or more drop in systolic blood pressure for 12–19-year-olds
- Pediatric POTS associated with post-concussive syndrome

Children and teens improve!

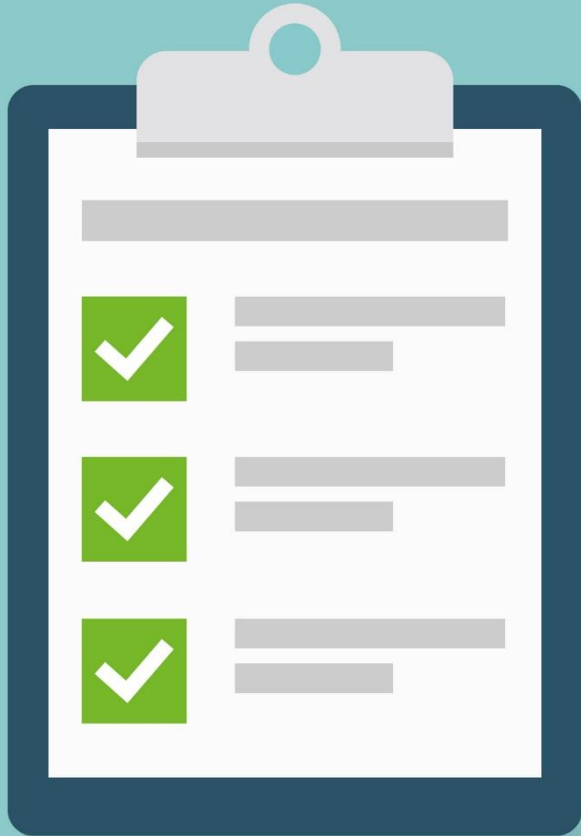
- At 1 year, 48.4% were symptom free
- At 6 years, 85.6% were symptom free

Boris JR. Pediatric Postural Orthostatic Tachycardia Syndrome. *Pediatrics*. 2022;149(6):e2021054945

Tao, C. Long-Term Outcomes of Children and Adolescents With Postural Tachycardia Syndrome. *Front Pediatr*.2019

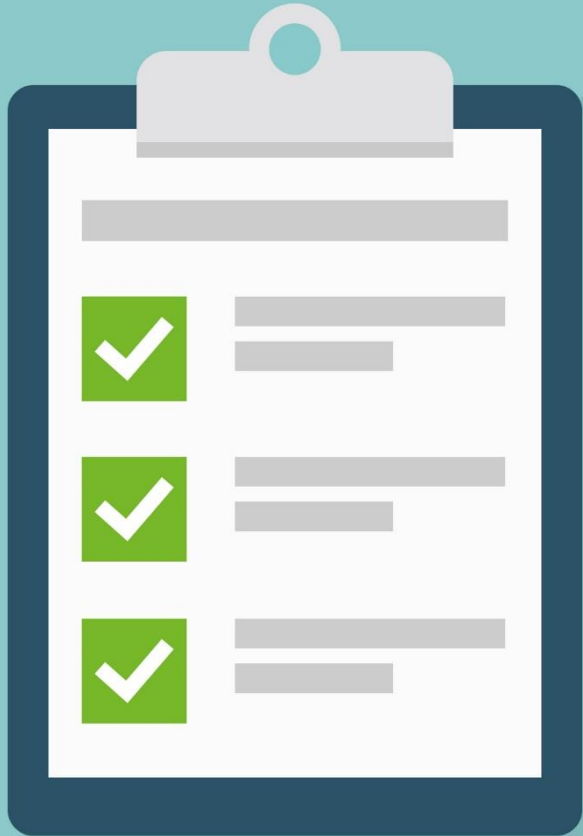


Pregnancy Guidelines



- 2.5+ liters fluid daily
- 7+ grams salt or as directed by physician
- ?? gluten-free diet
- Light recumbent exercise
- Compression stockings if tolerated
- Therapy, as needed

Long COVID POTS Guidelines



- Salt supplementation of 7-10 grams
 - Caution for those with heart failure, renal concerns, or elevated blood pressure, who may have 4 mg sodium/daily or smaller increases
- 3 liters fluid a day
- Refer to RDN
- Small meals preferred
- Statement mentions diets change: gluten-free, low FODMAP, low histamine, plant-based—but anecdotal support only

Blitshteyn S,. Consensus Guidance Statement on Autonomic Dysfunction in PASC. *PM R*. 2022;14(10):1270-1291.

Fedorowski A,. et al. Autonomic dysfunction and postural orthostatic tachycardia syndrome in post-acute COVID-19 syndrome. *Nat Rev Cardiol*. 2023.

A woman with braids, wearing a pink long-sleeved shirt and grey leggings, is sitting on a light blue yoga mat on a grassy lawn. She is smiling and looking towards the left. In the background, two other women are also sitting on mats on the grass. One woman is wearing a pink shirt and the other is wearing a yellow shirt. The background is filled with trees and foliage, suggesting a park or outdoor setting.

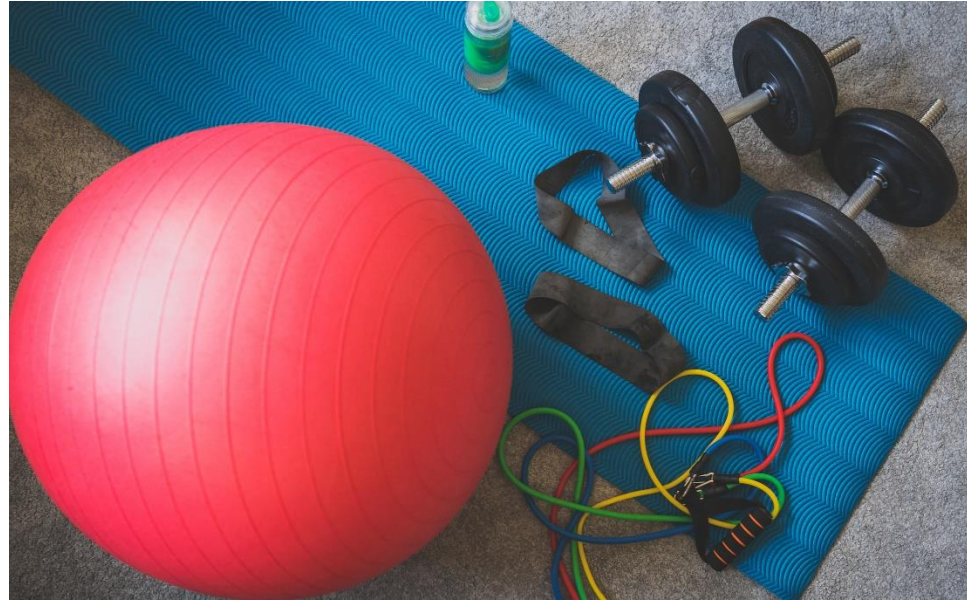
Movement Guidelines

Exercise Protocols



Different protocols—Levine, CHOP, Dallas, etc.

MUST be modified for the individual

- Reclined aerobic exercises
 - Swimming
 - Rowing
 - Recumbent bicycling
- CHOP Modified Dallas Protocol (Ideal use for PT or Exercise Physiologist)
 - Cardio Training
 - Long-Term Maintenance Cardio Training
 - Includes an 8-month training schedule



Movement Guidelines

POTS	Long COVID POTS	Long COVID POTS & ME/CFS
	<u>Types of exercise</u> semi-recumbent/recumbent biking, swimming, rowing 	
Gradually including up to 30 minutes exercise at least 4 times per week	Individualized plan Self-paced exercise at intensity where patient can converse in full sentences Beginning ~5 minutes/day, natural increases as patient gets stronger	Individualized plan Self-paced / titration Supportive medical team Avoid graded exercise
Referral to physical therapy recommended for patients with hypermobile EDS, ME/CFS, cardiac complications, and/or severe deconditioning		
Guidelines are evolving		



Long COVID

Movement

- In the beginning, less is more

Pacing

- considering “energy budget” or energy envelope

Recumbent exercises → sitting → standing



A close-up photograph of a person's hands resting on their chest, wearing a white shirt. The person's hands are positioned over their heart area, with fingers slightly spread. The person has dark skin and is wearing a white, long-sleeved shirt. The background is softly blurred, showing what appears to be a couch or bed with cushions. The overall lighting is warm and natural, suggesting an indoor setting with soft light. The text "Lifestyle Techniques" is overlaid in the center of the image in a black, serif font.

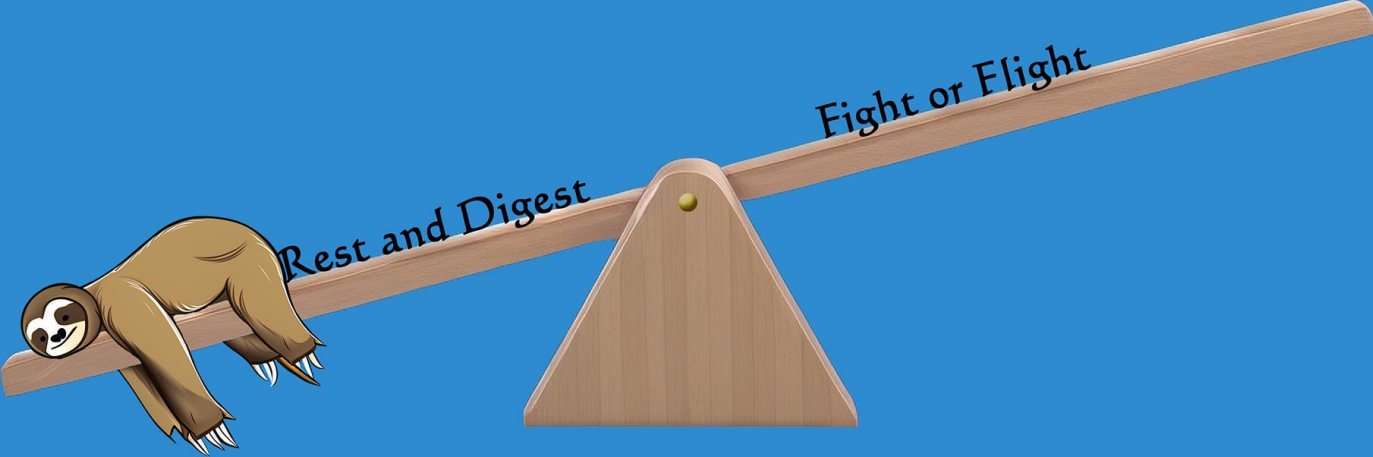
Lifestyle Techniques

Tips

- Compression stockings
- Staying cool
- Elevate head of bed
 - Slight elevation of head at night can be helpful
 - Greater than 10-degree tilt



Autonomic Nervous System



Parasympathetic

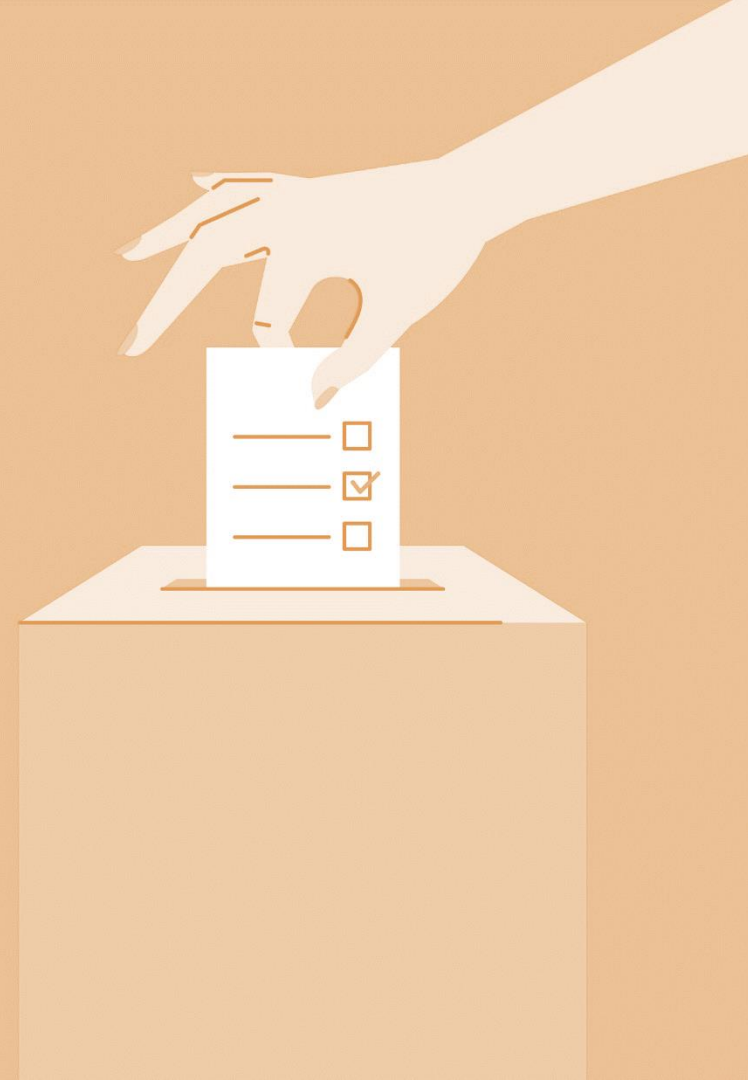
Sympathetic



Poll

As it relates to caring for patients with complex conditions, are you more likely to consult with colleagues to develop a plan of care, or consult specialty physicians and non-physicians within the healthcare team to develop an interprofessional care plan?

- A. Consult with colleagues
- B. Consult specialty physicians and non-physicians within the healthcare team



Why is Interdisciplinary Care so Important for Patients with POTS?

1. Most have multiple complex medical issues—neurologic, autonomic, cardiovascular, digestive, nutritional challenges, etc.
2. Many are coping simultaneously coping with fatigue and cognitive dysfunction

Reaching Out for Support

Social work

- Helping patients cope with grieving, loss, transitions around health and disability

Psychotherapy

- Focused on a wide range of mental health/emotional health issues

<https://www.psychologytoday.com/>



Medication

Often a key part of management!



Assembling your dream team:

Depending on individual needs...

- Pediatrician
- Primary care
- Nurses/NP
- Cardiologist
- Neurologist
- Autonomic specialist
- Gastroenterologist
- Allergist
- Registered Dietitian
- Physical therapist
- Social worker & therapist
- GI Psychologist
- Occupational therapist



Case Studies

Case Study #1

“Jen” 20-year-old Female College Student

Active in high school, but for the last year, she has had ongoing:

- Headaches
- Brain fog
- Dizziness
- Easily fatigued

(even with 9-10 hours of sleep a night)

Due to difficulty focusing, she is taking a semester off from school and she is staying home with her parents

Symptoms:

Headaches, brain fog, dizziness, fatigue, nausea, abdominal pain, bloating, and constipation

She has decreased appetite and weight loss

Jen was diagnosed with POTS a few weeks ago by her neurologist and she is seeking advice

Where to begin?



Breakfast:

Coffee

Kind bar

Lunch:

Yogurt and granola

Crackers

Protein bars

Dinner:

Whatever mom makes—protein and carb

Fluids: Unsure of water, maybe 40 oz? 1 cup tea

Case Study #1 Cont.

**“Jen”
20-year-old
Female College
Student**

What is she eating?

- Inadequate intake, signs of restriction due to fear of abdominal pain and nausea
- Increase fuel throughout day, especially morning

Fluids—What is keeping her from increasing?

- Increasing, going up to 2-3 liters water

Taper up on salt, ask physician for a sodium prescription

- If none given, start with 5 grams through salt or supplements, coordinating with physician and monitoring

Consider relaxation before meals, GI psych apps

Case Study #1 Cont.

**“Jen”
20-year-old
Female College
Student**

Ask about current movement, capacity/motivation

- Recommended gentle Pilates, recommended getting a referral to nearby PT

Consider compression garments

...but abdominal binders may make abdominal pain/nausea worse

How much are digestive issues affecting QOL? If major, GI consult.

If minor,

- Add in ginger for nausea
- Consider IBgard, etc.
- Swap for lactose-free yogurt
- Consider methylated multi*

*Mittal N, et. al. Improvement of hyperadrenergic postural orthostatic tachycardia syndrome (POTS) with methylated B vitamins. *BMJ Case Rep.* 2021.

Case Study #2

“Susan” 32-year-old lawyer and formerly active mother of a 3-year-old and 5-year-old

She got COVID in December 2021, and went right back to work and Orange theory after 6 days. A week later she tested positive again, and she has had long COVID symptoms since. In May 2022, she was diagnosed with PASC, POTS, ME, IBS, and GERD.

Symptoms:

Fatigue, dizziness, headaches, bouts of IBS-D with abdominal pain

She has heard that a low histamine diet or AIP diet may be helpful and wants to know what supplements she should take

Where to begin?



Diet Recall

Breakfast:

Skips, usually 2-3 cups coffee

Lunch:

Frozen meals (Lean Cuisine, Healthy Choice, etc.)

Dinner:

Take out, diet to go, or factory premade meals

Snacks: Cookies, chips, wine on weekends

Fluids: 4-5 glasses water daily

Case Study #2 Cont.

“Susan” 32-year-old lawyer and formerly active mother of a 3-year-old and 5-year-old

Not all at 1st session:

- What’s keeping her from drinking more? Fluids: 8+ cups
- Salt: asking physician for a salt prescription; if none, starting with 5 grams and gradually increasing
- Wine: ask about impact and decrease, especially if histamine sensitive and refer to knowledgeable allergist
- Assess for EDs
- Coffee: impact on GERD? Decrease or eliminate
- Simplify food prep. If motivated, consider a GFD for 4 weeks
- Refer to a *knowledgeable* PT
- Provide work resources: Askjan.com/social work referral

Case Study #2 Cont.

“Susan” 32-year-old lawyer and formerly active mother of a 3-year-old and 5-year-old

As patient feels better, where do we go?

- Depends on patient’s priorities
- Work on IBS symptoms
 - Refer to GI
 - Test for Celiac

If appropriate:

- Trial of a GFD?

Let's Talk....

How do you and members of your healthcare team collaborate to develop a plan of care that places the interests of patients and populations first?



Let's talk...

What helps you better coordinate communication between healthcare team members?

- If possible, have a center of care
- Established channels of contact
- Protocols assisting urgent clients
- Good HIPPA-friendly means for regular communication via text, email, phone, etc.

Putting it into Practice

1. The # of people with POTS is increasing, so it should be something all HCWs consider & are prepared to help manage.
2. Diet & lifestyle are first-line management strategies and should be implemented 1st; however, medications are often necessary.
3. Guidelines differ for POTS and Long COVID POTS, and the picture is still evolving.
4. Don't go at it alone. POTS is a complex condition and has many comorbidities. It takes a village...

Questions?

Cheryl Iny Harris, MPH, RDN

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Working with ARFID in Real Life: The Clinician's Experience for Individuals Struggling with ARFID

PRESENTED BY

Emily Presbrey

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Lisa Carroll

MS, RD, LDN

April 20, 2023
2-3:30pm ET



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