

COVID-19 Increases the Prevalence of Postural Orthostatic Tachycardia Syndrome: What Nutrition and Dietetics Practitioners Need to Know



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POSTURAL ORTHOSTATIC tachycardia syndrome (POTS) is a common complex disorder of the autonomic nervous system, also known as dysautonomia, which was estimated to affect 1 to 3 million people in the United States as of 2019.¹ POTS is defined as a clinical syndrome marked by an excessive increase in heart rate (ie, tachycardia) after a shift to standing posture.¹ Viral infections are an established trigger for POTS, and an unprecedented number of people have contracted viral infections due to SARS-CoV-2.¹ Researchers have documented the development of POTS as a postinfectious complication after COVID-19 in previously healthy patients.²⁻⁷ According to the American Autonomic Society's 2021 statement,⁷ experts from the United States, Canada, and the United Kingdom indicated that the incidence of POTS has increased since the start of the pandemic, but new numbers on prevalence are not yet available.

According to UK National Institute for Health and Care Excellence's (NICE) definition, the initial 4-week phase of COVID-19 is the acute phase. Symptoms that persist more than 12 weeks past COVID infection are known as "long COVID," which also encompasses long COVID POTS.⁷

The United States is in its third year of the COVID-19 pandemic and 513,790,870 people worldwide have been infected as of the beginning of May 2022; a number that continues to grow.⁸ It is likely that the number of people with POTS will also increase after the spike in COVID-19 infections due to the Omicron variant.

Diet and lifestyle management is recommended as the first line of treatment

for patients with POTS. It is critical that registered dietitian nutritionists (RDNs) have the expertise to provide dietary and lifestyle advice for proper management of POTS and to coordinate with the rest of the health care team.⁹ The aim of this article is to provide practice tools to support RDNs as POTS cases become more common.

POTS DIAGNOSIS, SYMPTOMS, AND COMORBIDITIES

Orthostatic intolerance describes symptoms that result from a shift to an upright or standing position. POTS is the most common cause of chronic orthostatic intolerance. Orthostatic intolerance leads to tachycardia and a range of other symptoms.¹⁰ A primary marker of POTS is the increase in heart rate by ≥ 30 beats/min when moving from a recumbent position to a standing posture (or 40 beats/min for someone aged 12 through 19 years), in the absence of a ≥ 20 -point drop in systolic blood pressure, known as orthostatic hypotension.^{9,11} POTS is characterized by symptoms that include lightheadedness, palpitations, tremor, generalized weakness, blurred vision, exercise intolerance, fatigue, and brain fog.^{9,12} Symptoms must be present for 3 or more months with no previously identified organic cause.¹¹ Symptoms usually abate quickly after lying down.^{9,11} POTS affects multiple systems of the body, with cardiovascular, neurologic, autonomic, and even gastroenterological symptoms, and can be diagnosed by a cardiologist, neurologist, autonomic specialist, or a pediatrician in the case of an adolescent.¹ As many of the symptoms of POTS might prompt patients to seek the services of an RDN, it is vital for health care professionals to notice and refer patients for evaluation when warranted.

POTS affects women predominately (4:1 female to male ratio); the typical age range is 12 through 50 years.¹ According to data from before the onset of COVID-19, 42% of patients reported that a virus preceded their POTS symptoms.¹³ In addition to the circulatory symptoms experienced by people with POTS, which are predominantly experienced when sitting or standing, studies found that $>90\%$ of patients report 1 or more gastrointestinal symptoms that are independent of posture.^{14,15} Nausea, abdominal pain, and bloating are the digestive symptoms reported most commonly.^{14,15} Typically, patients with concomitant hypermobile Ehlers-Danlos syndrome, hypermobility spectrum disorder, or mast cell activation syndrome and POTS, in particular, present with an elevated burden of gastrointestinal symptoms due to the intersection of the conditions.^{14,16}

People with POTS experience a range of comorbid conditions at much higher rates than the general population, which often complicate care (Figure 1). Many of these conditions affect both dietary intake and nutritional status. A 2019 survey of 3,835 participants with POTS reported a physician's diagnosis of common conditions. The most common diagnoses reported were migraine headaches (40%), irritable bowel syndrome (30%), hypermobile Ehlers-Danlos syndrome or hypermobility spectrum disorder (25%), myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) (21%), fibromyalgia (20%), iron-deficiency anemia (16%), autoimmune disease (16%), gastroparesis (14%), and mast cell activation syndrome (9%).^{11,15} Although celiac disease generally affects 1% of the population, research indicates a prevalence of 4% among people with POTS.¹⁷

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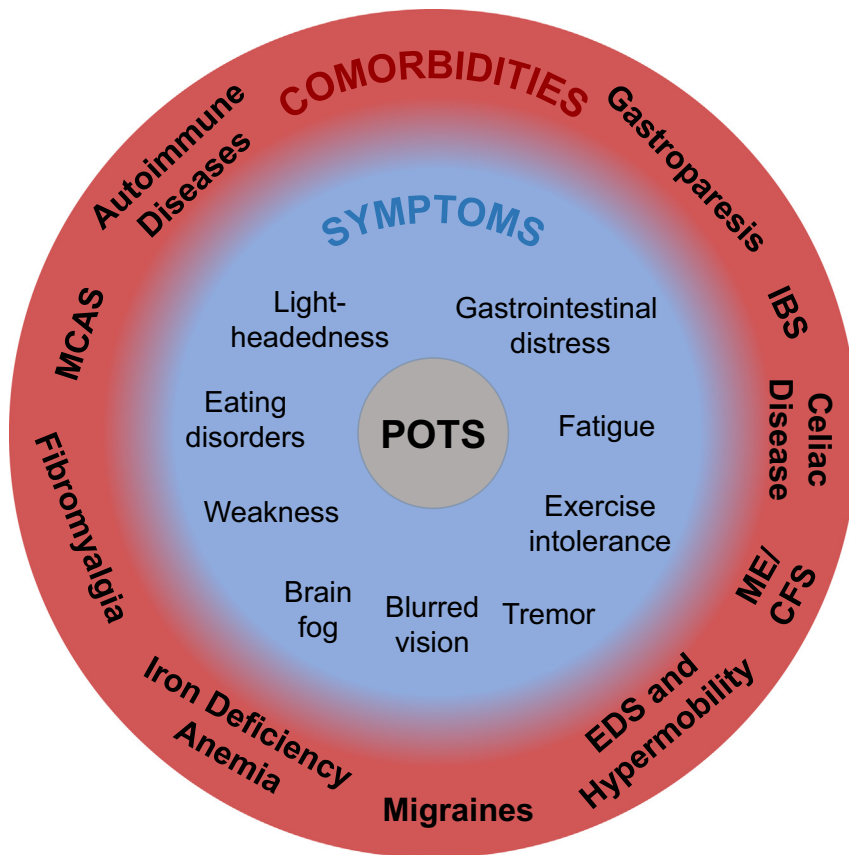


Figure 1. Comorbidities and symptoms of postural orthostatic tachycardia syndrome (POTS).^{10,15,18} EDS = Ehlers-Danlos syndrome and hypermobility spectrum disorder; IBS = irritable bowel syndrome; MCAS = mast cell activation syndrome; ME/CFS = myalgic encephalomyelitis/chronic fatigue syndrome.

NUTRITION ASSESSMENT AND MANAGEMENT OF PATIENTS WITH POTS

The nutrition care process for patients with POTS begins with a diet diary and assessment of nutrition and lifestyle habits. The RDN looks for dietary

adequacy and the fundamentals of healthy nutrition. This includes patterns that could lead to lightheadedness, weakness, fatigue, and brain fog, such as undernutrition, deficiencies in macronutrients, signs of an eating disorder, or other imbalances. The RDN

also looks for consumption patterns that are known to exacerbate POTS symptoms, such as dehydration or consumption of alcohol or caffeine.¹² General nutrition recommendations for POTS can include eating small frequent meals and also consuming primarily lower glycemic carbohydrates.¹⁹ Empirical evidence suggests this will reduce postprandial hypotension (Figure 2).

Fluids and Salt

One of the mainstays of POTS treatment is the consumption of fluids and salt; although this is quite simple, compliance can be challenging. The 2015 Heart Rhythm Society Expert Consensus Statement on the Diagnosis and Treatment of Postural Tachycardia Syndrome recommends considering the consumption of up to 2 to 3 L of water and 10 to 12 g of NaCl (salt) daily.⁹ The Canadian Cardiovascular Society Position Statement on Postural Orthostatic Tachycardia Syndrome, published in 2020, recommended 10 g of salt via high-salt foods, salt sticks, and tablets, and at least 3 L of oral fluids¹¹ (Figure 3). Ten grams of salt translates to roughly 2 teaspoons of table salt daily. Two liters of fluid is approximately 8.5 cups and 3 L is 12.7 cups. For a frame of reference, the 2020-2025 Dietary Guidelines for Americans recommends limiting sodium consumption to 2,300 mg daily for adults, or 2.3 g.²²

Although high salt recommendations have been used empirically by POTS experts for decades, research has been scant and the guidelines have been

- Consume 2-3 L of water daily^{9,11}
 - Start fluids early in the morning, even before getting out of bed¹⁹
- Increase sodium as tolerated, up to 10-12 g/d⁹
 - Consult with medical team regarding sodium goal
 - If not provided, start with 6 g salt daily, divided throughout the day. Increase gradually²⁰
 - Patient can add salt to food. Or, if needed, patients can use slow-release salt tablets^{9,11}
 - Too much salt at one time can trigger nausea²¹
- Patients should avoid alcohol, which may increase symptoms of POTS¹²
- Patients should avoid caffeine, which may increase symptoms of POTS¹²
- Patients should avoid dehydration, which exacerbates the symptoms of POTS¹²
- Small frequent meals and fewer refined carbohydrates are recommended for glycemic balance¹⁹
- Coordinate all recommendations with interprofessional team

Figure 2. Current dietary recommendations for postural orthostatic tachycardia syndrome.

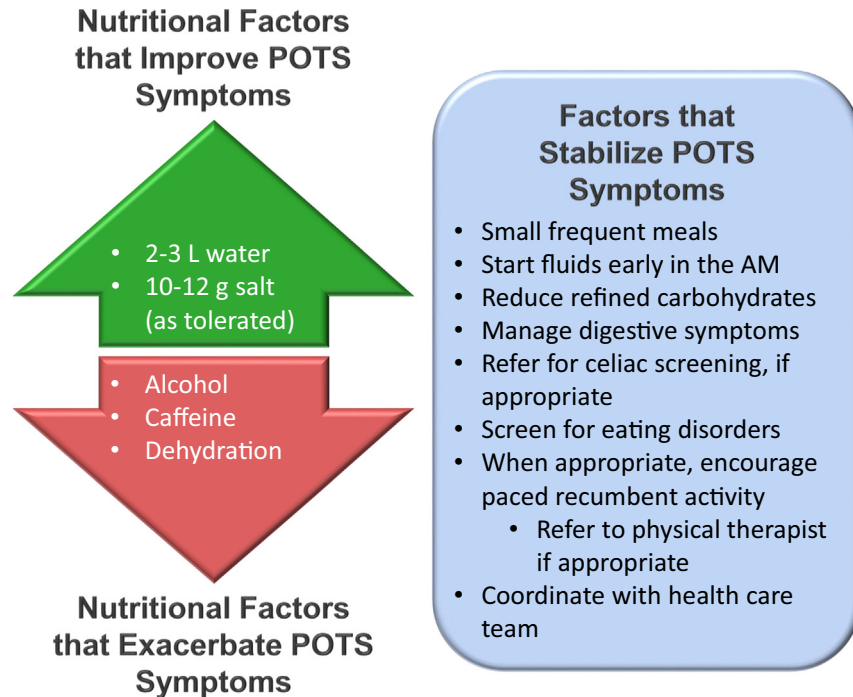


Figure 3. Nutritional guidance for postural orthostatic tachycardia syndrome (POTS).^{9-11,14,17-19,21,23-26}

based primarily on clinician observations. The largest trial, published in 2021, followed 14 patients with POTS and 13 healthy controls for 6 days in a crossover study with either a high-sodium diet, defined as 300 mEq daily, or 6.9 g, or a low-sodium diet, which was 10 mEq daily, or 230 mg. The group of patients with POTS consuming the high-sodium diet experienced increases in plasma volume, decreased changes in heart rate, and lower standing norepinephrine levels, which all represent therapeutic benefits.²⁷

This advice runs counter to standard nutritional recommendations and may be perplexing for patients and practitioners alike.²² The current hypothesis is that the sodium intake helps expand plasma and blood volume, which can improve orthostatic intolerance.²⁰ However, for patients with multiple comorbidities, such as hypertension, renal disease, or cardiac conditions, there are no specific recommendations aside from frequent monitoring of blood pressure.²⁰ RDNs must request a sodium goal from the patient's provider, customize recommendations to the patient's individual needs, and closely monitor the patient's response.

Gastrointestinal Problems and Nutrient Deficiencies

As mentioned, most patients with POTS experience a variety of gastrointestinal symptoms. Medical nutritional therapy must be tailored specifically to manage those concerns properly. Some patients may have a range of typical nutritional deficiencies commonly seen secondary to gastrointestinal disorders, such as gastroparesis, celiac disease, or small intestinal bacterial overgrowth.²³ Research indicates that deficiencies in fat-soluble vitamins, such as vitamins A, E, D, and K and essential fatty acids, may occur due to either digestive malabsorption or a restrictive diet.²³ Low iron, folate, and/or vitamin B12 may be due to dietary restrictions.²³ Thiamin deficiency is relatively uncommon, but has been shown to have a profound effect on a small subgroup of patients.^{23,28} If there is reason to suspect that a patient might have vitamin deficiencies, the RDN should collaborate with the patient's health care team to advocate for testing. Correcting these deficiencies is vital.

In the general population, the rate of celiac disease is approximately 1%.¹⁷ In a study of 100 patients with POTS, the prevalence of biopsy- and serology-

proven celiac disease was 4%.¹⁷ Because the risk of celiac disease is 4 times higher than in the general public, patients should be screened for celiac disease before any dietary adjustments if there is reason to suspect any type of gluten or FODMAP (fermentable oligo-, di-, monosaccharides, and polyols) sensitivity.¹⁷ The same study found that an additional 6% of patients with POTS reported self-diagnosed gluten sensitivity, but did not have serologic or other diagnostic markers of celiac disease.¹⁷ Common deficiencies among people with newly diagnosed celiac disease include iron, folate, zinc, magnesium, vitamin D, and vitamin B12.²⁹ The RDN should ensure that patients with POTS with celiac disease have been screened and are supplementing appropriately.

Eating Disorders

Researchers have noted that the risk factors for POTS overlapped with symptoms and risk factors seen in people with eating disorders. Both conditions are diagnosed frequently in White, adolescent women who experience fatigue, dizziness, and changes in heart rate.¹⁸ Both groups are more likely to experience chronic pain than their peers without these conditions.¹⁸ Researchers have examined the correlation between POTS and eating disorders in adolescents; 73.9% reported restrictive eating and 10.4% of the 71 patients reported a prior diagnosis with a specific eating disorder, which is significantly higher than the national average.¹⁸ Some dietary adjustments are expected, given the comorbidities; for example, avoidance of gluten in patients with celiac disease, avoidance of foods causing anaphylaxis in patients with mast cell activation syndrome, and a lower-fiber diet for people with gastroparesis. However, this study suggests that rates of eating disorders and disordered eating may be higher than expected for patients with POTS. This area has not yet been studied in adults and needs more research.

RDNs support a balanced relationship with food for patients with POTS by advocating for as wide and varied a diet as possible, given physiologic constraints, avoiding restrictive advice when possible, and screening regularly for eating disorders.^{18,23} There are several tools available to screen



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

Figure 4. Physical activity guidelines for postural orthostatic tachycardia syndrome (POTS).^{11,21,24-26} EDS = Ehlers-Danlos syndrome and hypermobility spectrum disorder; ME/CFS = myalgic encephalomyelitis/chronic fatigue syndrome.

patients for eating disorders, such as the SCOFF (Sick, Control, One, Fat, Food) questionnaire, EAT-26 (Eating Attitudes Test), and the Nine Item Avoidant/Restrictive Food Intake Disorder Screen. It is important to note that although these screeners are validated for general populations, they are not validated for patients with chronic illnesses or gastrointestinal disorders, which are greatly overrepresented among patients with POTS. The Nine Item Avoidant/Restrictive Food Intake Disorder Screen might overinflate the scores of patients with digestive diseases.^{18,30} An eating disorder specialist can help determine whether a patient is avoiding a food due to POTS symptoms or an eating disorder.¹⁸

The RDN should also weigh the “pros and cons” of any potential therapeutic diets if there is any concern of disordered eating or an eating disorder in the patient, and modify the diets when possible to maximize the benefit for the patient.

SUPPORTIVE LIFESTYLE PRACTICES

Physical Activity

The nutrition intake process should include questions about physical activity and movement. Deconditioning can exacerbate the symptoms of POTS.^{9,12} This can lead to a downward spiral, because the worsening of symptoms will generally discourage exercise. Patients may report changes in activity level due to shifts in access to a gym or work changes because of the COVID-19 pandemic.

There are different exercise rehabilitation protocols, depending on whether the POTS diagnosis followed a COVID-19 infection. Patients with ME/CFS may need to adapt exercise protocols (Figure 4).

For patients with POTS unrelated to COVID-19, recommendations support gradually incorporating 30 minutes of aerobic, semi-recumbent exercise. Examples include a recumbent bike,

rowing machine, or swimming at least 4 days per week.¹¹ Experts note that it may take 4 to 6 weeks for patients to begin to see improvements in POTS symptoms. Exercise may help a portion of patients achieve remission of POTS symptoms.¹¹ As patients get stronger, they may be able to progress to other types of upright physical activities.

The American College of Cardiology’s “Expert Consensus Decision Pathway on Cardiovascular Sequelae of COVID-19 in Adults” released guidance in May 2022 regarding the needs of patients with COVID-19.²⁴ After patients are medically cleared to resume exercise, the recommendations are to begin recumbent exercise, such as rowing, cycling, or swimming.²⁴ The advice is to begin below the patient’s maximal capacity, with natural increases as the patient gets stronger.²⁴ An example provided is for patients to start with daily recumbent exercise for 5 to 10 minutes per day at an intensity that

allows for conversation in full sentences.²⁴ In this model, patients would increase the amount of time, for example, an additional 2 minutes daily per week.²⁴

The UK's NICE 2022 guidelines for long COVID did not make specific recommendations regarding exercise, citing conflicting research.²⁵ The NICE guidelines did recommend careful self-pacing and more research.²⁵

As mentioned, there is an overlap between patient populations with POTS and those who have ME/CFS. The UK's NICE guidelines specifically caution against graded exercise protocols for people recovering from COVID-19 who have ME/CFS.²⁴ The UK's National Institute for Health and Research gave similar warnings about graded exercise for people with ME/CFS in their review, "Living with COVID."²⁶ They noted that people with long COVID and ME/CFS often experience overlapping symptoms, including exercise intolerance.²⁶ Noting the potential benefits of movement, the National Institute for Health and Research advocates for "symptom-titrated physical activity" and pacing of activities of daily life, including exercise.²⁶

Physical activity guidelines for patients with POTS after long COVID will be further refined as more comprehensive information becomes available.

RDNs work with patients to identify safe access to equipment, given the potential constraints due to COVID-19. For patients with severe symptoms, substantial deconditioning, or with comorbidities, particularly those with ME/CFS, hypermobile Ehlers-Danlos syndrome, or hypermobility spectrum disorder, the guidance of a physical therapist with specific expertise on these conditions or a formal cardiac rehabilitation program can be supportive.^{11,21}

Regulating Body Temperature

Other potential tools for easing symptoms of POTS include regulating temperature and compression garments. Excessive heat can exacerbate POTS symptoms, and cooling improves orthostatic intolerance.^{9,21} Simple measures, such as spritzing with cool water, using a cooling vest, or carrying a portable fan can improve quality of life.²¹

Compression Garments

Compression garments can be a tool to reduce venous pooling or the pooling of blood in lower extremities.¹¹ Compression garments that cover the calf and thigh only might be less effective, but garments that cover the calf, thigh, and abdomen are helpful for some patients.^{11,21} It may require experimentation of type and degree of compression so that the garments do not trigger bruising or digestive distress.^{11,21}

Psychological Stress

A range of studies have pointed to the stresses of COVID-19, social isolation, and uncertainty of the past few years, leading to increases in depression, anxiety, eating disorders, post-traumatic stress disorder, and other challenges.³¹⁻³⁴ Patients with a new diagnosis of POTS or patients with an existing diagnosis, particularly those with other comorbidities and disabilities, may experience a magnified sense of stress, loss, or trauma due to difficulty accessing needed care or fears for their safety and current or future well-being.²¹ Patients need a compassionate provider to empathize with the difficulty navigating a complex diagnosis in the middle of a pandemic without the usual forms of social support. A referral to a therapist may also be warranted, ideally within an interdisciplinary team, or the RDN may need to provide a list of therapists who are currently accepting new patients.

PUTTING THE RECOMMENDATIONS INTO PRACTICE

Some patients experience difficulty increasing water intake, especially up to 2 to 3 L. Guidance suggests that fluid intake is most beneficial in the morning, even starting before getting out of bed.¹⁹ Phone reminders or computer apps can be supportive tracking tools to help patients meet their desired targets.

Consuming 10 to 12 g of salt may seem like a daunting task for many patients. Often, patients are started at a lower dose initially, such as 6 g, and salt is increased gradually to find an optimal dosage.²⁰ If the patient does not dislike the taste of salt, they can measure out the salt into a container, and use it on

foods through the day. If salt intake through foods is insufficient to meet the goal, patients may try slow-release salt tablets, as too much salt at one time may provoke or worsen nausea.²¹ There is speculation that a glucose and salt solution may be more effective at expanding blood volume, but this hypothesis needs to be adequately tested before recommendations are made. The addition of glucose may contribute to weight gain or difficulty with glycemic management.²¹

CONCLUSIONS

POTS is a common, physiologically complex condition that is increasing due to COVID-19. RDNs are an invaluable part of the interprofessional team helping patients implement first-line treatments, such as fluids, salt, a low-glycemic diet, medical nutrition therapy for digestive difficulties and eating disorders, and lifestyle modifications. Coordination with other specialties is necessary, as is an understanding of the unique stressors of patients navigating medical challenges during a pandemic.

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