Patient & Family Guide

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Postural Orthostatic Tachycardia Syndrome (POTS) Self-Management

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Contents

Postural Orthostatic Tachycardia Syndrome (POTS) Self-Management

What is Postural Orthostatic Tachycardia Syndrome (POTS)?

Postural Orthostatic Tachycardia Syndrome (POTS) is a problem where your **autonomic nervous system** (your body's automatic control system) does not regulate (control) your heart rate when you stand up or change positions.

POTS happens when you stand up and within 10 minutes:

- Your heart rate increases (goes up) by either:
    - 30 beats per minute (bpm) or more (if you are 20 years old or older)
      or
    - 40 bpm or more (if you are between 12 to 19 years old)
- Your blood pressure **does not** drop by more than 20/10 mmHg
  and
- You have these symptoms (called **orthostatic intolerance**) often for at least 3 months (90 days)

There is no cure for POTS, but it can be managed. Many people get much better over time.

This pamphlet explains ways to manage your POTS. The treatments in this pamphlet can be used with medication as prescribed by your health care provider.

Talk with your health care provider before making any changes to your current POTS treatment plan.

What are the symptoms of POTS?

- Common symptoms may include:
  - Feeling lightheaded or dizzy
  - A fast, pounding heartbeat or feeling like your heart is jumping, racing, or fluttering (palpitations)
  - Fatigue (tiredness) and exercise intolerance (not able to exercise because of other symptoms, like dizziness)
  - Brain fog, trouble concentrating
  - Nausea (upset stomach)
  - Shakiness or tremor
  - Headaches
  - Visual disturbances (blurred vision, dry eyes, eyes sensitive to light)
- Symptoms usually get worse when you are standing and are better when you are lying down. Things that may make your symptoms worse:
  - Standing or sitting for a long time
  - Physical activity
  - Heat (like hot weather, a hot shower)
  - Large meals that are high in carbohydrates (carbs)
  - Dehydration (not having enough fluids) or skipping meals
  - Drinking alcohol
  - Changes in your menstrual cycle (period)

Common comorbid conditions

- A **comorbid condition** is when you have more than one condition at the same time.

Comorbid condition	Common symptoms	Percentage of people with POTS who also have this condition
Migraine headaches	• Frequent headache, often throbbing and on one side • May be associated with a prodrome (a group of warning signs your body gives you before a migraine starts)	About 40%
Hypermobile Ehlers–Danlos syndrome or hypermobility spectrum disorder	• Hyperextensible (bend farther than normal) joints with frequent dislocation • A lot of pain around the joints	About 25%
Myalgic encephalomyelitis/ chronic fatigue syndrome (ME/CFS)	• Severe (very bad) fatigue with regular activities • Post-exertional malaise (PEM) (see page 14)	About 21%

Comorbid condition	Common symptoms	Percentage of people with POTS who also have this condition
Fibromyalgia	• Serious pain spread through the muscles and connective tissue	About 20%
Autoimmune disorders	• Often previously diagnosed • Chronic (ongoing) dry eyes or mouth	About 16%
Mast cell activation disorder	• High risk of having allergies • Dermatographism (a condition where light scratching or pressure on the skin causes temporary red, raised welts) • Frequent severe flushing (skin suddenly becomes red)	About 9%
Celiac disease	• Abdominal (stomach area) cramps and diarrhea (loose, watery poop) • Gluten sensitivity	About 3%

Adapted from Raj, S. R., Fedorowski, A., & Sheldon, R. S. (2022), CMAJ, 194(10), E378–E385. Data originally from Shaw et al., used under CC BY-NC-ND 4.0.

Ways to manage your POTS symptoms

Fluids

- People with POTS may have a lower than normal blood volume (amount) (called **hypovolemia**).
- Drinking more fluids can help to expand (make bigger) your blood volume. This can:
  - Make it easier for your body to get used to standing
  - Lower your symptoms (like dizziness and palpitations)
- It may help to quickly drink 500 ml (2 cups) of water before activities (called **bolus water drinking**) that make your symptoms worse (like standing for a long time). This can help to quickly raise your blood pressure.

How much fluid do I need?

- **Try to drink 2 ½ to 3 L of fluids a day** (water is best). Ask your health care provider how much is right for you.
- Fluids include:
  - Water (still or sparkling)
  - Electrolyte drinks (like Pedialyte®, Liquid I.V., Nuun)
  - Herbal tea, milk, broth-based soups, smoothies
- Try to limit or avoid:
  - Drinks that are high in sugar (like pop) and energy drinks
  - Alcohol (this can make you dehydrated and make your symptoms worse)
  - Too much caffeine (you may be able to handle some caffeine. Ask your health care provider how much is right for you)

Tips to help you get enough fluids

- Keep a thermos of cold water on your bedside table. Drink a glass of cold water as soon as you wake up, before you get out of bed. Keep lying down for 15 minutes, then get up slowly.
- Set reminders on your phone to drink throughout the day.
- Always keep a 750 ml reusable water bottle with you.
  - Fill it 4 times a day = 3 L
- Write down how much fluid you are drinking or use an app on your smartphone.

Salt (sodium)

- Salt helps your body:
  - Retain (keep) fluid
  - Expand your blood volume
- Most health care guidelines recommend a low sodium diet for middle aged and elderly people. **For most people with POTS, it is very important to take in more salt to help manage your symptoms**.
- **Make sure to increase how much salt you eat slowly over several days. This can help to lower stomach upset**.

Important:

- **Talk to your health care provider before taking in more salt if you have**:
  - High blood pressure (hypertension)
  - Kidney disease
  - Heart failure
  - Liver disease
  - Diabetes
  - Metabolic syndrome

How much salt do I need?

- **Try to take in 2 tsp (10 to 12 grams) of table salt (4 to 5 g of sodium) a day**.
- To find out how much salt you are taking in now, visit:
  Sodium Calculator - Project Big Life
  › www.projectbiglife.ca/sodium/calculator

Note: Nutrition labels list sodium, not salt.

1 g of table salt = about 393 mg of sodium.

What is the difference between salt and sodium?

Table salt	Measurement	Amount of sodium
1 g	About ⅕ tsp	393 mg
5 g	1 level tsp	About 1,965 mg
10 g	2 level tsp	About 3,930 mg
12 g	About 2 ½ tsp	About 4,716 mg

Note: A level tsp means salt fills the spoon without going over the rim. Use a flat edge (like a knife) to scrape off any salt that goes over the rim so the salt is level (flat).

What are your questions?

Please ask a member of your health care team. We are here to help you.

Check the amount of sodium on nutrition labels

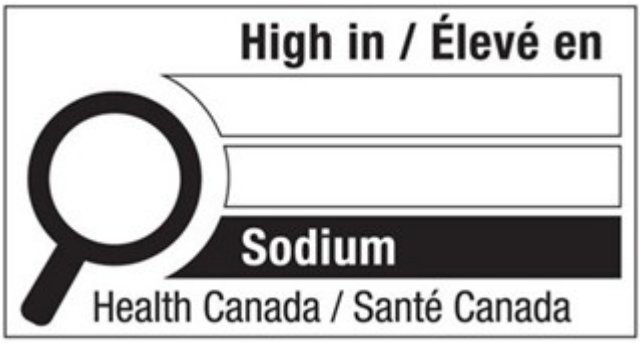
Nutrition Facts

Per 1 cup (250 mL)

Calories 130	% Daily Value*
Fat 4 g	5 %
Saturated 0.5 g + Trans 0 g	3 %
Carbohydrate 20 g	
Fibre 1 g	4 %
Sugars 4 g	4 %
Protein 4 g	
Cholesterol 0 mg	
Sodium 1060 mg	46 %
Potassium 300 mg	6 %
Calcium 50 mg	4 %
Iron 1.5 mg	8 %

*5% or less is **a little**, 15% or more is **a lot**

Look for items that are high in sodium



From Health Canada. (2022, June 29). Sodium: Using the food labels. Government of Can https://www.canada.ca/en/health-canada/services/nutrients/sodium/using-the-food-labels.html

To take in more salt:

- Check food labels to find out how much sodium is in the foods that you already eat.
- Eat foods that are high in sodium (like pickles, olives, cheese, nuts, canned soups, pretzels, soy sauce).
  - › Try to choose healthy foods (like nuts and seeds) and avoid highly processed foods (like instant noodles, fast food, processed [deli] meats).
- Add salt to meals, hot water with lemon juice, or broths.
- If you find it hard to eat enough salt, try buffered salt supplements.

Examples of foods with about 1,000 mg of sodium:

Food	**Amount**
Table salt	½ tsp
Dill pickles	4 pickles
Olives	10 olives
Feta or halloumi cheese	3 oz (85 g)
Salted pumpkin seeds	½ cup
Salted almonds or cashews	½ cup
Soy sauce	1 Tbsp

Other foods high in salt include:

- › Beef jerky
- › Canned beans
- › Kimchi
- › Sauerkraut
- › Broth

Compression garments

- Compression garments put gentle pressure on your body to help prevent blood from pooling in your lower body and abdomen (stomach area).
- They can also lower sudden heart rate increases and other symptoms caused by standing. They do this by improving blood flow back to your heart.
- Compression that extends to your waist or abdomen (stomach area) is best.
  - › Wearing both leg and abdomen compression garments lowers orthostatic tachycardia (fast heart rate) more than leg compression alone. Below-the-knee stockings do not move enough pooled blood to help with POTS symptoms.
- Talk with your health care provider about a prescription for medical compression garments.

Tips:

- Compression garments work best if you put them on before getting out of bed in the morning.
- Make sure to wear compression garments when you will be standing or walking for a long time.
- Make sure the garments fit well.
  - › Garments that are too tight will not be comfortable.
  - › Garments that are too loose may not work well.
- If you find it hard to wear full, waist-high stockings, try high-waist compression shorts or leggings with an abdominal binder (compression belt).
- If you have problems putting on compression garments, there are aids to help. Talk with an expert (occupational therapist or a sales rep at a specialty health care store) about what aid is right for you.

Type	Compression level	Notes
Athletic compression (like 2XU, CW-X®)	15 to 20 mmHg	• Good garments to start with • Can be bought over-the-counter
Medical-grade stockings (waist-high)	20 to 30 mmHg	• Commonly recommended • May need a prescription
Higher compression (waist-high)	30 to 40 mmHg	• For more severe symptoms • Must be prescribed and fitted at a specialty health care store
Abdominal binder or shapewear (like Spanx®)	Depends on the garment	• Targets abdominal pooling • Can be worn alone or with compression stockings

If you have private health insurance, it may cover medically-prescribed compression garments. Check with your private health insurance provider.

Physical activity

- Regular aerobic (cardio) exercise is one of the most effective treatments for POTS. A structured exercise program can help to improve your heart rate control, blood volume, and overall quality of life.

Based on your personal health and any comorbidities, some exercises may not be right for you. If you are having trouble getting started, talk to your primary health care provider, specialist, or a physiotherapist (PT).

Exercise program

- Try to get 30 minutes of aerobic exercise 5 to 6 days a week. The goal is to exercise at least 4 days a week.
- **Consistency (exercising regularly) matters more than intensity (how hard you exercise).**
- Pacing is an important part of managing POTS. People with POTS often have fatigue and it can be one of the hardest symptoms to manage.
- It can help to set a schedule:
  - › Choose a time for exercise and stick to it.
  - › On days when you have more energy, do a bit more. On days when you have less energy, do a bit less.

Six things to keep in mind:

1. Do not start standing up.

- › Standing up during exercise can be challenging with POTS. Try exercises where you are not standing up (like recumbent [reclined] biking, rowing, swimming). These are easier on your cardiovascular (heart) system.
- › Exercise progression (exercising longer or making your exercises harder):
  1. Lying
  2. Sitting
  3. Supported standing
  4. Standing
  5. Dynamic exercise (like walking, swimming, cycling)

2. Exercise for 30 minutes at a time.

- › If this is too much at first, start with shorter sessions and increase them over time.
- › If you have a comorbidity (see pages 3 to 4), you may need to start with a much shorter time. Some people may have to start with 5 minutes or less.

› If you need help with progression, talk with a PT (see **Pacing** on page 14). Progression can be as low as adding 1 more minute of cardio or 1 more rep of strengthening exercises every 1 to 2 weeks.

3. **Exercise at least every second day (4 days a week)**.
   › If you exercise less than this, you are not likely to get the aerobic benefits needed to manage your POTS symptoms. If you have a comorbidity, you may need to start with fewer sessions per week. Talk with a PT, if needed.
4. **Be patient**.
   › It can take 6 to 9 months of regular exercise to see an improvement.
5. **Manage your expectations**.
   › Many people feel more tired and worn out than usual in the first few weeks. This is normal. It usually gets better as your cardiovascular (heart) fitness improves. Set reasonable goals for progressing.
6. **Add leg strengthening**.
   › Building the muscles in your legs, especially in your thighs, supports the return of blood to your heart when standing. Add resistance exercises for your lower body with, **not** instead of, your aerobic exercise.

Recommended exercises:

Aerobic (not standing)	**Leg strengthening**
• Recumbent biking • Rowing machine • Swimming or aqua fitness • Seated calisthenics (strength training)	• Start with exercises that can be done lying down, like: › Bridges › Straight leg raises › Clamshells

Pacing

- **It is especially important to pace your activities if you have post-exertional malaise (PEM)**. This is when your symptoms (like pain, fatigue, cognitive dysfunction [problems with memory or thinking]) get worse after minor physical or mental effort. This can affect your usual daily activities and can last for 24 hours (1 day) or longer. This is common if you have a comorbidity (see pages 3 to 4) like ME/CFS, or long COVID (post COVID).
- **Activity pacing** is a way to self-manage your symptoms. It helps you to manage, or "budget," your energy. This can help you to use your energy better.
  - Activity pacing involves balancing activity and rest. The goal is to increase what you are able to do so you can take part in meaningful activities.
- **How do you use your energy budget each day?** Think about how much of your energy goes to:
  - Physical efforts (like moving your body or working your muscles)
  - Cognitive efforts (concentrating, processing, and remembering information, planning and making decisions)
  - Social efforts (interacting with and understanding other people)
  - Sensory inputs (hearing, sight, touch, smell, taste)
  - Stress (like money problems, navigating the health care system)
  - Emotions (strong, ongoing emotions use the most energy, whether they are happy or sad)
- **How do you plan your day?**
  - What time of day do you have the most energy?
  - What activities are most important to you?
  - Are you balancing your activities (switching between easier and harder tasks)?
  - How often are you taking planned rests?

All of these factors can affect your ability to self-manage your POTS symptoms. Talk with an OT or a PT to make the best use of your energy.

The FITT framework

- The **FITT (Frequency, Intensity, Time, Type) framework** can be used to help you increase your physical activity. Talk with your health care provider if you have questions or need more support.
- Rate your **perceived exertion** (how much effort you feel you are putting in) on a scale from 1 to 10, with 10 being the most effort. This is called the **RPE scale** (see page 16).

Frequency (how often you exercise)	**Intensity (how much effort you exert)**	**Time**	**Type**
• Start exercising 2 to 3 times a week to let your body recover fully after each session. • Wait at least 1 day, but no more than 2 days, between sessions.	• Avoid post-exertional malaise (PEM) or **hyperadrenergic response** (when your body releases too much adrenaline). See below. • Start at a perceived exertion of 2 to 3 RPE. Increase the intensity slowly over time to a 4 to 6 RPE.	• Start at 70% of your maximum tolerance (see next page). • At first, this may only be a few minutes or blocks of a few minutes at a time with short rest breaks in between.	• Progress from exercising while lying down to recumbent exercise, to seated exercise, to upright exercise. • You may find that some types of exercise feel better than others (for example, you may tolerate walking better than recumbent biking).

- A **hyperadrenergic response** is when your body's "fight or flight" system overreacts.
- Using your heart rate to find your perceived exertion may not work as well for you because even slight effort can cause bigger increases in your heart rate (when compared to people without POTS).

Progression:

- **Only progress when you are able to tolerate your current level of exercise for at least 6 sessions in a row, while also recovering well with very little post-exertional malaise (PEM) or hyperadrenergic response**.

- To progress your exercises:
  1. First increase the length of your exercise sessions
  2. Then increase the intensity and/or type of exercise
  3. Then increase the frequency
- **Do not** progress by more than 20% for either time or intensity.

Modified from Lau, D. H., Fedorowski, A., Raj, S. R., et al. (2026). *Heart, Lung and Circulation*, 35(2), 171–185.

- Depending on your health and comorbidities, progression may have to be even slower. As little as a 10% increase in activity may be the limit for some people.
  - › For example, if your maximum walking distance is 10 minutes, start at 7 minutes and increase by 1 minute every 1 to 2 weeks.
  - › If you max out at 10 reps of resistance exercise, start with 7 reps and increase by 1 rep every 1 to 2 weeks. This can help to lower fatigue and PEM over time.

Rate of Perceived Exertion Scale

Use the RPE scale below to find the intensity of the exercise you are doing.

RPE scale	Rate of perceived exertion
10	**Max effort activity** • Feels almost impossible to keep going. Completely out of breath, unable to talk. Cannot maintain for more than a very short time.
9	**Very hard activity** • Very difficult to maintain exercise intensity. Can barely breathe and speak only a few words.
7-8	**Vigourous activity** • Borderline uncomfortable. Short of breath, can speak a sentence.
4-6	**Moderate activity** • Breathing heavily, can hold short conversation. Still somewhat comfortable, but becoming noticeably more challenging.
2-3	**Light activity** • Feels like you can maintain for hours. Easy to breathe and carry a conversation.
1	**Very light activity** • Hardly any exertion, but more than sleeping, watching TV, etc.

Healthy NS

- HealthyNS offers Nova Scotia residents free, online health and wellness classes, and one-on-one support.
  - www.nshealth.ca/primary-care-and-family-medicine/healthy-ns#Selfmanagement
- To self-manage your POTS symptoms, you will need to take care of your mental, emotional, and physical health. HealthyNS can help with:
  - One-on-one support for health goal coaching and physical activity counselling
  - Self-management of your POTS symptoms
  - Lowering your health risks
  - Mental wellness
  - Healthy eating
  - Physical activity
  - Parenting
  - Self-directed resources

Other ways to manage your symptoms

Work

- Consider talking with your primary health care provider (family doctor or nurse practitioner) about work accommodations, like:
  - Taking breaks more often
  - Working shorter days or weeks
  - Working while sitting instead of standing

Sleep position

- Try raising the head of your bed by 10 to 15 cm using bed risers. This gentle tilt can cause you to retain salt and water, which helps to maintain (keep) blood volume.
  - **Do not** use pillows. They can slide and do not work as well.

Counter-pressure maneuvers (movements)

- To **counter** something means to do the opposite. Tensing (squeezing) your muscles can help to counter blood pooling and return blood to the heart for a short time. This can help to prevent or delay fainting.
- When you start to feel symptoms:
  - Cross your legs and tense your thigh, bum, and abdominal muscles.
  - Bend your knees and lower into a squat.
  - Grip your hands together and pull in opposite directions to tense your arm muscles.
  - Rock up onto your toes repeatedly while standing.
  - March in place: Lift one foot, then the other, to tense your thigh calf and muscles.

Heat management

- **Do not** take long, hot showers or baths. Use a shower bench or chair and lukewarm water.
- Carry a portable fan or a personal cooling device in warm weather.
- On hot days, stay in the shade, drink cold fluids, and limit time outdoors.
- In summer, plan outdoor activities for cooler parts of the day (like early morning or evening).

Eating habits

- Eat smaller meals more often, instead of large meals.
- Limit meals that are high in carbohydrates. They may cause your blood pressure to drop after eating.
- Include protein and fibre at each meal. This can help to even out your blood sugar.
- Avoid alcohol or only drink small amounts with food.

Daily living

- Stand up slowly from lying or sitting. Sit on the edge of the bed for a minute before standing.
- **Do not** stand in one place without moving for long periods of time. If you must stand, shift your weight, march in place, or use a stool.
- You may wish to get a disability parking permit if your symptoms are severe. Talk with your primary health care provider about this, if needed.
- Try calming activities (like restorative yoga, listening to nature sounds, gentle stretching).

Medications

- **Important**: There are no medications specifically approved for POTS in Canada or internationally.
- Some medications may be prescribed "off-label" to help manage your POTS symptoms. This means they are prescribed to you for POTS, but are usually used for a different condition. Talk with your primary health care provider about whether medication for POTS is right for you.
- This section only gives a brief overview of possible medications for POTS. Ask your primary health care provider or specialist which medications are right for you.
- Each off-label medication prescribed for POTS works in one of these ways. It may:
  - Increase your blood volume
  - Lower your heart rate
  - Constrict (make narrower) your blood vessels
  - Change your nervous system activity

It is usually best to use medications (if needed) together with other ways of self-managing your symptoms.

Type of medication	Example	How does it help?	Who is it for?
Beta blocker	Propranolol	• Lowers your heart rate, which can lower palpitations and tachycardia when you stand up • A low doses is often effective	• People with high heart rates and related symptoms
Heart rate agent	Ivabradine	• Slows your heart rate without affecting your blood pressure • May work better than a beta blocker	• Use is limited because of the high cost and risks during pregnancy
Vasoconstrictor	Midodrine	• Constricts blood vessels to lower blood pooling and raise blood pressure • Taken during daytime (**do not** take at bedtime)	• People with low blood pressure or **acrocyanosis** (your hands, feet, fingers, or toes turn a bluish, purple, or grey colour)
Mineralocorticoid	Fludrocortisone	• Helps your kidneys retain salt and water to increase blood volume.	• People who are not able to take in enough salt

Type of medication	Example	How does it help?	Who is it for?
Cholinesterase inhibitor	Pyridostigmine	• Improves the signals from your nerves to your blood vessels, which may help to lower your heart rate when you stand up • Helps to lower fatigue and weakness, and helps empty your bowels (so you can poop easier)	• People with severe fatigue and weakness. • People with chronic loose stools (poop) or diarrhea **should avoid** taking this medication.

- It may take time to find the medication that is right for you. Your health care provider will decide based on:
  - › Your symptoms
  - › Any other health conditions you may have

Do not start, stop, or change a medication without talking to your health care team first.

If you are prescribed a medication, ask:

- › How it will help you
- › What are the possible side effects?
- › How will it interact with (affect) your other self-management strategies?

Bring this pamphlet with you to your appointments.

Keeping a journal

- Keeping a daily journal can help you and your health care team find patterns, track your improvement, and adjust your self-management plan. It may help to write down:
  - Daily fluid and salt intake
  - Time spent resting and standing
  - Resting and standing heart rate (a smartwatch or a pulse oximeter can help)
  - Exercise type and length, and how you felt
  - Sleep quality
  - How bad your symptoms are (on a scale of 1 to 10)
  - Anything that triggers your symptoms or makes them worse (like heat, eating, having your period)

Call your health care provider or go to the nearest Emergency Department right away if you have:

- Fainting with injury or repeated fainting
- Chest pain or severe shortness of breath (trouble breathing)
- Heart rate that stays above 150 bpm at rest
- New or worsening neurological symptoms (like weakness, numbness, vision changes)
- Severe dehydration (like dark urine [pee], not able to keep fluids down)
- Symptoms that suddenly change or get worse

Your health care team

- Depending on your needs, your POTS health care team may include:
  - **Primary health care provider**: Your main contact for POTS management and referrals, and help with work accommodations (like extra time for tasks)
  - **Medical specialist**: They can help to confirm your POTS diagnosis and help with complex POTS
  - **Physiotherapist (PT)**: Try to find a PT who has experience with POTS and any comorbidities you may have to make sure they make an exercise program that is safe for you.
  - **Occupational therapist (OT)**: They can help with pacing (see page 13) and daily activities
  - **Registered dietitian**: They can help you find the amounts of fluids and salt that are right for you while eating healthy

Resources

Dysautonomia International

- Education, support groups, and provider directories
  - www.dysautonomiainternational.org

Open Medicine Foundation® Canada

- Research and awareness for POTS and ME/CFS
  - www.omfcanada.ngo

POTS UK

- Resources for managing POTS
  - www.potsuk.org/managingpots

This pamphlet is for educational purposes only. It is not intended to replace the advice or professional judgment of a health care provider. The information may not apply to all situations. If you have any questions, please ask your health care provider.

Find all patient education resources here:
www.nshealth.ca/patient-education-resources

Connect with a registered nurse in Nova Scotia any time:
Call 811 or visit: https://811.novascotia.ca

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To be reviewed July 2029 or sooner, if needed.
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