Understanding

POTS

Postural Orthostatic Tachycardia Syndrome

Whether you just received a diagnosis, suspect you might have POTS, or love someone who does — this guide is for you.

No gatekeeping. No jargon walls. Just what people wish they'd found sooner.

7 Sections **Complete Overview** **Print-Ready** **Letter Size PDF**

A PLAIN-LANGUAGE GUIDE FOR PATIENTS, CAREGIVERS & ADVOCATES

FREE · SHARE FREELY · NO SIGNUP REQUIRED

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SECTION
01

WHAT IS POTS?

What Is POTS?

POTS — POSTURAL · ORTHOSTATIC · TACHYCARDIA · SYNDROME

A disorder of the autonomic nervous system affecting heart rate regulation when standing.

The autonomic nervous system controls everything your body does automatically: heartbeat, breathing, digestion, and blood pressure. In POTS, that system misfires when you change positions — particularly when standing up.

When a healthy person stands, blood vessels constrict quickly to push blood upward. In POTS, that response is delayed or fails — blood pools in the lower body and the heart compensates by racing, often 30+ beats per minute higher than when lying down.

> “
>
> *POTS is not anxiety. It is not deconditioning. It is a measurable, physiological disorder — and it is real.*
>
> ”

Estimates suggest POTS affects 1–3 million Americans, predominantly people between ages 15 and 50. It is also frequently triggered or worsened by viral illness including COVID-19.

SECTION
02

COMMON SYMPTOMS

Common Symptoms

POTS presents differently in everyone. Symptoms often feel vague, fluctuate daily, and overlap with many other conditions. You do not need all of these — even a few are significant.

Racing Heart
Heart rate surges 30+ bpm upon standing. Palpitations are common, especially in the morning.

Dizziness
Particularly when standing, bending, or after prolonged sitting. Can lead to near-fainting.

Brain Fog
Difficulty concentrating, word-finding problems, memory lapses — thinking through cotton.

Fatigue
Profound, unrefreshing exhaustion that does not improve with rest or sleep.

Nausea & GI Issues
Nausea, bloating, gastroparesis-like symptoms — the gut has its own autonomic involvement.

Temperature Issues
Feeling too hot or cold inappropriately, poor heat tolerance, abnormal sweating patterns.

Blood Pooling
Legs may turn purple or mottled when standing — blood accumulating below the waist.

Headaches
Chronic headaches related to poor cerebral blood flow or pressure changes when upright.

SECTION
03

GETTING DIAGNOSED

Getting Diagnosed

The average POTS diagnosis takes 4–6 years from symptom onset — not because someone is not sick enough, but because awareness is low and symptoms mimic many other conditions.

1 **Track Your Symptoms**
Log heart rate lying down vs. standing, symptoms, triggers, and timing. Data is your strongest advocate in the doctor's office. A simple notebook works fine.

2 **At-Home Tilt Test**
Lie flat 10 minutes, record heart rate. Stand; record at 1, 3, 5, 10 minutes. A rise of 30+ bpm (40+ in adolescents) is significant.

3 **See the Right Specialist**
Cardiologists, electrophysiologists, or neurologists with dysautonomia experience. Primary care can refer, but rarely diagnoses POTS independently.

4 **Formal Tilt Table Test**
The gold standard. A motorized table tilts you upright while heart rate and blood pressure are monitored continuously over 30–45 minutes.

5 **Rule Out Other Causes**
Thyroid issues, anemia, and dehydration cause similar symptoms. Basic labs help exclude these before confirming a POTS diagnosis.

> “*You are allowed to advocate for yourself. You are allowed to ask for testing. You are allowed to seek a second opinion.*”

SECTION
04

TYPES OF POTS

Types of POTS

POTS has several recognized subtypes and many people overlap between them. Understanding your subtype can significantly guide treatment decisions.

Hyperadrenergic POTS
High norepinephrine when upright. BP may rise with standing. Tremors, anxiety-like symptoms. High-sodium approaches may worsen it.

Neuropathic POTS
Small nerve fiber damage causes poor vasoconstriction and heavy blood pooling. Often shows skin discoloration when upright.

Hypovolemic POTS
Low blood volume — sometimes despite normal labs. Responds well to sodium, fluids, and fludrocortisone.

Secondary POTS
POTS as a symptom of another condition: EDS, MCAS, autoimmune disorders, Long COVID. Treating the root may improve POTS.

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05

MANAGING DAY-TO-DAY

Managing Day-to-Day

There is no cure for POTS, but most people find significant relief through lifestyle changes and — when appropriate — medication. Management is deeply individual. Start with the foundations.

Lifestyle Foundations

- High sodium diet (with doctor approval)
- 2–3+ liters of fluid daily
- Compression garments — waist-high, 20–30 mmHg
- Elevate head of bed 30–45 degrees
- Avoid prolonged standing or heat exposure
- Small, frequent meals throughout the day
- Rise slowly from lying or sitting

Exercise Approach

- Start horizontal: rowing, swimming, recumbent bike
- Avoid upright exercise in early stages
- Gradually increase duration before intensity
- Consistent pacing — rest is part of the protocol
- Work with a POTS-aware physical therapist
- Track how exercise affects your symptoms

Common Medications

General awareness only — medication decisions belong to you and your healthcare provider.

Beta-blockers	Propranolol, metoprolol — reduce heart rate. Used cautiously; can worsen fatigue.
Fludrocortisone	Helps kidneys retain sodium to increase blood volume. Common first-line option.
Midodrine	Constricts blood vessels to reduce pooling. Must be taken upright.
Ivabradine	Reduces heart rate without BP effects of beta-blockers. Increasingly used for POTS.
IV Saline	Rapidly increases blood volume for acute flares or ongoing management.

SECTION
06

ADVOCATING FOR YOURSELF

Advocating for Yourself

Nobody is going to fight for your health the way you will. This is one of the hardest realities of chronic illness — and one of the most empowering, once you learn how.

1 **Come prepared.**
Bring a symptom timeline, at-home heart rate data, and a list of your top three concerns. Doctors retain information from structured, prepared patients far more effectively.

2 **Name it.**
Do not only describe your symptoms — say the words: "I am concerned this could be POTS or another form of dysautonomia. Can we discuss testing?" Naming it changes the conversation.

3 **Own your records.**
Request copies of all labs, notes, and test results. You legally own your medical records. Keep them organized and bring them to every new provider.

4 **Find your community.**
Dysautonomia International, the Dysautonomia Support Network, and online peer communities offer provider recommendations and peer support that can change the trajectory of your care.

5 **Pace intentionally.**
Rest is not giving up. Pacing is a clinical skill — learning your limits and honoring them is one of the most effective management tools available. Boom-bust cycles worsen POTS.

6 **Seek a second opinion.**
If you are dismissed or told symptoms are anxiety without proper testing — that is a sign to find another provider, not a sign to stop advocating. Your instincts matter.

> “*You are not too sensitive. You are not making it up. You are navigating a real condition in a medical system that is still learning — and that takes real strength.*”

SECTION
07

RESOURCES & WHAT TO HAVE ON HAND

Resources & What to Have on Hand

Organizations

- Dysautonomia International
- Dysautonomia Support Network
- The Dysautonomia Project
- Standing Up to POTS
- POTS UK

Keep in Your Kit

- Heart rate monitor or smartwatch
- Electrolyte packets (LMNT, Liquid IV, Nuun)
- Compression stockings — waist-high
- Symptom tracking journal
- Medical ID bracelet
- Portable fan for heat management

Quick Reference: Key Numbers

30+ bpm	Heart rate increase upon standing (adults) indicating possible POTS
40+ bpm	Heart rate threshold for adolescents under age 19
4–6 years	Average time from symptom onset to POTS diagnosis
10 minutes	Lie flat time before starting an at-home orthostatic test
20–30 mmHg	Recommended compression stocking pressure for most POTS patients
2–3+ liters	Daily fluid intake target — always confirm range with your doctor
3–4g sodium	Daily sodium target (higher end) — confirm with your provider

> “*If this guide helped you, share it. Someone out there is still searching for words to describe what is happening to their body — and this might help them find them.*”

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