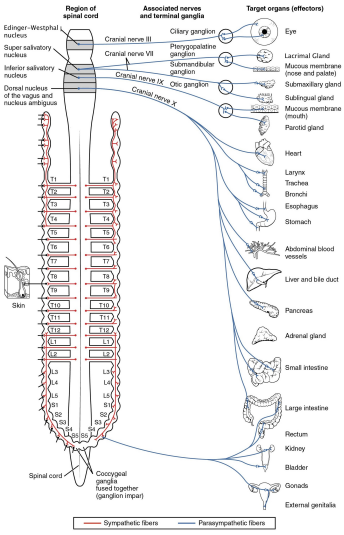
Understanding Dysautonomia

When the Autonomic Nervous System Misfires

Identify Your Type. Manage Triggers. Reclaim Daily Function.



Online: https://go.riasalimd.com/dysautonomia-guide

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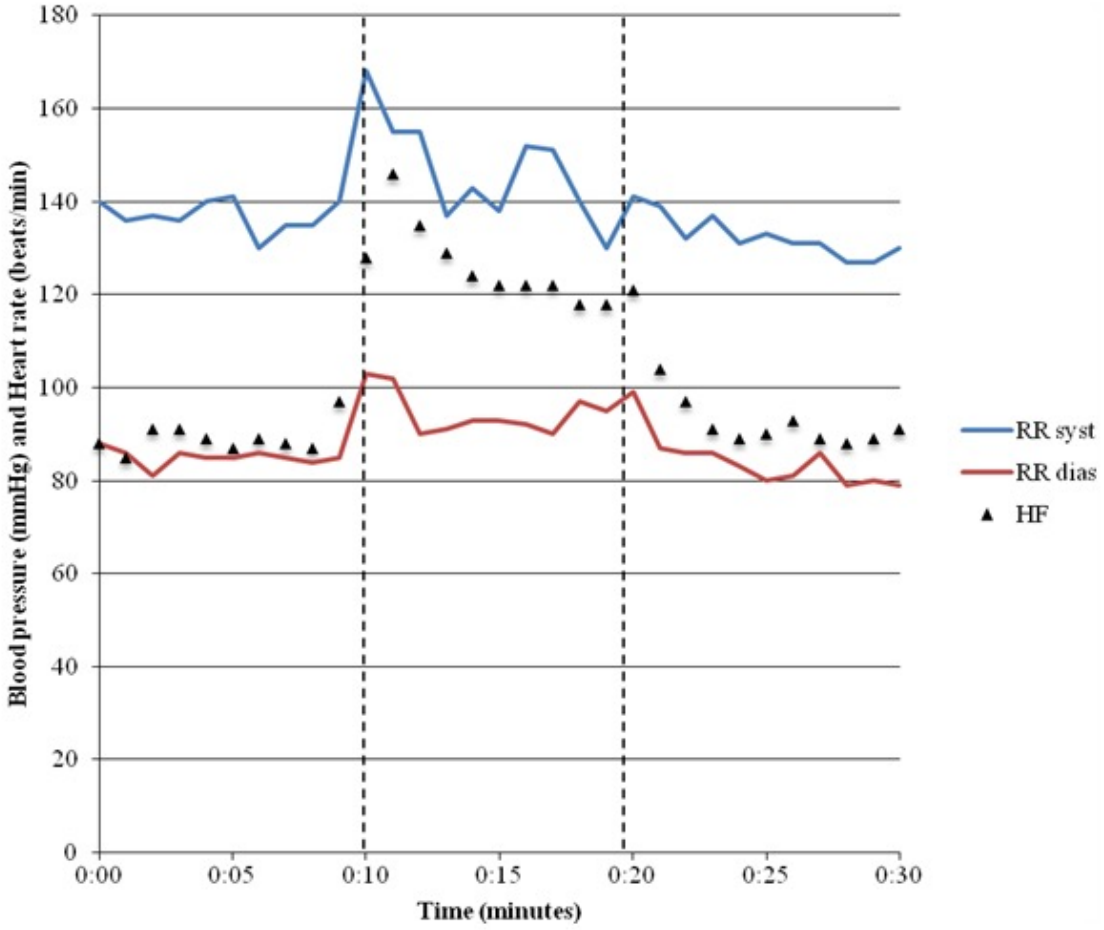
Names & Terms You Will Hear

Term	Meaning
Dysautonomia	A broad term for any problem with the autonomic nervous system. This system runs heart rate, blood pressure, sweating, and digestion.
Autonomic neuropathy	Nerve damage that blocks autonomic signals. Common causes are diabetes, amyloidosis, and autoimmune disease.
POTS (Postural Orthostatic Tachycardia Syndrome)	Heart rate rises 30 bpm or more within 10 minutes of standing. Blood pressure stays normal. This is the most common type.
Orthostatic hypotension (OH)	Blood pressure drops 20 mmHg or more within 3 minutes of standing. The body cannot keep blood pressure steady when upright.
Neurally mediated syncope / Vasovagal syncope	Fainting from an abnormal reflex. The reflex slows the heart and drops BP. It is the most common cause of fainting in healthy people.
Pure autonomic failure (PAF)	Slow loss of autonomic nerve function. No other brain signs are present. It causes severe OH and loss of sweating.
Multiple system atrophy (MSA)	A brain disease that causes autonomic failure plus balance or movement problems. It is the most severe form of dysautonomia.
Hyperadrenergic POTS	A subtype of POTS. Standing causes a surge of norepinephrine. This raises standing BP and causes palpitations along with fast heart rate.
Tilt table test	A diagnostic test. You are secured to a table that tilts upright. Heart rate and blood pressure are watched the whole time.
Valsalva maneuver	A forced exhale against a closed airway. It tests autonomic reflexes during tilt table and echo tests.

What Is Dysautonomia?

- The autonomic nervous system (ANS) is your body's autopilot. It runs heart rate, blood pressure, digestion, sweating, and bladder control.
- Dysautonomia means the ANS is not working right. The signals are wrong, too strong, or missing entirely.
- The most common form is POTS. Your heart rate jumps 30 bpm or more when you stand. Blood pools in the legs. This causes dizziness, fast heart rate, and fatigue.
- POTS affects an estimated 1 to 3 million Americans. Most are women aged 15 to 50. Average time to diagnosis is 4 to 6 years.
- Causes include autoimmune nerve damage, bed rest, COVID-19 infection, diabetes, Ehlers-Danlos syndrome, and mast cell problems.
- Post-COVID POTS has grown fast since 2020. About 2 to 14 percent of post-COVID patients meet POTS criteria.
- Dysautonomia is not a mental health problem. It is a physical disorder. Tilt table tests and blood tests confirm the diagnosis.



A real tilt table test tracing, positive for POTS. Blue line: systolic blood pressure. Red line: diastolic blood pressure. Triangles: heart rate. The dashed lines mark the moment the patient was tilted upright — heart rate jumps from about 90 to over 145 beats per minute while blood pressure stays roughly steady. This is the classic POTS pattern. Image: Said SAM, Wikimedia Commons (CC BY 4.0).

Why It Matters

- Without treatment, dysautonomia limits daily life. Many patients cannot stand for more than a few minutes.
- POTS in young women is often labeled anxiety or panic disorder. Diagnosis is delayed 4 to 6 years on average. The right diagnosis leads to real treatment.
- Low blood pressure on standing causes falls. Falls are the top cause of injury death in adults over 65.
- Multiple system atrophy is the worst form. Average survival is 6 to 9 years from when symptoms start.
- Most POTS patients improve with treatment. Salt, fluids, and exercise help 50 to 80 percent of patients within 12 to 24 months.
- Post-COVID dysautonomia may involve autoimmune damage. Treating the cause may speed up recovery.

Risk Factors

Some patients are more likely to develop this condition. Knowing your risk helps your care team take extra precautions.

Risk Factor	Why It Increases Risk
Female sex, ages 15–50	POTS is 5 times more common in women. Peak onset is in the teen years and early adulthood. Hormone changes affect nerve tone.
Viral illness / COVID-19	Post-viral POTS is the fastest-growing type. COVID-19 can damage autonomic nerves through immune and clotting injury.
Prolonged bed rest / deconditioning	Bed rest shrinks blood volume fast. POTS can develop in days to weeks. It is common after illness or surgery.
Hypermobile Ehlers-Danlos syndrome (hEDS)	Loose joints let blood pool in veins more easily. POTS occurs in 30 to 40 percent of hEDS patients.
Diabetes mellitus (long-standing)	Diabetic nerve damage affects about 20 percent of patients within 10 years. It causes low standing blood pressure, fast resting heart rate, and slow stomach emptying.
Autoimmune conditions	Sjögren's syndrome, lupus, and small fiber neuropathy can damage autonomic nerves. Certain immune proteins are found in some POTS patients.
Mast cell activation syndrome (MCAS)	MCAS often occurs alongside POTS. Mast cell chemicals cause blood vessels to widen, making symptoms worse.
Medications	Alpha-blockers, diuretics, and some antidepressants can worsen low standing blood pressure. Review all medicines with your doctor.

Treatment Options

- Fluid and salt are the foundation of POTS treatment. Drink 2 to 3 liters of water daily. Take 3,000 to 10,000 mg of sodium daily. Ask your doctor about your sodium goal if you have high blood pressure or heart disease.
- Wear waist-high compression stockings (30 to 40 mmHg) or an abdominal binder. Put them on before getting out of bed. Higher compression gives more benefit.
- Exercise is the most powerful long-term treatment. Start with recumbent exercise: rowing, swimming, or recumbent cycling. Aim for 30 minutes, 3 times per week. Most POTS patients cannot do upright exercise at first.
- Fludrocortisone (0.05 to 0.2 mg daily) helps kidneys hold more salt and water. It is a first-line drug for POTS and low standing blood pressure. Watch for low potassium and high lying-down blood pressure.
- Midodrine (2.5 to 10 mg, three times daily) tightens blood vessels. It raises blood pressure and cuts the drop when standing. Do not lie down within 4 hours of a dose.
- Low-dose beta-blockers (propranolol 10 to 20 mg) or ivabradine lower the fast heart rate in POTS. Ivabradine (5 to 7.5 mg twice daily) is preferred for hyperadrenergic POTS. It slows heart rate without lowering blood pressure.
- Pyridostigmine (30 to 60 mg twice daily) boosts nerve signals in the autonomic system. It has a mild effect on POTS with few side effects. It is a good option for patients who cannot take vasopressors.
- IV saline (0.9 to 2 liters) gives fast relief during severe episodes. It is not a long-term fix.
- Treat the root cause. Options include immune therapy for autoimmune POTS, antihistamines for MCAS, and better diabetes control.

Comfort Measures at Home (No Medication Needed)

These simple steps support healing and ease symptoms. Use them alongside any medication your doctor prescribes.

- Before standing, squeeze your leg and belly muscles for 5 to 10 seconds. This pumps blood back to the heart before your ANS can lag.
- While standing, cross your legs and squeeze them together. Or stand with feet apart and lean slightly forward. Both moves reduce blood pooling in the legs.
- Raise the head of your bed 20 to 30 degrees using blocks under the frame. Do not use extra pillows alone. This helps your kidneys hold more salt during the night.
- Drink 16 oz of cold water quickly before you stand for a long time. Cold water tightens blood vessels. This effect lasts 30 to 45 minutes.
- Avoid heat. Hot showers, saunas, and hot baths widen blood vessels. They make POTS much worse. Use cool or lukewarm water instead.
- Eat small meals often. Large meals pull blood to the gut and can drop your blood pressure. Limit refined carbs and alcohol.
- Salty snacks are easy salt sources. Try pickles, olives, salty crackers, or electrolyte drinks. Liquid IV and LMNT are popular options.
- During long standing, shift weight between feet, do calf raises, or march in place. This works the leg muscle pump.
- Know your warning signs before fainting: dizziness, gray vision, sweating, and nausea. Lie down at once. Raise legs above heart level. This stops most fainting spells.
- Keep a symptom journal. Write down time of day, meals, heat, and missed medicines. Patterns help your care team improve your plan.

Risks, Benefits, and Alternatives

Every choice has trade-offs. Use this table to start the shared decision conversation.

Option	Risks	Benefits	Alternatives
Fluids + sodium + compression	Too much sodium can raise blood pressure or worsen heart failure. Compression garments must be worn every day and can feel tight.	First-line treatment. No drug side effects. Works well for mild to moderate POTS. Targets the root cause: low blood volume.	Try medicines or exercise if symptoms persist.
Fludrocortisone	Risks: low potassium, high lying-down blood pressure, fluid weight gain, and ankle swelling. Avoid in heart failure or kidney disease.	Boosts blood volume. First-line drug for POTS and low standing blood pressure. Low cost and widely available.	Midodrine, pyridostigmine, or more dietary sodium. Combine with fluids for best effect.
Midodrine	Risks: high lying-down blood pressure, goosebumps, and scalp tingling. Avoid in severe heart disease or kidney disease.	Raises standing blood pressure by squeezing blood vessels. Works fast — relief in 30 to 45 minutes. Good for low-flow POTS and low standing blood pressure.	Fludrocortisone, pyridostigmine, or droxidopa for neurogenic low standing blood pressure.
Beta-blockers / Ivabradine	Beta-blockers may cause fatigue and worsen low standing blood pressure. Ivabradine may cause light flashes or slow the heart too much.	Lowers the fast heart rate in POTS. Ivabradine is preferred for hyperadrenergic POTS. It lowers heart rate without affecting blood pressure.	Pyridostigmine or midodrine for volume-dependent POTS.

Common Misconceptions

Myth	Reality
Dysautonomia is just anxiety.	Anxiety and POTS share some symptoms, like fast heart rate and dizziness. But POTS is a real physical disorder. It is confirmed by heart rate and blood pressure changes on a tilt table test. Many POTS patients develop anxiety after years of missed diagnosis. Treating anxiety alone does not treat POTS.
A high heart rate means a dangerous arrhythmia.	In POTS, the fast heart rate is a reflex. Blood pools in the legs when you stand. The heart speeds up to compensate. The rhythm is normal — just fast. It is called sinus tachycardia. It is not a sign of heart disease.
I just need to exercise more and push through it.	Upright exercise often makes POTS worse early on. The right program starts with recumbent exercise: rowing, swimming, or cycling. This builds fitness without triggering symptoms. Pushing through upright exercise too soon causes flares.
Dysautonomia is rare.	POTS alone affects 1 to 3 million Americans. Low standing blood pressure affects more than 20 percent of adults over 65. Post-COVID autonomic problems affect millions worldwide. Together, these are among the most under-diagnosed heart and nerve conditions.
A tilt table test will give us all the answers.	The tilt table test confirms the problem and shows the type. But it does not always find the cause. More tests may be needed: nerve studies, skin biopsy, blood tests, and heart echo.
Salt and fluids alone will cure POTS.	For mild POTS, fluids and salt are often enough. For moderate to severe POTS, most patients also need exercise and at least one medicine. The goal is better function, not always a full cure.

Myth	Reality
Dysautonomia goes away on its own.	Post-viral and post-COVID POTS can improve within 12 to 24 months. Teen-onset POTS often improves after puberty. But POTS from Ehlers-Danlos or autoimmune nerve damage needs long-term management. It does not resolve on its own.

Possible Complications

Knowing what can go wrong helps you spot problems early. Most complications are uncommon, especially with treatment.

Where / What	What Can Happen
Falls and injuries	Low standing blood pressure and fainting cause falls. Falls are the top cause of injury death in older adults. Lifestyle changes and medicine adjustments cut this risk.
Fainting and injury	Unprotected falls during fainting can cause head injuries and fractures. Learning your warning signs and lying down fast prevents most episodes.
Deconditioning	POTS creates a harmful loop: symptoms lead to less activity, which worsens symptoms. Breaking the loop with guided recumbent exercise is key.
Anxiety and depression	Years of missed diagnosis and daily symptoms often cause anxiety and depression. Mental health support is a real part of good care.
High lying-down blood pressure	Midodrine and fludrocortisone can raise blood pressure when you are flat. Keep the head of the bed raised and avoid lying down within 4 hours of midodrine.
Progression to MSA	Multiple system atrophy is a serious brain disease. Average survival is 6 to 9 years. Focus on symptom control and get neurology care early.

Points to Know

If you remember nothing else, remember these key points.

- Drink 2 to 3 liters of water AND meet your salt goal every day. This is the single most important step for POTS and mild low standing blood pressure.
- Wear waist-high compression stockings (30 to 40 mmHg) before getting out of bed. An abdominal binder also helps — blood pools in the belly too.
- Start a recumbent exercise program: rowing, swimming, or recumbent cycling. Aim for 3 to 5 sessions per week. It is the best long-term treatment.
- Raise the head of your bed 20 to 30 degrees using blocks. This cuts overnight fluid loss and improves morning symptoms.
- Drink 16 oz of cold water fast before long periods of standing. It protects you for 30 to 45 minutes.
- Heat is your enemy. Hot showers, saunas, and high temperatures make POTS worse. Plan ahead and cool down fast.
- At the first sign of fainting — dizziness, gray vision, nausea — lie down right away. Raise your legs above your heart. Do not try to stay upright.
- Track patterns: time of day, meals, heat, and missed medicines. Bring the log to every visit.

When to Call Us - and When to Call 911

If you are not sure, call. We would rather hear from you twice than miss a real problem.

- Fainting (passing out) — call us. Any new fainting episode needs an evaluation.
- Heart rate at rest above 120 bpm for more than 30 minutes — call us.
- Blood pressure below 80/50 mmHg or ongoing dizziness despite treatment — call us.
- Chest pain, severe shortness of breath, or sudden one-sided weakness — call 911.
- New nerve symptoms: slurred speech, double vision, trouble swallowing, or sudden weakness — call 911.
- Symptoms much worse than usual for more than 24 hours with no clear cause — call us.
- Unable to keep fluids down due to nausea or vomiting and symptoms are getting worse — call us or go to urgent care.
- Bad side effects from medicines (severe headache lying down, blood pressure above 180/110, or chest pressure) — call us before taking the next dose.

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Trusted Resources

The links below are the trusted resources Dr. Ali used to write this guide and that he recommends you visit for more information. Each is a clickable link in the digital version and a Short.io tracked URL on the printed version.

- Dysautonomia International - Top patient advocacy group — doctor directory, research updates, patient community, and treatment guides.
- Mayo Clinic — Postural Tachycardia Syndrome (POTS) - Clear overview of POTS: symptoms, causes, and treatment.
- Cleveland Clinic — Dysautonomia - Full overview of dysautonomia types and when to get help.
- Vanderbilt Autonomic Dysfunction Center - Leading US center for autonomic disorders — research, patient help, and doctor referrals.
- Standing Up to POTS — Patient Community - Patient-led resources, exercise plans, and diet guides for POTS.

Sources Used to Build This Guide

Every recommendation in this guide is grounded in one or more of the studies, guidelines, or trusted resources below. Short links are tracked so Dr. Ali can see which references patients are reading; nothing personally identifying is captured.

- Freeman R et al. Consensus Statement on the Definition of Orthostatic Hypotension, Neurally Mediated Syncope and the Postural Tachycardia Syndrome (Auton Neurosci 2011) *[Consensus Statement]*
  Defines diagnostic criteria for orthostatic hypotension, POTS (HR increase ≥ 30 bpm within 10 min of standing), and neurally mediated syncope.
- Raj SR. Postural Tachycardia Syndrome (POTS) (Circulation 2013) *[Review]*
  Comprehensive POTS overview: epidemiology (predominantly young women), pathophysiology subtypes (hyperadrenergic, hypovolemic, neuropathic), and management.
- Sheldon RS et al. 2015 Heart Rhythm Society Expert Consensus Statement on the Diagnosis and Treatment of Postural Tachycardia Syndrome, Inappropriate Sinus Tachycardia, and Vasovagal Syncope *[Guideline]*
  HRS expert consensus on diagnosis and management of POTS and vasovagal syncope — primary evidence basis for pharmacological and non-pharmacological recommendations.
- Benarroch EE. Postural Tachycardia Syndrome: A Heterogeneous and Multifactorial Disorder (Mayo Clin Proc 2012) *[Review]*
  Heterogeneous pathophysiology of POTS — three subtypes (neuropathic, hyperadrenergic, autoimmune/mast cell); supports individualized management approach.
- Lahrmann H et al. EFNS Guidelines on the Diagnosis and Management of Orthostatic Hypotension (Eur J Neurol 2006) *[Guideline]*
  European guidelines for orthostatic hypotension: non-pharmacological (compression, head-up tilt sleeping) and pharmacological (fludrocortisone, midodrine) management.
- Low PA, Sandroni P. Autonomic Neuropathies (Continuum 2012) *[Review]*
  Classification of autonomic neuropathies including pure autonomic failure (PAF), multiple system atrophy (MSA), and diabetic autonomic neuropathy; prognosis differs significantly.
- Vernino S et al. Autoimmunity in Postural Orthostatic Tachycardia Syndrome (PACE 2012) *[Review]*
  Autoimmune mechanisms in a subset of POTS — anti-ganglionic AChR antibodies, post-infectious POTS; relevant for COVID-19 long-hauler dysautonomia.
- Goldstein DS et al. Dysautonomias: Clinical Disorders of the Autonomic Nervous System (Ann Intern Med 2002) *[Review]*
  Taxonomy of dysautonomias, differentiation from normal adrenergic tone variation, and catecholamine-based diagnostic approach.
- Boris JR, Bernadzikowski T. Demographics of a Large Paediatric Dysautonomia Population (Cardiol Young 2018) *[Cohort]*
  Pediatric and young adult onset data; highlights female predominance, symptom duration before diagnosis, and quality-of-life impact.
- Thieben MJ et al. Postural Orthostatic Tachycardia Syndrome: The Mayo Clinic Experience (Mayo Clin Proc 2007) *[Cohort]*
  Largest single-center POTS series; natural history, symptom burden, and functional outcomes.

- Bryarly M et al. Dysautonomia: Cardiovascular Manifestations and Differential Diagnosis (JACC 2019) *[Review]* Cardiologist-focused review covering cardiovascular manifestations of dysautonomia, differential diagnosis from cardiogenic causes, and diagnostic workup.

About This Guide

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Reviewer note: Reviewed against Dysautonomia International, Cleveland Clinic autonomic disorders page, and Mayo Clinic POTS resources. Ours adds: subtype taxonomy table, non-pharmacological protocol in ranked priority order, Valsalva/tilt-table explainer, and post-COVID dysautonomia section.

Disclaimer

This guide is for educational purposes only and does not replace medical advice from your physician. Recommendations may not apply to every patient. Always follow the specific instructions of Dr. Ali and your care team. In an emergency call 911 or go to the nearest emergency department.

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