

One-Page Clinical Summary – POTS & hEDS: The Postural Spiral

Understanding Circulatory Dysregulation in Hypermobile Bodies

If you have **hypermobile Ehlers-Danlos Syndrome (hEDS)** and experience **dizziness, rapid heart rate, fatigue, or brain fog when you change posture**, you might be dealing with a form of **dysautonomia** called **POTS (Postural Orthostatic Tachycardia Syndrome)**. It's one of the most common, yet misunderstood, co-conditions seen in hEDS patients.

This resource explains what POTS is, why it happens, and how it may be part of a bigger pattern of circulatory collapse in connective tissue disorders.

What is POTS?

POTS stands for **Postural Orthostatic Tachycardia Syndrome**. It's a condition where:

- Heart rate increases **30+ bpm within 10 minutes of standing** (or 40+ bpm in teens)
- Blood pressure may stay normal or fluctuate
- Blood pools in the lower body, reducing brain perfusion
- Symptoms improve when lying flat or with increased fluid/salt intake

POTS is diagnosed through **active stand tests** (like the NASA Lean or MALMO protocols) and sometimes tilt-table testing. It's more common in **young women and people with connective tissue disorders**.

Why Is It Linked to hEDS?

In hEDS, **connective tissue is more stretchy and less supportive**, including in blood vessels, fascia, and valves. This means:

- **Blood vessels dilate or collapse more easily**
- **Fascia doesn't maintain vascular tone**
- **Venous return to the heart becomes sluggish**, especially on standing
- Neurovascular signalling is delayed or inconsistent

This results in **reduced blood flow to the brain**, leading to dizziness, fatigue, brain fog, and anxiety-like symptoms.





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What Does It Feel Like?

People with POTS may experience:

- Dizziness, especially when standing
- Racing or pounding heart
- Brain fog and blurry vision
- Shortness of breath or "air hunger"
- Shakiness, nausea, or tremors
- Fatigue that worsens with upright activity

Some describe it as their body being **allergic to standing up**.

The Spiral Collapse Theory

In hEDS, many systems are underpinned by **fascial and fluid balance**. When posture shifts:

- Blood pools in the lower extremities
- Fascia fails to rebound or support return flow
- The **ECM loses pressure stability**, disrupting brain and nerve perfusion

This may trigger **mast cell activation**, worsening symptoms further. It's a **systemic spiral** — not just "low blood pressure".

What Helps?

Non-Medical Supports:

- **Increase salt and water** (if safe)
- **Electrolyte solutions or oral rehydration salts**
- **Waist-high compression garments** (not just calf)
- **Reclined or horizontal exercise** (bike, pool, rebounding)
- **Avoid long hot showers or sudden posture shifts**
- **Pacing and energy management**



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Medical Management (Doctor Guided):

- Beta blockers (e.g. propranolol)
- Fludrocortisone, midodrine, or ivabradine
- Treat overlapping conditions (MCAS, low B12/iron, deconditioning)

ConnectED Tools

The **ConnectED App** helps you:

- Track symptoms daily and across posture/activity
- Prepare reports for your GP or specialist
- Log hydration, salt intake, and flare triggers

What Science Says

- POTS may stem from **neurovascular miscommunication** in hypermobile bodies
- Fascia and ECM collapse may be part of the reason vessel tone fails
- Many patients are misdiagnosed with anxiety or panic disorders
- Treatment requires **multi-system awareness**

This page is for education only and is not a substitute for medical care. Please consult your healthcare provider for advice specific to your needs.

About the Author

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Tracy is an intensive care nurse and systems thinker with lived experience of hypermobile Ehlers-Danlos syndrome (hEDS), dysautonomia, and mast cell activation. She is the founder of **ConnectED Health**, an initiative combining clinical research, patient insight, and AI technology to improve diagnosis and care for complex, multisystemic conditions. Tracy works collaboratively with researchers and clinicians to bridge the gap between emerging science and real-world patient care.