

Caregiver Guidance: Supporting Autonomic Crises in hEDS/POTS

Purpose

This actionable guide is intended to support someone in a caregiving role during episodes of autonomic instability in a person with hypermobile Ehlers-Danlos Syndrome (hEDS) and POTS. It's not intended for diagnostic use but rather to ensure safe, trauma-informed support and coordination until clinical care is possible.

1. Know the Profile

- hEDS often comes with **autonomic dysfunction**: rapid heart rate, blood pressure swings, digestive issues, brain fog, fatigue, and temperature dysregulation.
- Episodes may feel like a “neurochemical storm,” driven by mast cell activation, acetylcholine imbalance, and metabolic bottlenecks.

2. Red Flags for Escalation

Call Emergency Services (000 in Australia) Immediately If:

- Sudden or worsening **double vision, arm weakness, confusion, slurred speech, or coordination loss**
- HR > 120 bpm or blood pressure > 150/90 mmHg for prolonged periods
- Severe abdominal pain, vomiting blood, or bloody stool
- Acute onset of burning urination, chills, or fever
- Consciousness changes or inability to stand or walk safely
- Seizures
- If your gut tells you something is very wrong.

Even if vitals appear somewhat stable, neurological or systemic red flags matter. In hEDS/POTS, invisible instability is still instability.

3. Roles During a Crisis

Task	Description
Vital Monitoring	Every 10–15 mins: BP, HR, temp, respiratory rate, oxygen saturation (if available)
Hydration & Salt	Encourage drinking two cups electrolyte solution or water + $\frac{1}{4}$ – $\frac{1}{2}$ tsp salt; monitor intake and urine colour
Support & Grounding	Use calm tones, offer small reassurance, encourage breathing exercises, avoid rushing stimuli
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Medication Prep	Keep rescue meds visible and gather dosing info; avoid triggering ambient noise or bright lights
Handover Prep	Print or have the Home Triage Summary available to summarise history clearly for ED staff
Emotional Anchor	Remind your person that you believe and are here, especially given medical trauma or PTSD

4. Self-Care for You

- You're not just a support role, you're your own person too. You *can* take breaks.
- Get clear rest periods; practice grounding breathing, hydration, light lunch or tea breaks.
- Consider connecting with *EDS caregiver communities* or peer support groups.

5. Preventative Support Suggestions

- Support maintenance of regular hydration (2–3 L/day) and salt intake (~10 g NaCl/day)
- Assist with *upright isometric pump exercises* before standing (e.g., toe raises, leg crossing)
- Encourage consistent compression garments (e.g., thigh-high socks or abdominal binder) if tolerated
- Create a pre-crisis comfort kit: electrolyte drink, P5P/Vit C, antihistamine, rescue meds, cooling packs, light blanket



6. Communication Tips

- Speak slowly, gently, framing time as “just a few quiet minutes” to avoid overstimulation
- Ask simple, validating questions: “*Can I get you another drink?*” — offers care without pressure
- When fear escalates, validate: “*I’m right here, we have your plan, you are not alone.*”

References

- Ehlers-Danlos Society: Emergency Care resources and guidance for HCPs
- NHS & POTS UK: Standards and self-management approaches for dysautonomia in hEDS/POTS
- Eccles, J. (2023). Coping with Autonomic Symptoms: HSD Summit, Ehlers-Danlos Society.

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.