Hypermobile Ehlers-Danlos Syndrome (hEDS)

A Patient Guide for Physical Therapists

WHAT IS hEDS? hEDS is a heritable disorder of connective tissue, the structural 'glue' of the body, causing joint instability, skin fragility, and systemic effects. Severity varies widely, from mild laxity and intermittent bracing to wheelchair use and complex multisystem involvement. Standard PT protocols designed for the general population can cause serious harm in hEDS patients (including HSD).

~1 in 500 people affected	Avg. 10+ years to diagnosis	3:1 to 4:1 diagnosed are female	No cure: management-focused

HOW HEDS AFFECTS THE BODY — SYSTEMIC INVOLVEMENT:

Patient has checked applicable symptoms

Neurological

- ☐ Migraines & headaches
- ☐ Brain fog/cognitive fatigue
- ☐ Small fiber neuropathy
- ☐ Proprioception deficits
- ☐ Anxiety/depression (often neurological in origin)

Gastrointestinal

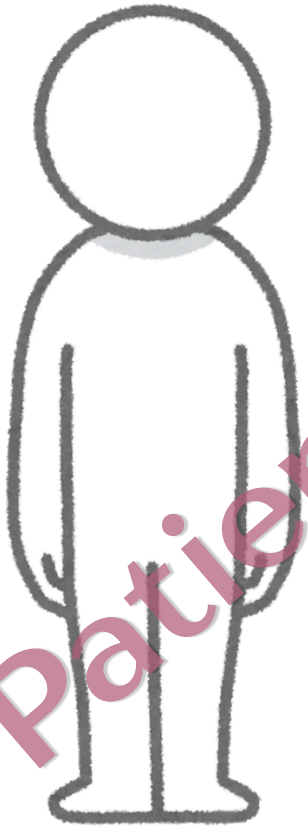
- ☐ IBS
- ☐ Gastroparesis/ delayed emptying
- ☐ GERD & acid reflux
- ☐ Food intolerances

Immune / MCAS

- ☐ MCAS — mast cell overactivation
- ☐ Flushing, hives, itching
- ☐ GI distress & food reactions
- ☐ Chemical/environmental sensitivity

Fatigue & Sleep

- ☐ Profound fatigue
- ☐ Non-restorative sleep
- ☐ Post-exertional malaise
- ☐ Chronic widespread pain at rest



Cardiovascular

- ☐ POTS — heart rate spikes on standing
- ☐ Blood pooling & dizziness
- ☐ Palpitations

Dermatological

- ☐ Soft, velvety, hyperextensible skin
- ☐ Stretch marks without weight change
- ☐ Easy bruising
- ☐ Poor wound healing

Genitourinary

- ☐ Pelvic floor dysfunction
- ☐ Bladder urgency/frequency
- ☐ Chronic pelvic pain
- ☐ Menstrual irregularities

Musculoskeletal

- ☐ Chronic widespread pain
- ☐ Subluxations & dislocations
- ☐ Muscle fatigue & weakness
- ☐ Joint hypermobility & instability
- ☐ Cervical instability (may contribute to headache, cranial nerve symptoms, or myelopathy)

The hEDS Trifecta: Frequently Co-Occurring Conditions

hEDS	+	POTS	+	MCAS
Joint instability Structurally abnormal connective tissue Systemic symptoms		Heart rate spikes on standing Dizziness & fatigue Brain fog & cognitive dysfunction Exercise intolerance		Mast cell overactivation Flushing, hives, itching GI distress & food reactions Chemical/environmental sensitivity

Standard PT Can Harm hEDS Patients In hEDS, joints are structurally unstable due to abnormal connective tissue, not muscle weakness alone. Protocols designed to push range of motion, load unstable joints, or work through pain can cause subluxations, dislocations, and prolonged flares. Post-exertional malaise means a patient may feel fine during a session and be bed-bound the next day. The Muldowney Protocol was developed specifically for EDS and hypermobility patients and provides a sequenced, joint-protective framework. If you are unfamiliar with hEDS-specific PT, this is the recommended starting point.

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DO

- Treat whole body, not just presenting joint
- Use low-load, high-rep strengthening to build stability without stressing joints
- Prioritize proprioceptive retraining; position sense is frequently impaired
- Respect post-exertional malaise: a good session can cause a multi-day flare
- Use bracing and taping to support unstable joints during exercise
- Consider aquatic therapy to reduce joint load
- Familiarize yourself with the Muldowney Protocol for hEDS
- Address pelvic floor dysfunction; refer to pelvic floor PT specialist if needed
- Monitor for signs of mast cell reaction during exercise: flushing, hives, itching, or GI symptoms. Exertion can trigger MCAS in some patients.

DON'T

- Apply standard strengthening protocols; they are frequently inappropriate for hEDS
- Push through pain; pain in hEDS is a signal, not a barrier to overcome
- Focus only on the referring complaint; instability is systemic
- Use high-impact or ballistic exercises
- Interpret a good session as progress if the patient crashes afterward
- Assume the patient is deconditioned due to inactivity; fatigue and malaise are physiological, not motivational
- Dismiss subluxations or dislocations during session as exaggeration

TREATMENT APPROACH: SESSION SEQUENCING & COORDINATION

- Stabilize proximal joints before progressing to distal
- Start load and duration lower than you think necessary; build a pacing plan with the patient
- Incorporate proprioceptive and balance work throughout every session
- Reassess frequently; hEDS symptoms fluctuate significantly between sessions
- Assess pelvic floor dysfunction; refer to pelvic floor PT specialist if needed
- Coordinate with pain management and rheumatology as appropriate
- Consider aquatic therapy during high-symptom periods
- Use the Muldowney Protocol or equivalent hEDS-specific framework as your starting structure

Sources: Malfait et al. 2017 (AJMG) | Tinkle et al. 2017 (AJMG) | Genetics in Medicine Open 2025 | ehlers-danlos.com | [illegible] | [illegible]

This document was created to provide a focused reference for physical therapists less familiar with hEDS.
Standard PT protocols can cause harm in this population. This reference is intended to support a safer, more effective treatment approach.

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MY CURRENT MEDICATIONS & SUPPLEMENTS	WHAT HELPS:
	WHAT MAKES IT WORSE:

CURRENT BRACING & ASSISTIVE DEVICES: (braces, splints, compression garments, mobility aids)

WHAT I NEED FROM TODAY'S APPOINTMENT

My primary concern today:

Questions I have:

Treatment or activity modifications requested:

Referrals needed:

Other:

CURRENT SYMPTOM SEVERITY: (1-10 Refer to Mankoski Pain Scale (pg 4))

Joint Pain/Instability Pain Severity:

Fatigue Severity:

GI Symptoms Type/Frequency:

Heart rate/dizziness Triggers/Frequency:

Additional symptoms and concerns:

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MANKOSKI PAIN SCALE

Use this scale when rating your pain severity in CURRENT SYMPTOM SEVERITY

#	What the pain is like	Typical treatment	In my own words
0	No pain.	No medication needed.	"I feel completely normal."
1	Very minor annoyance — occasional minor twinges.	No medication needed.	"Hardly notice it."
2	Minor annoyance — occasional strong twinges.	No medication needed.	"Annoying but manageable."
3	Annoying enough to be distracting.	Mild OTC painkillers may help.	"Hard to ignore, affects my focus."
4	Can be ignored if very focused, but still distracting.	Mild OTC painkillers relieve pain for 3-4 hours.	"Getting in the way of tasks."
5	Can't be ignored for more than 30 minutes.	Mild OTC painkillers reduce pain for 3-4 hours.	"Stops me mid-task."
6	Can't be ignored. Can still go to work and participate in social activities.	Stronger prescription pain relief needed; works 3-4 hours.	"Present all the time. I push through."
7	Difficult to concentrate, interferes with sleep. Can still function with effort.	Stronger painkillers only partially effective.	"Hard to function. Sleep is disrupted."
8	Physical activity severely limited. Can read/converse with effort. Nausea possible.	Strongest painkillers minimally effective.	"Mostly bed-bound. May feel nauseated."
9	Unable to speak. Crying out or moaning uncontrollably. Near delirium.	Strongest painkillers only partially effective.	"Cannot communicate. Losing control."
10	Unconscious. Pain causes passing out.	Strongest painkillers only partially effective.	"Passed out or on the verge of it."

Mankoski Pain Scale developed by Andrew Mankoski, 1995. Adapted for patient communication. Not a clinical diagnostic tool.

IMPORTANT NOTE FOR HEDS PATIENTS & PROVIDERS:

People with hEDS often have an altered pain baseline due to central sensitization — a process in which the nervous system becomes increasingly sensitized to pain signals over time.

A "5" for this patient may be what others feel as a "8."
Please do not compare severity numbers to those of patients without chronic illness.

This scale helps us communicate.
It is not a measure of tolerance, willpower, or how "bad" things really are.

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