Hypermobile Ehlers-Danlos Syndrome (hEDS)

A Patient Guide for Psychiatrists & Psychologists

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.

~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

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

Genitourinary

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

Cardiovascular

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

Musculoskeletal

- ☐ Joint hypermobility & instability
- ☐ Subluxations & dislocations
- ☐ Chronic widespread pain
- ☐ Muscle fatigue & weakness
- ☐ Cervical instability (can cause neurological issues)

Dermatological

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

Fatigue & Sleep

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

DO

- Recognize anxiety and depression in hEDS as frequently secondary to undertreated physical illness
- Screen for ADHD and autism: both occur at significantly elevated rates in hEDS patients
- Apply a trauma-informed framework: many hEDS patients carry significant diagnostic trauma from years of dismissal
- Validate the physical reality of the patient's condition before addressing psychological responses to it
- Coordinate with rheumatology, neurology, and pain management
- Recognize that cognitive symptoms (brain fog, memory difficulties) may have physiological origins
- Support the patient in navigating the medical system; advocacy fatigue is real and debilitating

DON'T

- Diagnose somatic symptom disorder in a patient with undiagnosed or undertreated hEDS
- Attribute physical symptoms to anxiety or depression without ruling out physiological causes
- Close the case psychologically once a mental health diagnosis is made
- Interpret a patient's emotional distress about their physical symptoms as evidence those symptoms are psychogenic
- Dismiss cognitive complaints as purely anxiety-related without considering dysautonomia and central sensitization
- Treat psychological symptoms in isolation without acknowledging the chronic illness context
- Assume that improvement in mood means physical symptoms were psychologically driven

CONSIDER / REFER

- Trauma-informed therapy for diagnostic trauma and medical PTSD
- CBT adapted for chronic illness: not standard CBT, which can pathologize illness behavior
- ACT (Acceptance and Commitment Therapy) for chronic pain and illness adjustment
- Coordination with pain management regarding central sensitization and psychological amplification
- Referral back to rheumatology or neurology if physical symptoms remain inadequately explained or treated

COMMON MISDIAGNOSES IN hEDS PATIENTS PRESENTING TO PSYCHOLOGY AND PSYCHIATRY		
Often Diagnosed As	**Consider Instead/Also**	**Key Differentiator**
Somatic Symptom Disorder	Undiagnosed or undertreated hEDS	Physical symptoms have a documented connective tissue basis; SSD requires ruling out organic cause first
Health Anxiety / Illness Anxiety Disorder	Appropriate illness monitoring in a patient with real, fluctuating symptoms	Patients with hEDS have legitimate reason to track symptoms; vigilance is adaptive, not pathological
Conversion Disorder	Dysautonomia, small fiber neuropathy, cervical instability	Neurological symptoms in hEDS have identifiable physiological mechanisms
Borderline Personality Disorder	ADHD, autism, and chronic illness trauma	Emotional dysregulation and intense medical advocacy in hEDS patients frequently reflects undertreated neurodivergence and diagnostic trauma; a BPD diagnosis should not preclude physical illness workup
Factitious Disorder / Malingering	Complex multisystem illness with inconsistent objective findings	hEDS symptoms fluctuate day to day and are frequently invisible on standard testing; this is a feature of the condition, not evidence of fabrication
Treatment-Resistant Depression	Depression secondary to undertreated physical illness	Mood symptoms that do not respond to psychiatric treatment alone warrant physical illness review
Panic Disorder	POTS, MCAS	Tachycardia, flushing, and autonomic surges have physiological triggers in this population
Generalized Anxiety Disorder	Anxiety secondary to chronic pain, dysautonomia, and medical dismissal	Anxiety that developed after or alongside physical symptoms warrants physical workup before a primary anxiety diagnosis is assigned

Anxiety, Depression, and hEDS: Consequence, Not Cause Anxiety and depression are common in hEDS, but the direction of causation matters clinically. Autonomic dysfunction, chronic pain, central sensitization, and years of medical dismissal are each independently sufficient to produce significant psychological distress. Attributing physical symptoms to anxiety in a patient with undiagnosed hEDS does not resolve the anxiety, it compounds it. Trauma-informed care that validates the physical reality of the patient's condition first, and addresses psychological responses to that reality second, produces meaningfully better outcomes than frameworks that treat the psychological presentation as primary.

ADHD, Autism, and Connective Tissue: An Emerging Association Research increasingly supports a significant overlap between hEDS and neurodevelopmental conditions including ADHD and autism spectrum disorder. Proposed mechanisms include shared autonomic nervous system dysregulation, connective tissue involvement in neural architecture, and overlapping genetic pathways. Clinically, this means a psychiatric evaluation for a patient with hEDS should routinely include screening for ADHD and autism, not as incidental findings, but as statistically likely comorbidities. Identifying and treating neurodivergence in this population can significantly improve quality of life and reduce the burden of symptoms that have often been misattributed to anxiety or personality factors.

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

This document was created to provide clinical context for providers less familiar with the psychiatric and psychological dimensions of hEDS. Anxiety, depression, and cognitive symptoms in this population frequently have physiological origins. This reference is intended to support evaluation that reflects that reality.

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

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

WHAT I NEED FROM TODAY'S APPOINTMENT

My primary concern today:

Questions I have:

Medication changes:

Referrals needed:

Other:

CURRENT SYMPTOM SEVERITY: Rate 0–10 using the Workbook Pain Scale (pg. 4)

Mood Severity (depression, emotional dysregulation):

Anxiety Severity (generalized, situational, medical):

Cognitive Symptoms (brain fog, memory, concentration):

Sleep Quality and Disruption:

Pain Severity (current baseline):

Fatigue Severity:

Additional Symptoms:

Sources: Malfait et al. 2017 (JAMG) | Tofts et al. 2017 (JAMG) | Genetics in Medicine Open 2025 | ehlers-danlos.com | PMC7895047 | PMC7568549

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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 Andrea 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.