Hypermobile Ehlers-Danlos Syndrome (hEDS)

A Patient Guide for OB/GYN Providers

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

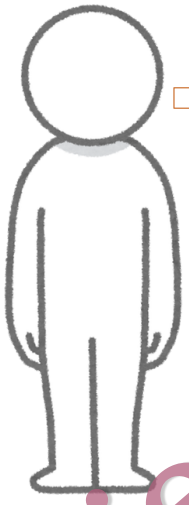
- ☐ IBS
- ☐ Gastroparesis/ delayed emptying
- ☐ GERD & acid reflux
- ☐ Food intolerances

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

Dermatological

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

Fatigue & Sleep

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

Musculoskeletal

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

DO

- Anticipate increased joint instability and symptom flares during pregnancy. Relaxin amplifies connective tissue laxity significantly
- Plan delivery with tissue fragility and wound healing in mind
- Ask about anesthesia resistance before epidural placement or surgical procedures
- Monitor for pelvic girdle instability throughout pregnancy and postpartum
- Refer to pelvic floor PT specializing in hypermobility early, before and after delivery
- Coordinate with rheumatology, pain management, and cardiology for complex pregnancies

DON'T

- Dismiss menstrual irregularities or heavy bleeding without investigating hormonal and connective tissue contributions
- Attribute chronic pelvic pain solely to endometriosis or fibroids without considering pelvic floor dysfunction and hEDS
- Assume standard episiotomy and surgical repair timelines apply. Tissue fragility affects healing significantly
- Use standard epidural dosing without first asking about anesthesia resistance
- Recommend high-impact exercise during pregnancy without considering joint instability
- Overlook MCAS as a contributor to pregnancy complications and medication sensitivities

CONSIDER / REFER

- Pelvic floor PT referral early in pregnancy and postpartum
- Endometriosis evaluation if pelvic pain is present
- Pelvic girdle support belt and mobility aid planning for pregnancy
- Rheumatology coordination for complex or high-symptom pregnancies
- Cardiology referral if POTS symptoms worsen during pregnancy
- Modify delivery planning: shorter push phases, positioning accommodations, wound closure technique adjusted for tissue fragility
- Extended postpartum monitoring for wound dehiscence and delayed healing
- Pain management coordination for labor and postoperative pain in patients with central sensitization
- Low histamine and MCAS-aware medication review if reactions to prenatal supplements or medications occur
- Progesterone and hormonal management discussion for patients with cycle-linked symptom flares

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

Pregnancy Amplifies hEDS: Planned Management Changes Outcomes
Relaxin, the hormone that loosens ligaments in preparation for delivery, is produced throughout pregnancy and acts systemically in hEDS patients whose connective tissue is already lax. The result is frequently a dramatic increase in joint instability, subluxations, pelvic girdle pain, and autonomic symptoms during pregnancy and postpartum. This is not typical pregnancy discomfort; it is a physiological amplification of an existing connective tissue disorder. Early PT referral, mobility planning, delivery accommodation, and postpartum monitoring are not optional extras for hEDS patients; they are standard of care. Postpartum flares can be severe and prolonged; patients should be counseled to expect this and supported proactively rather than reactively.

Endometriosis, Cycle-Linked Flares, and hEDS Endometriosis occurs at significantly elevated rates in hEDS patients and shares a pattern of delayed diagnosis and frequent dismissal. Both conditions disproportionately affect women, both produce symptoms that are frequently attributed to anxiety or normal variation, and both benefit from early intervention. Separately, many hEDS patients experience significant symptom worsening in the luteal phase of their menstrual cycle. Progesterone and estrogen affect connective tissue laxity; the drop in progesterone before menstruation is associated with increased joint instability, pain flares, and autonomic symptom worsening. This is a recognized physiological pattern, not psychosomatic cycling.

COMMON MISDIAGNOSES IN hEDS PATIENTS PRESENTING TO OB/GYN

Often Diagnosed As	Consider Instead/Also	Key Differentiator
Primary dysmenorrhea	hEDS with cycle-linked autonomic and connective tissue flares	Progesterone drop triggers joint instability and systemic worsening, not uterine cramping alone
Endometriosis (sole diagnosis)	hEDS with pelvic floor dysfunction and/or endometriosis	Both conditions coexist at elevated rates; pelvic floor dysfunction requires separate evaluation and treatment
Vaginismus or psychosexual disorder	hEDS pelvic floor hypertonicity	Hypertonic pelvic floor is a mechanical consequence of joint instability compensation, not a psychological condition
Vulvodynia	hEDS with small fiber neuropathy and central sensitization	Altered pain baseline; neuropathic and central sensitization mechanisms drive symptoms
Anxiety or somatic disorder	hEDS with POTS and autonomic dysfunction	Orthostatic symptoms, palpitations, and dizziness are physiological, not psychiatric; tilt table or active stand test differentiates
Medication or latex allergy	MCAS in the context of hEDS	Episodic multisystem reactions; responds to H1/H2 antihistamines; standard allergy panels typically negative
Typical pregnancy discomfort	hEDS pregnancy amplification	Relaxin acts systemically on already-lax connective tissue; symptoms reflect physiological amplification, not normal variation

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 OB/GYN providers less familiar with hEDS.
Pregnancy, hormonal cycling, and pelvic floor involvement each carry specific implications in this condition that this reference is designed to make quickly accessible.

Anesthesia and Surgical Risk in hEDS: Plan Ahead Anesthesia resistance is a recognized but poorly understood phenomenon in hEDS patients. Local anesthetics, including lidocaine, may be partially or fully ineffective, and higher doses may be required for adequate pain control. This applies to epidurals, local nerve blocks, and procedural anesthesia for in-office procedures such as IUD placement and colposcopy. Patients should be asked about prior anesthesia resistance before any procedure, not only surgical ones.

Tissue fragility in hEDS affects wound closure, healing timelines, and surgical outcomes. Sutures may not hold as expected; dehiscence and delayed healing are documented risks. Episiotomy repair, C-section closure, and laparoscopic port sites all require technique modification and extended postpartum monitoring. Standard recovery and return-to-activity timelines should not be assumed to apply.

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: Complete this section using the Mankoski Pain Scale (pg. 3)
Pelvic pain frequency and severity:
Period pain frequency and severity:
Pelvic floor symptoms, frequency and severity:
Additional symptoms:

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If currently pregnant or planning pregnancy: Use the Wankoski Pain Scale below for rating pain

Gestational week/trimester:

Current pregnancy symptoms/severity:

Primary concern for this pregnancy:

WANKOSKI 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 hrs.	"Getting in the way of tasks."
5	Can't be ignored for more than 30 min.	Mild OTC painkillers reduce pain for 3-4 hrs.	"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 hrs.	"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."

Wankoski Pain Scale developed by Andrea Wankoski, 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 "6."
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.