Understanding Hypermobile Ehlers-Danlos Syndrome (hEDS)

A Guide for Family & Friends

WHAT IS hEDS? hEDS is a genetic connective tissue disorder. Connective tissue is the structural framework that holds the body together. It is found in joints, skin, blood vessels, organs, and the gut. In hEDS, that framework does not function as it should, causing the body to work much harder than normal to maintain stability and function. It affects virtually every system in the body. There is currently no cure; management is the goal. Because connective tissue is everywhere, hEDS looks different for everyone. Some people need braces or mobility aids on difficult days, others appear to manage with little visible support. Both are the same condition.

~1 in 500 people affected	Avg. 10+ years to diagnosis	Affects every organ system	No cure: management-focused

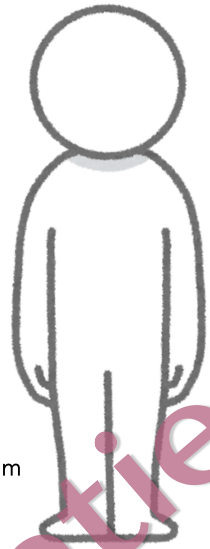
HOW HEDS AFFECTS THE BODY — SYSTEMIC INVOLVEMENT

Neurological
- ☐ Migraines & headaches
- ☐ Brain fog/cognitive fatigue
- ☐ Small fiber neuropathy
- ☐ Proprioception deficits
- ☐ Anxiety/depression

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

Musculoskeletal
- ☐ Joint hypermobility & instability
- ☐ Subluxations & dislocations
- ☐ Chronic widespread pain at rest (distinct from activity-related pain)
- ☐ Muscle fatigue & weakness
- ☐ Cervical instability (may contribute to headache, cranial nerve symptoms, or myelopathy)

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



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

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
- ☐ Pain at rest unrelated to exertion

WHAT hEDS FEELS LIKE

Area	What your loved one may experience
Pain	Widespread, constant, and variable; joints, muscles, and nerves. Often worse after activity or on waking. Not the same as ordinary soreness.
Fatigue	Profound exhaustion that sleep does not fix. The body expends enormous energy maintaining stability that others do not have to think about.
Joints	Joints that partially or fully dislocate; sometimes from ordinary movements like reaching, rolling over, or standing up.
Brain fog	Cognitive difficulty with memory, concentration, and word-finding. Real and neurological in origin, not emotional or motivational.
GI issues	Nausea, pain, bloating, and unpredictable digestion are common. Eating can be complicated and anxiety-inducing.
Heart rate	A significant number of hEDS patients also have POTS. Their heart rate spikes on standing, causing dizziness, presyncope, and exhaustion from simply being upright.
Sensory	Sensitivity to light, sound, smell, and temperature is common, especially when fatigued or during a flare.
Emotional	Living with chronic, invisible, invalidated pain takes a profound emotional toll. Anxiety and depression are common and understandable responses.

WHY IT IS INVISIBLE — AND WHY THAT MAKES IT HARDER

NEDS does not show up on most standard tests. There is no blood marker, no scan, no visible wound. Your loved one may look completely well while their body is working at an extraordinary effort just to get through the day. This is one of the most isolating aspects of the condition and one of the most commonly misunderstood.

WHAT INVISIBILITY ACTUALLY MEANS

- **Normal appearance:** The body compensates silently. Looking well does not mean feeling well.
- **Normal test results:** Standard labs and scans are usually normal. This does not mean nothing is wrong. NEDS requires specialist evaluation and is diagnosed clinically, not by bloodwork.
- **Variable symptoms:** Fluctuation is a feature of the condition, not evidence of exaggeration. Symptoms can change hour to hour based on activity, stress, hormones, and sleep.
- **Energy limits:** Many NEDS patients live with a severely limited energy budget. Activities that seem small can deplete that budget entirely and trigger days of recovery.

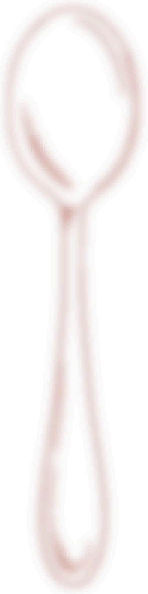
WHAT GOOD DAYS AND BAD DAYS MEAN

A good day is not recovery. It is the body coping better than usual, and it often comes at a cost.

- Overdoing it on a good day frequently causes a crash the following day or days later. This is called post-exertional malaise and it is physiological, not behavioral.
- Rest is not laziness. It is essential medical management.
- Pacing (deliberately managing activity levels to stay within the body's available energy) is a clinically recommended strategy for NEDS, not a personal preference or avoidance behavior.
- Appearing functional at an event may cost days of recovery that are invisible to everyone who saw them there.
- A good day followed by a bad day is not inconsistency. It is the nature of the condition.
- Weather, stress, hormones, and activity level all directly affect symptom severity.

What you can do with this knowledge: don't use a good day as evidence that things are improving, and don't use a bad day as evidence of giving up. Both are part of the same condition.

A NOTE ON ENERGY: SPOON THEORY



Spoon theory (originally described by Christine Miserandino, 2003) is a simple framework for understanding what it feels like to live with a limited and unpredictable energy supply. The idea is this: imagine starting each day with a fixed number of spoons, each one representing a unit of energy. Healthy people rarely count their spoons. They have enough that spending them doesn't require planning. People with chronic illness start with far fewer, and every activity costs one: getting dressed, making a meal, having a conversation, answering a text.

When the spoons are gone, they're gone. There is no pushing through to find more. And unlike healthy fatigue, sleeping doesn't reliably restore them.

What this means practically:

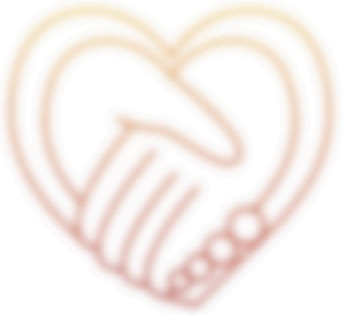
- Your loved one may have to choose between showering and cooking. Between attending an event and recovering from it. These are not dramatic choices. They are daily math.
- When they cancel plans, they are not prioritizing something else over you. They ran out of spoons.
- When they seem fine in the morning and exhausted by noon, the morning cost more than it looked like it did.

The goal isn't to count spoons for them. It's to understand that the counting is always happening, whether you can see it or not.

HOW TO SUPPORT SOMEONE WITH hEDS

PRACTICAL SUPPORT

- Offer specific help rather than "let me know if you need anything." People with chronic illness struggle to ask
- Adjust plans without making it a big deal. Flexibility is a genuine kindness
- Help with tasks that require physical effort: carrying, driving, standing in lines
- Understand that cancellations aren't personal, they are medical
- Learn what their triggers are and quietly help avoid them
- Ask what a good day looks like for them. It may be very different from what you expect



Emotional support is different from practical help, and often matters more.

EMOTIONAL SUPPORT

- Believe them. The most important thing you can do
- Do not compare their experience to your own tiredness or pain
- Acknowledge the grief involved in losing abilities and activities
- Do not make them feel guilty for resting, cancelling, or needing accommodations
- Check in on bad days without expecting them to perform gratitude
- Understand that they are not their illness. Ask about their interests, not just their symptoms
- Your willingness to learn and understand matters.

DURING A FLARE: don't try to fix it. Ask "is there anything you need right now?" and accept "nothing" as a complete answer. Quiet presence is often more helpful than action.

WHAT NOT TO SAY -- AND WHAT HELPS INSTEAD

Instead of saying...	**Try saying...**	**Why it matters**
"But you looked fine yesterday."	"I know every day is different for you."	Symptoms fluctuate by nature. Good days do not mean recovery.
"You just need to push through it."	"What would help you most right now?"	Pushing through worsens hEDS. Rest is treatment, not weakness.
"Everyone gets tired."	"I know your fatigue is different from ordinary tiredness."	Fatigue is neurological and structural. It is not comparable to typical tiredness.
"Have you tried yoga/diet/...?"	"Is there anything new that's helped?"	Unsolicited advice implies the person hasn't tried. They have. Extensively.
"You're too young to be this sick."	"I believe you."	hEDS often begins in childhood or adolescence. Age is not a measure of illness.
"At least you don't look sick."	"I'm sorry today is hard."	Invisible illness means the suffering is real even when it isn't visible.
"I wish you'd try to be more positive."	"This sounds really hard. I'm here."	Chronic pain + isolation cause real emotional suffering. Presence matters more than advice.
"Have you tried seeing a therapist?"	"I'm here for you."	Chronic illness causes real psychological distress, but suggesting therapy in response to physical symptoms implies the symptoms are psychological in origin.

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

MANKOSKI PAIN SCALE Use this scale when communicating your pain 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 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."*

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.

A note to the person sharing this document: You do not owe anyone a perfect explanation of your illness.
Sharing this guide is an act of courage.
The people in your life who read it with an open heart are showing you something important about who they are.