

The "It's All in Your Head" Myth: Why hEDS is So Hard to Diagnose

If you are reading this, you might know the feeling of being a "medical mystery."

For many people with **Hypermobile Ehlers-Danlos Syndrome (hEDS)** or **HSD**, the struggle doesn't start in adulthood—it starts in the playground. You might have gone through grade school, high school, and college feeling constantly tired, struggling with "growing pains" that never went away, or finding it hard to focus because of brain fog.

You likely tried to push through, but eventually, the pain, fatigue, and joint issues (subluxations) made it impossible to function at school or work.

The Cycle of Misdiagnosis

By the time many patients find a specialist, they have often seen dozens of doctors. The story is almost always the same:

1. You explain you hurt *everywhere*.
2. The tests come back "normal."
3. The doctor labels you with "**Anxiety**" or a "**Functional Disorder**."

What is a "Functional Disorder"? This is a medical term that essentially means, "The structure of your organs looks fine, so we don't know why they aren't working." It is a frustrating label that often leaves patients feeling dismissed.

Why Do Doctors Miss It?

It isn't necessarily that the doctors are unobservant; it is that the medical system is set up to look at body parts separately, not the whole person.

hEDS and HSD are **multi-system** disorders. They don't just affect your joints. Because your connective tissue is everywhere, your symptoms are everywhere:

- **Urinary:** Bladder issues or frequency.
- **GI:** Stomach pain, nausea, or digestion problems.

It's All in Your Head "Myth"

- **Ocular:** Eye strain or vision changes.
- **Neurological:** Headaches, dizziness, or nerve pain.

A urologist only looks at the bladder. A neurologist only looks at the brain. Because they struggle to tie these completely different problems into one single syndrome, they default to the easiest explanation: *"It must be psychiatric."*

The "Anxiety" Reality Check

It is true that many patients with hEDS/HSD struggle with anxiety and depression. However, it is vital to get the cause and effect right.

Doctors often think you are in pain *because* you are anxious. The reality is usually the opposite: **You are anxious because you are in chronic pain.**

Living with a debilitating, undiagnosed illness that limits your ability to function is traumatic. The mental health struggles are a **secondary result** of the physical suffering—not the cause of it. You aren't imagining the pain; you are just reacting to a body that is struggling to keep up.