

"Benign" Does Not Mean "Easy": The Reality of Living with hEDS

If you look up Hypermobile Ehlers-Danlos Syndrome (hEDS) in a medical dictionary, you might see the word "**benign**."

In medical speak, "benign" simply means "not fatal." It means you have a normal life expectancy. But for the patients living with it, that word can feel insulting.

While hEDS won't shorten your life, it can drastically affect the **quality** of your life. It is important to acknowledge that "benign" conditions can still be disabling, sometimes leaving patients bedridden or requiring a wheelchair, not because they are dying, but because their body cannot function upright.

The Brain and The Gut: The "Invisible" Struggle

Beyond the joint pain, two massive areas of suffering often get overlooked because they are invisible from the outside:

1. The Starving Brain (Cognitive Dysfunction) Remember the "blood pooling" we discussed? When you stand up and blood stays in your legs, your brain doesn't get enough oxygen.

- **The Result:** This isn't just feeling a little tired. It causes severe **brain fog**, memory loss, and difficulty focusing.
- **The Misdiagnosis:** Because your brain is struggling, you might be diagnosed with ADD/ADHD, anxiety, or depression. These are often just symptoms of a brain that is chronically under-fueled.

2. The Traffic Jam in the Stomach (GI Issues) The same faulty nerves that control your blood vessels also control your digestion. They are supposed to tell your stomach to move food along. When they misfire, traffic stops.

- **Gastroparesis:** This means "paralyzed stomach." Food sits there too long, causing nausea.
- **IBS:** Alternating between constipation and diarrhea is common.
- **Crucial Note:** In **hEDS**, the gut is slow or irritable. In the rare **Vascular EDS**, the gut is fragile and prone to rupture. Knowing the difference (via genetic testing if needed) is

Reality of Living with hEDS

vital for your peace of mind.

The Power of a Name

The patient in our previous story was diagnosed at age 48. That is decades of wondering, *"What is wrong with me?"*

This is why getting a diagnosis—even late in life—is a medical intervention all by itself. We often see patients **cry with joy** when they finally get the news.

- They aren't crying because they are sick.
- They are crying because they are **validated**.

They finally know they aren't "crazy," "lazy," or "just anxious." They have a known, physiological condition.

There is Hope

While there isn't a "cure" for hEDS, understanding that your fatigue and brain fog are caused by **Dysautonomia** (the nervous system glitch) opens the door to treatments that actually work.

By treating the nervous system—integratively and with medication—many patients regain function they thought was lost forever. You may not be able to change your collagen, but you *can* retrain your nerves.