

The One We Can't Miss: Understanding Vascular EDS

In the world of Ehlers-Danlos Syndrome, there is one specific type that doctors are always on high alert for. It is rare, but it is the one diagnosis we absolutely **must make early**.

It is called **Vascular EDS (vEDS)**.

Why is this one different?

As we discussed in the last post, the common type (hEDS) can be painful and exhausting, but it is **benign**—meaning you have a normal life expectancy.

Vascular EDS is different. Because it affects the strength of your major blood vessels and organs, it can be life-threatening. The average life expectancy for untreated patients is often in the 40s. This is why getting a diagnosis *before* an emergency happens is the most important goal of any EDS specialist.

The "Silent" Disguise

Here is the tricky part: **Vascular EDS often doesn't look like EDS.**

If you have the common type (hEDS), you probably have super-stretchy skin and very loose elbows and knees.

- **vEDS patients usually do NOT have stretchy skin.**
- **vEDS patients usually do NOT have loose large joints** (though their fingers or toes might be flexible).

Because they don't look like the "textbook" flexible patient, they are harder to spot during a physical exam. This requires doctors (and patients) to be detectives.

The Red Flags: It's All in the History

Since the physical signs are subtle, the clues almost always come from your medical history or your family tree.

You should alert your doctor immediately if you or a family member have a history of:

1. **Aneurysms or Dissections:** This is when a blood vessel bulges or tears. If this happened to a relative at a young age, it is a major warning sign.

2. **Organ Rupture** : A history of intestines or bowels tearing (perforation) without a clear cause.
3. **Surgical Complications**: If tissue tore unexpectedly or failed to heal during surgery, especially during childbirth or gynecological procedures.
4. **Severe Bleeding**: We aren't just talking about easy bruising (which is common in all types). We mean significant, hard-to-stop bleeding.

The Takeaway

If you have hypermobility and pain but **none** of the red flags above, the odds are overwhelmingly in your favor that you have the benign type (hEDS).

However, if your family history includes sudden vascular events or organ trouble, do not ignore it. Genetic testing can confirm vEDS, allowing you to take preventative steps that can save your life.