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## **The 24-Doctor Mystery: A Case Study of "Hidden" hEDS**

Does this story sound familiar to you?

A 48-year-old woman walks into a doctor's office. She isn't there for a check-up; she is there because she is desperate. She has seen over **two dozen doctors** in her life—neurologists, heart specialists, rheumatologists—and yet, she still feels terrible.

She has been told she has "Generalized Anxiety." She has been told she has "Fibromyalgia." She has been told it is all in her head.

But she knows it isn't. This is the story of how she finally found the answer.

### **The History: "Growing Pains" That Never Stopped**

Looking back, the clues were there since childhood.

- **School:** She was a cheerleader and gymnast (a common history for hypermobile people because they are naturally flexible), but she was always exhausted. She was even home-schooled for a year because she was too tired to go to class.
- **Work:** She had to stop working full-time because of chronic "body aches" and brain fog.
- **Daily Life:** She was clumsy. Her ankles sprained easily. Her jaw clicked (TMJ). She bruised if you barely touched her. She had trouble sleeping and constantly felt "anxious."

### **The Tipping Point**

She managed to survive like this for years until she caught a mild case of COVID-19. Afterward, her body seemingly crashed.

Suddenly, her heart would race, and she felt dizzy every time she stood up. The brain fog became unbearable. The "auto-pilot" glitch we discussed earlier (Orthostatic Intolerance) had gone into overdrive.

### **The Examination: Finding the Clues**



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When she finally saw a doctor who understood connective tissue disorders, they didn't just listen to her heart; they looked at the *physical evidence* that 24 other doctors had missed.

### 1. The "Party Tricks" (Beighton Score) The doctor tested her flexibility using the **Beighton Score**.

- Could she bend her pinky finger back past 90 degrees? **Yes.**
- Could she touch her thumb to her forearm? **Yes.**
- Did her knees and elbows bend backward? **Yes.**
- Could she touch the floor with her palms flat? She could when she was younger, but her back was stiffer now.

### 2. The "Heel Bumps" The doctor looked at her heels and found small, skin-colored bumps called **Piezogenic Papules**.

- *What are they?* Because her tissue is weak, small bits of fat push through the skin layers when she puts weight on her heels. It is a classic sign of EDS.

### 3. The Wrist Test The doctor asked her to wrap her thumb and pinky around her other wrist. Because she had long, slender fingers (a trait called *arachnodactyly*), her pinky overlapped her thumb easily.

### 4. The Vital Signs When she stood up, her heart rate jumped from 92 to 120 beats per minute. Her blood pressure dropped. This confirmed her autonomic nervous system was struggling to fight gravity.

## The Diagnosis: Tears of Relief

The doctor put it all together: The flexibility, the skin signs, the dizziness, the fatigue, and the history of joint pain.

She met the criteria for **Hypermobile Ehlers-Danlos Syndrome (hEDS)**.

When the doctor explained that she wasn't "crazy," that her anxiety was a physical reaction to a struggling nervous system, and that there was a name for her pain, **she began to cry**. She finally felt vindicated.

## The Lesson



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This patient suffered for decades because specialists have "tunnel vision." The cardiologist looked only at the heart; the neurologist looked only at the nerves.

**Connective tissue disorders require a "wide lens."** If you see yourself in this woman's story—if you are the "anxious" patient who is flexible, tired, and hurting—it might be time to stop asking "What is wrong with my heart?" and start asking "What is wrong with my wiring?"