Ehlers-Danlos Syndromes (EDS)

Understanding Connective Tissue Disorders & Hypermobility Spectrum Disorder (HSD)

What is Ehlers-Danlos Syndrome?

Ehlers-Danlos Syndrome (EDS) is a group of connective tissue disorders that are generally inherited and are varied both in their genetic causes and how they affect the body. The most common characteristics are joint hypermobility (joints that move more than normal), skin hyperextensibility (skin that can be stretched more than normal), and tissue fragility (easy bruising, wounds taking longer to heal and scars that heal abnormally).

Ehlers-Danlos Syndromes are currently classified into 13 subtypes (as of 2017) but by far the most common types are Hypermobile (hEDS) and Classical (cEDS). Each subtype has a set of clinical criteria that help guide with diagnosis.

An individual's experience with EDS is personal in terms of symptoms and severity and may not necessarily be the same as another person's experience. Diagnostic criteria exist to help distinguish EDS from other connective tissue disorders, and one type of EDS from another. There are many more possible symptoms for each EDS type than are listed in the official criteria. The symptoms listed here are the most common ones.

Living with Ehlers-Danlos Syndromes

Living with Ehlers-Danlos Syndromes (EDS) can be an incredibly challenging journey, often filled with misdiagnoses and misunderstood symptoms. EDS is a group of inherited connective tissue disorders that affect everything from your skin and joints to your blood vessels and internal organs. The hallmark of most types is joint hypermobility, but the condition is far more complex than that.

A body with EDS can behave unreliably, and issues can be widespread and range in severity, from barely noticeable to life-threatening. It can appear as though a person has a large number of seemingly-unrelated symptoms. This is one reason why medical professionals not familiar with Ehlers-Danlos Syndromes have trouble recognising the varied symptoms as all related to 'one cause'. It may take decades to get properly diagnosed. Misdiagnoses of Arthritis, Fibromyalgia and Chronic Fatigue Syndrome are common because many of the symptoms, especially joint and muscle pain, chronic fatigue, headaches, autonomic dysfunction, and other symptoms overlap with those of EDS.

Understanding Ehlers-Danlos Syndromes

EDS is caused by faults in the structure or processing of collagen, the "glue" that holds your body together. This can lead to a wide and varying range of symptoms, including:

- Significant joint hypermobility, with frequent and painful subluxations or dislocations.
- Soft, fragile skin that may bruise or tear easily.
- Chronic, widespread musculoskeletal pain and debilitating fatigue.
- Autonomic dysfunction, such as Postural Orthostatic Tachycardia Syndrome (POTS), causing dizziness and fainting.
- Gastrointestinal problems and other systemic issues.

What are the symptoms of Ehlers-Danlos Syndromes?

The hallmark clinical manifestations of an Ehlers-Danlos Syndrome are most often joint and skin related and may include:

Joint Symptoms

- **Joint Hypermobility:** Joints move beyond the normal range.

Skin Symptoms

- **Soft & Velvety Skin:** Stretchy skin (most associated with Classical EDS).

- **Loose/Unstable Joints:** Prone to frequent spraining, dislocations, and subluxations.
- **Pain & Degeneration:** Joint pain and early onset of osteoarthritis.

- **Fragility:** Skin tears or bruises easily (bruising may be severe).
- **Scarring & Healing:** Severe/unusual scarring; slow and poor wound healing.

Systemic & Less Common Symptoms

- Chronic, debilitating musculoskeletal pain (especially in Hypermobile EDS)
- Fatigue and persistent tiredness
- Gastrointestinal problems (e.g. Irritable Bowel Syndrome)
- Mitral valve prolapse, heart arrhythmia, scoliosis, and hernias
- Poor response to local anaesthetic
- Arterial, intestinal, or uterine fragility/rupture (life-threatening, Vascular EDS)

Associated Conditions

- **POTS (Postural Orthostatic Tachycardia Syndrome):** Heart rate increases when standing up, manifesting as fainting or dizziness.
- **Dysautonomia Issues:** Blood pressure changes and autonomic regulation issues.
- **MCAD / MCAS (Mast Cell Activation Disorder):** Sometimes severe and unusual allergy symptoms.

What are Hypermobility Spectrum Disorders (HSD)?

Hypermobility Spectrum Disorders (HSD) are a group of conditions related to Generalised Joint Hypermobility (GJH). HSD is diagnosed if a patient has GJH with pain and doesn't fulfil the criteria for Hypermobile EDS.

When do EDS symptoms appear?

Types and severity of symptoms vary for each individual. Although some EDS symptoms can appear in infancy or early childhood, it is more common to start noticing symptoms from the teenage years. Joint pain and dislocations/subluxations are often the first symptoms that start requiring attention.

Many with EDS were once very good at sport or activities that required hypermobility (e.g., gymnastics and ballet) and developed frequent injuries and increasing joint and muscle pain as a result. However, perhaps the most common situation is someone in adulthood who has had pain and other symptoms for many years without answers, or has been diagnosed with other conditions that don't quite make sense.

How is EDS and HSD diagnosed?

If you think you might have Ehlers-Danlos Syndrome (EDS) or Hypermobility Spectrum Disorder (HSD), ask your GP if such a diagnosis might fit your symptoms. A double appointment may be helpful to provide adequate time for a detailed discussion. It is quite possible that your GP will have not heard of EDS before, or knows little about it.

The Importance of a Diagnosis

A correct diagnosis is important because, although EDS/HSD are not curable, many symptoms are treatable. Knowing the type of EDS/HSD gives you and your medical support team some idea of where problems might come from and why they are happening.

Prevention of further injury by avoiding certain activities and strengthening of key muscles can also be a helpful strategy once a diagnosis has been made. A diagnosis is also helpful to avoid complications for those patients who may need to consider surgery.

The more patients that are diagnosed with EDS will help the EDS movement worldwide. As the numbers increase, more education and awareness will happen, increasing the likelihood of expanded research that might lead to finding key treatments, and even a cure.

Step + Stride Podiatry

Specialists in Musculoskeletal & Hypermobility Management

At Step + Stride Podiatry we provide a safe, knowledgeable, and collaborative environment for managing the musculoskeletal component of your EDS symptoms. We see you, we hear you, and we understand that your needs are unique.