What is the prevalence of EDS?

Each type of EDS has a different prevalence in the population.

Hypermobile EDS (hEDS) is the most common type of EDS by far. hEDS accounts for about 90% of EDS cases and is thought to affect at least 1 in 3,100-5,000 people. hEDS is currently classified as a rare disorder, but the true prevalence is not known and may be underestimated.

Classical EDS (cEDS) and vascular EDS (vEDS) are much rarer than hEDS. cEDS affects roughly 1 in 20,000-40,000 people. vEDS affects about 1 in 100,000-200,000 people.

All other types of EDS are classified as ultra-rare, affecting less than 1 in 1 million people.

What causes EDS?

EDS is caused by specific variants in genes that provide the instructions for making collagens and related connective tissue proteins. Some types of EDS are associated with multiple different genes. The genetic cause(s) of hEDS have not been identified.

Can EDS be inherited?

EDS can be passed on from parent to child. Each type of EDS is inherited in either a dominant or recessive inheritance pattern. The inheritance pattern of each type determines the likelihood of passing the condition on to a child.

WE CARE

What resources are available to people with EDS?

The Ehlers-Danlos Society offers a variety of resources for those affected by EDS and HSD around the world.

- **Helpline**
- **Virtual Support Groups**
- **Healthcare Professionals Directory**
- **Support Group and Charity Directory**
- **Inspire**
- **Videos**
- **EDS ECHO**

For more information on EDS, scan the QR code below

The Ehlers Danlos Society

What are the Ehlers-Danlos Syndromes?

What is EDS?

The Ehlers-Danlos syndromes (EDS) are a group of 13 heritable connective tissue disorders:

- Hypermobile EDS (hEDS)
- Classical EDS (cEDS)
- Vascular EDS (vEDS)
- Arthrochalasia EDS (aEDS)
- Brittle cornea syndrome (BCS)
- Cardiac-valvular EDS (cvEDS)
- Classical-like EDS (clEDS)
- Dermatosparaxis EDS (dEDS)
- Kyphoscoliotic EDS (kEDS)
- Musculocontractural EDS (mcEDS)
- Myopathic EDS (mEDS)
- Periodontal EDS (pEDS)
- Spondylodysplastic EDS (spEDS)

Connective tissue is found throughout the body, where it provides support, protection, and structure to other parts of the body. The Ehlers-Danlos syndromes are caused by genetic changes that prevent connective tissue from functioning properly.

What are the signs and symptoms of EDS?

Each type of EDS has its own set of features and distinct diagnostic criteria. Some symptoms are common across all types of EDS, such as:

- Joint hypermobility
- Skin hyperextensibility
- Tissue fragility

Other symptoms are only observed in specific types of EDS. Even within the same type of EDS, people can experience very different symptoms from each other.

What is joint hypermobility?

Joint hypermobility means that a person's joints have a greater range of motion than is expected or usual. Some people have joint hypermobility that does not cause them pain or other issues. The problem occurs when hypermobile joints are unstable or place too much strain on other parts of the body. Joint instability occurs when the bones of a joint aren't held in place securely. This can lead to joint subluxations, dislocations, sprains, and other injuries. Joint instability can cause both acute and chronic pain and interfere with daily life.

What is tissue fragility?

Tissue fragility means that the body's organs and other structures are more vulnerable to damage. Tissue fragility can present as easy bruising and poor wound healing in many types of EDS. Some types of EDS can also cause severe fragility of the skin, blood vessels, abdominal organs, eyes, gums, and bones.

What is skin hyperextensibility?

Skin hyperextensibility means that the skin can be stretched beyond the normal range. Mild skin hyperextensibility may be observed in people with any type of EDS. More severe skin hyperextensibility is observed in certain types of EDS. People with EDS may also have other skin characteristics and symptoms, such as unusual skin texture, skin fragility, very thin skin, delayed wound healing, and abnormal scarring.

How is EDS diagnosed?

Each type of EDS has its own clinical diagnostic criteria. If a person meets the diagnostic criteria for a type of EDS, a genetic test should be done to confirm the diagnosis.

The genetic cause(s) of hEDS have not yet been identified, so there is currently no genetic test available to diagnose hEDS. The diagnosis of hEDS is given to those who meet the clinical diagnostic criteria for hEDS.

To view the diagnostic criteria, scan the QR code below

How is EDS managed?

There are no disease-specific treatments for any type of EDS, so EDS is managed by addressing each person's symptoms. Each type of EDS can cause a variety of symptoms in different areas of the body. Therefore, people with EDS often require multiple providers in different specialties to manage their care. Each person's care plan should address their individual needs.

GET IN TOUCH

For more information on The Ehlers-Danlos Society's work, to get involved, or to donate, please visit:

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