

What are the Ehlers-Danlos syndromes?

The Ehlers-Danlos syndromes are a group of genetic connective tissue disorders with symptoms affecting the whole body.

Those affected face challenges to their physical and mental health. Symptoms are widespread and can be disabling. One of the rarer types significantly reduces life expectancy. Hypermobility spectrum disorders (HSD) have similar symptoms to the most common type of Ehlers-Danlos syndrome, the hypermobile type. People now diagnosed with HSD may have been classified in the past as having Ehlers-Danlos syndrome.



13,000

The Ehlers-Danlos syndromes affect at least 13,000 people in the UK (1 in 5,000).

They affect women, men and children of all races.



10 years



is the average time to diagnosis in the UK.

The Ehlers-Danlos syndromes can be difficult to recognise because some symptoms can be mistaken for other conditions.

Family history and genetics

Ehlers-Danlos syndromes are genetic conditions, meaning other family members may be at risk of having the condition.

There is a 50% chance the condition will be passed on to children.

A person can also have one of the Ehlers-Danlos syndromes when there is no family history.



50%

Symptoms

The symptoms of the most common types include:

Fatigue



Chronic pain



Difficulty regulating blood pressure



Gut, bowel and bladder problems



Prolapsing organs



Fragile, stretchy skin which damages easily



Loose joints which dislocate easily

The rarer types have additional distinctive signs and symptoms.

Support

The Ehlers-Danlos Support UK supports people with Ehlers-Danlos syndromes and hypermobility spectrum disorders. We provide information and support through physical and virtual support groups, a helpline, website and events. We educate medical professionals to recognise the conditions and we promote and fund research to advance knowledge about them.

Call our helpline today: **0800 907 8518**



EHLERS-DANLOS SUPPORT UK

Visit: **ehlers-danlos.org**