

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
types

There are 13 classified types of Ehlers-Danlos syndromes (EDS), 12 of which are rare.

Hypermobile EDS (hEDS) is much more prevalent than previously thought.

10
years

The average time to diagnosis in the UK is ten years

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 they can be passed on to children.

There is a 25–75% chance the condition will be passed on to children, depending on the type.

A person can also have EDS without a family history. There is no genetic test for hEDS.



EDSUK

Symptoms

The symptoms of the most common types include:

Fatigue

Chronic pain

Difficulty regulating blood pressure

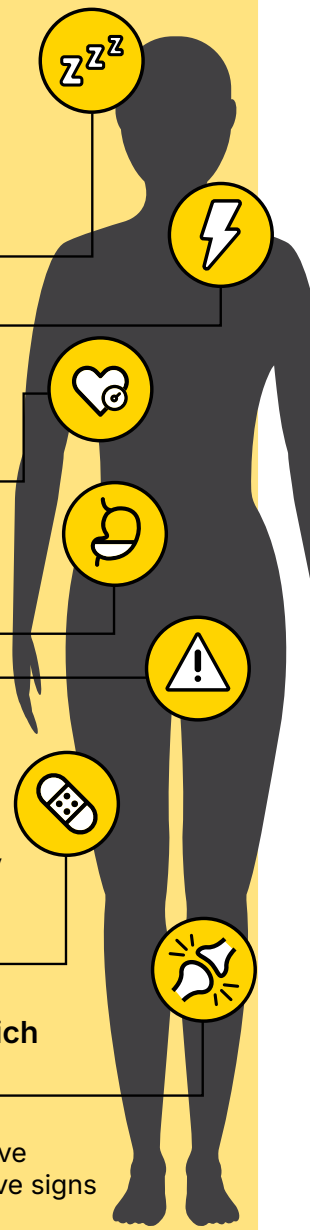
Gut, bowel and bladder problems

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 is the voice of the EDS and HSD community in the UK. We bring together people with EDS and HSD in the UK to equitably access diagnosis, treatment and care. We do this through:

Awareness: We advocate for and empower our community to drive change. We raise their voices, and work with the NHS across the UK in pursuit of services accessible by all. **Support:** We provide a platform to support and connect our community. We deliver information and advice on living with EDS and HSD. **Knowledge:** We build knowledge through information, training and enabling research. We confront misunderstanding and challenge inequality.

Call the Adviceline **0800 907 8518** or email **adviceline@ehlers-danlos.uk**

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