EDS
EHLERS-DANLOS SUPPORT UK

Freephone Helpline

0800 907 8518

Monday to Friday 9am – 5pm

Who are we?

The Ehlers Danlos Support UK (EDS UK) was set up in 1987 to support, advise and inform those living with the Ehlers-Danlos syndromes. We aim to help them live a full, active and positive life. We remain the only UK based charity that exclusively represents and supports people with all types of EDS.

THE EHLERS-DANLOS SYNDROMES (EDS)

EDS
EHLERS-DANLOS SUPPORT UK

SUPPORT AND INFORMATION FOR PEOPLE AFFECTED BY THESE CONDITIONS

Enquiries/Membership/Fundraising
0208 736 5604

Email
info@ehlers-danlos.org

Website
ehlers-danlos.org

Social Media
@EhlersDanlosUK

We have support groups running across the UK, run by our volunteers, both online and face to face.

To find out who your local area coordinator is, please visit **ehlers-danlos.org/support**

We run regular events and conferences to bring our community together, produce literature and merchandise to increase understanding and improve management of the condition. We have many support groups around the country providing members with a local peer support network, both face-to-face and online.

We run a freephone helpline which is available to everyone including people with EDS, friends, families, carers, and healthcare professionals.

EDS UK strives to educate the medical community, promote continuity of care, improve accurate diagnosis and provide information on specialist treatment and management of the condition. We also support vital research to further understand EDS, improve its management and work towards a cure.

FREE membership

Membership to EDS UK is free and provides patients and families touched by the Ehlers-Danlos syndromes access to local support groups, online management information, regional closed Facebook groups and priority tickets to EDS UK conferences and events.

Please visit **ehlers-danlos.org** for more details.

#InvisibleVisible

The Ehlers-Danlos Support UK is a Charity registered in England and Wales (1157027) and Scotland (SC046712). Registered Company No. 8924646. Registered Address: Devonshire House, Manor Way, Borehamwood, Hertfordshire WD6 1QQ

ehlers-danlos.org

What are the Ehlers-Danlos syndromes?

The Ehlers-Danlos syndromes (EDS) are a group of genetic disorders in which connective tissue is abnormal due to gene mutations.

This results in abnormally fragile and hyper-extensible tissues throughout the body which can lead to a range of symptoms. Individuals can be affected very differently.

Possible signs and symptoms

Thirteen different types of the condition have been classified to date. The most common types are covered here. Not all of the symptoms listed will be present in everyone with EDS and the list is not exhaustive.

Hypermobility spectrum disorders (HSD) have similar symptoms to the most common type of EDS, the hypermobile type (hEDS).

The treatment of symptoms is generally the same for HSD and hEDS.

Hypermobile EDS (hEDS) signs and symptoms:

- **Joint hypermobility** (loose, unstable joints leading to subluxations and dislocations)
- **Chronic, widespread pain**
- **Brain fog and fatigue**
- **Mildly stretchy or soft, velvety skin, slow healing, easy bruising** and **scarring**
- **Gastrointestinal tract dysmotility/dysfunction**
- **Autonomic dysfunction** (including PoTS)
- **Temporo-mandibular joint (TMJ) dysfunction**
- **General tissue fragility** leading to hernia, cervical instability, pelvic floor prolapse and urinary dysfunction
- **Mitral valve prolapse** (usually mild in hEDS)
- **Resistance to local anaesthetics**
- **Marfanoid habitus** (tall, slim stature, long fingers and toes)

Classical EDS (cEDS) signs and symptoms:

- **Hyperextensible (stretchy) skin, easy bruising, fragile skin, slow healing** and **atrophic scars**
- **General tissue fragility** leading to hernia, pelvic floor prolapse and cervical instability
- **Joint hypermobility** (loose, unstable joints leading to subluxations and dislocations)
- **Prematurely aged appearance**
- **Dermatological symptoms** are often more pronounced than in hEDS

Vascular EDS (vEDS) signs and symptoms:

- **Thin, fragile skin, visible blood vessels, easy bruising** and **slow healing**
- **Fragile blood vessels** which can lead to aneurysm and vascular rupture
- **Fragile organs** which can lead to organ rupture (most often bowel or uterine)
- **Hypermobility of small joints** (fingers)
- **Thin lips, thin nose, small earlobes and protruding eyes**
- **Joint contractures** due to shortened ligaments
- **Pneumothorax** (collapsed lung)
- **Talipes equinovarus** (club foot) apparent at birth
- **Reduced life expectancy**

For further information on the less common types of EDS and their possible symptoms please visit our website **ehlers-danlos.org**

Diagnosis problems

The following issues can be faced by people with the Ehlers-Danlos syndromes:

- EDS is often misdiagnosed or can be dismissed, with the belief that it does not exist
- People can wait for more than 10 years to obtain a diagnosis
- Some are even made to believe they suffer from a mental health disorder
- Parents can be accused of child abuse due to the symptoms the condition can present

This lack of understanding of EDS results in a lack of care, responsibility and unnecessary referrals to inappropriate specialists. There is an urgent need to raise awareness of EDS, especially within primary care.

Management problems

- EDS is a recognised, multisystemic, inherited connective tissue disorder that manifests in several diverse forms
- Even when recognised, EDS is frequently managed inappropriately
- Inappropriate management may result in avoidable disability and reduced quality of life.

Inadequate services

- There are inadequate specialist EDS services throughout the UK
- It is often difficult for people with EDS to travel long distances due to their symptoms. Local, joined up, multi-disciplinary services for EDS management are urgently needed throughout the UK to ensure continuity of care.

Useful resources

The GP Toolkit: **ehlers-danlos.org/toolkit**

The Schools Toolkit: **theschooltoolkit.org**