CONDITION

Ehlers-danlos syndrome

Ehlers-danlos syndrome is a group of inherited conditions that affect connective tissue supporting the joints, skin, blood vessels, and organs.

WHAT IT IS
Inherited conditions that weaken connective tissue

BODY SYSTEM
Joints, skin, blood vessels, and other organs

MAIN SYMPTOMS
Flexible joints, joint instability, stretchy skin, easy bruising

WHAT CAUSES IT
Inherited changes affecting connective-tissue proteins

HOW IT IS DIAGNOSED
Clinical criteria and type-specific genetic testing

MAIN TREATMENT
Physiotherapy, joint protection, symptom control, specialist monitoring

CAN IT BE CURED?
No, inherited tissue changes remain

IS IT AN EMERGENCY?
Sometimes, with sudden severe pain or collapse

LONG-TERM OUTLOOK
Often manageable; vascular types carry serious risks

Overview

Ehlers-Danlos syndrome usually refers to the Ehlers-Danlos syndromes, or EDS: a group of inherited conditions affecting connective tissue. Connective tissue provides strength and support throughout the body, including in the joints, skin, blood vessels, and internal organs.

There are several types of EDS. Hypermobile EDS is associated mainly with unusually flexible joints, joint instability, pain, and fatigue. Classical EDS often has more noticeable skin stretching and fragile skin. Vascular EDS can weaken blood vessels and certain organs, making it uncommon but potentially serious.

EDS affects people differently, including people with the same type. Having flexible joints alone does not mean that you have EDS. Some people have joint hypermobility without other health problems, while others have a related condition called hypermobility spectrum disorder.

Symptoms

Symptoms depend on the EDS type and which tissues are affected. They may begin in childhood, although some problems become clearer during adolescence or adulthood.

Joint symptoms can include:

A partial dislocation, called a subluxation, happens when the joint surfaces move out of their normal position but still touch. A full dislocation means the joint surfaces separate.

Skin symptoms may include soft or unusually stretchy skin, easy bruising, slow wound healing, and scars that become wide or thin. These findings are more prominent in some EDS types than in others.

Persistent pain and fatigue are common in hypermobile EDS. Sleep problems, headaches, digestive symptoms, and dizziness when standing are also reported. These problems can have many causes, so they need individual assessment rather than being assumed to come from EDS.

Vascular EDS may cause easy bruising and thin, translucent skin. Its most important risks involve tears or ruptures in arteries and certain internal organs. Someone can have vascular EDS without being extremely flexible.

- Joints that move beyond the usual range
- Repeated sprains, partial dislocations, or full dislocations
- Joint or muscle pain
- Poor balance or awareness of joint position
- Early wear of some joints

Causes and risk factors

EDS is caused by inherited changes that affect connective tissue. In many types, the changed gene affects collagen or a protein involved in making or organizing collagen. Collagen is a major structural protein that helps tissues resist stretching and injury.

A specific genetic cause is known for most EDS types. The genetic cause of hypermobile EDS has not yet been identified, so there is currently no laboratory test that confirms it.

Inheritance patterns differ by type. Many types can be inherited when one parent passes on one changed gene copy. Others develop only when a person inherits a changed copy from both parents. A new genetic change can also arise in someone with no known family history.

Having a close relative with EDS may increase the chance of having the same type, but symptoms can differ between relatives. A family history of unexplained artery rupture, bowel rupture, or death at a young age may be particularly relevant when vascular EDS is being considered.

EDS is not caused by exercise, posture, diet, or emotional stress.

Diagnosis

Diagnosis begins with your symptoms, medical history, and family history. A physical examination looks at joint movement, skin features, scars, bruising, and other signs linked to particular EDS types.

Joint flexibility is often measured with the Beighton score. This checks movement at several joints and gives a score out of nine. The score is useful, but it cannot diagnose EDS by itself. Age, previous injuries, surgery, pain, and natural differences in flexibility can affect the result.

Hypermobile EDS is diagnosed using clinical criteria. These consider generalized joint hypermobility, other connective-tissue features, family history, and joint-related complications. Other possible explanations must also be assessed. Children and adolescents may be evaluated using age-appropriate approaches and reassessed as their bodies mature.

Genetic testing can confirm many other EDS types, including classical and vascular EDS, when testing finds a disease-causing gene change that fits the person's features. Testing is usually arranged with genetics expertise because results can be complex. A negative test does not rule out hypermobile EDS because its genetic cause is unknown.

Other tests may be used to check for complications or alternative conditions. These could include heart imaging, eye assessment, or scans of blood vessels, depending on the suspected type and personal or family history. Such tests do not confirm hypermobile EDS.

Treatment and management

There is no treatment that corrects the inherited connective-tissue change. Care focuses on protecting vulnerable tissues, maintaining function, managing symptoms, and monitoring type-specific risks.

Physiotherapy can help build strength, improve balance, and support unstable joints. Exercise is usually introduced gradually and adjusted to avoid repeated joint injury. The aim is controlled movement and strength, not increasing flexibility. Repeatedly stretching already loose joints may worsen instability.

Management may also include:

Pain medicines should be considered in the context of your other conditions, bleeding tendency, and current medicines. Long-term pain often responds best to a combined plan rather than relying on one medicine.

Contact and collision sports may present extra risks for unstable joints. People with vascular EDS may need more specific limits on heavy lifting, high-impact activity, and procedures that could injure blood vessels or organs. Advice should be tailored to the EDS type and your health.

Pregnancy is possible for many people with EDS, but joint, pelvic, bleeding, wound-healing, and cardiovascular risks may need planning. Vascular EDS requires specialist care because pregnancy and childbirth carry greater risks.

- Occupational therapy to make daily activities easier
- Braces, splints, supportive footwear, or mobility aids when appropriate
- Pain management using physical, psychological, and medical approaches
- Wound care planned around fragile skin and slower healing
- Treatment of associated sleep, digestive, bladder, or dizziness symptoms
- Specialist monitoring for people with higher-risk EDS types

Complications

Repeated instability can lead to injuries, reduced mobility, and persistent pain. Some people develop early osteoarthritis, which is wear and damage within a joint. Fatigue and fear of injury may also make work, education, exercise, or social activities harder.

Fragile skin can split with relatively minor injury and may heal with wide or thin scars. Easy bruising does not always indicate dangerous bleeding, but unusual or heavy bleeding should be assessed.

Other possible complications include hernias, pelvic organ prolapse, dental problems, and symptoms involving digestion or bladder control. Not everyone develops these problems, and they should not automatically be attributed to EDS.

Vascular EDS carries a risk of sudden tears in arteries, the bowel, or the uterus during pregnancy. Some rarer EDS types can also affect the spine, eyes, heart valves, or breathing. The relevant risks depend strongly on the specific type.

Prevention

EDS itself cannot currently be prevented because it is inherited. Lifestyle choices do not cause it.

Some injuries and complications may be reduced through appropriate strengthening, joint protection, safe activity choices, and type-specific monitoring. These steps lower risk but cannot remove it completely.

Genetic counselling can explain inheritance, testing, and reproductive options. It can be helpful before pregnancy or when several relatives may be affected. The purpose is to support informed choices, not to tell you whether to have children.

Living with it and what to expect

EDS is lifelong. The underlying connective-tissue difference does not go away, but symptoms can change over months and years.

Joint flexibility may lessen with age, while pain or stiffness can become more noticeable. Periods of growth, injury, reduced activity, pregnancy, illness, or hormonal change may affect symptoms. A setback does not always mean that the condition is steadily worsening.

Many people learn to manage daily life through pacing, strength work, supportive equipment, and changes to work or study tasks. Some remain active with limited support. Others need ongoing help because of pain, fatigue, repeated injuries, or a rarer EDS type.

Regular follow-up should match your needs and EDS type. Hypermobile EDS care often focuses on symptoms and function. Vascular and some rarer types require specialist monitoring because serious complications may occur even when day-to-day symptoms seem stable.

When to get medical help

Arrange a routine appointment if you have repeated dislocations, frequent sprains, persistent joint pain, unusual skin fragility, or easy bruising without a clear explanation. Assessment is also reasonable if these features occur with a family history of EDS or unexplained artery or organ rupture.

Seek prompt medical advice for a new dislocation, a wound that will not close, unexplained heavy bleeding, or a rapid change in symptoms. A dislocated joint should not be repeatedly forced back into place without appropriate training and advice.

Call emergency services for:

These symptoms are especially important if you have vascular EDS or are being assessed for it. They can also be emergencies in people without EDS.

- Sudden, severe, unexplained chest, abdominal, back, or head pain
- Collapse, fainting with severe pain, or signs of shock
- Sudden weakness, facial drooping, speech difficulty, or loss of vision
- Severe breathlessness or coughing up blood
- A painful injured limb that becomes cold, pale, blue, numb, or weak

Common questions

Is Ehlers-Danlos syndrome the same as being double-jointed?

No. "Double-jointed" usually describes joint hypermobility, meaning a joint moves beyond the usual range. EDS also involves other features and complications. Many flexible people do not have EDS.

Can a blood test diagnose hypermobile EDS?

No genetic or blood test currently confirms hypermobile EDS. It is diagnosed from clinical criteria after other explanations have been considered. Genetic testing can confirm many other EDS types.

Does EDS get worse with age?

The inherited tissue difference remains, but its effects do not follow one fixed course. Flexibility may decrease, while pain, stiffness, or the effects of past injuries may become more noticeable. Good management can improve function even when the condition itself remains.

Can I exercise if I have EDS?

Many people can and should stay active, but exercise may need to be adapted. Controlled strengthening and low-impact activity are often better tolerated than repeated stretching, collision sports, or movements that make joints slip. The safest approach depends on joint stability and EDS type.

Is EDS life-threatening?

Most people with hypermobile or classical EDS do not face the same life-threatening risks as people with vascular EDS. Vascular EDS can cause serious artery or organ complications. Confirming the type is therefore important when vascular features are suspected.

Can I have a normal pregnancy with EDS?

Many people with EDS have successful pregnancies, but risks differ by type. Planning may include obstetric, anaesthetic, genetic, and cardiovascular input. Pregnancy with vascular EDS needs specialist assessment because the risks are substantially higher.

Sources

- Malfait F, Francomano C, Byers P, et al. The 2017 international classification of the Ehlers-Danlos syndromes. American Journal of Medical Genetics Part C . 2017;175:8-26
- GeneReviews: Hypermobile Ehlers-Danlos Syndrome. National Center for Biotechnology Information
- GeneReviews: Vascular Ehlers-Danlos Syndrome. National Center for Biotechnology Information
- GeneReviews: Classic Ehlers-Danlos Syndrome. National Center for Biotechnology Information
- NHS. Ehlers-Danlos syndromes
- Castori M, Tinkle B, Levy H, et al. A framework for the classification of joint hypermobility and related conditions. American Journal of Medical Genetics Part C . 2017;175:148-157