Ehlers-Danlos Syndrome

A Hereditary Connective Tissue Disorder

EDS
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Ehlers-Danlos Syndrome

Hiding in Plain Sight

Multisystemic

Faulty collagen structure leads to fragile tissue and body-wide dysfunction. Possible symptoms include:

Musculoskeletal System: Unstable joints, full and partial dislocations (subluxations) can cause sprains, tendinopathies, muscle tears, trapped and stretched nerves, acute and chronic pain.

Cardiac/Autonomic Nervous System (ANS): Problems regulating heart rate, rhythm, or blood pressure; lightheadedness; fainting upon standing. Symptoms may resemble anxiety.

Digestive System: GERD, gastroparesis, IBS.

Central Nervous System: Headache, dysautonomia. Can be affected by instability in the neck, skull/spine juncture.

Other: Fatigue, pain, sleep dysfunction, pelvic organ prolapse, hernias, fragile skin, slow healing, easy bruising, poor local anesthetic effect. Sometimes blood vessel or hollow organ rupture.

Disabling

The variety and frequency of symptoms often makes keeping a job impossible for people with EDS.

People with EDS can be seriously injured by ordinary activity. Standard physical therapy and exercise can be harmful—specialized programs are necessary.

Cardiac/ANS dysfunction can be as disabling as congestive heart failure.

Gastrointestinal symptoms often require intensive therapy: dietary modifications, medications, and surgery/feeding tubes in some cases.

Impaired balance and coordination can lead to falls and injury.

Injury, chronic pain, and profound fatigue can severely limit activity and lead to poor school performance, loss of employment, and social isolation.

Vascular-type EDS often causes complications that lead to early death.

Underrecognized

EDS is "likely the most common, though the least recognized, heritable connective tissue disorder." Dr. Marco Castori

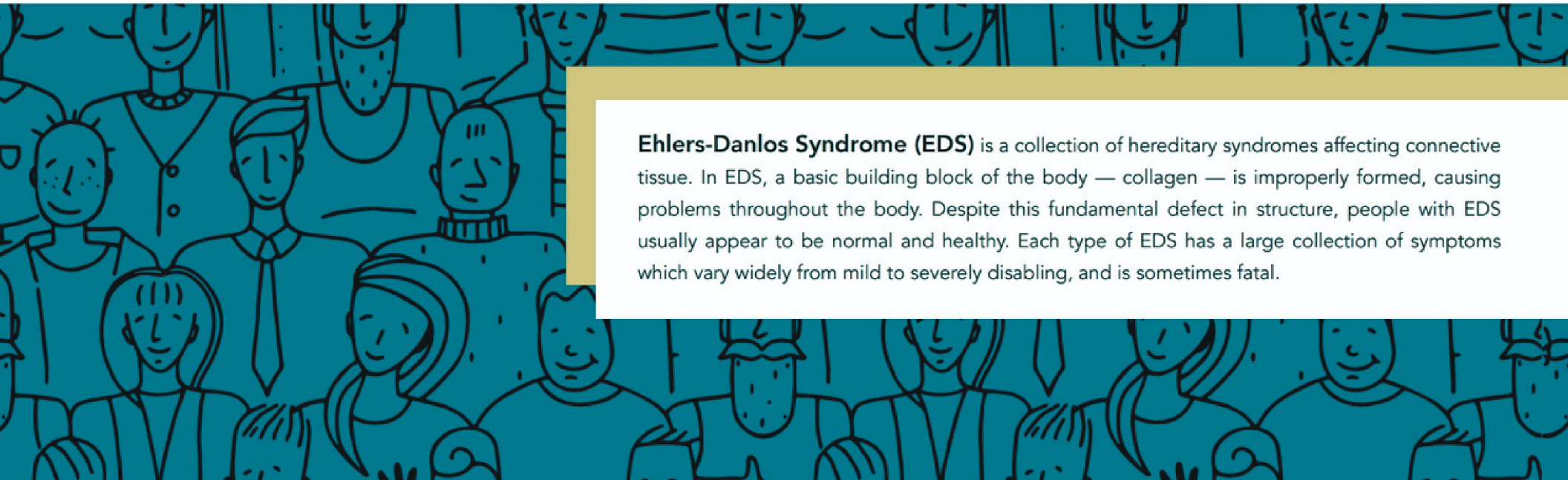
Experts estimate that EDS affects as many as 1 in 100 people—more common than multiple sclerosis and Down syndrome. Most people with EDS suffer for decade(s) before receiving the correct diagnosis.

"EDS may affect 1-5% of the general population." (Dr. Brad Tinkle)

"Only 5% of EDS cases are being recognized." (Prof. Rodney Grahame)

The most common form of EDS does not have a characteristic physical appearance, but the clinical picture is often easily recognized by those familiar with EDS.

Generalized joint hypermobility, measured by the Beighton scale, can be an important indicator that EDS may be an underlying problem. A geneticist can evaluate and diagnose EDS.



Ehlers-Danlos Syndrome (EDS) is a collection of hereditary syndromes affecting connective tissue. In EDS, a basic building block of the body — collagen — is improperly formed, causing problems throughout the body. Despite this fundamental defect in structure, people with EDS usually appear to be normal and healthy. Each type of EDS has a large collection of symptoms which vary widely from mild to severely disabling, and is sometimes fatal.