

EHLERS DANLOS SYNDROME

WHAT IS IT?

An inherited connective tissue disorder where a gene mutation creates weakened collagen throughout the body. Collagen is a building block of several different systems throughout the body: musculoskeletal, neurological, gastrointestinal, and cardiovascular. This can cause a number of different symptoms with a wide variety of presentation between people

POSSIBLE SYMPTOMS

Musculoskeletal

pain, dislocations, muscle tightness, poor posture, headaches, chronic fatigue

Cardiovascular

lightheadedness, dizziness, poor endurance, fainting, referred heart pain

Gastrointestinal

constipation, IBS, issues with eating GERD, bloating

Neurological

poor balance, poor coordination, increased pain perception

Other

easy bruising, skin hyperextensibility, poor immune system, anxiety, depression, issues sleeping

CONSIDERATIONS FOR HEALTHCARE PROVIDERS

- Every doctor plays a role in the patient's care
- Treatment may require trial and error to find what works best
- Follow up and communication between appointments is key
- Difficulty with anesthesia and pain medication
- Patients may not look like there is an issue but their pain is real

MODIFICATIONS FOR PATIENTS

- If the healthcare provider is not familiar with EDS, you may need to educate healthcare professionals on EDS
- Be prepared with documentation of your symptoms with context, medications and any lab reports (MRI, X-ray, blood work)
- Seek specialist referrals for doctors familiar with EDS