

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

TIPS TO KNOW

- Every day is different. One day they can feel good while the next the have to stay in bed all day.
- This diagnosis is a journey.
- EDS does not go away. Treatment is all about managing symptoms and improving quality of life.
- Every daily tasks takes consideration of how they will feel
- Walking through this journey requires a lot of mental processing.
- Every person handles this differently.
- Being realistic and optimistic is the best outlook.
- Any period of inactivity may cause a set back.
- It is common to have a very bad injury/pain such as an ankle sprain that will only last for a few days.

HOW TO SUPPORT SOMEONE WITH EDS

Allow them to process and feel how they feel. Although you may think they know what is going on, they may not have all the answers. They need a support system to celebrate the small wins and allow them to have down days. The biggest thing to realize is that they may look like they are not injured or are "fine" but they have real pain and limitations.