



## EDS and Physical Therapy: What to Expect

### What is EDS?

Ehlers-Danlos Syndrome (EDS) is a family of different types of heritable, connective tissue disorders. Each specific type comes with its own features ranging from joint hypermobility, skin hyperextensibility, to gastrointestinal dysfunction, and more.

### What is Physical Therapy?

Physical Therapists are healthcare practitioners who help with the management of movement disorders, pain, stiffness, weakness, etc., in order to improve patient's ability to move, function, and live more active lives. Doctors of Physical Therapy help people recover from injury or surgery as well as help with preventative training.

### How can PT help patients with EDS?

PT has been proven to help individuals with EDS by using manual therapy techniques for pain management as well as developing tailored exercise programs that strengthen muscles, stabilize joints, and enhance proprioception, thereby reducing the risk of dislocations and injuries. Additionally, they educate patients on joint protection techniques and body mechanics to prevent further complications.

### What to expect

#### 1st visit: Evaluation (60-90min)

- Medical History
  - PT collects detailed verbal medical history from patient/guardian/caregiver.
- Discussion of patient priorities
  - PT will review patient's primary concerns and goals.
- PT assessment
  - PT will look at movement patterns, strength, mobility and any other relevant areas based on patient's needs.
- Prognosis/Plan
  - PT devises treatment plan with patient and discusses expected timeline of recovery.
- Treatment
  - PT will begin with short treatment session on Day 1.

#### Follow-up Visits: Treatment (40-60min)

- Treatment will vary based on the individual. Typical session includes:
  - Manual Therapy: Various hands-on techniques aimed at relieving pain and/or improving mobility.
  - Neuromuscular re-education: Various techniques to change movement patterns and/or muscle activation.
  - Postural correction/ergonomics: Discussion and practice of the importance of posture as well as education on work/home ergonomic setups.
  - Strength/conditioning: Gradual progression of strengthening exercises specific to the patient.



## **FAQ**

### **Is it going to hurt?**

- Discomfort is common with Physical Therapy, with or without EDS. Patient's with EDS often have higher levels of reported pain in general and thus are more inclined to report more pain with PT. Discomfort should return to baseline within 2-4 hours. Muscular soreness should subside within 2-3 days. Treatment will always be adjusted, during and after session, based on patient response with regressions/progressions applied as appropriate.

### **When will I start seeing a difference?**

- In general, patients with EDS take longer to heal/adapt to tissue changes so they will likely need extended time in PT. Neuro-muscular/postural changes often occur within the 1st month, true strength changes can start to be seen at 6 weeks.

### **How often will I need PT?**

- Most patients attend PT twice a week in order to get proper stimulation needed for muscle growth. However, those with EDS may need extended recovery time and are only able to tolerate once per week initially.

### **How long will I need PT?**

- Depending on their specific impairments, those with EDS are commonly in PT anywhere from 2 months to 2+ years.

### **References**

- Engelbert RH et al. (2017). The evidence-based rationale for physical therapy treatment of children, adolescents, and adults diagnosed with joint hypermobility syndrome/hypermobile Ehlers-Danlos syndrome.
- The Ehlers-Danlos Society. (2023). Physical Therapy.
- Rombaut L, Deane J, Simmonds J, et al. (2015). Knowledge, assessment, and management of adults with joint hypermobility syndrome/Ehlers-Danlos syndrome hypermobility type among Flemish physiotherapists.