

Ehlers-Danlos Syndrome (EDS)

What is Ehlers-Danlos syndrome (EDS)?

Ehlers-Danlos syndrome (EDS) is a collection of inherited conditions that cause the tissues that connect parts of the body (connective tissue) to be loose. This can cause loose joints, stretchy skin, and delayed healing of the skin. This collection of conditions was reclassified in 2017, so it is important to have information that is specific to the child.

How common is it?

- Frequency varies depending on the type, but inherited types are found at 1 in 20,000 births.
- The most common type is hypermobile EDS. Classic EDS is also common, and less common is vascular EDS.

What are some common characteristics of children who have EDS or of EDS as children present with it?

Children with EDS can often bend their thumbs down to their wrists, place their palms on the floor easily, or twist their joints in unusual ways. Their skin can seem soft and doughy, and it might bruise more easily. Some of these children might have low muscle tone, and some may be somewhat delayed in their motor milestones. They may have a high arched palate or crowded teeth. They have normal intelligence and usually function normally in a classroom.

Who might be on the treatment team?

- Pediatrician/primary care provider in the medical home
- Physical therapist
- Geneticist

What adaptations may be needed?

Medications

No medications are recommended, but pain relievers such as ibuprofen may be prescribed for joint pain. Ice or gel packs may help pain.

Physical Environment and Other Considerations

- Full backpacks are difficult for children with hypermobile EDS, and they may tire more easily.
- Writing may be more difficult for these children because of the hypermobility of their finger joints.

Dietary Considerations

No special diet is needed.

What should be considered an emergency?

- Dislocated joints might occur more frequently. Children are sometimes skilled at relocating their joints if dislocations happen frequently and without cause.
- Tearing or rupture of one of the large blood vessels that carry blood to the body can occur infrequently but is always a medical emergency.

What are some resources?

- Ehlers-Danlos National Foundation: “Educator’s Guide: Meeting the Needs of the Ehlers-Danlos Child” and “Parent’s Guide: Helping Your Child Succeed at School” (Web page), https://ehlers-danlos.com/wp-content/uploads/EDNF_ParentsGuideForEducators.pdf
- GEMSS (Genetics Education Materials for School Success): “Learn more physical characteristics found in certain types of EDS” (Web page), www.gemssforschools.org/conditions/ehlers-danlos/default/learn-more
- Medline Plus: “Ehlers-Danlos Syndrome” (Web page), <https://medlineplus.gov/ehlersdanlossyndrome.html>