
What is Ehlers-Danlos Syndrome?

Ehlers-Danlos Syndrome (EDS) is a condition that is as black and white as the zebra ribbon that symbolizes the condition. Individuals with the condition are considered medical zebras because of how the condition mimics other conditions. At one time, EDS was considered to be rare; however, now it is considered to be underdiagnosed. Due to awareness and ongoing professional programs, recognition of EDS is improving.

EDS is caused by a defect in the structure, production, or processing of collagen or proteins that interact with collagen, such as mutations in the COL5A or COL3A genes. Not all mutations have been identified for all the subtypes of EDS.

Individuals who are affected by this genetic connective tissue disorder can exhibit many signs such as joint hypermobility, fragile or soft skin, elastic skin, chronic fatigue and pain, spinal issues, neuropathic pain, joint instability, tendon ruptures, easy or unexplained bruising, chronic headaches, arterial dissection, easy bleeding, unexplained fractures and dislocations, and more. Because of these symptoms, this genetic disorder can be a life altering or deadly condition.

Not all who have EDS are affected the same way, which causes it to be misunderstood and underdiagnosed.

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About CEDSA

The Center for Ehlers-Danlos Syndrome Alliance (CEDSA) is founded on the principals that children are our future and individuals with EDS need a strong supportive voice to improve their medical care, education, rights, and overall quality of life.

CEDSA works to help parents understand issues and treatment options for their children with EDS. We work with schools to find resolutions to education issues.

CEDSA advocates are driven to ensure justice for parents who have been wrongfully accused of child abuse and educate agencies as to how EDS can be mistaken for child abuse.

CEDSA's Board of Directors believes that all of our volunteers, medical and professional advisors, and associate consultants work as a team. The wonderful volunteers are the hub of the team! They truly make a difference by providing the coping and success tools to improve life with EDS.

As a non-profit organization, CEDSA relies on the generosity of others and fundraising awareness events in order to provide the multitude of programs that help individuals with EDS and other co-morbid conditions. See our website for the complete list of programs and services that CEDSA offers.

Center for Ehlers Danlos Syndrome Alliance

4805 Hospital Dr. Cass City MI 48726
Telephone: (989) 872-3372
staff@cedsa.org www.CEDSA.org
www.facebook.com/CEDSAorg

Individual Health Plans for Students

Center for Ehlers Danlos Syndrome Alliance Inc.



www.CEDSA.org

Students with Ehlers-Danlos Syndrome (EDS) need Individual Health Plans (IHP)

- EDS is a chronic health condition that can affect or have the potential to affect safe and optimal school attendance and academic performance.
- EDS can be complex and unfamiliar to school staff. Additionally, the child's requirement for nursing can be frequent and sometimes emergent; therefore, accurate and adequate documentation of the child's chronic medical conditions and individual needs is critical.

Who needs to write and oversee the IHP?

- Development of IHPs is a nursing responsibility, based on standards of care regulated by state nurse practice acts, and cannot be delegated to unlicensed individuals.
- It is the responsibility of the school nurse to implement and evaluate the IHP at least yearly and, as changes in health status occur, determine the need for revision and evidence of desired student outcomes.



Who can have input in writing an IHP?

The student's specialists, PCP, EDS expert advocate, and parent all can have input as to the contents of the IHP. It is important that accurate documentation is provided to the school nurse so that the plan will be written with the best possible outcome.

Is the IHP protected by HIPAA?

The IHP is not protected by HIPAA in most states since it becomes part of a student's education record, and those records are protected by FERPA (Family Educational Rights and Privacy Act). Some schools maybe be required to follow HIPAA laws if the provide medical treatments.

The plan can be shared with school staff as well, and in many cases, a summary sheet is given to all who have interactions with the student.

Does an IHP replace and Student Emergency Plan?

NO! The Student Emergency Plan (Emergency Care Plan or Emergency Action Plan) is developed based on the IHP, and is written in clear action steps and provided to school staff to assist them in responding to a health crisis.

What should be included in the IHP?

- The diagnoses (DXs) of the student
- Whether or not the condition will affect the student's attendance to school.
- Allergies and the reactions
- Medications and dosages
- How the DXs impact the student's access to the education setting and curriculum
- What serious risks the student's health poses at school
- What surgical procedures the student has had and ongoing treatment
- Triggers or situations to avoid that would increase symptoms
- DXs prognosis