Ehlers – Danlos Syndrome (EDS)

Symptoms or Behaviors

Joint pain

Arthritis

Chronic pain

Soft and more flexible skin

Easy bruising

Double-jointedness

Flat feet

Increased joint mobility

Joints popping

Joint dislocation

Enlargement of the large vessel coming out of the heart

Easy fainting or unexplained heart racing.

(Revised 2013)

About the Disorder

Definition: Ehlers-Danlos Syndrome (EDS) is an inherited disorder marked by joint hypermobility (extremely loose joints), hyperplastic skin that bruises easily, and weakness of tissues. EDS is usually grouped into six major types: Classical, Hypermobility, Vascular, Kyphoscdiotic, Arthrochalasia and Dermatosperaxis. Most types affect the joints and skin; the Vascular type affects the blood vessels and internal organs. **Hypermobility Type (HT):** Joint hypermobility is the major manifestation. This type is the most common form and least serious of all, but does have significant issues usually related to muscle and skeletal problems. Any joint can be affected and dislocations are frequent. **Symptoms:** Joint pain is common and many people with EDS HT develop arthritis at younger ages than expected. Chronic pain can become disabling for some. The skin may be soft and more flexible than the average person's skin. Easy bruising can also occur. Symptoms also include: double-jointedness, flat feet, increased joint mobility, joints popping, and joint dislocation. Other complications that can be found in some affected people include mild aortic root dilatation (enlargement of the large vessel coming out of the heart) and orthostatic hypotension which can be recognized by easy fainting or unexplained heart racing.
Signs and Tests: Examination by the health care provider may show the following: Excess joint laxity and joint hypermobility; mitral valve prolapse; periodontitis; soft, thin or very stretchy (hyperextensible) skin. **Tests performed to diagnose EDS include:** Collagen typing (performed on a skin biopsy sample); collagen gene mutation testing; Echocardiogram (heart ultrasound).

Treatment: There is no specific cure for EDS. Usually, treatment is primarily focused on trying to avoid joint pain and dislocations. Most joint dislocations in EDS can be easily resolved, but some may need a visit to a doctor or emergency room. Exercise to maintain muscle tone and strength is helpful to reduce the number of joints dislocations and long term chronic pain, but the exercise should not stress joints. Other treatments can include physical therapy, especially for those with gross motor delays or persistent pain. Bracing is occasionally necessary. Pain medications can be used if pain becomes significant. Frequent joint dislocations may require surgery for stabilization. If chronic pain becomes disabling, pain specialists may be helpful.

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Educational Considerations

Recommended Activities: Activities that are typically helpful include walking, cycling, and swimming. Exercise equipment such as elliptical machines may also be helpful.

Educational Implications: People with EDS have a normal life span and intelligence is normal. Physical therapy, occupational therapy, and adaptive physical education may be needed to address the student's specific needs. Assistive technology/ equipment may be necessary to address fatigue and joint pain during longer written assignments.

Instructional Strategies and Classroom

Accommodations: Staff may need to provide:

- Curriculum modifications (extra time for assignments, modifications to length of assignment due to fatigue)
- Extended passing time if needed, and possible support from PT, OT, and DAPE
- May not be able to keep pace with peers during written work and may become fatigued from longer written assignments.
- Students may need to complete work orally, or use a portable computer with possible word prediction.
- Alternative note taking methods
- If student is experiencing visual-motor difficulties (copying from the board can be difficult along with other drawing activities) he/she may require modifications
- Extra set of books at home
- Evacuation plan
- Rest periods if needed
- Pencil grips
- It is important for students with EDS to maintain muscle tone and strength but **should not stress joints**. Activities that are typically helpful include walking, cycling, and swimming. ****Should limit: heavy lifting, high impact exercise (e.g., jumping) and avoid long distance running.**

Resources

Ehlers Danlos National Foundation (EDNF)
1760 Old Meadow Road Suite 500
Mclean, Virginia 22102
(703) 506-2892 ednfstaff@ednf.org

Mayo Clinic
http://www.mayoclinic.com/health/ehlers-danlos-syndrome/Ds00706

Regional Rheumatologist Doctors for Ehlers-Danlos Syndrome
401 Phalen Blvd.
Rheumatology FL 3
St. Paul, MN 55101
(651) 254-7800

CentraCare Clinic- Women and Children's – Genetic Program
David J. Tilstra, M.D. CentraCare Clinic
1900 CentraCare Circle
St. Cloud, MN 56303
www.centracare.com/clinics/women_child/genetics

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