

EDS and Speech and Language Issues Poster

Serving Ehlers Danlos Syndrome Clients

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WHAT IS EHLERS-DANLOS SYNDROME?

Ehlers-Danlos Syndrome (EDS) is a group of genetic connective tissue disorders, which causes a defect in these tissues.

This defect is a result of faulty collagen, a protein that serves as “glue” by giving strength and elasticity to the connective tissue.

Weak connective tissues create problems with the movements and attachments of joints, and the endurance of tissues in the body.

What are the symptoms of Ehlers-danlos?

Skin problems: soft velvet-like texture, fragility that causes easy bruising or tears, severe scarring

Joint problems: loose/unstable and prone to dislocations, pain, early onset of osteoarthritis, hyperextensibility

Miscellaneous problems: musculoskeletal pain, poor muscle tone, gum disease, arterial/intestinal/uterine fragility

Types of Ehlers-Danlos Syndrome:

There are six major types of EDS, each “running true” in a family. In other words, a parent will only pass on the type they have if their child inherits EDS.

Each type is given with a nonexclusive list of common symptoms.

Classical Type:

Stretchy, velvety skin, wide scars, joint hypermobility

Hypermobility Type:

Hypermobility of joints, common joint dislocations, chronic joint and limb pain

Vascular Type:

Most serious type due to arterial or organ rupture, facial characteristics, shortened life



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expectancy

Kyphoscoliosis Type:

Severely weak muscle tone and joint laxity at birth, fragile tissues, delayed gross motor development

Arthrochhalasis Type:

Hip dislocation at birth, severe joint hypermobility

Dermatosparaxis Type: _

Severe skin fragility and bruising, soft and doughy skin texture

The effects of EDS on Speech and Hearing:

- Complications with speech and hearing are common among people with EDS.
- Due to faulty collagen and weak joints, certain attachments are not made correctly in the ears, larynx, and mouth.
- Poor attachments of muscles and cartilage interfere with actions necessary for functions such as hearing, swallowing, and articulating.

Speech and hearing problems associated with Ehlers-Danlos:

Articulation problems

Loose joints and a poor sense of proprioception make it difficult for precise movement of the articulators.

Swallowing problems

The arytenoids are joints held together by collagenous muscles, cartilages, and ligaments. Improper function of these joints creates a problem with tight vocal fold closure during a swallow, leading to aspiration. Weak muscles also make it difficult to maintain good neck posture, another factor involved in swallowing.

Hoarseness/Weak Voice

The vocal folds are composed of layers of tissues, easily bruised and strained due to tissue fragility and weakness. The lungs are also affected by EDS, leaving some with a limited capacity to produce the appropriate intensity for speech.

Fluency

Although the exact cause of stuttering has yet to be determined, some researchers believe it is multidimensional in nature, caused by psychological and physiological components. People who stutter have been observed to have trouble coordinating their articulators, initiating laryngeal and oral movements, and using proprioceptive feedback in oral movements. Due to muscle weakness, these problems occur in people with Ehlers-Danlos



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Syndrome, and may therefore result in errors in fluency.

Hearing impairment/Sensitivity

Hypermobility of the joints of the bones in the middle ear (malleus, incus, and stapes) creates problems with effective sound conduction across the middle ear. This loss of energy in route to the inner ear leads to a mild to moderate conductive hearing loss. Because the inner ear is also responsible for balance, improper function leaves some affected with bouts of dizziness.

Effective treatment for the Ehlers-Danlos Syndrome client:

Due to problems with speech and hearing, some individuals with EDS may seek speech therapy. Since each type causes different symptoms, therapy should be planned around each client.

Goals for therapy should include:

- Articulation: increase oral-motor strength of weak articulators, increase breath support for better airflow, speak at a slower pace with shorter utterances to increase intelligibility
- Swallowing difficulties: take smaller bites of food and better prepare the bolus for one clean swallow, practice a double swallow if needed, maintain good neck posture
- Voice disorders: perform vocal warm-up exercises before periods of prolonged speaking, practice good vocal hygiene behaviors to maintain the health of the vocal folds, breath from the diaphragm instead of pulling the lungs in
- Fluency: slow speech rate, use gentle voice onsets and soft articulatory contacts during speech
- Hearing loss: receive a complete audiological exam, obtain an assistive device such as a hearing aid, and attend visits to an Audiologist for maintenance of the aids

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