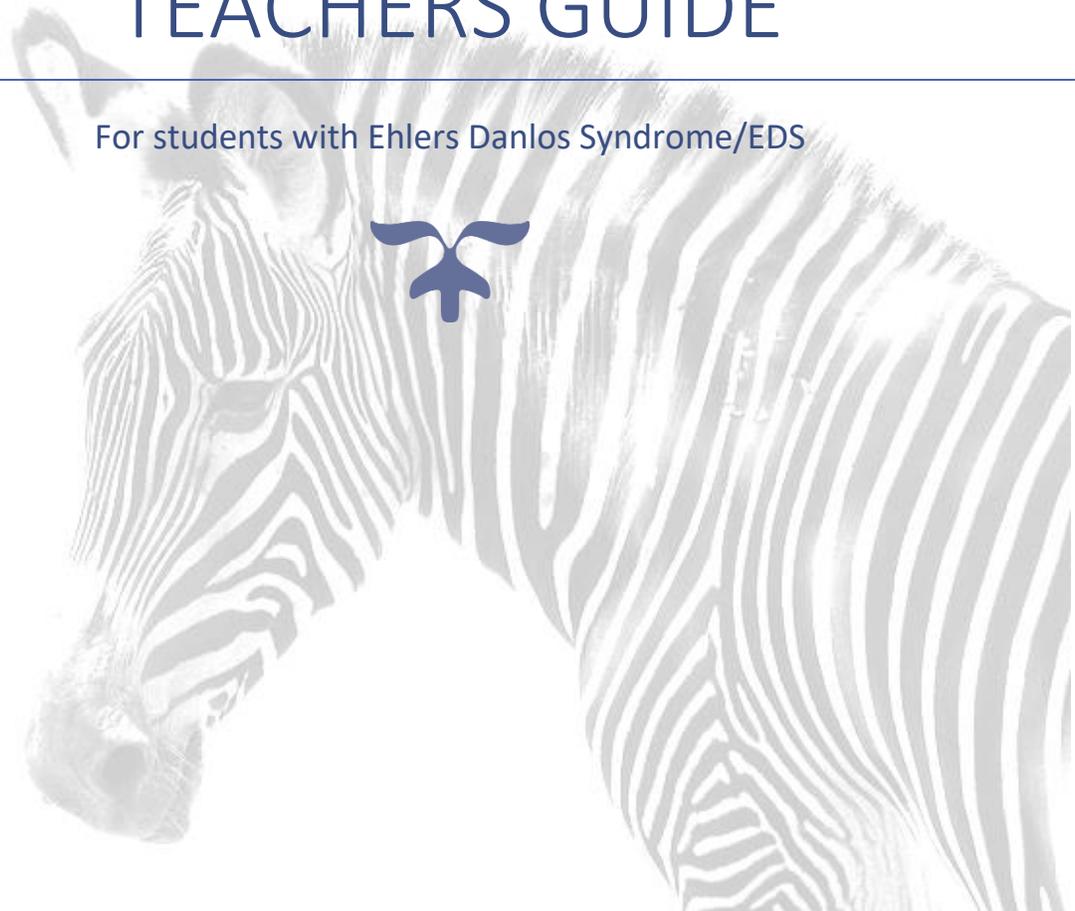


TEACHERS GUIDE

For students with Ehlers Danlos Syndrome/EDS



INFORMATION IN THIS GUIDE WAS GATHERED AND EDITED BY

Andrea D Julian ACE CPT, Patient, Parent, Advocate

Special thanks to:

Sheila Roush PT NCS and the EDS team

Lindsey Hershberger DPT, Danyelle Lupeky PT, Christina Cooper PT,NCS and Cecilia Emery OTR



What is Ehlers Danlos Syndrome (EDS)?

Ehlers Danlos Syndrome is a complex genetic disorder of the body's connective tissues, specifically a defect in the patient's collagen strand. Collagen has been described as the "glue" that holds our bodies together. This "glue" makes up our internal organs, skin, muscles, ligaments and eyes, therefore making EDS a complicated systemic disorder that can manifest in many ways. EDS is often undiagnosed for many years because the symptoms are mistaken for other diseases.

EDS is diagnosed by a geneticist or other medical professional by means of family history, Beighton Criteria and genetic testing of different collagen strands. EDS is an autosomal dominant gene which makes family history of complications very important to the diagnostic process. The Beighton Criteria is a list of abnormalities common in an EDS patient. Family history and Beighton Criteria are often enough for a diagnosis. However blood work can be done as well if the situation calls for it.

Each EDS patient is unique and some cases are more severe than others, even among siblings. Because EDS is systemic, manifestations of the disorder are widespread and may differ on a daily basis sometimes. It is hard to keep up with an EDS student's symptoms, but they will be able to recognize symptoms on their own and can keep you aware as needed.

As you will find out, there are many disorders that go along with, or that are caused by EDS. These are called comorbid disorders. Such disorders like Raynaud's Phenomenon are usually only seen secondary to other diseases such as EDS and it is therefore a comorbid disorder. This guide does not touch base on every comorbid disorder but it does touch base with the most common among adolescents.

What Complications are associated with EDS?

The severity of a student's EDS complications will vary student to student and will even range among siblings. EDS symptoms can vary over a patient's lifetime. Injury, growth spurts and hormone changes can trigger symptoms. The different types and severities require a customized approach by the medical team and school staff for the individual student. Some of these complications may include:

Dysautonomia/Postural Orthostatic Tachycardia Syndrome (POTS)

POTS is a common form of dysautonomia found in people with EDS. It is an autonomic failure of the nervous system and will cause a student to "pass out" or get dizzy upon standing from a seated position, temperature changes, standing still for a number of minutes and stress. It causes an increase in heart rate as the body attempts to maintain circulation to the brain.

Skin

Soft velvety skin; Varies in hyper extensibility; Tears easily and can make a small cut a huge problem; Bruising can be severe; Slow and poor wound healing can be expected; Severe scarring is common

Joint Hypermobility

Joint moves beyond its normal range; loose/unstable joints that are prone to frequent dislocations and or subluxations. Joint pain, early onset osteoarthritis, and chronic debilitating pain are common.

Decreased Proprioception

Proprioception is the sensation of joint position. This is important for posture and balance. Patients with decreased proprioception will seem fidgety but their body is sensory seeking. These students will assume unusual postures. Poor balance will cause a student to seem clumsy.

Other common complications

Early onset debilitating musculoskeletal pain; arterial, intestinal, uterine fragility or rupture; scoliosis; poor muscle tone; Mitral Valve Prolapse; dilated aortic root; gum disease; visual problems including, myopia, astigmatism, ocular migraines causing temporary blindness; Chronic Fatigue Syndrome; Gastrointestinal complications. These and other complications are different student to student and should be addressed in an emergency plan designed by the parent, teacher and medical experts.

Possible Medical Emergencies at school

Each child is different so it is important to know your EDS student well. Are they prone to fainting? Do they sublux or dislocate joints easily? Are they bleeders? All of this and more should be outlined in an Emergency plan. The following complications are found in the general EDS population, but every patient is different.

Dislocations/Subluxations

This often occurs due to loose ligaments and tendons. A joint can become dislocated or subluxed without injury. Affected joints are commonly the knees, shoulders, hips, ribs and also the fingers and wrists.

Occupational and Physical Therapists help students learn how to avoid injury and protect and preserve their joints. This will often require accommodations in physical education.

Ice packs should be kept on hand in the office.

Skin

A minor cut can become a major wound with some EDS patients. Such wounds should be handled with care. Proper repair of these wounds by a physician is often necessary.

Excessive sun exposure should be avoided and sunscreen is recommended.

Vascular

If a student has cardiovascular type EDS make sure to have an emergency plan in place if student needs urgent care.

Symptoms of aortic root dissection are often mistakenly thought to be drug overdoses. If symptoms are caught soon enough and action is taken, the student's life could be saved.

Gastrointestinal

Abdominal pain and nausea are quite common.

Students often suffer from gastro paresis and constipation due to laxity in the intestinal walls.

Gluten and dairy intolerance are common, as well as other food allergies. This should be discussed in the Emergency Plan.

POTS/Dysautonomia

Students with POTS can feel faint upon standing from a seated or lying position.

The student may find it difficult to bend over or stand still for very long without feeling faint or nauseous or even pass out.

(POTS continued)

Maintaining hydration will help manage POTS symptoms. Allowing these students to carry water bottles would be ideal.

Raising the sodium and electrolyte levels can help reduce symptoms. (naan tablets, Gatorade, crackers)

Students that suffer from POTS or any other form of dysautonomia should have their personal symptoms outlined in an Emergency Plan.

Take extra caution with warm temperatures. Accommodations may be needed for PE

Proprioceptive Dysfunction

Sensory processing disorder

Manifests itself as kids who are clumsy, uncoordinated and have difficulty performing basic normal childhood tasks and activities. This can lead to embarrassment and avoiding physical tasks.

This dysfunction causes a person to have no true perception of body awareness.

Students with this disorder may be in the nurse's office often for bruises and cuts from falling, tripping etc.



Steps to Academic Success

Provide a safe environment

When possible, carpeted areas are preferable to slippery floors and avoiding stairs in favor of an elevator. Different chairs and sometimes exercise balls are brought into the classroom for students with EDS. These tools are especially helpful to students with Proprioception Dysfunction.

Appropriate Physical Education

Each student with EDS will have different needs and/or restrictions. These needs and restrictions should be discussed between the parent and physical education teacher. Some schools will also allow physical therapy as a substitute for PE. An ideal fitness plan would involve core strengthening, balance training and recumbent aerobic exercise.

High impact, high velocity activities or contact sports could cause serious injury.

Impaired mobility, weakness around joints, poor coordination and poor proprioception can make a student embarrassed or disheartened. It is important not to push a student to do an activity they are uncomfortable doing. They may cause unnecessary injury to themselves or someone else in order to not be singled out.

Students with cardiovascular involvement are at risk for aortic rupture. Any aerobic exercise should be done with careful monitoring and clearance from the student's cardiologist.

Dysfunction of the autonomic system can cause a student with POTS or Dysautonomia to have an inappropriate response to exercise. Severe post exercise pain, fatigue and inability to keep up with other kids their age is commonly seen.

Cognitive profiles and testing accommodations

Premature birth is a complication associated with EDS and these children may experience the delays associated with it.

There are motor problems due to hypermobile fingers and wrists that can cause poor handwriting or Dysgraphia. Seeing a school or personal OT can help with coordination.

Consideration for chronic absence

Due to frequent illness and injury the EDS child will usually have a high absence rate. Additional tutorials and time are helpful. For long term recovery, at home instruction may be preferable.

Some schools post homework and books online. This is helpful to the student and parent to stay on track while the student is out. If the school has a site the parent should be made aware.

Meeting the Needs of the EDS Child

In making plans to meet the needs of the EDS child a 504 plan or IEP should be addressed. A physical therapist or occupational therapist would be helpful in evaluating adaptations needed in the school.

The following is a list of accommodations that other EDS students have found to be beneficial:

PE/Sports

Modified PE

Alternative PE Credits

Restrict contact sports

Restrict weight bearing activities on arms, wrists and shoulders (handstands, push-ups, pull-ups)

Limit sun exposure

Classroom needs

Allow storage of ice packs/gel packs

Rest periods may be needed if fighting fatigue

Two sets of texts books, or online books for home

Priority seating

Allow use of a chair or bean bag instead of sitting on the floor for circle time

Adjusted chair or table height

Use of elevators

Allow for frequent bathroom breaks

Allow extra time for bathroom breaks due to constipation

Book bag on wheels

Help with note taking

Extra time to get to and from class

Extended time for tests and assignments

Extra time on timed/standardized tests

Eliminate handwriting grade in favor of grades for content and effort

Assign lockers at eye level

Worksheets that allow fill in blanks or underlining in lieu of rewriting existing questions/sentences

Water bottles or time for water breaks

Assistive Equipment

Chair with arms for upper body support

Height adjustments of chairs/desks

Pad for chair seat or back

Pencil grips or adapted pencils

Pad or bean bag for sitting on the floor

Dragon Dictate or voice to type program for severe involvement of wrist and/or finger

For free live webinars and to find support groups in your area please visit us at www.ChronicPainPartners.com

Andrea Julian can be contacted by:

Facebook: Dayton Zebras

E-mail: daytonzebras@gmail.com

Phone: (937)476-1608

