



Coping with School with EDS/HSD

By: Shani Weber, M.S.



This webinar is for: **Kids, Teens, Parents, and Teachers**

Kids coping with school who have a type of EDS or HSD

Teens coping with school who have a type of EDS or HSD

Parents helping their child with a type of EDS or HSD cope with school

Teachers helping their students who have a type of EDS or HSD cope with school



KIDS

Living with a type of Ehlers-Danlos syndromes (EDS) or hypermobility spectrum disorders (HSD) can be hard.

Going to school when you have a type of EDS or HSD can be hard too.

We are going to learn ways to make school better,



**Learn about your EDS or HSD
so that you can teach others.**



**If you have a type of Ehlers-Danlos Syndromes (EDS),
you can say:**

Ehlers-Danlos syndromes or EDS are genetic connective tissue disorders. EDS can cause many symptoms in the body. Most people with EDS have hypermobile joints that stretch more than normal, stretchy skin, and fragile tissue. Some people with a type of EDS have symptoms that are severe. Some people with a type of EDS have symptoms that are mild. Learn more about Ehlers-Danlos syndromes at www.Ehlers-Danlos.com.



**If you have a type of hypermobility
spectrum disorders (HSD), you can say:**

Hypermobility spectrum disorders or HSD causes joints that stretch more than normal. HSD can be diagnosed when other health conditions are ruled out, including Ehlers-Danlos syndromes. HSD can cause symptoms in many places in the body. Some people have severe symptoms with HSD and some people have mild symptoms with HSD.



You need to be a good reporter

What are you feeling?

Where does it hurt?

What do you need?

Who should you tell?



What can you do to feel better?

There are many ways to help yourself feel better.

Start collecting tools!

Pain Management Tools: heat pads, ice, pain creams, braces

Dysautonomia Tools: water, salt, compression socks

Sad or Anxious Tools: 5 senses, memory game, deep breathing

Hand Pain Tools: Big pens and pencils, keyboard, voice-to-text



Play, Play, Play!

You need strong muscles so play in lots of ways.

Ride a bike. Swim and play in the water. Go for a hike.

Play with friends.



TEENS

Keeping up with schoolwork, making friends who understand, and managing your symptoms is a lot to do when you have a type of EDS or HSD.

If you also have fears of the future, dating, going to college, and working, it can become overwhelming.

Learn ways to cope better so that you can follow your dreams.



Learn about your type of EDS or HSD

so you can teach others.



If you have a type of EDS, you can say:

Ehlers-Danlos syndromes (EDS) are a group of connective tissue disorders that can be inherited. EDS can cause symptoms in many parts of the body. Some people are mildly affected or severely affected. EDS are generally characterized by joint hypermobility which means joints that stretch further than normal, stretchy skin, and fragile tissue. Learn more about Ehlers-Danlos syndromes at www.Ehlers-Danlos.com.



If you have a type of HSD, you can say:

Hypermobility spectrum disorders or HSD are a group of conditions related to joint hypermobility. HSD are diagnosed after other possible health conditions are ruled out, such as all types of the Ehlers-Danlos syndromes. HSD can cause symptoms in many parts of the body and can be mild or severe. Learn more about hypermobility spectrum disorders at www.Ehlers-Danlos.com.



Learn to listen to your body and report your needs

What are you feeling? Where does it hurt? What can you do about it?

What do you need? Is it something you can do or do you need help?

To whom do you report your need for help?



It's easy to check in with yourself and report your needs, right? Wrong!

This takes emotional strength that you have to build, piece by piece. First, you need to process what you have and how you feel about that.

You may feel anger that you have a type of EDS or HSD. You may feel sad you can't do everything your friends do. You may feel anxious about your future. All of those feelings are normal.



It's normal to feel grief.

It is painful to know we have a type of EDS or HSD and that our condition makes school more difficult. We wish we didn't have the fatigue, the lack of energy, or pain, and that we didn't have EDS/HSD.. We may imagine what our lives would be like without EDS/HSD. Maybe we could take a full course load, play a sport, act in the school play, go out with friends, and not have to feel so different. It's okay to want this for yourself and to feel sad that it's not your reality. It's also okay to feel angry and cheated as you watch your friends live their lives without being slowed by illness. You may feel left behind or misunderstood or lonely. These are normal feelings.



Here's the thing: You are in a different situation than most of your peers. You may feel shame about being different, but nothing about that shame is rooted in fact. You have a type of EDS/HSD. You didn't ask for it and you didn't cause it, but there it is. You still deserve to exist in this world and live as fully as possible. You deserve to learn at school, to take part in activities, to make and keep friends. You may have to think more creatively about how best to accomplish these goals, but there are people who can help you do this.



Use tools to feel and function better

Deep breathing exercises can help lower anxiety and lessen pain.
Heating pads, pain creams, and seat cushions can help lessen pain.
Rolling backpacks, large pens, keyboards, and voice-to-text help.
Staying well rested, nourished, and hydrated are crucial.
Being active each day to increase muscle tone to support your joints is important too.



Create a plan

Plans can be formal or informal.

Formal plans include I.E.P.s, 504 Plans, and other accommodations services.

Informal plans include what you need, like what to do when symptoms worsen or where to keep your medication.



**Feel as well as you can,
Function as well as possible,
Take excellent care of yourself,
And know your true worth.**



Parents

The family and the school need to work together to establish and maintain good communication and cooperation. Everyone needs to understand what is needed and expected to support your child. The family and the school also need to be clear about what can, and cannot, be done so that everyone's expectations are achievable and realistic.



The goals

- **Share information**
- **Develop a care plan**
- **Keep up good communication**
- **Make changes where necessary**
- **Seek extra support**



Learn all you can

As a first step, it is important for you and your child to try to understand your child's needs, and to learn as much as you can about her type of EDS/HSD and its care. The more information parents and children have, the less frightening the present and future will seem. Knowledge is empowering. It can help both you and your child feel more in control of the condition and the impact and effects on your child's life and on your family. You can learn about types of EDS and HSD at www.ehlers-danlos.com.



Balance need to inform with privacy

Your child's privacy needs to be considered. Some children want to teach every teacher and student about their type of EDS or HSD. Some children may not want to whole school to know.

Determine together who needs to know and who will inform them.



Balance need for care and independence

Children's capacity for independence varies from child to child and will steadily increase with maturity. Some children need lots of adult help to manage symptoms or consume a special diet. At the same time, watch for signals from her that she is able to assume greater responsibility, and help her take on more of the management of the illness little by little as she gets older.



Make independence the goal

Some children avoid accepting more independence and self-management of their condition. Families may not mean to but foster dependency because they find it easier to maintain responsibility for their child's care, rather than teaching the child to perform certain tasks and relying on her to do so. Also, some children may enjoy being the object of their parents' special attention. They may relish having certain tasks' performed for them, and may resist taking responsibility.



What can you do at home?

- Stay on a schedule.
- Be consistent with limits, rules, and expectations.
- Encourage opportunities with friends and to be active.
- Create a balance amongst school, symptom management, and fun.
- Take time to talk with your child about their EDS/HSD and life.
- Consider talking with a mental health professional if you or your child are struggling.



Teachers

Learn about types of EDS and HSD

Types of Ehlers-Danlos syndromes (EDS) are a group of heritable connective tissue disorders which are known for joint hypermobility, stretchy skin, and fragile tissue with pain and symptoms in many body systems. <https://www.ehlers-danlos.com/what-is-eds/>



Hypermobility spectrum disorders (HSD) are a group of conditions related to joint hypermobility (JH). HSD are intended to be diagnosed after other possible answers are excluded, such as any of the Ehlers-Danlos syndromes (EDS) including hypermobile EDS (hEDS). HSD, just like hEDS, can have significant effects on our health. <https://www.ehlers-danlos.com/what-is-hsd/>



Accommodations and Supports

When you have a student with a type of Ehlers-Danlos syndromes (EDS) or hypermobility spectrum disorders (HSD), you and their family may need to help the student safely access the learning opportunities.

This may be formally, such as through an I.E.P. or 504 Plan, or may be informally such as by allowing the student to use a seat cushion or to have a water bottle. See more in the Educators' Guide to EDS and HSD: <https://ehlers-danlos.com/wp-content/uploads/Educator-Parent-Guide-2016.pdf>



In most cases, you cannot “see” your student’s EDS or HSD

It can cause intense and/or continual pain: for example, joint subluxations and dislocations,, post-surgery, GI and back problems.

Symptoms can be unpredictable and fluctuating. Students may have limited energy and difficulty walking, standing, or sitting for a long time. Their conditions or the side-effects of medications may cause them to become dizzy or confused, making it hard for them to pay attention in classes, complete out-of-class assignments, do library research, and stay focused during exams.



What do your students want you to know?

“Sometimes just sitting in class is an accomplishment so if I look like I’m ‘zoning out,’ it’s not because your class is boring or I can’t be bothered, it’s because I am simply trying to gain control.”



“I can understand your frustration when students don’t do the homework you set; however, it isn’t always intentional. Sometimes medication a person takes at night can have a sedative effect, hindering their ability to complete homework. However, asking in front of the class for an explanation is embarrassing and degrading. We might not want our peers to know about what we are going through.”



“Chronic illness has its name for a reason – it is long-term and in some cases lifelong. Sometimes it may seem like we are improving, but it doesn’t always stay that way. There are good times and bad times. We are just as frustrated about it as you are, so please be patient.”



What is the school's responsibility?

It's the Law!

The school's legal responsibility under federal law is mainly in providing children with needs the resources to progress through their education, Schools must follow requirements outlined in the Americans with Disabilities Act (ADA) and the Individuals with Disabilities Education Act (IDEA), if in the U.S., and similar laws in other countries.



Thank you!

If you have questions, you can contact me:

Shani Weber

Shani.Weber@ehlers-danlos.com