



The Ehlers Danlos Society

• EDS/HSD WEBINAR •

EDS/HSD AWARENESS & ADVOCACY 101

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How to talk about EDS/HSD

- Use accurate, verifiable, up-to-date information from reputable sources
- Answer questions with what you do know, redirect when you don't
- Share your story to provide context

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Terminology

“EDS” is not one disorder

- the Ehlers-Danlos syndromes (EDS)
- hypermobility spectrum disorders (HSD)

Types

- Correct: hypermobile Ehlers-Danlos syndrome, hEDS
- Incorrect: EDS type III, EDS 3, Ehlers-Danlos

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Develop your “elevator speech”

- How do you answer the question, “What is EDS/HSD” in 30 seconds or less?
- Factual example: Ehlers-Danlos syndromes and hypermobility spectrum disorders are groups of connective tissue disorders that may be inherited and can produce a range of complex problems across multiple systems of the body.

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Develop your “elevator speech”

- Factual example: EDS is a group of 14 inherited connective tissue disorders. The hallmark symptoms of EDS usually present across all types are hypermobile joints, skin hyperextensibility, & tissue fragility.
- Analogy: EDS and HSD impact the connective tissues that are present throughout the body that helps to hold everything together. A body with an Ehlers-Danlos syndrome or hypermobility spectrum disorder is like a house built with faulty building materials.

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Social media

- Great place to start!
- Large reach, minimal work
- Practice responding behind the screen

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Know your audience

What do many of your followers have in common?

- How can you tailor your posts to appeal to that group?

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Stop the scroll

- You only have a few seconds to capture attention!
- Photos and videos perform better with algorithms
- Stick to the medium that showcases your strengths
- What social media posts do you remember? Why were they memorable?

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One thing at a time

- Focus on one story, symptom, or challenge per post
- Dig deep
- Back up your experiences with credible sources

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DO

- Keep it brief
- Be accurate
- Welcome and answer questions
- Let people know where they can learn more
- Only share what you are comfortable sharing

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DON'T

- Be afraid to make a post not everyone will like (Impossible!)
- Lose credibility with inaccurate or out-of-date information
- ONLY post about EDS/HSD
- Be discourteous or rude
- Feel like you need to reinvent the wheel

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Remember

- You never know who is paying attention
- Awareness has a ripple effect
- A single post can make a huge difference

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JOIN US



JOIN THE CHALLENGE

EDS/HSD Awareness Month
May 2019

#myEDSchallenge #myHSDchallenge



ehlers-danlos.com/2019-awareness-month

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What Is Advocacy?

Advocacy is an ongoing process of building **partnerships** so that others will **act** for and with you, turning passive support into educated **action**.

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Advocacy Can Happen Anywhere!

- Medical Settings
- Families
- Schools
- Community Meetings
- Government
- Daily Life

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You Can Be A Great Advocate!

Make a Goal.

Have Reasonable Expectations.

Advocacy is about Partnerships ~ Not Battles.

These strategies can be used anytime you advocate, whether with doctors and at hospitals, with family members, with schools, or in your community.

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What is your Goal?

Appeal to:

The Head – What do you want them to know?

The Heart – What do you want them to feel?

The Hand – What do you want them to do?

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Know Your Audience!

Examples:

- Doctors like facts and information. (**Head**)
- The General Public and Reporters like to feel something. (**Heart**)
- Let everyone know what you want them to do. (**Hand**)

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Have Reasonable Expectations.

Those who have not experienced EDS or HSD can't know exactly what it is like.

Similarly, those with EDS or HSD can't know exactly what it is like for the ones with whom we are speaking.

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Reasonable Expectations Include:

- It takes a long time to change laws or change the hearts and minds of the public ~ Be patient yet persistent.
- Many different people want to be heard ~ Make your message concise and powerful.
- Not everyone will agree with you ~ Don't take it personally.

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Advocacy Is About Building Partnerships

- Use words like "We" and "Us" to emphasize you are a team.
- Find ways to laugh together or things you have in common.
- Keep explanations simple and matter-of-fact. Don't feel the need to over-explain.

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Build Your Advocacy Skills

- Believe in yourself and the importance of your message.
- Educate yourself about your condition and know where to find additional resources.
- Practice what you are going to say before you need to say it...Be prepared.

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Beyond What You Say...

- Make eye contact.
- Be courteous and concise.
- Treat others with the same calmness and respect as you want to be treated.

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Your Strength Is Your Story!

Your story is unique to you. Use your story, backed up with facts, to make the points you need.

It is better to say, "I don't know" to questions than to give incorrect information.

Practicing what you want to say, learning facts about your condition and issues important to you, and sharing your story can help you be an excellent advocate.

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Places Where You Can Advocate:

- Volunteer to be a practice patient at a local medical school or hospital
- Ask your doctors how to reach their colleagues and talk with them about EDS/HSD
- Present at a local community meeting such as a Girl Scout/Boy Scout meeting, Parent Teacher Organization, Health Support group meetings, or Faith based group and pass out EDS and HSD brochures
- Write to and meet with your elected representatives about EDS/HSD and issues important to our community.
- Provide posters and brochures to schools, gyms, doctors, hospitals, libraries, and other public areas.
- Hold a fundraiser to raise funds for the Ehlers-Danlos Society. Fundraisers may be bake sales, car washes, a sponsored night at a restaurant or club, a run/walk/cycle event, or anything you come up with.

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More Places You Can Advocate:

- Visit forums where people are describing symptoms, let the members who sound like they may have EDS or HSD know what they are and where they can find more information about it. (www.ehlers-danlos.com)
- Speak at government meetings or public hearings.
- Talk with people behind you in line.
- Get your story on TV news or in print (newspapers, magazines, online sites).

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You are the perfect person to raise EDS and HSD Awareness!

You can make a difference!

Will you?

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