Advocacy From Home

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What Is Advocacy?

Advocacy is an on-going process of building partnerships so that others will act for and with you, turning passive support into educated action.
First, Learn All You Can About Types of EDS and HSD

To raise awareness, educate others, and change laws, it is important to learn about types of EDS and HSD so that you know what you are talking about.

Read through our website and watch videos on our YouTube channel. www.ehlers-danlos.com

Advocacy Basics

• Have a goal.
• Have reasonable expectations.
• Learn about your topic.
• Practice.
• Build Partnerships, not battles.
• Be confident, believe in yourself.
Make A Goal

- Know what community or issue you are representing.
- Know the decision-makers.
- Know who else is advocating on this issue and their position.
- Use the strength of your story rather than attempting to be an expert of the issue.

Have Reasonable Expectations

- Know that it takes a long time to change laws or change the hearts and minds of the public - So be patient yet persistent.
- Know that many people want to be heard - So make your message concise and powerful.
- Know that not everyone will agree with you - So don’t take it personally.
Advocacy Is About Growing Partnerships and Not About Battles

- State your needs clearly. People are not mind readers.
- Keep explanations simple and matter-of-fact. Don’t feel the need to over-explain.
- If the way you are trying to solve a problem is causing a roadblock, adjust your strategy in a way that promotes partnerships.

Building Partnerships The Way You Make Friends

- Sympathize with the challenges and pressures the other person is under.
- Use words like “We” and “Us” to emphasize you are a team.
- Find ways to laugh together or find things you have in common.
- Compliment and thank the other person.
- Grow the relationship to get the decision you need.
Build Partnerships By Learning About Others

- Research all involved and look for commonalities in your experiences, positions, or beliefs.
- Introduce yourself to fellow advocates and decision-makers. Develop partnerships where possible.
- Write thank-you notes to those with whom you speak.

From Home

- Raise EDS and HSD awareness and educate others.
- Ways to advocate for laws to change.
- Learn advocacy tips.
Raise EDS And HSD Awareness From Home

Most people think posts on social media platforms are the only way to raise awareness from home. It is a good way so we will begin there.

- Post factual information about EDS and HSD from good sources.
- Give a glimpse into your reality.
- Share posts from the Ehlers-Danlos Society and other good sources.

But Social Media Is Not The Only Way...

- Host a virtual meeting with family and friends to teach them about types of EDS and HSD.
- Send awareness brochures through email or the mail: [https://www.ehlers-danlos.com/brochures/](https://www.ehlers-danlos.com/brochures/)
More Ways To Spread EDS And HSD Awareness

- Raise awareness while hosting a fundraiser such as a virtual trivia tournament, virtual games, virtual puzzles, raffles, and more.

Advocacy To Change Laws From Home

- Email or call your elected representatives and staff in government departments to introduce yourself and share your thoughts on issues important to you and our community.
- Share EDS and HSD information and how proposed laws or rules will impact those living with a type of EDS or HSD.
More Ways To Advocate With Governments

• Pay attention to when public meetings or times of public comment on proposed changes are and submit your comments.
• Post EDS and HSD information and how laws impact our community on the social media pages of elected officials.

Be confident!

• You are the expert of you!
• Your story and experiences are valid and valuable!
• You are the perfect advocate for you and those you love!
More Tips

- Make eye contact.
- Being courteous and concise.
- Know where you can go for information or other resources.
- Say, “I don’t know, but will get the answer for you”, when needed.

Many More Tips

- Practice what you are going to say before you need to say it...be prepared.
- Treat others with the same calmness and respect as you want to be treated.
- Proofread everything before posting or emailing government officials.
Tips, Tips, Tips

- When one approach doesn’t work, try a different approach or ask for what you need from a different person.
- Be persistent...if you don’t get your goal met at first, try again with a letter, an email, calling a supervisor, or by having a friend or family member help.

You Are The Best Advocate

- Learn about your topic.
- Have a goal.
- Have reasonable expectations.
- Build partnerships.
Learn-Goal-Expectations-Partnerships

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

Whether at home or not.

Thank you!

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