



Sharing Your VEDS Story: A Guide for the Community

Raising awareness about Vascular Ehlers-Danlos syndrome (VEDS) starts with you. Your personal story can be a powerful tool for educating others and bringing critical attention to this rare condition.

Key Resource: [Share your story.](#)

Why Share Your Story?

- ❑ **Educational Impact:** Personal narratives help people understand the nuances of VEDS better than statistics can.
- ❑ **Community Support:** Your story can inspire and offer hope to others facing a VEDS diagnosis.
- ❑ **Medical Advocacy:** A compelling story can make VEDS more memorable to healthcare providers and may reinforce its significance, potentially leading to more informed treatment decisions and emergency responses.

Tips for Sharing on Social Media:

- ❑ **Be Authentic:** Share your lived experiences, challenges, and victories.
- ❑ **Visual Content:** Use photos or short videos to capture attention and add depth to your story.
- ❑ **Hashtags and Tags:** Use relevant hashtags like #VEDS, #RareDisease, or tag relevant organizations (like @vedsmovement!) to increase visibility.
- ❑ **Privacy:** Remember, once shared, your story is public. Make sure you're comfortable with what you're disclosing.

Talking to Your Primary Care Physician:

- ❑ **Prepare a Timeline:** Show the journey of your symptoms, diagnoses, and treatments.
- ❑ **Be Concise:** Doctors have limited time; get to the point while covering key aspects.
- ❑ **Ask Questions:** Inquire about preventive measures, emergency protocols, and referrals to specialists.

Discussing VEDS with a Specialist:

- ❑ **Research Ahead:** Do some reading and understand the jargon so you can speak their language. If they use words you're not familiar with, don't be afraid to ask for clarification!
- ❑ **Collaborate:** Treat the interaction as a partnership; you're both aiming for the best health outcome.

- **Document:** Keep records of your visit, advice given, and any changes in your treatment plan.

Educating Pre-Hospital Providers:

- **Carry an Emergency Card:** Always have information readily available that indicates you have VEDS.
- **Use Layman's Terms:** Keep it simple; avoid medical jargon when possible (due to time sensitivity, differences in their training, and to avoid confusion).
- **Be Direct:** Time is critical in emergencies. Clearly state your condition and any complications you've had in the past.

Tips for Effective Storytelling:

- **Relate to the Audience:** Whether it's a medical professional or social media followers, consider what would resonate with them.
- **Show, Don't Tell:** Use examples to illustrate your points.
- **End Strong:** Conclude with the 'so what'—why your story matters and what can be done to help.

By sharing your story, you not only bring attention to VEDS but also contribute valuable personal insight that could shape how others understand and respond to this condition!