

WHAT MATTERS TO YOU

Sharing Your Story



Adapted from: the National Eating Disorders Association's tips on Sharing Your Story Responsibly

With acknowledgement to: the Patient Experience Local Health Involvement Group

As someone with personal health care experiences, (either your own or that of a loved one), you are in a unique position to offer understanding and vital information to others. At the same time, it is important to carefully consider the potential impact of your message on others, as well as on your personal well-being. An individual sharing their story may be left feeling exposed, vulnerable, and/or emotionally overwhelmed. Below are strategies to help you present your story in a genuine way while protecting your personal well-being. Whether you are sharing your story during an interview, in a written piece, or in front of an audience, here are some suggestions to guide you.

Remember your reason for speaking

Before sharing your story, carefully consider your motivations for doing so. While it may be personally rewarding to be honest and open about your experience, remember that you have an important opportunity with your audience. Make sure you leave your audience with the message that patients' stories and experiences are an essential element of all health care-based decisions.



Be prepared



Details are important. Make sure you find out who will be in the audience, how much time you're expected to speak, what the physical layout of the room will be, if you can bring personal items, etc. Don't be afraid to ask questions of the organizer prior to agreeing to participate and don't be afraid to make requests for things that will make the experience easier for you. For example, will having someone walk out with you to debrief afterwards be helpful? The more prepared you are with details ahead of time, the more you can focus on your talk when you arrive.



Recognize your limits

Telling your story is very personal. Showing emotion is completely understandable and expected but you need to recognize if your emotions will prevent you from telling your story effectively. Rehearsing your story ahead of time or writing it out so you can read it may help with this. Be prepared that your audience may show emotion as well when listening to your story.

Know what you are and are not willing to share

Just because you've taken this step to share your story does not mean you have to disclose every aspect of your experience. Keep a commitment to yourself not to disclose more than you are comfortable with. Be armed with phrases such as "That is more than I am willing to share" or "I believe you have enough understanding without talking about _____." This will help protect you should questions arise that you are not comfortable answering.

Be ready for assumptions, questions and comments



Remember that the extent of knowledge and preparation will vary widely within and between audiences. Even with people's very best intentions, they may say something that could be interpreted as hurtful or too personal. Never feel obligated to respond to comments you don't feel comfortable with. If you would prefer not to answer any questions, make sure you let the organizer know that ahead of time.

Consider bringing a spouse or good friend along

Having someone to wait with, sit beside you during your talk and debrief with afterwards can be incredibly helpful. Make sure your companion has heard your story ahead of time in its entirety so they don't become overwhelmed with emotion as well.



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