

Guidelines for Sharing Stories of Recovery

As someone with a personal connection to the field of eating disorders, be it through your own experience or that of a loved one, you are in unique position to offer hope, understanding and vital information to others. At the same time, it is important to carefully consider the potential impact of your message on the public, as well the effects of self-disclosure on your personal well-being. Research and anecdotal evidence show that even with the best intentions, personal testimonies can provide dangerous ideas that may contribute to disordered eating behaviors. Furthermore, an individual sharing their story may be left feeling exposed, vulnerable to judgment, and/or emotionally overwhelmed. Below are strategies to help you present your story in a useful way while protecting your personal well-being. An effective recovery story helps others toward the direction of health, hope, and understanding.

How to Protect Your Personal Well-Being

Be committed to your own recovery. Before becoming an advocate for eating disorders awareness, be sure you are first and foremost an advocate for *you*! Sharing your story is a big responsibility. Understand that it may feel like a lot of pressure and will likely bring up a lot of emotions. It is imperative to stay focused on your own recovery before taking steps to help others. If you are currently working with a professional, or have worked with one in the past, please ask for their feedback regarding your decision to share your story.

Recognize your limits. While you are an expert of your own experience, remember that this experience is unique to you. It is important to not answer questions that you don't know the answer to or provide advice that suggests "this is what works for everyone." Remember, since you are not an expert or professional in the field, you are not responsible for being someone's therapist or for their recovery. You *can*, however, help to put individuals in contact with professionals specializing in eating disorders. You might even think about inviting a professional to participate in or be available for questions during your presentation if one is not already scheduled to be there.

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 prepared for assumptions/questions. Remember that the extent of eating disorders knowledge varies widely among the audience. Be prepared to address common myths about eating disorders and keep in mind what a valuable opportunity this is to clear up those all-too-prevalent misunderstandings. Refer to NEDA's various handouts for more information (see next page for handout suggestions).

Always keep in mind 'why'. 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 obligation to your audience members. Make sure you leave your audience with the message that there *is* hope, that recovery and freedom from food and weight concerns *is* possible, and professional help *is* available.



How to Share a Story Responsibly

Eating disorders are serious illnesses that must be covered in a careful and responsible manner. Try not to inadvertently glamorize them or promote copycats who may experiment with life-threatening behaviors. 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 in your coverage of eating disorders:

Don't focus on graphic images or physical descriptions of the body at its unhealthiest point. Research strongly suggests that testimonies which dramatize dangerous thinness can provoke a "race to the bottom" among those struggling with or susceptible to an eating disorder (i.e. "She is thinner than I am and she's still alive. I should lose more weight."). A focus on the physical descriptions of the body is not only dangerous, but can also be misleading. Individuals with eating disorders come in all shapes and sizes – just like in life!

Don't provide 'tips' or play the numbers game. "I ate only XXX calories a day" or "He took as many as XX laxatives at a time" can turn a well-intentioned story into 'how-to instructions' for someone to follow. You might instead highlight that our self-worth cannot be measured by the numbers on a scale or the size of our clothes. Stories can also effectively – and responsibly – be illustrated by focusing on the mental and physical consequences of the eating disorder (e.g. disrupted friendships and isolation, fear and depression, fatigue, decreased ability to concentrate, medical complications, etc.) rather than the specific behaviors or number counting that perpetuated the eating disorder.

Watch out for 'anorexia chic'. Eating disorders and those who have them should not be glamorized or, worse yet, presented as people with "astounding will-power" or "incredible self-control." This threatens to not only inaccurately portray eating disorders as "desirable," but can also give the false impression that if one only had enough will-power or self-control, they could overcome an eating disorder too. Eating disorders are not just a 'fad' or a 'phase,' and one doesn't 'catch' an eating disorder for a period of time. Remind the audience that eating disorders are illnesses, not choices.

Be careful about providing testimony of how you "bravely fought this illness alone." Perhaps you did, but most do not – the vast majority of those who recover from their illness do it only with the ongoing help of trained professionals. Make sure you reinforce that it is courageous and necessary to ask for support and help during the recovery process.

Emphasize the seriousness of eating disorders without portraying them as hopeless. Always encourage people to seek help for themselves or loved ones who are suffering. Recovery is often a long and expensive process – but it is achievable and there are many options available.

Always provide a resource list. Include contact numbers, addresses or web links to information and local and national treatment resources. Otherwise you risk raising fears and concerns without providing an outlet for support and vital help. The NEDA website, www.NationalEatingDisorders.org, and toll-free Information and Referral Helpline, 1-800-931-2237, provide extensive resources nationwide.

If you need more information, ask! The National Eating Disorders Association has the latest recovery resources and can connect you to treatment professionals or educational outreach volunteers in your area. The NEDA website and informational handouts provide the most accurate and up-to-date information on eating disorders including statistics that can add relevance and importance to your stories. Some specific facts sheets that may assist in your coverage include "Statistics," "What is an Eating Disorder," "What Causes Eating Disorders," "kNOw Dieting," "Listen to Your Body," "Sharing with EEEase" and "Treatment of Eating Disorders."

Thank you for using your voice to highlight the seriousness of eating disorders and provide hope, understanding and resources to others!

