




Advocacy



ED RECOVERY
On Campus

Advocacy Toolkit
by Eliza Lanzillo



Struggling with an eating disorder can be an incredibly isolating experience. It is often accompanied by feelings of shame, guilt and even self-hatred. At the same time, one's eating disorder may provide a safety-net, taking on the persona of a friend who you simply cannot survive without. Ironically, letting go of that "friend" is the only way to survive. There are many misconceptions about eating disorders that contribute to the stigma experienced by those who struggle with them. Educating the public on the reality of eating disorders is critical to decreasing the stigma associated with these illnesses and increasing help-seeking behavior.

As Program Director of Advocacy Initiatives for Hynes Recovery Services, I am excited to contribute to the much needed advocacy efforts in the field. In order to effectively enact change, eating disorder survivors, allies, clinicians, and researchers will need to work together to generate increased awareness and improve patient outcomes. Additional research initiatives, participation in lobbying efforts, and openly sharing personal experiences are a few examples of the multitude of advocacy efforts necessary to bring attention to the critical needs of individuals and families affected by eating disorders.
- Eliza Lanzillo

If you'd like to join our efforts and/or become an **Advocacy Ambassador**, please reach out to us at your earliest convenience. In doing so, you'll have the opportunity to inform policy makers in your community and during EDC Advocacy Days about the critical need for increased support on behalf of individuals struggling with this potentially life-threatening disorder.

Sharing Your Story

When I first began treatment for my eating disorder, I did everything in my control to keep it a secret. I was ashamed, embarrassed, and angry. I felt that if others were aware I was in treatment, then I would really have to commit to recovery – something that I was not yet ready to do. With time, I began to see the value in recovery and my feelings of shame were gradually replaced with a sense of pride for seeking help and working towards restoring my health.

Having spent significant time contemplating when and how to tell someone about my eating disorder, I have learned that there is no one right time or place. Ultimately, feeling a desire to share and believing that you are ready are the two most important considerations when making the decision to open-up about your experience.

Below are a few suggestions that may help you if you decide to share your experiences publically or with friends, family or others.

- **Understand your motivations for sharing your story.** Why do you want to share your recovery story? Will doing so be helpful to you? To others? There is no right reason for wanting to talk about your experience with an eating disorder. However, understanding your personal reasons for wanting to share is an important part of the process.
- **Avoid the details of your disordered behavior.** Depending on how you choose to share your story, you may not have complete control over your audience. It is wise to omit information that may be triggering to this audience, such as specific behaviors or weights.
- **Remember, you are an expert of your experience – not necessarily an expert in the field.** You are the one person who is qualified to speak about your experience. However, lived experience with an eating disorder does not necessarily make you an eating disorder expert. Don't answer questions that you do not know the answers to and provide references to any statistics you share. It is also a good idea to be familiar with resources, such as the NEDA Helpline (800-931-2237), in case you are contacted by an individual that would benefit from speaking with a trained professional.
- **Strive to include concrete tips.** Sharing your story is an excellent opportunity to share what was helpful to you or suggestions for how to help a loved one who may be struggling. Don't hesitate to include tips and coping strategies that may be useful to others!
- **You can decide to whom you want to tell which details of your story.** Just because you've decided to share with one person, it does not mean that you owe all of the details to everyone.
- **Expect the unexpected in terms of reactions.** Some people may be unsure how to process the information you are sharing with them. Know ahead of time what types of questions you are willing to answer, and what topics you feel comfortable discussing.

In the same way that recovery is a process, so is the decision to share your story. Deciding to engage with others about your story can have positive, powerful impacts for both you and others.

Lobby Day Reflection

Registering to attend the 2017 Eating Disorders Coalition (EDC) Lobby Day, I did not know what to expect. As president of Brown University's chapter of Active Minds, I had been actively involved in several mental health advocacy initiatives over the years, but attending a Lobby Day would be a completely new experience.

The morning of October 5th, I woke up before my alarm – a rare event that I attribute to the combination of nerves and excitement. While not a Maryland native, I have lived in the area for nearly two years and was assigned to advocate on behalf of the state. Upon joining my team members for our morning training session, I felt immediately welcomed into a community of like-minded individuals with a shared passion and goals. Opening remarks were provided by Dr. Bryn Austin, the EDC President, and Kitty Westin, founder of the Emily Program Foundation.

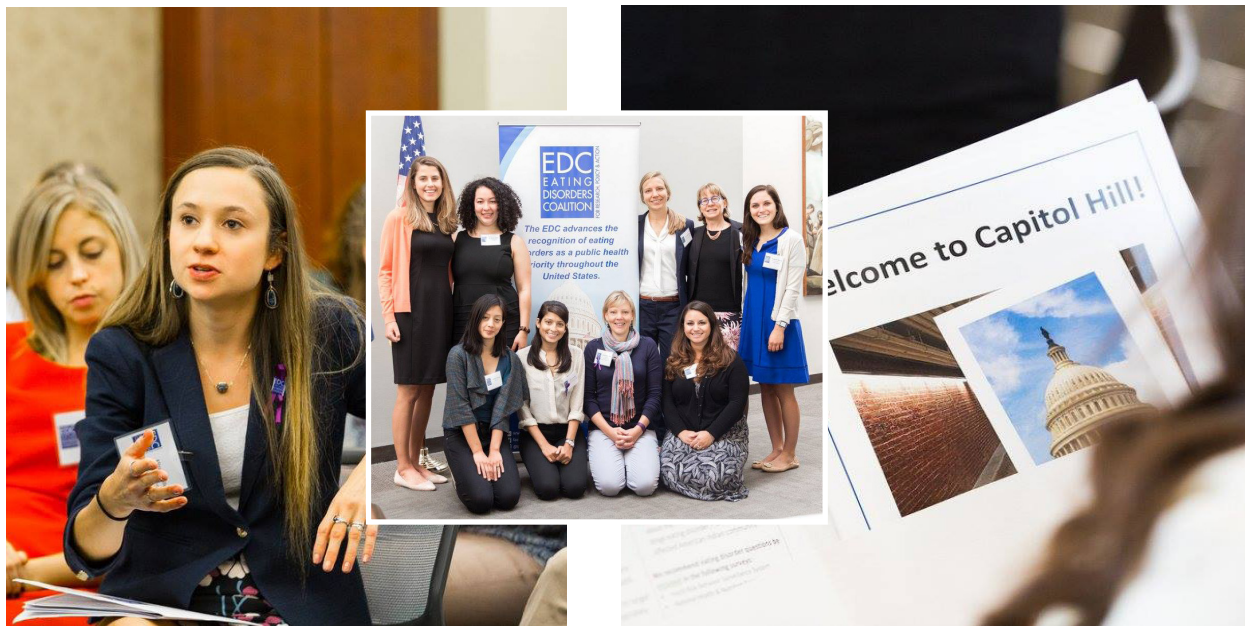
The collection of inspirational and educational presentations left me feeling motivated, energized and hopeful – feelings that I am confident those around me experienced as well. During the training session, we were informed of our two “asks” for the day.

Our first goal was to request that the annual public health surveys by the Centers for Disease Control and Prevention (CDC) include questions about disordered eating behavior. Interestingly, questions about Anorexia Nervosa and Bulimia Nervosa were included in the CDC's Youth Risk Behavior Surveillance from 1992 until 2015, at which point the questions were removed. The root cause for their removal is unknown, but their absence has significant implications for the direction of eating disorder research. Without an accurate and up-to-date prevalence estimate of these behaviors, we do not have all of the information needed to inform research directions aimed at improving early identification, treatment and sustained recovery. Moreover, it is critical that questions are not limited to Anorexia and Bulimia. In fact, Binge Eating Disorder is the most common eating disorder and accordingly, failure to include questions related to this disorder would be a disservice to the public.

Our second goal was to urge Congress to recognize National Eating Disorders Awareness (NEDAwareness) Week. This effort is being led by Senators Tammy Baldwin of Wisconsin and Shelley Moore Capito of West Virginia through the introduction of a Senate Resolution to recognize the last week of February as NEDAwareness Week. Specifically, the resolution will (1) recognize NEDAwareness Week, (2) recognize the prevalence of eating disorders and need for treatment, (3) support the goals and ideals of raising public awareness for eating disorders, (4) acknowledge that eating disorders can be successfully treated and people can recover, and (5) encourage the government and citizens to support NEDAwareness Week through programs and activities and promote awareness of eating disorders. Having personally participated in NEDAwareness Week for several years, I can attest to the power of this event as an opportunity for advocates and individuals with personal experience throughout the country to come together to recognize eating disorders as a critical public health concern and fight for change.

Lobby Day Reflection

Beyond presenting our two major “asks” during our congressional meetings, members of our group were asked to share personal stories of the role eating disorders have played in our lives. While the majority of advocates had personal experience with an eating disorder, there were several people who shared stories of supporting friends or family members through the recovery process. I have publically shared my own recovery story on several occasions, yet when it came time for me to speak in front of congressional staff I cannot deny feeling nervous. However, I was comforted by the support from my team members and instant connection I experienced from this group of like-minded, passionate strangers. In addition, many of the staff we met with expressed genuine interest and curiosity in our stories, a response that left me feeling hopeful and proud of my decision to share my experience.



Photography courtesy of Jae Yi (www.jyphoto.com)

After completing our congressional meetings, we congregated together as a group to share our highlights and reflect on the day. The highlight of my own day was realizing the power of using my voice for change. I left Capitol Hill experiencing a range of positive emotions – I felt empowered, I felt valued, I felt supported, and I felt heard. I look forward to participating in many more EDC Lobby Days and encourage all those who may be nervous or hesitant in the same way I was to take the leap of faith – you will be happy you did.

¹ Swanson, S. A., Crow, S. J., Le Grange, D., Swendsen, J., & Merikangas, K. R. (2011). Prevalence and correlates of eating disorders in adolescents: Results from the national comorbidity survey replication adolescent supplement. *Archives of general psychiatry*, 68(7), 714-723.

Social Media Guidelines

Writing about your eating disorder (ED) experience can be an effective way to facilitate your own recovery while supporting others going through a similar experience. Media such as letters to the editor, op-eds, and blog posts present an opportunity to voice your opinion to a wider audience and encourage others to take a stance. If you live in an area where you believe eating disorder recovery does not receive enough support, you can also use these types of publications to push for policy change or increased access to resources.

What's the difference between a letter to the editor and an op-ed piece?

A letter to the editor (LTE) is a piece sent to a publisher about an issue of concern. Typically, letters to the editor are written in direct response to an article printed by the target publication. While similar in nature, an op-ed is a piece devoted to commentary, feature articles and opinions. When it comes to raising awareness about eating disorders (EDs), both LTEs and op-eds can serve as a great platform to publicly voice your perspective.

Below are a few tips to help in the process of developing an LTE, op-ed piece, or blog post.

LTE/Op-ed considerations:

- **Familiarize yourself with the guidelines:** Before you start the writing process, it is wise to become familiar with the publication guidelines. Most publications have a word limit on LTEs and op-eds. LTEs are generally 250 words or less, while op-eds are typically around 700 words. It is also important to find out where to submit your content (usually this is done via email or an online form).
- **Open with a personal experience:** An effective way to “hook” your readers can be to open your piece with a personal experience. You can choose the degree of detail you would like to share (and never share more than you are comfortable with).
- **Provide a specific and feasible call to action:** Generally, the goal of an LTE or op-ed piece is to get readers to take action. Aim to incorporate a specific and doable call to action.
- **Consider your audience:** Who do you anticipate will read your piece? What is the typical audience of readers for the target publication? Who are you hoping will read your submission? It can be helpful to consider these questions before developing your content.
- **Support statements with evidence:** Your opinion will be given more weight if you are able to support it with scientific evidence. When possible, include references to relevant research and statistics (and be sure to cite your references).

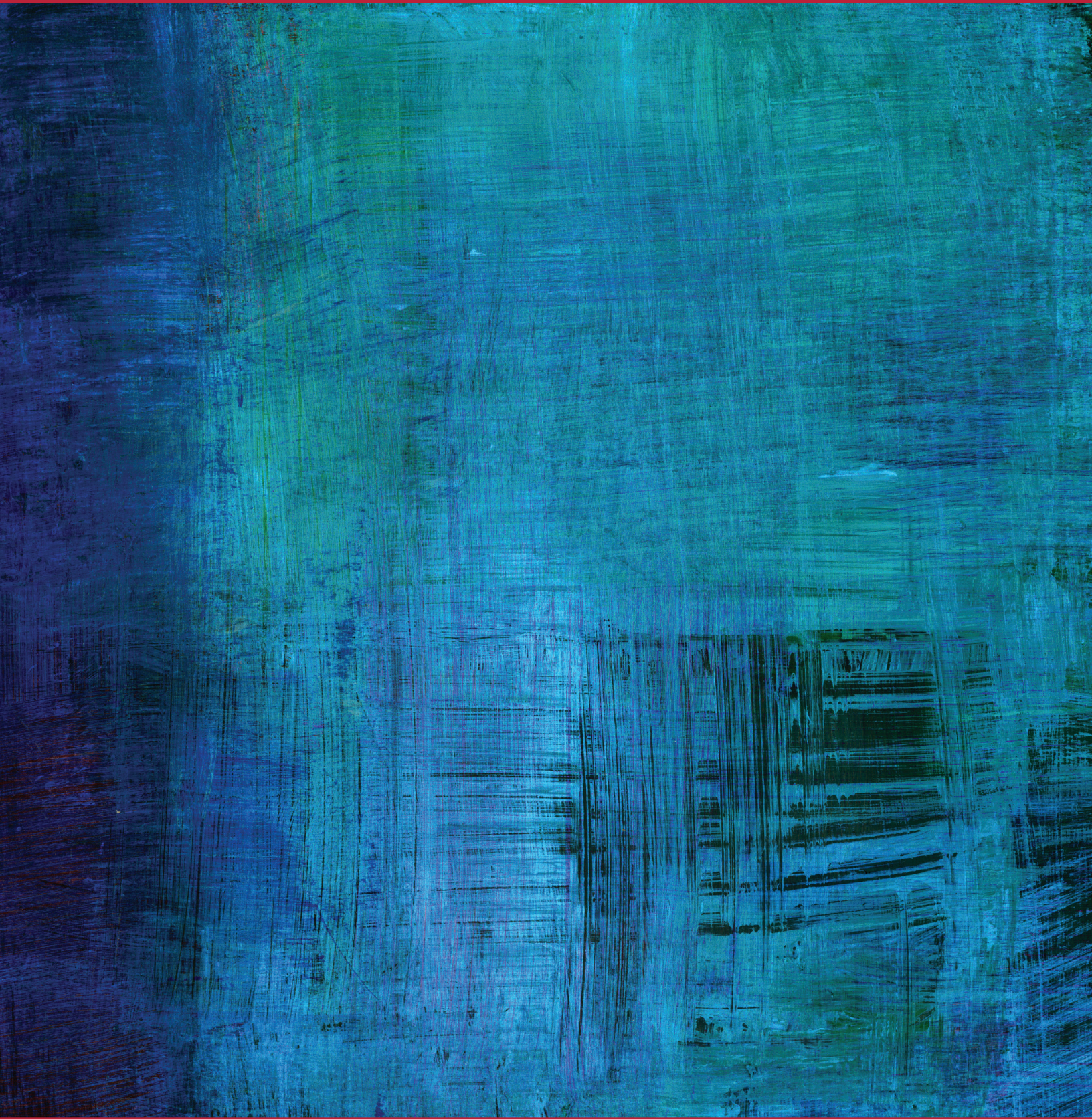
Social Media Guidelines

In comparison to Op-eds and LTEs, blogging is often more personal. At the same time, depending on how you chose to frame and share your blog, it has the opportunity to reach even wider audiences.

Blogging considerations:

- **Just start somewhere!** Getting started is often the hardest part. Begin writing about whatever comes to mind and trust that your piece will come together. You can always (and should) go back and edit.
- **Focus on feelings, not behaviors:** Describing how you felt at different points in your ED journey can be a powerful way to help your audience understand your experience. However, it is important to avoid discussion of specific ED behaviors that have the potential to be triggering to your readers.
- **Avoid the use of numbers or “before and after” photos:** “Before and after” weight restoration photos can be highly triggering to individuals struggling with disordered eating. Importantly, the majority of people suffering from an ED are not underweight. Inclusion of such photos has the potential to perpetuate the myth that EDs are uniquely about weight loss. While we cannot control how our audience reacts to our material, photos often prompt self-comparison and may lead someone to feel they are not “sick enough” to seek treatment.
- **Think critically about how much you are comfortable sharing:** In general, once something is shared online, it’s out in there for good and you lose some control over your audience. Keep this in mind when sharing details of your personal experience.
- **Write for you:** While it is very likely that a blog post about your experience will resonate with and help some of your readers, there is no shame in writing as a means to facilitate your own recovery. However, don’t try to tell the story you think your readers want to hear; instead, share your personal truth.

Whether it’s through an LTE, Op-Ed, or blog post, sharing parts of your ED experience can be a rewarding way to help others and continue on your own recovery path. Likewise, voicing your opinion about eating disorder related policy through the lens of your personal experience is often an effective way to raise awareness.



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