



NATIONAL EATING DISORDERS ASSOCIATION
MAKING CONNECTIONS

Language & Eating Disorders



PLUS

Talking With Your Child About Their Weight: Helpful or Harmful?

Jerica M. Berge, PhD

NEDA Lobby Day: Change, One Step at a Time

Tobi Martin

Navigating the Holiday Season

Robyn Cruze and Espra Andrus, LCSW

Finding a Cure Through the Feeding Hope Fund

Julie Finkelstein

Letter from the PFN Chair | By Deborah Kreiger, Florida

Hello Everyone,

As we wrap up 2013 with this issue of **Making Connections**, the “In Focus” section discusses language, communication and eating disorders. The topic of language surfaces often in our discussions as a committee because each of us understands the delicate balance, responsibility, implications and power that exists in language; in the words that we speak everyday to our loved ones, our friends and colleagues and to perfect strangers.



I have always had a fondness for words, either verbal or written, but it was not until our daughter was struggling with her eating disorder that I became so acutely aware of the power of words. They made me feel vulnerable, cautious, and fearful of their impact. Never before had I been as guarded about common everyday words and the possible ways they would be interpreted. It was frightening for me. Something as natural as the language we speak every day can have layers of meaning and to someone who is struggling and needs to hear the right messages, our deftness with language and the ability to share and communicate, so that our words offer love, support and understanding can become a daunting and seemingly insurmountable challenge.

In the articles that follow, language and communication is explored in greater detail, and I hope you will find both comfort and guidance as we learn from these authors and from one another.

As we celebrate the holidays in our own meaningful ways, let us also remember to be sensitive to those family members and friends who may be struggling or who are early in recovery. Our words and actions should be wrapped in thoughtfulness and understanding, two intangible gifts that will be forever treasured.

I wish you a peaceful, safe and joyous holiday season,

Deborah ■

IN THIS ISSUE

- | | |
|---|---|
| <p>2 Letter from the PFN Chair</p> <p>3 Editor’s Note</p> <p>4 The Language of Partners</p> <p>5 ED Lingo 101 for Siblings</p> <p>6 The Language of the Brain</p> <p>7 What Readers Are Saying</p> <p>8 The Communication Illusion</p> <p>9 Talking with your Child about their Weight: Helpful or Harmful?</p> <p>11 Communicating with Your Loved One: Education, A Listening Ear and Unconditional Love</p> <p>12 The Path to My Recovery Voice</p> <p>13 Navigating the Holiday Season</p> <p>14 Strategies for Enjoying the Holidays: Tips from Fellow Readers</p> | <p>16 2013 NEDA Conference Delivers the Latest on Eating Disorders and Challenges the Field to Move Forward</p> <p>18 NEDA’s First Federal Lobby Day a Great Success!</p> <p>19 Change, One Step at a Time</p> <p>20 Research Summary Shared Genetic and Environmental Risk for Eating Disorder Symptoms and Alcohol Use Disorder</p> <p>21 NEDAwareness Week Feb 23–Mar 1: <i>I Had No Idea</i></p> <p>22 Finding a Cure Through the Feeding Hope Fund</p> <p>24 Upcoming: PFN Webinar Series</p> <p>25 Book Review: <i>Ed Says U Said</i></p> <p>26 NEDA Walks 2014</p> <p>26 NEDA Walk Volunteer Spotlight</p> <p>27 Network Spotlight: The Elisa Project</p> <p>27 Meet the NEDA Staff!</p> <p>28 Call for Submissions: “Hope”</p> |
|---|---|

Editor's Note | By Susie Roman, Director of Programs

Dear Readers,

It has been an event-filled fall, and we thank all who attended and contributed to the success of the NYC NEDA Walk, 2013

NEDA Conference in Washington, D.C., first-ever NEDA Federal Lobby, and NEDA Walks across the country! We are excited to bring you updates on the impact of our collective efforts to improve education, lobby for change and raise funds to support critical programs.

At NEDA, we often hear from those who have a loved one struggling that there is a great deal of anxiety, confusion and trepidation about how to communicate with their boyfriend, girlfriend, spouse, sibling, child, friend, niece, cousin, grandparent, etc. Sometimes, trying to know what to say, how to express concerns in a



supportive way and maintaining a healthy relationship, can feel overwhelming. Drawing on the wisdom and experiences of your fellow PFN members, this issue of *Making Connections* offers real-world strategies for improving communication, and, since it is the holiday season, provides tips for dealing with stressful events. The articles featured in the *In Focus* section highlight the importance of being mindful about the ways in which language matters, while also acknowledging you may not always know exactly what to say, but can continue learning as you help someone navigate the journey to recovery. We hope that you will feel empowered to talk with your loved ones about the anxieties that can accompany holiday festivities, and plan ahead to make them an enjoyable celebration.

Themed *I Had No Idea*, National Eating Disorders Awareness Week (NEDAwareness Week) is right around the corner, February 23 – March 1, 2014. Those who

have dealt with an eating disorder in their life know best how critical education and access to resources are. We all have an opportunity to pass along our knowledge about eating disorders to others who may not be aware of the seriousness, early signs, importance of seeking professional help and available resources. The NEDAwareness Week website (NEDAwareness.org) offers many fun and easy ways to make a difference. We hope you'll join us!

We plan our upcoming issues of *Making Connections* based on your ideas and submissions. Don't forget to write to us at pffnetwork@myneda.org to let us know what topics you'd like to see included in the future (or to submit an article of your own!). I hope you all are enjoying a warm and joy-filled holiday season.

Sincerely,
Susie Roman
Director of Programs ■

PFN STEERING COMMITTEE:

Deborah Kreiger, Florida (*Chair*)
Lorri Antosz-Benson, California

Don Blackwell, JD, Florida
Nancy Hemendinger, New York

Phoebe Megna, Connecticut
Mike Polan, New York

Adam Radwan, New York
April Rebollo, Washington

NEDA Board of Directors

NEDA President & CEO

Lynn Grefe, MA

NEDA Board Emeritus:

Craig Johnson, PhD
Robbie Munn, MA, MSW
Don Nielsen
Dorothy Sprague

Bob Kovarik, *Chair*
Oakton, Virginia
Deborah Q. Belfatto, *Vice Chair*
Summit, New Jersey
Lisa Ryan Burke, *Treasurer*
Summit, New Jersey
Phoebe Megna, *Secretary*
Darien, Connecticut
Russell Marx, MD, *Chief Science Officer*
San Diego, CA

Karen Andonian
Clyde Hill, WA
Evelyn Attia, MD
New York, NY
Ric Clark
Larchmont, NY
Mary Curran
West Simsbury, CT
Julie Finkelstein
Purchase, NY

Mary Lipton
New York, NY
Kimberli McCallum, MD
St. Louis, MO
Tamara Pryor, PhD
Denver, CO
Elizabeth Sarquis
Minneapolis, MN
Allison Kreiger Walsh, JD
Orlando, FL
Steve Wonderlich, PhD
Fargo, ND

NEDA Board Senior Advisors:

Ovidio Bermudez, MD, *Media Advisor*
Douglas Bunnell, PhD, *Navigators Advisor*

Amy Baker Dennis, PhD, *Conference Advisor*
Walter Kaye, MD, *Research Advisor*

Margo Maine, PhD, *Advocacy Advisor*

NEDA Junior Board:

Laura Serico, MA, *Chair*
Lindsay Belfatto, *Vice Chair*
Troy Roness, MEd, *Secretary*

Christopher Skarinka, *Treasurer*
Brooks Brodrick, PhD
Erin Hall

Elizabeth Sexton, MPA
Lauren Steiner

For more information on NEDA's Leadership Councils, please visit
www.nationaleatingdisorders.org/leadership-councils



IN FOCUS

Language, Communication and Eating Disorders

The Language of Partners

By Emily Farquharson, NEDA Navigator, New York

I was raised with the belief that language is important. I was taught that the precision of my words could greatly affect the impact of what I say. When I first met my partner a little over two years ago, one of the main things we bonded over was our love of language. A creative writer herself, I could see how carefully she spoke. On our fourth or fifth date, with such precision, she nervously told me that she had an eating disorder, that she'd struggled with anorexia for almost a decade and that she had problems with over-exercising. She told me about her treatment team and her experience with programs in the past. She told me that she was in recovery, but that recovery was a long process. My reaction was rather confused. I didn't know very much about eating disorders at all. Initially, all I could say was that I was sorry she had to go through all that, and that it was okay.

In the following months, I was overwhelmed. I felt like I couldn't talk to anyone. Language became more difficult. I was scared to talk to my new girlfriend about it. That was the hardest part. I had no idea how to communicate with her. I also knew that as a gay woman, she had probably faced many of the obstacles that members of the LGBT community face, obstacles that I had faced: the added pressure of even more stigma, potentially lack of family support, and an even more difficult time with self-acceptance. This meant that at the time that she was going through the process of accepting her own sexual orientation and coming out to her friends and family, she was struggling with an eating disorder as well. I knew that could not have been



easy. How many times would she have to come out? How many times would she have to have such carefully worded conversations?

Communication felt like an obstacle, a hurdle that I had to get over. I felt immense pressure to "say the right thing." Of course, this meant that I often felt like I said the wrong thing. However, I soon realized that I needed a balance. I had to stop being so afraid of saying the wrong thing – it's going to happen sometimes, and that's okay. However, that didn't mean that I shouldn't be mindful of what and how I communicate.



I realized, too, the importance of being open and honest about my concerns for her. I decided that, when I'm worried, I just have to tell her how I feel in the most supportive possible way. For example, if she made a disordered comment about her body while we're out to dinner, I would tell her that the comment made me nervous or that it scared me. I would remind her that those comments are the product of her disorder, that I don't see what she sees. I'd tell her how beautiful she is, inside and out. And, then we'd continue on with our dinner, talk about

other things. Don't ignore the symptom, but be able to move on after addressing it. Letting go of the conversation—being mindful that we can't fix everything right away—are key to maintaining our relationship. That style of our day-to-day communication allows the focal point of our relationship to be the fact that we love each other; that we love each other's company. The focal point doesn't have to be her eating disorder, and it isn't.

Aside from changing the way I communicate in a relationship, I also changed the way I communicate to others. Prior to meeting my partner, I

wasn't all that mindful of my vocabulary about food or my own body. I now know how much it matters. It matters because the way that I talk about food and myself sends a message to her. The all-too-casual conversation of negative talk about food content and body image are no longer acceptable for me. I have completely eliminated that kind of speech from my vocabulary. And, it's amazing. This alteration of

my language was initially for the benefit of my partner, but it truly has benefited me. By changing my outer dialogue about my body, I've changed the inner dialogue about my body. I love living this way. It's so freeing.

When a person is concerned about a loved one who struggles with an eating disorder, it is so easy to be at a loss for words. All I can say is that whenever I feel at a loss for words, the following truths suffice: "I love you," "I believe in you and your strength," and "I'm here for you."

ED Lingo 101 for Siblings: Learning to Listen to My Sister As Just My Sister, Not As Her Eating Disorder

BY Adam Radwan, NEDA Navigator and PFN Steering Committee Member, New York



English is my first language, but throughout my life I've had opportunities to learn and speak Arabic, French, Polish, Spanish, and even Latin. For me, learning new languages meant learning about new cultures, ideas and perspectives, all of which excited me. Of course, I had my moments where I would complain about the difficulties of Arabic grammar, or question why the French rarely pronounce the last letter in words; yet I found the experience of communicating with more and more people to be profoundly powerful.

There is one more language that I left off from that list, and that is because it is in a unique category of its own: eating disorders language, or, as I have come to call it, ED Lingo. I define ED Lingo in the general sense as the way in which one communicates about an eating disorder. I was first introduced to ED Lingo seven years ago when my younger sister was diagnosed with anorexia nervosa. This was not a language I signed up to learn, but knew that I should if I wanted to support my sister.

I remember being with her at her first inpatient treatment facility. While she was filling out paperwork, I was in the waiting room, nervously skimming through a brochure called "Essential Facts about Eating Disorders." My eyes zoned in on a list of words and terms that were completely foreign to me: emotional eating, body dysmorphia, pervasive refusal syndrome, triggers and behaviors. Feeling overwhelmed, I took a deep breath and slowly placed the brochure back on the table.

From that point on, communicating with my sister and her eating disorder proved nearly impossible. We were never on the same page with anything. What were once simple questions like "How was

your day?" or "Can you pass the ketchup?" suddenly became taboo to ask. I would repeatedly tell her how beautiful and amazing of a person she was, but she never heard me. Even complimenting her on a certain color she was wearing would almost always end up in an argument or shouting match. Our conversations soon became scripted and would often end with her yelling, "YOU DON'T KNOW WHAT IT FEELS LIKE AND YOU WILL NEVER UNDERSTAND!"

That wasn't always the case though. My sister and I are only 18 months apart and like most siblings close in age, we grew up with our own form of communication that included a varied mix of words,

but that did not mean I couldn't be there to support her.

It took me several years of feeling angry and frustrated to finally accept the reality of it all and be at peace with the silence that lingered between us. We were not communicating like we used to — and that was perfectly okay. We were both adapting to our new respective worlds, she as someone recovering from an eating disorder, and I as someone supporting a loved one in recovery. It was almost like we were going through a bout of growing pains, except this time in our twenties.

Standard language textbooks don't tell you this, but there is power in silence.

Silence provides you with a safe space to accept, reflect and just be with yourself, however you are. More importantly, it is in that same space where you are given the chance to choose how to listen to others and interpret things around you. What I created in my silence was choosing to listen to my sister as just my sister, not as her eating disorder. And, what that has given me is a greater sense of freedom and ease in our communication. I'm no longer stuck on the limitations that a disease such as an eating disorder brings in between two people; instead, I am

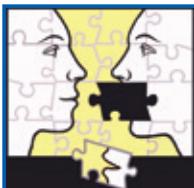
choosing to stand in a place of honesty and unconditional love for both my sister and myself.

As my sister continues to make strides in her recovery, I am convinced that part of it has to do with our renewed communication. We are only looking forward, not back—and for that, I am excited to still be a student of ED Lingo. The one good thing about learning ED Lingo is that there are no tests and final grades. All a stellar student needs is to exercise compassion, forgiveness, and love. ■



sounds, hand signals, and eccentric dance moves. It was our own private language that we created and coded, which meant that only we could understand each other. Our parents tried their best to understand, but were never quite able to crack the sibling code.

This time, my sister was right. Our sibling code was outdated and expired; the illness made it impossible for our old code to work in the same way because it changed the way she heard and reacted to what I said, which in turn frustrated me. I would never know how she felt, and I would never understand what she went through on a daily basis. I was silenced because I did not have an eating disorder,



The Language of the Brain

By Dr. Jeffrey DeSarbo, D.O., Board Certified Psychiatrist, ED-180 Eating Disorder Treatment Programs, New York

The language of an eating disorder resides in the brain, making neuroscience critical to better understanding the brain functioning in people with eating disorders. Existence entails what you are thinking about from moment-to-moment. And, what you think about from moment-to-moment is an important determinant of the quality of your life. But where do our thoughts come from? The language of thought appears to originate in the brain. We can tell when one is thinking or processing information in the brain when we see electrochemical signals with neuroimaging on CTs, MRIs, PET Scans and SPECT. Still, we only see the signals and not the thoughts.



When someone suffers from an eating disorder, we know from what they tell us and the things they do that their thoughts are overwhelmingly distressful, all-consuming and often distorted. Imagine the quality of life that goes along with these moment-to-moment thoughts. A person who suffers with an eating disorder has a certain way in which they hear things, say things, perceive things and do things. Patients often describe the experience of living with an eating disorder as a personified voice, often referred to as Ed, which instructs behaviors and creates negative thoughts about the individual's self-worth, appearance and abilities.

Over the past couple of decades, the advancement of neuroimaging has led many researchers on a path to better understand origins of this brain language and what it means for eating disorder onset, treatment and recovery. The scientist who do this work have been making important discoveries into the biological

aspects of eating disorders like anorexia and bulimia nervosa, binge eating disorder and related conditions such as body image distortions. As the language of the neurobiological factors of eating disorders becomes deciphered, many patients and loved ones have been able to lessen their self-blame and recognize the role that genetics and biology plays with their condition. Onset and recovery is not only explained by a change in observable behaviors, but there are unseen functional and anatomical changes in the brain itself that help explain the behavioral changes.

Patients often describe the experience of living with an eating disorder as a personified voice, often referred to as Ed, which instructs behaviors and creates negative thoughts about the individual's self-worth, appearance and abilities.

Over the past few decades, there have been several hundred high-tech, scientific studies on the brain and eating disorders. Through this collective work develops a picture of how the brain impacts an eating disorder and vice versa. While single studies provide some basis of conceptualization, it is the body of evidence that leads to a deeper understanding of the brain and biology's role with an eating disorder. Studies teach us a word; the sum total of all the studies teaches us the language.

Amongst the insightful and fascinating studies are those which help us understand the role of genetics. Researchers have been consistently finding that genetic factors may account for over 50% of the contribution to the onset of anorexia and bulimia nervosa.¹ Other researchers have also found that the role of genetics

appears to become more influential as an individual goes from childhood into adolescence.² By understanding the impact of heredity, we can see that having an eating disorder is no more of a choice than a person genetically predisposed to other heritable illnesses.

Other studies help decipher the language of eating disorders by discovering anatomical changes in the brain. With conditions such as anorexia nervosa, neuro-imaging has shown us that there is brain cell loss of both grey and white matter.^{3,4}

Now researchers are trying to decipher what the results of this brain cell loss are, and how much can be restored with recovery.⁵ For instance, researchers discovered that with anorexia nervosa, there is cell loss in the parietal lobe of the brain that is directly associated with one's internal language that creates a drive for thinness.⁶

But, the brain science is not a simple this-causes-that story. For instance, Estonian researchers discovered that certain changes in a serotonin neurotransmitter found in girls with eating disorders could also be responsible for a drive for thinness.⁷ Other scientists have identified several key hormones and brain processes that may be malfunctioning in people with eating disorders. Leptin and ghrelin, two such hormones, interact with a variety of other hunger and satiety signals to help keep our bodies fueled properly. In one study, leptin levels were significantly elevated in the women with binge eating disorder compared to healthy women, but they were significantly lowered in women with anorexia or bulimia.⁸ In yet another study on brain function and eating disorders, researchers demonstrated there is often a change in blood flow in women with anorexia nervosa who have

► *continues on next page*

► Language of the Brain *continued*

body image distortions.⁹ These blood flow changes are similar to patients who have psychotic disorders where their perceptions are also distorted and may help explain the cause of such significant alterations in self-perception. So, we can see that important biological factors interact with cultural pressures and social stressors that may contribute to onset of these disorders.

It is these types of studies, conducted by dedicated scientists that will lead the way to more sophisticated understandings of how eating disorders take hold in the brain, and effective interventions to prevent and disrupt these processes. Such progress is time-consuming and requires money, but this type of research will likely be what is needed to make major breakthroughs in treatment protocols. In the meantime, it would do our field well to help patients, their families and the public know that there is growing evidence that helps explain how the thoughts and behaviors associated with an eating disorder may be more under the control of biology than simple will. Education is an important part of ensuring people express

concern if they are worried a loved one is struggling, so that they can get the help they deserve. Early intervention for treatment, and the support of loved ones, are critical in offering patients the best chance for full recovery. ■

References

1. Bulik CM, Thornton LM, Root TL, Pisetsky EM, Lichtenstein P, Pedersen NL. "Understanding the relation between anorexia nervosa and bulimia nervosa in a Swedish national twin sample." *Biol Psychiatry*. 2010 Jan 1;67(1):71-7.
2. Klump KL, Burt SA, McGue M, Iacono WG. "Changes in genetic and environmental influences on disordered eating across adolescence: a longitudinal twin study." *Arch Gen Psychiatry*. 2007 Dec;64(12):1409-15.
3. Swayze VW 2nd, Andersen AE, Andreasen NC, Arndt S, Sato Y, Ziebell S. "Brain tissue volume segmentation in patients with anorexia nervosa before and after weight normalization." *Int J Eat Disord*. 2003 Jan; 33(1):33-44.
4. Joos A, Hartmann A, Glauche V, Perlov E, Unterbrink T, Saum B, Tüscher O, Tebartz van Elst L, Zeeck A. "Grey matter deficit in long-term recovered anorexia nervosa patients." *Eur Eat Disord Rev*. 2011 Jan-Feb;19(1):59-63.
5. Roberto CA, Mayer LE, Brickman AM, Barnes A, Muraskin J, Yeung LK, Steffener J, Sy M, Hirsch J, Stern Y, Walsh BT. "Brain tissue volume changes following weight gain in adults with anorexia nervosa." *Int J Eat Disord*. 2011 Jul;44(5):406-11.
6. Joos A, Klöppel S, Hartmann A, Glauche V, Tüscher O, Perlov E, Saum B, Freyer T, Zeeck A, Tebartz van Elst L. Voxel-based morphometry in eating disorders: correlation of psychopathology with grey matter volume. *Psychiatry Res*. 2010 May 30; 182(2):146-51.
7. Akkermann K, Paaver M, Nordquist N, Oreland L, Harro J. "Association of 5-HTT gene polymorphism, platelet MAO activity, and drive for thinness in a population-based sample of adolescent girls." *Int J Eat Disord*. 2008 Jul;41(5):399-404.
8. Monteleone, P., Di Lieto, A., Tortorella, A., Longobardi, N., & Maj, M. (2000). Circulating leptin in patients with anorexia nervosa, bulimia nervosa or binge-eating disorder: relationship to body weight, eating patterns, psychopathology and endocrine changes. *Psychiatry Research*, 94(2), 121-129. doi: 10.1016/S0165-1781(00)00144-X
9. Gordon CM, Dougherty DD, Fischman AJ, Emans SJ, Grace E, Lamm R, Alpert NM, Majzoub JA, Rauch SL. "Neural substrates of anorexia nervosa: a behavioral challenge study with positron emission tomography." *J Pediatr*. 2001 Jul;139(1):51-7.

What Readers Are Saying

► June Making Connections

Thank you for sending extra NEDA newsletters to give away to our guests! NEDA is a huge resource to not only the people we reach, but to us as well. We will be sure to put the newsletters in our giveaway bags. Thank you!
— A Treatment Professional

► In reference to a new support group for parents:

It has been so well received. We are growing like wild fire. The magazines were a terrific resource for the moms and dads. Thank you again! — A Support Group Leader

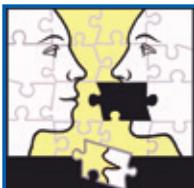
Each issue we highlight additional opportunities to learn from other PFN members and eating disorder professionals through the PFN Webinar Series. Webinar attendees have found them to be helpful in many ways. Here are just a couple of comments from your fellow readers/listeners:

► Sport is a Culture Webinar

Wonderful presentation, I learned so much as a fitness professional and athlete in recovery myself, so that hopefully I can help in the future. — A Webinar Attendee

► Diabulimia Webinar

Thank you for the Diabulimia Webinar! It was truly informative and interesting. I work in the field of EDs and am also just very intrigued by these disorders. I look forward to more in the future. — A Treatment Professional



The Communication Illusion: Nurses and Doctors Recognized A Chance to Tell Me I Needed Help

By Carrie Eaton, RN, MSN-CNL, PhD Student, New York

If you could unlock a recovered eating disordered brain to peer inside most people would be amazed at the distinct memories of the journey. As a seasoned nurse, perhaps my memories are more technical than a non-healthcare professional, but whether you are a nurse, college student, or stay at home mom, there are likely healthcare providers you recall for their compassion and those you remember for their unfortunate ignorance about eating disorders.



I will admit there is tremendous investigative work involved in diagnosing an eating disorder when a patient presents with alternative complaints. Eating disordered patients are notoriously ambivalent to admit the true nature of their presenting symptoms. However, it takes basic screening tools accompanied by a time and energy investment to uncover that a teen or adult is enmeshed in the web of disordered eating. Early intervention holds the key to unlocking a potential lifetime struggle. As a RN, I view an intervention as a valid investment in a patient's future.

With this in mind, it is important that healthcare providers are educated to view patients' symptoms and recognize what may be a clear red flag of an undiagnosed eating disorder. In the hospital setting, we screen for potential latex allergies, drug and alcohol use, sexually transmitted infections, depression, suicide risk and a myriad of other possibilities. How often do nurses and doctors screen for high risk eating disorder behaviors? Simply asking, "Do you have a history of an eating disorder?" is not enough. In the words of George Bernard Shaw, "The single biggest problem with

communication is the illusion that it has taken place." It is important to appreciate that people with eating disorders are often reluctant to seek help. Therefore, screening should consist of identifying physical symptoms of a potential eating disorder coupled with open-ended questions and empathetic understanding in an effort to elicit detailed information on an admission history. The cornerstone of relationship-based care includes human connection and trust. How can a provider establish both elements in order to bridge the gap between treating presenting symptoms versus discovering the underlying causes – the eating disorder?

In an era where patient satisfaction directly aligns with reimbursement, relationship-based care is the foundation of success. Many eating disordered individuals are struggling to perfect their eating disorder while simultaneously contemplating help. Medical professionals are in a unique position to identify when someone is struggling and open the door for them to get treatment by providing appropriate referrals. Therefore, the clinical question lies in how healthcare providers can feed hope to patients presenting with ED symptoms and behavior without rupturing the delicate balance of a therapeutic alliance. Having experience on both sides of the spectrum, there are some basic suggestions to consider:

- 1. Compassion and trust resonate deeply.** The way in which a patient with an eating disorder responds to healthcare providers correlates to the level of interpersonal connection, established trust, and sense of control reciprocated to them.
- 2. Medical stabilization is a temporary band-aid.** An eating disorder is not a choice, but a complex mental illness requiring a combination of medical and mental health intervention.

- 3. Explore treatment options with patients suffering from an eating disorder even if they are reluctant.** Opening the door towards the recovery process provides hope to a population that often feels a sense of hopelessness.
- 4. Define the patient's eating disorder goals. Do they include recovery?** The answer(s) may be a startlingly realistic gauge of their mental state and readiness for intervention.
- 5. Lend levity to the self-conscious eating disorder patient.** Make them laugh, as you would any other patient. Beneath the eating disorder and the façade of control is a real person.

In 2003 and again in 2005, I was fortunate enough to come across well-educated healthcare providers who recognized the red flags associated with my eating disorder. I crossed paths with providers who, in my personal opinion, remained true to the root of their profession by practicing the art of human caring and collaboration. I specifically recall the social worker who committed me to residential treatment in 2003 saying, "This is a gift you will appreciate someday." At that moment, it felt like a curse, but despite being reluctant and angry at the prospect of intervention, treatment providers persisted in their endeavors and ultimately saved my life. I am one of the lucky ones. The hospitalist who spent well over an hour at my bedside during my relapse in 2005, helping me comprehend treatment trade-offs in the face of an eating disorder, is now my primary care physician. He took the time to decipher the illusion of control I created and broke down barriers using communication. He made me laugh, cry, and connect on a personal level. He asked me to define my eating disorder goals and discussed attainable alternatives to the self-destructive path I was following. I am forever grateful for his persistence. I am here today because nurses and doctors recognized the chance to provide, "...a wakeup call, a teachable moment, a chance to tell..." (Nauert, 2012, p.2) me, I needed help.

→ continues on next page

► The Communication Illusion *continued*

With a full recovery on my plate, I volunteered last spring on the NEDA Helpline. I was reluctant at first. However, utilizing the NEDA Helpline training helped me take back the opportunity to make a difference one call at a time. Successfully implementing helpline skills and the positive outcome of my own battle with an eating disorder enabled me to provide meaningful connections with callers. The most difficult part of the NEDA Helpline is leaving the telephone in its cradle and walking away. Just like in bedside nursing, there are people who resonate with you after a shift. Thoughtful letters, gifts, positive survey feedback, and evidence-based outcomes let me know I am maximizing my potential to change lives during hospital work, but the NEDA Helpline is confidential and callers can choose to remain anonymous, which leaves many questions unanswered. For example, one distraught mom asked me directly

about my eating disordered background and posed the following inquiry: "What made you recover?" Although I could not reveal to her the answer, as the call was about her and we do not talk about our personal experiences on the Helpline, her question echoes in my head as I explore my mind and soul for a powerful answer. My nursing brain continues an endless attempt to formulate an evidence-based response, but I can only extract the answers from my heart. I have an insatiable desire to succeed in life. I achieved multiple goals while simultaneously enmeshed in anorexia. For a moment, I allowed a therapist, who I admire and remains my mentor to this day, to paint me a picture of a future without anorexia. She helped me weigh the facts and showed me the potential for gaining back life as opposed to focusing on giving something up. I was intrigued to determine if my anorexic discipline, patience and fortitude extended beyond a tangled

reliance in eating disordered identity. The heart is a life-sustaining organ, and I wanted to know if mine could propel me beyond sustenance towards a world of opportunity. Perhaps Jostein Gaarder (*Sophie's World*, 1991, p. 14) says it best, "Of course everyone needs food. And of course everyone needs love and care. But there is something else – apart from that – which everyone needs, and that is to figure out who we are and why we are here." The strength and potential of a healthy heart that isn't encapsulated by an eating disorder is unparalleled. ■

References:

- Gaarder, J. (1991). *Sophie's World*. Farrar, Straus and Giroux.
- Nauert PhD, R. (2012). Spotting Eating Disorders in the ER. *Psych Central*. Retrieved on February 7, 2013 from: <http://psychcentral.com/news/2012/11/20/spotting-eating-disorders-in-the-er/47951.html>
- Shaw, George Bernard quotes. Retrieved from ThinkExist.com on February 7, 2013.

Talking with your Child about their Weight: Helpful or Harmful?

By Jerica M. Berge, PhD, MPH, LMFT, CFLE, Minnesota

During adolescence, weight-related problems including both obesity and eating disorders¹⁻³ are prevalent. Parents may wonder whether talking with their adolescent child about eating habits and weight will be useful and promote healthful eating, or whether it will have unintended consequences and promote unhealthy or disordered eating behaviors. Previous research has shown a connection between family and parent weight teasing and more frequent use of disordered eating behaviors (e.g. dieting, laxative use, fasting, binge eating) in adolescents, however, these results are not always consistent⁴⁻³² and little to no research has looked at whether parent conversations focused on adolescent's eating habits or weight (e.g. conversations about the importance of healthful eating versus conversations that primarily focus on the child's weight or size) have the same negative effects on youth disordered eating behaviors as weight teasing.^{8,33,34}



Healthful Eating and Weight: Associations With Adolescent Disordered Eating Behaviors, conducted on 2,793 socio-economically and racially/ethnically diverse adolescents and their parents (n=3,709) in the Midwest aimed to address these very issues. In project *Families and Eating and Activity among Teens* (F-EAT), mothers and fathers were asked what type of conversations they were having with their adolescents ages 11-17 years regarding eating habits. For example, did they talk about healthful eating behaviors with their adolescents, did they focus on the weight, shape or size of their adolescent during these conversations, or did they avoid these types of conversations all together?

Results of this study identified two key messages for parents and providers. First, regardless of the weight (normal weight versus overweight/obese) or gender (female vs. male) of the adolescent, mothers and fathers who focused on eating healthfully in their conversations with their adolescents versus focusing on the adolescent's weight/shape/size, had adolescents who tried fewer disordered eating behaviors such as, binging, purging, taking laxatives, diuretics or dieting.

Second, when there were two parents as compared to one parent having conversations focused on eating healthfully versus focusing on the adolescent's weight/shape/size, adolescents tried the fewest amounts of disordered eating behaviors.

What do these parent conversations look like in the real world? Parents who focus on healthful eating conversations, say things like, "I think it is important for us to eat our fruits and vegetables so that we will be healthy and strong." Parents who focus on weight/shape/size conversations, say things like, "If you don't want to gain weight, you need to eat your fruits and vegetables," or "I'm worried that you are gaining weight, so you need to eat more fruits and vegetables." Parent messages with a more positive undertone, such as "being healthy and strong" are more likely to empower adolescents to make more healthful eating choices, whereas pointing out perceived negative attributes in one's child, such as, "being heavy or putting on weight," draw focus to something that may be 'wrong' with the child. Focusing on what the child believes to be negative about their weight/shape/size increases the likelihood that the child will resort to

► *continues on next page*

► Talking with your Child about their Weight *continued*

more harmful behaviors, such as disordered eating behaviors to do something about the ‘problem.’

What if your child approaches you and says they think they are fat? Parents have a unique opportunity to be a part of their child’s most vulnerable moments and to challenge the belief system that thinner automatically equals better and healthier. Knowing how to reinforce good choices/decisions and educate about the many important indicators of health, versus reinforcing the negativity the child is feeling, is key. In moments like these, parents who say something like, “I can tell that you have been thinking hard about this. I’m glad you are concerned about your health, and I’m happy to be your partner in trying to be more healthy,” rather than “You’re not fat...,” or “I can help you lose weight” helps the child to focus on the important message of being healthy, instead of focusing on the attribute of body size. Focusing on behaviors, such as healthy eating, versus physical attributes, provide opportunities for the child to refocus their attention on something they can do something about, rather than focusing on an attribute they think may be hard to change (and perhaps do not need to change in order to be healthy).

Overall, results of this study suggest that focusing on healthful eating conversations with children may be more helpful versus harmful in regard to adolescents trying disordered eating behaviors. Additionally, when both parents focus their conversations on healthful eating behaviors it is the most helpful to adolescents. These study results give parents something they ‘can do’ with their adolescents to make a difference! ■

References

- Ogden C, Carroll M, Curtin L, Lamb M, Flegal K. Prevalence of high body mass index in US children and adolescents, 2007-2008. *Journal of the American Medical Association*. 2010;303(3):8.
- Ogden CL, Carroll, M.D., Curtin, L.R., McDowell, M.A., Tabak, C.J., & Flegal, K.M. Prevalence of overweight and obesity in the United States, 1999-2004. *JAMA*. 2006;295(13):1549-1555.
- Ogden C, Carroll MD, Kit BK, Flegal KM. Prevalence of obesity and trends in body mass index among US children and adolescents, 1999-2010. *Journal of the American Medical Association*. 2012;307(5):483-490.
- Eisenberg ME, Neumark-Sztainer D, Haines J, Wall M. Weight-teasing and emotional well-being in adolescents: Longitudinal findings from Project EAT. *Journal of Adolescent Health*. 2006;38:675-683.
- Haines J, Neumark-Sztainer D, Eisenberg ME, Hannan PJ. Weight-teasing and disordered eating behaviors in adolescents: Longitudinal findings from Project EAT (Eating Among Teens). *Pediatrics*. 2006;117:e209-215.
- Neumark-Sztainer D, Falkner N, Story M, Perry C, Hannan PJ, Muleri S. Weight-teasing among adolescents: Correlations with weight status and disordered eating behaviors. *International Journal of Obesity and Related Metabolic Disorders*. 2002;26(1):123-131.
- Eisenberg ME, Neumark-Sztainer D, Story M. Associations of weight-based teasing and emotional well-being among adolescents. *Archives of Pediatrics and Adolescent Medicine*. 2003;157:733-738.
- Libbey HP, Story, M.T., Neumark-Sztainer, D.R., & Boutelle, K.N. Teasing, disordered eating behaviors, and psychological morbidities among overweight adolescents. *Obesity*. 2008;16(Suppl 2):S24-S29.
- van den Berg P, Neumark-Sztainer, D., Eisenberg, M.E., & Haines, J. Racial/ethnic differences in weight-related teasing in adolescents. *Obesity*. 2008;16(Suppl 2):S3-S10.
- Hanna AC, Bond MJ. Relationships between family conflict, perceived maternal verbal messages, and daughters' disturbed eating symptomatology. *Appetite*. 2006;47(2):205-211.
- Keery H, Boutelle K, van den Berg P, Thompson JK. The impact of appearance-related teasing by family members. *Journal of Adolescent Health*. 2005;37(2):120-127.
- Neumark-Sztainer D, Wall M, Haines J, Story M, Sherwood N, van den Berg P. Shared risk and protective factors for overweight and disordered eating in adolescents. *American Journal of Preventive Medicine*. 2007;33:359-369.
- Neumark-Sztainer D, Wall M, Story M, van den Berg P. Accurate parental classification of their overweight adolescents' weight status: Does it matter? *Pediatrics*. 2008;121:e1495-1502.
- Mellin AE, Neumark-Sztainer D, Patterson J, Sockalosky J. Unhealthy weight management behavior among adolescent girls with type 1 diabetes mellitus: The role of familial eating patterns and weight-related concerns. *Journal of Adolescent Health*. 2004;35(4):278-289.
- Keery H, Eisenberg ME, Boutelle K, Neumark-Sztainer D, Story M. Relationships between maternal and adolescent weight-related behaviors and concerns: The role of perception. *Journal of Psychosomatic Research*. 2006;61:105-111.
- Fulkerson JA, McGuire MT, Neumark-Sztainer D, Story M, French SA, Perry CL. Weight-related attitudes and behaviors of adolescent boys and girls who are encouraged to diet by their mothers. *International Journal of Obesity*. 2002;26:1579-1587.
- Snoek HM, van Strien T, Janssens JM, Engels RC. Longitudinal relationships between fathers', mothers', and adolescents' restrained eating. *Appetite*. 2009;52(2):461-468.
- McCabe MP, Ricciardelli LA. A prospective study of pressures from parents, peers, and the media on extreme weight change behaviors among adolescent boys and girls. *Behaviour research and therapy*. 2005;43(5):653-668.
- Keel PK, Heatherton TF, Hamden JL, Hornig CD. Mothers, fathers, and daughters: Dieting and disordered eating. *Eating Disorders*. 1997;5(3):216-228.
- Baker CW, Whisman MA, Brownell KD. Studying intergenerational transmission of eating attitudes and behaviors: Methodological and conceptual questions. *Health Psychology*. 2000;19(4):376-381.
- Cooley E, Toray T, Wang MC, Valdez NN. Maternal effects on daughters' eating pathology and body image. *Eating Behaviors*. 2008;9(1):52-61.
- Kichler JC, Crowther JH. The effects of maternal modeling and negative familial communication on women's eating attitudes and body image. *Behavior Therapy*. 2001;32:443-447.
- Dixon R, Adair V, O'Connor S. Parental influences of the dieting beliefs and behaviors of adolescent females in New Zealand. *Journal of Adolescent Health*. 1996;19:303-307.
- Field AE, Austin SB, Striegel-Moore R, et al. Weight concerns and weight control behaviors of adolescents and their mothers. *Archives of Pediatrics and Adolescent Medicine*. 2005;159(12):1121-1126.
- Wertheim EH, Mee V, Paxton SJ. Relationships among adolescent girls' eating behaviors and their parents' weight-related attitudes and behaviors. *Sex Roles*. 1999;41:169-187.
- Francis LA, Birch LL. Maternal influences on daughters' restrained eating behavior. *Health Psychology*. 2005;24(6):548-554.
- Dixon RS, Gill JM, Adair VA. Exploring paternal influences on the dieting behaviors of adolescent girls. *Eating Disorders*. 2003;11(1):39-50.
- Sanftner JL, Crowther JH, Crawford PA, Watts DD. Maternal influences (or lack thereof) on daughters' eating attitudes and behaviors. *Eating Disorders*. 1996;4(2):147-159.
- de Lauzon-Guillain B, Romon M, Musher-Eizenman D, Heude B, Basdevant A, Charles MA. Cognitive restraint, uncontrolled eating and emotional eating: correlations between parent and adolescent. *Maternal and Child Nutrition*. 2009;5(2):171-178.
- Agras WS, Bryson S, Hammer LD, Kraemer HC. Childhood risk factors for thin body preoccupation and social pressure to be thin. *Journal of the American Academy of Child and Adolescent Psychiatry*. 2007;46(2):171-178.
- Ogden J, Steward J. The role of the mother-daughter relationship in explaining weight concern. *International Journal of Eating Disorders*. 2000;28(1):78-83.
- Field AE, Javaras KM, Aneja P, et al. Family, peer, and media predictors of becoming eating disordered. *Archives of Pediatrics and Adolescent Medicine*. Jun 2008;162(6):574-579.
- Grilo CM, Wilfley DE, Brownell KD, Rodin J. Teasing, body image, and self-esteem in a clinical sample of obese women. *Addictive Behaviors*. 1994;19(4):443-450.
- Jackson T, Grilo CM, Masheb RM. Teasing history, onset of obesity, current eating disorder psychopathology, body dissatisfaction, and psychological functioning in binge eating disorder. *Obesity Research*. 2000;8(6):451-458.
- Berge JM, Maclehone R, Loth KA, Eisenberg M, Buccianeri MM, Neumark-Sztainer D. Parent conversations about healthful eating and weight: associations with adolescent disordered eating behaviors. *JAMA Pediatr*. Aug 1 2013;167(8):746-753.

Communicating with Your Loved One: Education, A Listening Ear and Unconditional Love

BY Kathy Porter, NEDA Navigator, New Mexico

As an individual who has personally struggled with an eating disorder, as well as a close friend of two individuals who have struggled, I have seen both sides of the battle. For those who are supporting someone in the recovery process, there is so much education about these illnesses available, but it can be overwhelming and scary. Many people lack a strong education in knowing how to support, and truly be a great help, to individuals who make the brave, admirable, and life-saving decision to enter recovery and reclaim the life that has been essentially stolen. Luckily, there are now programs like the NEDA Navigators (of which I am a part), which can help parents, friends and other family members learn how to break down communication barriers and be a strong part of the recovery process.

It is important to point out, first, that I have a strong belief that the majority of things that are said to individuals in recovery stem from well-meaning people who genuinely care and have the best of intentions. However, many things said with good intentions serve as triggers and can actually fuel the eating disorder, rather than begin to put an end to the vicious nature of the disease.

I have witnessed, firsthand, language's impact on the friends I have supported, as well as having navigated through the most complex of emotions at times in the journey of recovery myself. We are unique beings, yet our experiences are similar in many ways. Because of the nature of eating disorders, many people interpret common well-intentioned statements, such as "Well, honey, you would feel better if you would just eat a sandwich," as invalidating, or a simplification of their struggle. Even though the person said it with love and compassion (or, at the very least, did not intend for it to be harmful), the individual battling the eating disorder may feel as if the person does not understand the illness. Taking the time to learn about how you can



express your concerns in a productive way is important. NEDA's website (www.myneda.org/learn) provides many tips and guides to assist along the way.

When helping a loved one through the journey to self-love, recovery and claiming their life back, I would strongly encourage you to first serve as a listening ear. In fact, that in itself, can be one of the most effective forms of communication in being a source of support for someone you truly love. Communication does not always have to involve the spoken word, but instead is displayed through a variety of things: a reassuring smile to someone who tearfully confides their thoughts in you, a pat on the back, a hug (if the person in question is open to it and feels comfortable being touched), or the gift of your presence. The longer I live, and the more I learn about eating disorders, the more convinced I become that the gift of presence is universal—I have yet to meet one person who doesn't want to be heard. Additionally, I know very few people who actually like being alone all of the time, and even though self-isolation is often a frequent behavior with eating disorders in general, feeling the presence of someone sitting by your side, even when no words are spoken, can serve as a reinforcement that you are worthy of support and recovery.

It can be extremely difficult to know what to say to a loved one in the throes of

an eating disorder. If the news of one's struggle comes as a shock, the difficulty level only increases. All individuals are unique, too, and each story of a battle with an eating disorder is different. In other words, it is difficult to know, beforehand, if what you are about to say will strengthen and uplift your loved one, or will be perceived in a way that may be harmful; there will be mistakes, but you can take the step of becoming as educated as possible about how to keep the lines of communication open to provide ongoing support. Being present and attentive to the way your loved one feels will be helpful. As a person who has been on the side of struggling to recover, I heard time and time again that people wanted to help, but didn't know how because they couldn't understand what I was going through. It's worthwhile to point out that sometimes the person struggling doesn't know exactly what may help. Being a living illustration of unconditional love always helps, though. Making the decision to enter recovery, even though overwhelming, feels even better when you know you have support behind you. So, my advice to parents, families and friends is to communicate your intention to listen and learn and check in regularly to provide encouragement that your loved one can beat the disease. ■

Concerned about a friend or family member? Learn how you can help.

NEDA's **Parent Toolkit** www.nationaleatingdisorders.org/parent-toolkit provides guidance through the challenges many family members experience when navigating how to offer support. Here are some helpful *recommendations* about what to do, and what to avoid: www.nationaleatingdisorders.org/sites/default/files/Toolkits/parenttoolkit/index.html

If you are concerned about a friend, be sure to check out NEDA's *Tips for Talking to a Friend Who Might Be Struggling with an Eating Disorder*: www.nationaleatingdisorders.org/what-should-i-say



The Path to My Recovery Voice

By Ashley J. Galante, NEDA Navigator, Illinois

During the darkest days of my disorder, I used many different voices on the people who were an integral part of my life. Each voice was like a different language with its own particular motives:



My family voice tried to convince them that I was happy and healthy rather than struggling with my eating disorder, depression and anxiety.

My friend voice said I was always ready to go out and have a good time. It also assured them that I was there to solve their problems and help them through their crises even when I was dealing with my own.

My relationship voice told my boyfriend that treatment was working, and that our relationship was going to be just fine despite my disorder trying to tear it apart.

My treatment voice made me an excellent liar and a petulant patient. During therapy, I would be the first person to share a success even if it was only a half-truth. Other times, I would refuse to eat during residential treatment and be forced to drink nutritional supplements. During the first few months of treatment, I desperately clung to my disorder.

Finally, there was the voice I used on myself, which controlled me from childhood until my early twenties. This inner voice told me I was a hopeless mess who was destined to live a life of lies and pain. It never let me love, like or even tolerate what I saw in the mirror every day. It told me that I would never amount to anything and screamed that my disorder would be the only thing I would ever be able to count on. As much as I

hated this voice, I also absolutely loved it. It kept me in my disorder—the only place I ever felt comfortable.

Despite their differences, all of the voices had one commonality: each was desperately trying to hide my disorder. All of these people wanted only what was best for me, but because of the tremendous amount of guilt I was carrying from my disorder, I felt the need to be dishonest in order to not feel like a burden to them.

As time passed, I could feel my disorder breaking me down psychologically and physically, while also destroying my personal relationships. Reluctantly, I began to believe I had a serious problem, and that this disease was going to be the end of me if I didn't work towards recovery.

I had to learn to reshape these voices by allowing myself to feel emotions and face problems without running to my disorder for the comfort and sense of control it always gave me. In time, I learned to trust my treatment team. I was also able to be honest with those who mattered most to me, and I allowed them to see me in my most vulnerable states. I finally accepted that I couldn't keep battling my disorder on my own, that I wasn't perfect, and that I needed the support of those who loved me unconditionally.

I am proud to now be a healthy, recovered, 28 year old woman. It was not an easy journey, but I overcame my eating disorder, in large part by reframing my thoughts, and reshaping my negative voices into constructive ones a recovery voice.

I knew that I wanted to use my recovery voice to be a mentor to others who are struggling. I became actively involved with NEDA in 2012 when I attended the

Chicago NEDA Walk for the first time. It was here that I was encouraged to go through the NEDA Navigator training program. I wanted nothing more than to be living proof that recovery is possible and that you can learn to love yourself again.

This year, I was honored to be the Event Coordinator for the 2013 Chicago NEDA Walk. Although I was extremely excited to be given such a role, I was also frightened. At times, I felt overwhelmed and was scared I would fail as a first-time coordinator. NEDA means so much to me and all I wanted was to have a successful event. Even though I am in recovery, those negative, discouraging voices can creep up on me occasionally. The difference now is that I can take that negativity, reframe it and create positive energy for myself.

The walk ended up being an incredible success. Chicago exceeded our fundraising goal, surpassed participation expectations and created a day that so many will never forget. As I walked, surrounded by my loved ones and the NEDA community, it was wonderful to see the work volunteers and I had done being appreciated and affecting so many lives. I could not have done it without my recovery voice, and now I will have that moment to cherish forever. ■



Navigating the Holiday Season

BY Robyn Cruze and Espra Andrus, LCSW, Colorado

Co-authors of *Making Peace with Your Plate: Eating Disorder Recovery*

I hated holidays when I was in my eating disorder. I felt like I was in a minefield of panic. I would tip toe through the eating disorder detonators only to have to deal with worried family.

My eating disorder would kick up a fuss months before any holiday gathering, acting like a sergeant in drill training. With every failure to honor its demands I would be mentally punished with visions of my family's faces looking at me in disgust. And, with every success of meeting its needs, I was rewarded with a fleeting sense of accomplishment before the demands would start again. Either way, holidays sucked for me and my family.

I adored my family. But, no presents or thoughts were ever put toward my family at holiday time, except when my eating disorder would ask me what they would think of this grotesque lump I saw in the mirror. I told myself I would get to the presents once I looked the way I needed to. Of course, I never got to the thinking of others part, and my family didn't care how I looked. They wanted me well, and that would be the best Christmas present of all.

One Christmas while living in London, I had booked my plane tickets to return to Australia for the dreaded family holidays. They were looking forward to seeing me even though the year before they wondered why I even came. I was always tired, didn't want to participate, grunted when being spoken to and picked at their meals they had spent hours preparing. But, this year my illness had kicked into another mode. I was binging on a whim, and my body was telling on me. My bloated face and stomach were telling a story of loss of control. When my dad called to check on my flights I broke down. "I'm fat Dad! Do you still want me to come?" Silence came. That silence was my Dad on the other side of the world petrified that his daughter who he profoundly loved and was worried for was expecting him to answer that question.

Holiday time has such great expectations for any family who partakes in them. But, for those suffering from eating disorders and their loved ones, holidays often become a time to "just get through." When I got into early recovery there had to be a strategy to remove my attention from my eating disorder and engage with my family and put food and eating in its place. I now know that I was not alone. For this reason, Espra Andrus, LCSW and I wanted to bring you some concrete tools to help you or your loved one get through the holiday season and move toward eating disorder recovery.

up for their life and the holidays instead of allowing the eating disorder to exclude them from the connections that they ultimately desire. To help you feel empowered over the holidays, here are some tools you can use:

Before the Holiday Gatherings Start

Catch the eating disorder voice, check the facts and prepare to talk back:

Make a list of things you can predict that people might say or do which will trigger your eating disorder thoughts. Next, list what those eating disorder thoughts

might be. After making your list, write down factual, pro-recovery responses to those eating disorder thoughts. My clients often write statements to remind them of reasons to leave the eating disorder out of the meal.



Let's get started with taking power back from the eating disorder by planning ahead for the holidays.

► Here's Espra:

My clients, like Robyn was, are petrified when the holidays are approaching, often saying that they would prefer to disappear than have to show up at events. Therefore, I spend many therapy sessions during the weeks leading up to the holidays preparing them to cope with the feelings of overwhelm, guilt and shame that their eating disorders bring to holiday events, interactions, and meals.

The key to taming the holiday terror is to, one step at a time, build a coping plan to help you/your loved one stabilize the eating disorder thoughts and behaviors. This plan can help those struggling show

Take back your power by structuring your schedule and surroundings: Plan ahead of time when to arrive and what activities to do. Plan when, how and who can support you to take breaks at regular intervals to help you stay centered.

Prepare to interact and engage with others by writing out a list of topics to discuss when you need to redirect or keep conversations going. This limits the opportunities for the eating disorder voice to convince you that you should isolate with it because you do not belong with others.

During Holiday Gatherings

Sit with Support: Decide ahead of time, if possible, where to sit. For example, the kids table or by someone who is not critical of foods or bodies and provides comfort. Plan to engage in conversation with family by having topics and questions prepared AND by listening to stories and things you can learn about others. Show up for the conversation, not the eating disorder.

Strategies for Enjoying the Holidays: Tips from Fellow Readers

At NEDA we know that holidays can be a stressful time for families and individuals struggling with, or pursuing recovery from, an eating disorder. So, we asked the NEDA community to share their strategies for navigating the holidays in the face of such challenges. A few themes emerged, and we've put them together here to offer helpful perspectives and steps you can take to maximize the enjoyment of your holiday gatherings. If you have a friend, or family member affected, take a few minutes to share these tips and discuss how you can be a part of their planning and support.

Work your support system.

Check in with a counselor, support group, or friend before and after a holiday event. Staying connected to your support system can be very helpful.

— A Reader Pursuing Recovery

Invite a friend to your holiday events. This makes you feel supported while you are around family who may not understand what you are going through. They can help through just being there and giving you a certain look at the table to encourage you to participate in the meal and enjoy it.

— A Reader Pursuing Recovery

Talk over your triggers and stressors with your family. A family member could communicate with extended family and other guests to be mindful of the types of comments and questions that may be triggering or difficult. For example, a well-meaning family member may comment on weight to indicate that they are happy treatment has been working, which may be triggering. Ask that comments such as "You look great. You've put on/lost some weight," be framed as, "You seem happy. I'm glad you are doing well."

— A Family Member

When I was struggling, I made a meal plan and goal to challenge myself and had a support help me through it during meal time. It proved itself to be very helpful to have one other person know what I was going through and support me to reach my goal. I felt like a winner at the end of the meal and the rest of

the holiday was a celebration of the good work I had done. I think we forget sometimes that the holidays are a time to celebrate our accomplishments, not beat ourselves up over what we haven't done yet.

— A Reader Pursuing Recovery

Cross generational boundaries.

Be mindful of the different support each generation of your family can offer. Hanging out with siblings, cousins and others of a similar age to you can be a nice way to connect around common



developments and gives you a chance to get support/empathy on specific life stage issues like being away at college, parenting stress, job hunting, retirement, etc. On the other hand, reaching out to older generations, like grandparents, is an opportunity to get outside of your own concerns, to see how priorities can shift throughout life and also to collect some family history. Even the youngest generations have something to offer you in your recovery-focused holiday. Spending time with the young children in your family during large family gatherings could be a good distraction from "grownup conversation" that might often be triggering for you. Hang out with the kids, play games with them and ask them about themselves.

— A Treatment Provider

Take a lesson from children. Children have such an innocent view on the world that it can sometimes help me remember the true purpose of food. With each bite you take enjoy the taste like a small child would. — A Reader Pursuing Recovery

Consider making it your goal to sit down with an older relative you don't see very often and asking him/her open-ended questions about past memorable holidays. — A Treatment Provider

Find ways to create distractions and stay engaged with loved ones.

Be the family photographer. Grab your camera and put yourself in charge of documenting the day. Many extended families only have rare opportunities to spend time together. Catching family memories on film will not only keep you focused on something other than the eating disorder, it will give people around you a reason to smile and be mindful of the special moments throughout the day.

— A Treatment Provider

When I find myself at functions without my best friend, I gravitate towards the groups of people who talk the most. As I mingle with these people, I, or the group, will move towards the food and grab some things as the conversation continues.

— A Reader Pursuing Recovery

Focus on important non-food-related aspects of your holiday observances.

Create a holiday goal that is *not* about recovery. It's important to plan ahead and to prioritize recovery but try not to get so wrapped up in recovery goals that you miss out on other meaningful experiences. We often encourage patients to come up with a fun or interesting goal for the holiday that will not only help to distract from eating disorder thoughts, but may also provide lasting feelings of hope and connection to others. You might try to get a quote from everyone at the party about what they're grateful for this year. You could also consider organizing a toy donation within your friends and family to donate to charity. When you have something positive you're working

► *continues on next page*

► Tips from Fellow Readers *continued*

towards, you're less likely to get caught up in the negative thoughts about food or body image.

– A Treatment Provider

Practice mindfulness. The whole holiday season can be stressful for someone in recovery with every store, restaurant and coffee shop bringing out their latest holiday foods. Don't let the onslaught of marketing get to you. Be aware of its presence, make a conscious choice not to let it cause you anxiety, and bring your focus back to yourself and your health.

– A Reader Pursuing Recovery

Challenge predictable or triggering thoughts before a holiday.

If you notice you have predictable patterns of negative thinking pop up at family gatherings or the same triggering thoughts sneak up on you during a specific holiday observance, take time to identify them in advance. Write them down and work on challenging the thoughts

ahead of time (on your own or with a therapist) so you're better prepared to defend against these specific negative/irrational thoughts on the actual day. You might even consider keeping a list of your positive affirmations or challenge statements with you for easy access. (If you know you'll have your phone handy, you could even send a text to yourself the day before.)

– A Treatment Provider

Allow yourself to enjoy the food.

Give yourself permission to enjoy your favorite holiday food. Keep reminding yourself that you are taking care of your body by giving it the nourishment it needs and that is OK.

– A Reader Pursuing Recovery

When I was stuck in my eating disorder, holidays were the worst times for me because they center around food, and my anxiety was on HIGH. My biggest tip is to practice MINDFUL EATING. That means to

be aware of each bite. Eat slowly. Savor the taste and textures. Enjoy the foods, and allow your body to use the food as it's meant to. – An Athlete in Recovery

Give yourself breaks, and plan to leave when you need to.

RSVP with a time limit. For example, "Thanks so much for inviting me. I'll be able to be there from 3:00 to 5:00." This provides you with some boundaries and an opportunity to leave the situation if it's becoming detrimental to your recovery. However, if things are going better than expected (which often happens) and you want to stay longer, then you can.

– A Treatment Provider

Develop signals and strategies for self-care. Plan cues/signals for the person struggling to let someone know they need an escape from the conversation or situation.

– A Family Member ■

► Navigating the Holiday Season *continued from page 13*

Give yourself the gift of enjoying your meal: Plan ahead of time, with your dietitian, which food options and serving sizes you might select in the event that you can only hear the eating disorder's voice telling you what or how much to eat. If you can hear your body's wise voice about what it needs and wants at the time of the meal, it is perfectly acceptable to go with that instead.

Limit your time at the dining table: Once you have finished your plate, put down your fork and knife and tell yourself you are "done" until the next meal.

During the first hour after a meal you are extremely vulnerable to the eating disorder. Plan ahead to fill that time:

Involve your family: During the day practice engaging with others, using your prepared conversation topics, activities, and intent of listening carefully. You might set a goal to learn two new things about everyone you speak to.

► Robyn:

After 10 years of recovery, I still don't get the fuss and food surrounding all the holiday seasons. But, I do now understand the importance of family and

what it means to my own sense of self and to my loved ones to have me engage, be present and be a part of events, especially in the time that we allocate to come together. Focusing our attention on how we can change our behavior and perceptions for the upcoming holidays is a great start in learning how to get through them and maybe even enjoy ourselves... with little interruption from an eating disorder. ■

Join the NEDA Forums!

Connect with fellow siblings, parents, partners/spouses, friends and others pursuing recovery. Whether you are personally affected by an eating disorder or supporting someone who is, the NEDA forums are designed to be a safe and welcoming space to discuss issues related to eating disorders, disordered eating and body image. Check out the community guidelines and join the conversation at www.myneda.org/forum.

2013 Annual NEDA Conference

A conference for individuals, families and professionals who care about eating disorders.



Of Monumental Importance

**Directing the National Spotlight
on Prevention, Treatment,
Research & Policy**

Washington D.C. | October 10-12, 2013
Hyatt Regency Washington on Capitol Hill

2013 NEDA Conference Delivers the Latest on Eating Disorders and Challenges the Field to Move Forward

This year's 2013 NEDA Conference in Washington, D.C. offered a diverse range of topics by top-notch presenters and cultivated opportunities to connect with, and learn from, other families, professionals and activists. The featured general sessions had a notable proactive tenor to them – they challenged all of us to move forward and grow as a field. Speaking publically about his experience as a parent of a child with an eating disorder for the first time, Dr. Thomas Insel was able to give his keynote address despite the government shutdown because he was attending as a parent and not as the Director of the National Institute of Mental Health. Striking a chord with many parents, he spoke about the challenges of facing an eating disorder diagnosis with your child. Dr. Insel also pointed out that there is still so much we don't know about why people recover from an eating disorder – citing the example of two family members who both struggled with anorexia and recovered on very different timelines despite similar backgrounds and family histories. Concluding his speech, he challenged the field to look at the success that has been made with



other brain based disorders – such as autism and Parkinson's – as an example of what can happen when advocates focus their attention toward improving the science.

Additional general sessions called attention to the critically important issues of weight stigma, males affected by eating disorders, and the need for greater understanding of diverse backgrounds and experiences within eating disorders. Dr. Rebecca Puhl highlighted the serious effects weight bias has on both individuals and society as a whole, presenting research that showed the detrimental effects of stigmatizing public health campaigns against obesity. Dr. Tim Freson presented research on males and the sociocultural constructions of masculinity, calling for more attention to be focused on the drive for muscularity and leanness as serious body image concerns among males. He pointed out the need for better tools to assess male body image concerns because the current scales still use very gendered language. Dr. Ted Weltzin followed with a discussion on treatment considerations for males and the ways in which treatment providers can cater more for men, because while

the behaviors in males are similar to those in females with eating disorders, the cognitions may differ significantly. He offered specific recommendations for treatment providers to be more inclusive and effective in treating male patients, such as updating intake forms to include practices more specific to males and giving males the opportunity to connect and identify with other males in treatment. And – always a NEDA Conference highlight – the Family Panel moved the audience to both laugh and cry as the speakers bravely shared their stories with honesty and candor giving each of the panelists a rousing standing ovation in appreciation of their insights. The Family Panel sent a powerful and vital message to attendees: recovery is possible, and treatment and support are critical to getting there.

With more than 600 people in attendance, this year's conference was our largest yet, and we are so grateful to everyone who traveled to DC and made this conference such a memorable experience for all. We look forward to seeing you next year for our conference in San Antonio, TX – *Thinking Big: Uniting Families and Professionals in the Fight Against Eating Disorders*. ■





Straight from Attendees!

The NEDA Conference is designed to offer the most up-to-date information in the eating disorders field – for families, professionals and educators – as well as foster hope, inspiration and action beyond the conference weekend. When asked what attendees found valuable about the NEDA Conference experience, we learned that conference-goers benefit in so many ways! Here are some of the highlights of what attendees found valuable:

The opportunity to attend my first professional conference in a welcoming environment was of great value.

— Young Professional

The scholarship, buddy system...and the chance to meet all different kinds of people at all different levels, both professionally and personally.

— Attendee in Recovery

Listening to high quality presentations by leading researchers was very informative. The testimonies by the individuals on Saturday [Family Panel] were moving and inspiring.

— Medical Professional

The workshops were really great and so many options!

— Family Member

I really enjoyed being able to experience a conference that had such an enormous variety of individuals, all of whom were extremely passionate about raising eating disorders awareness.

— Professional or student conducting eating disorders education and outreach

NEDA's First Federal Lobby Day a Great Success!

By Taryn O'Brien, NEDA STAR Manager

On Thursday, October 10, 2013, 200 passionate individuals converged in Washington, D.C. to meet with their representatives at NEDA's first Federal Lobby Day, co-sponsored by the Academy for Eating Disorders (AED) and the International Association of Eating Disorders Professionals (iaedp). Despite a government shutdown, the threat of a truckers strike around the Capitol District and rain, participants made their way to the Hill to use their voice to make a positive change. In their meetings with members of Congress, each of the 60 teams told their personal stories about how eating disorders have impacted their lives, and discussed the ways in which the legislators could support our mission.



Lobby Day attendees asked their legislators to join the National Eating Disorders Awareness Caucus, co-chaired by Congresswomen Nita Lowey (D-NY) and Renee Ellmers (R-NC). The Caucus' mission is to increase national awareness about eating disorders and support those who suffer by seeking to enhance prevention, facilitate therapeutic advances and improve access to treatment. The current pursuit of the Caucus is to call on the Government Accountability Office to conduct research into the prevalence, death rates, and the economic burden of eating disorders. The results of this research study will help to drive future policy efforts on both the state and federal level. Since our Lobby Day, we have nearly doubled our Caucus membership to 21!



Attendees also asked their representatives to sign on as a co-sponsor of S.562, the Mental Health Access Improvement Act of 2013. The bill provides for the reimbursement of services provided by Marriage and Family Therapists (MFTs) and Mental Health Counselors (MHCs) under Medicare part B. For individuals with eating disorders in rural areas, access to local Mental Health Counselors is vital.

On December 5th, as a result of NEDA's targeted outreach, Rep. Chris Gibson (R-NY) and Rep. Mike Thompson (D-CA) introduced H.R.3662, the Mental Health Access Improvement Act! This bi-partisan house bill is the counterpart to S.562. We are so appreciative of Rep. Gibson and Rep. Thompson's leadership on this issue.

H.R. 2101, The Federal Response to Eliminate Eating Disorders Act of 2013 (FREED Act), was created and introduced by the Eating Disorders Coalition. The FREED Act expands research, education and training on eating disorders, and improves access to care. This bill will help to better the lives of all affected by eating disorders in America. Since our Lobby Day, H.R. 2101 now has eight new co-sponsors!

In the weeks since Lobby Day, we received a number of follow up calls from members of Congress looking to support our cause and raise awareness about eating disorders. Representatives were inspired by the stories told by our participants, and NEDA thanks all who attended and shared their voice.

Congratulations, and thank you to everyone who participated! ■



Change, One Step at a Time

By Tobi Martin, NEDA Lobby Day Participant, California

What I imagined the 2013 NEDA Lobby Day to be when I registered ended up being so much more and truly one of the most fulfilling experiences in my life. My husband and I signed up for Lobby Day when we registered for the NEDA Conference because we thought it sounded interesting and was a fantastic opportunity to support positive change for eating disorders (ED). I had never imagined being able to lobby Congress for my daughter and the

had a bit of uncertainty about the day. One team member was an executive director at an eating disorder treatment facility and was passionate about insurance reform; the other was a determined, loving father who was there to support his daughter recovering from anorexia. My husband and I were participating to support our 17 year old daughter who is in her fourth year of fighting an eating disorder and to advocate for better eating disorder sponsorship and resources within the educational system. Our team bonded quickly and we all shared feelings of excitement for the opportunity in front of us.

NEDA took us through a morning of training, and then we set out for the Capitol. It was pouring rain as we walked to our first appointment, and we joked about showing up looking like we had just gotten out of the shower. When we walked into the Senate Capitol building, the beauty and gravitas took my breath away. Our first appointment was with Senator Harry Reid, the Majority Leader in the U.S. Senate. Due to the government shutdown, Senator Reid could not attend, so we met with his Chief of Staff. As we were new to a lobby day, it is fair to say that our first meeting was challenging; we were still forming as a team and learning "on the job." Quickly, the team realized we needed a game plan to successfully communicate our position, integrate our personal stories and close the meeting with our specific requests and appreciation.

We regrouped on the move and came up with a strategy for our next three meetings. As a team, we decided that I would open the meeting with introductions and intentions, my husband would advocate



for educational reform, the executive director of the treatment facility would share the need for better insurance coverage, and the other father in our group would share his personal story and open up the floor for questions. I would then close with the appropriate "asks" and say thank you for the time and support.

This approach worked especially well in our meeting with Congresswoman, Zoe Lofgren. It was an honor to meet with her and convey how her support would benefit those suffering from eating disorders. Congresswoman Lofgren seemed genuinely interested in listening and asked what she could do to help. With our new strategy in place, we were able to influence her to sign on to become a member of the National Eating Disorders Awareness Caucus. It felt like a huge victory for our team, NEDA and the eating disorder community.

With each meeting, I started to gain greater awareness of the unique opportunity we, as individuals, have to exert our constitutional right to lobby in support of our individual and community needs. I became mindful that, through advocacy, my personal pain could be transformed into activism and empowerment. This experience gave me a new perspective: advocacy on behalf of my daughter, my family, and the ED community can take many forms. The NEDA Lobby Day began with trepidation, and ended with inspiration and victory. Change often comes one step at a time, and I am proud that I took my first step at the 2013 NEDA Lobby Day in Washington D.C. ■



broader eating disorder community. On the plane to Washington D.C., the first thing I did was ask my husband (who is a U.S. Government instructor) for a better understanding of the legislative process and the role which lobbying plays on Capitol Hill. I knew this would be critical as I prepared for my first national NEDA Conference and Lobby Day ahead. After dinner on the night we arrived in D.C., we walked to the Capitol to absorb the opportunity in front of us. I was speechless as I admired the grandeur of these historic buildings. I thought of all of the people, over hundreds of years, who had traveled to meet with Congress to have their voices heard; I was about to be one of them.

The next morning, we checked in for Lobby Day at the hotel and were thrilled to see well over 200 people in the main conference room. This was our first NEDA event, and it was encouraging to see and feel the incredible energy in this community. I was told that I would serve as the captain of our lobbying team and was a bit anxious given that this was my first lobbying experience. Fortunately, my nerves were quickly calmed when I discovered others on our team were also new to lobbying, and we all

Tobi Martin is the proud mother of a wonderful, brave 17 year-old daughter recovering from an eating disorder and whom she loves more than she will ever know.

Research Summary | Shared Genetic and Environmental Risk for Eating Disorder Symptoms and Alcohol Use Disorder

By Melissa A. Munn-Chernoff, PhD, Missouri

Eating disorders and alcohol dependence often co-occur. Women with eating disorders who binge eat and purge (e.g., self-induce vomit or misuse laxatives) have higher rates of alcohol use disorder (alcohol abuse or dependence) than healthy control women¹, and nearly 40% of women presenting for treatment for alcohol abuse reported some eating disorder symptoms². The reasons for the connection between eating disorders and alcohol use disorder are unknown. One hypothesis is that eating disorders and alcohol use disorder have some of the same risk factors. These risk factors could be genetic and/or environmental in nature.



Family and twin studies can help provide clues to the nature of this shared risk by allowing us to determine whether it is due to genetic risk, environmental risk, or both. Previous family studies have, in general, shown very little evidence for shared genetic risk between eating and alcohol use disorders. Twin studies, however, have suggested otherwise. In twin studies, researchers compare identical twins (who share all of their genes) and fraternal twins (who share about half of their genes, making them no more genetically similar than non-twin siblings) to help separate out the effects of genes from the effects of environment, including the “shared” environment twins had when growing up. Using twins, other research³ has indicated that some of the genetic factors that influence the risk for alcohol dependence also influence the risk for bulimia nervosa. Although these twin studies have shed new light on the controversy surrounding shared genetic and environmental risk for these disorders, they only included women. Given the growing rates of eating disorders and high rates of alcohol dependence in men, it was important to see if the findings from these twin studies would also hold true for men.

In our article published in the September 2013 issue of the *Journal of Studies on Alcohol and Drugs*, we examined nearly 6,000 identical and fraternal adult male and female twins from Australia to see if there were overlapping genetic and environmental effects for two eating disorder symptoms – binge eating and purging behaviors – and alcohol dependence⁴. Of the adults in this study, nearly 25% of men and 6% of women had ever been alcohol dependent in their lifetime, based on their responses to a standard diagnostic interview. Almost 11% of men and 13% of women had ever had a problem with binge eating; about 14% of women had ever used two or more purging behaviors. (Men were not asked about purging behaviors.)

Overall, genetic susceptibility appeared key in the odds of developing any of the three traits. Genetic effects explained between 38% and 53% of the risk of developing these traits in both men and women. Moreover, some, but not all, of the genetic factors that made people susceptible to alcohol dependence also made them vulnerable to binge eat (in men and women) or engage in purging behaviors (in women). Specific genes that may contribute to these eating disorder symptoms, alcohol dependence, and their co-occurrence were not examined in this study.

What can we take away from these findings? First, it is important to recognize that eating disorders and their



symptoms can co-occur with alcohol problems in both men and women. Second, if someone you know has had problems with eating or with alcohol, they may also be at an increased risk for the other problem. As doctors, therapists, friends and family, we need to be vigilant about this issue and identify these problems to help the individuals we care about receive the right treatment. Finally, it is important to recognize that genetic risk is **not** set in stone. Genes and environment work together to increase risk for these traits, so just because someone has a genetic risk for a disorder does **not** mean that nothing can be done to reduce or eliminate the eating or alcohol problems. Understanding what may be happening in the environment, in addition to genetic risk, is a crucial step in treating eating disorders, alcohol use disorder, and their co-occurrence. █

References

- Root TL, Pisetsky EM, Thornton L, Lichtenstein P, Pedersen NL, Bulik CM. Patterns of co-morbidity of eating disorders and substance use in Swedish females. *Psychological Medicine* 2010;40:105-115.
- Peveler R, Fairburn C. Eating disorders in women who abuse alcohol. *British Journal of Addiction* 1990;85:1633-1638.
- Baker JH, Mitchell KS, Neale MC, Kendler KS. Eating disorder symptomatology and substance use disorders: prevalence and shared risk in a population based twin sample. *International Journal of Eating Disorders* 2010;43:648-658.
- Munn-Chernoff MA, Duncan AE, Grant JD et al. A twin study of the association between alcohol dependence, binge eating, and compensatory behaviors. *Journal of Studies on Alcohol and Drugs* 2013;74:664-673.

NEDA Announces Feeding Hope Fund Recipients!



Daniel Le Grange,
PhD



Denise Wilfley, PhD

proposals at www.myneda.org/feedinghopefund.

NEDA announced the first recipients of the Feeding Hope Fund for Clinical Research & Training grant at the 2013 Annual Conference in Washington, DC. Totaling \$400,000, the two grants were given to Daniel Le Grange, PhD and Denise Wilfley, PhD with an eye on utilizing technology to improve treatment for eating disorders. Learn more about the winning

I HAD NO IDEA

that
eating
disorders
can
destroy
lives.



GET IN THE KNOW www.nedawareness.org

NATIONAL EATING DISORDERS AWARENESS WEEK FEB. 23 - MAR. 1

Generously Sponsored By



Center for Eating Disorders at Sheppard Pratt | Eating Recovery Center
McCallum Place | The Renfrew Center | Timberline Knolls

Cambridge Eating Disorder Center | Center for Change | Columbus Park Collaborative
CRC Health Group | Fairwinds Treatment Center | Laearie Eating Disorders Program
Oliver-Pyatt Centers | Rosewood Centers for Eating Disorders | Tapestry
University Medical Center of Princeton at Plainsboro | Venitas Collaborative

NATIONAL EATING DISORDERS AWARENESS WEEK 2014 is around the corner, and there are so many ways for everyone – family members, friends, educators, health professionals, bloggers, and more – to get involved. The goal of National Eating Disorders Awareness Week is to promote public and media attention to the seriousness of eating disorders and improve education about the biological underpinnings, environmental triggers, warning signs and how to help those struggling. Education and direction to resources can lead to earlier detection, intervention, and help-seeking, ultimately improving likelihood of full recovery. During this time of national attention to the issue of eating disorders, we see a

great spike in people reaching out to NEDA for help, support and information.

This year's theme, *I Had No Idea*, highlights the need to address eating disorder misconceptions – as many individuals, families, and communities are not aware of the often devastating mental and physical consequences — and highlights available resources for treatment and support. By doing just one thing to educate your community about the seriousness of eating disorders and the resources available, you are making a difference. Check out NEDAwareness.org for many fun activity ideas, planning guides, shareable infographics, and more! ■

Finding a Cure Through the Feeding Hope Fund

By Julie Finkelstein, NEDA Board of Directors, New York

In May of 2010, our pretty typical, relatively calm, suburban household with two kids, a dog, three cats, a hamster and a chinchilla, (ok, maybe not so typical) was about to take a huge detour into the completely foreign and foreboding world of eating disorders (ED).

My 12 year-old daughter, Ryan, was about to finish sixth grade. She had been complaining of stomachaches on and off for months, but every time we were about to go see the pediatric gastroenterologist, she seemed to feel better. At some point, I even began to take the complaints with a grain of salt as visiting with the school nurse and finding an excuse to stay home from school were high on her list of favorite activities! But, by the time May rolled around she was beginning to call me from school more frequently and with more complaints. When I mentioned this to my husband, Barry, he suggested we follow through and take her to her regular pediatrician. Once there, we were shocked to learn that Ryan had lost 10 pounds; a few days later we were flabbergasted to hear the pediatric gastroenterologist announce, without an ounce of uncertainty, that Ryan had an eating disorder. Barry and I looked at her as if she had three heads and told her that that was impossible. Nothing seemed out of the ordinary to us. But, why then, had she lost 10 pounds? No one—not us, her sister, her friends or our friends had noticed. On occasion, someone would comment that she looked taller, but we soon realized that it was just an illusion. In hearing the doctor's diagnosis, what was most confusing was that Ryan had never talked about a desire to lose weight and didn't have any type of negative body image. She never thought much about her body at all even though she was in a leotard every day doing competitive gymnastics. (Now I know that those of you reading this just had an "aha" moment when I mentioned gymnastics. But, for the moment, hold on before making a rush to judgment.)

So, here we were with a child that we thought was healthy and happy, was doing well in school, had many friends including an adorable best friend (who, sadly, was forbidden to continue her friendship with Ryan for fear her illness

was contagious), a diagnosis that made no sense to us and the looming question...what now? No one I knew had a child with an eating disorder, so where were we to begin? How could we get a handle on what exactly this diagnosis meant, and what were we supposed to do next? Thankfully, a friend of mine connected me with another mother whose child was in recovery. I also spent hours reading everything I could find. It took a very short time for me to realize that we had just entered a world that was so foreign, it even has its own language. Swirling in my head were questions and statements like: "You need to put a treatment team together", "Do you know what triggered this?", "Will she need an outpatient, inpatient, residential, or intensive out-patient treatment facility?", "Has she shown signs of anxiety or OCD in the past?", "Have there recently been any major changes in her life?", "Does she binge, purge, restrict, only binge, only purge, or only restrict?", "What is going on in your house around food, what are you saying to Ryan about dieting and weight?", and the scariest question of all that I kept asking myself, "What have I done to cause this?" Finally, I began to find some answers. I came across an article that talked about eating disorders and genetics along with the quote, "GENETICS loads the gun and the ENVIRONMENT pulls the trigger." This was an epiphany for me. It gave me the assurance that this was not all my fault and more importantly, that Ryan did not choose to have an eating disorder. She was suffering from a mental illness that although you can't see it on paper or on an ex-ray or MRI like you can with a physical disease – this was real!

Ryan, Barry and I spent the next three months visiting our treatment team: the nutritionist, the adolescent pediatrician, and the therapist, but things were only getting worse. Ryan wouldn't listen to the nutritionist, she hated the pediatrician, and every time she saw the therapist (which was two to three times a week) she insisted I stay in the room while she sat curled up in the corner of the couch and didn't utter a word. By August, we were desperate. And, then someone suggested I go online to the website for the

National Eating Disorders Association. Finally, the answers to almost every question I had and every resource I needed was right there in front of me. We now had a map to help us navigate this confusing, exhausting, frustrating and scary road we were traveling. While scanning the list of doctors in and around the tri-state area, I saw a name I recognized, but to this day I still don't know why his name sounded familiar. I called him. My first impression was that he sounded so confident, reassuring and understanding. A few days later Barry and I were in his office feeling the waters, and three days later, we brought Ryan to meet him. As we expected, she immediately curled herself up in the corner of the couch. But, what we didn't expect was that this time she was not just hearing the voice of a doctor, she was actually listening. The proof came twenty minutes later when he asked Ryan if he could kick Barry and I out of the room and talk with her alone. Once again, we were looking at a doctor as if they had three heads. But, instead of saying no, Ryan made the slightest shrug of her shoulders as if to say she didn't really care. So, of course, we quickly walked out before she could change her mind. Forty-five minutes later the doctor asked us to come back and join them. And then, in a most respectful and calm way, he deferred to Ryan and asked her if he could share with us what she had shared with him. Once again that slight shrug of the shoulders said it all! Twenty minutes later, the doctor finally finished speaking. I kept wondering, what could he have possibly said to Ryan to get through to her? What was it about him that made her feel safe to talk about what she had told me over and over again was her private business? Whatever it was, he had succeeded. And when he made it very clear that she needed to be hospitalized immediately, she listened again, because she trusted him. And to this day, we all know that in a way, he had saved her life.

The next two days were, hands down, the worst forty-eight hours of our lives. On Wednesday morning, we carried Ryan into the car (she was almost too weak to walk) and she slept on my lap for the entire ride. We had no idea that it would

→ continues on next page

► Feeding Hope Fund *continued*

be eight weeks before we would make that ride home again with her. But while there, we quickly learned that she was in the safe care of another amazing doctor whose dedication to helping people with eating disorders was and continues to be unstoppable. His soft, but firm and authoritative tone made Ryan once again not just hear, but listen. And, in a very short time, she began to respond. Once again, a special doctor had saved her life.

Ryan was ultimately diagnosed with Eating Disorder Not Otherwise Specified (EDNOS). This is the diagnosis given, according to the DSM-IV when Ryan was ill, when someone exhibits many, but not all of the primary behaviors, of a particular disorder. In her case, Ryan NEVER had a body image issue! In fact, I will never forget the day she called from the hospital, crying, and said, "Mommy, I have never had a body image issue, but this is all anybody ever talks about. I think maybe now I am getting one." It was one of the saddest phone calls I have ever received.

Over the next few weeks, Barry and I commuted two hours, 2 to 3 days during the week (so much for our summer vacation) and then spent Saturdays in family therapy with the other patients and their families. Sundays we were able to take Ryan into town with the goal of working her back into society. In the meantime, our older daughter, Jessie, came home from camp. We couldn't even imagine what it was going to be like to come home to such chaos. Now we needed to be especially conscientious that Jessie got all the attention she deserved and didn't feel any less important than Ryan. During this time not only did Jessie exhibit a maturity way beyond her years, but we were amazed, thankful and will be forever grateful to her for helping us to do whatever was needed. She never once made us feel guilty for the amount of time we dedicated to Ryan's treatment. She understood what a challenge it was for us to manage everyone's physical and emotional needs, and she helped to make it easy. She balanced being a teenager, daughter and big sister with tremendous grace.

Over the course of the eight weeks Ryan spent hospitalized, her body became medically stable and she began to learn how to have a healthy relationship with food. Now, three years later, she will tell

What is the Feeding Hope Fund?

The Feeding Hope Fund will raise restricted funds designated for the distinct purpose of providing grants to:

- qualified clinical researchers who have been selected through our very competitive application process
- qualified clinical experts providing creative submissions for advancing the training and dissemination of evidence based treatments to fellow clinicians

What will my contribution do?

- Your contribution will address several key strategic goals of the Feeding Hope Fund. It will support and encourage clinical research in the field, it will provide models of dissemination and training, and it will inspire others to step forward, so that treatments are improved and a cure within our reach.

WHY WE NEED THE NEDA FEEDING HOPE FUND



you that she is not recovering, but has recovered. With her doctor's blessing, she continues to dedicate much of her time to her gymnastics with a healthy attitude and strong determination. We are so incredibly proud of her!

In new ways, the story continues. With a healthy child at home I have turned my focus to helping those who still suffer. NEDA has given me the opportunity to join their efforts as a member of their Board of Directors, and I spend the majority of my time focusing on the Feeding Hope Fund. This initiative reflects NEDA's dedication to moving the field forward to

improve research and access to evidence-based care. The Feeding Hope Fund provides much-needed grants to qualified clinical researchers and clinical experts to find a cure in the future and help those in the present. After all, considering 30 million people- daughters, sons, mothers, fathers, sisters, brothers, girlfriends, boyfriends, partners, friends, cousins, aunts, uncles and grandparents -will have a clinically significant eating disorder at some point during their lifetime, research funding in this field is negligible, compared to other serious mental illnesses. By donating to the Feeding Hope Fund, you can be part of finding a cure! ■

Upcoming: PFN Webinars Series

Eating Disorders in African-American Communities

Tuesday, December 17, 2013, 11 to 12:30 PM EST

2014 NEDAwareness Week Volunteer Speaker Training

Thursday, January 6, 2014, 3:30 to 5 PM EST

Writing Through Stress and Shame: Taking Our Power Back

Thursday, January 23, 2014, 5:30 to 7 PM EST

Eating Disorders At and Beyond Midlife

Thursday, February 20, 2014, 1 to 2:30 PM EST

Recently Archived Webinars

Eating Disorders, Body Image and Pregnancy

Recorded live on Thursday, November 21, 2013

Introducción a Desórdenes Alimentarios para la Comunidad qué Habla Español

(Dirigido en Español), Grabado en vivo el Jueves, 26 de Septiembre

Eating Disorders 101 for the Spanish Speaking Community

Recorded live on Thursday, September 26, 2013

Sport is a Culture: Understanding Unique Assessment and Treatment Considerations for Athletes and Eating Disorders

Recorded live on Thursday, August 29, 2013

To register for an upcoming webinar, or view a recorded webinar, visit www.nationaleatingdisorders.org/webinars

Need personalized guidance for yourself, or in support of a loved one affected by an eating disorder?

The NEDA Navigators are here to support you!

NEAD **N**avigators* are individuals who have experience, either personally or in support of a loved one, navigating the overwhelming systems and emotions involved with seeking treatment for an eating disorder. Volunteers, trained by NEDA staff and program Clinical Advisors, Douglas Bunnell, PhD and Ilene Fishman, LCSW, ACSW, are available to: Help you find treatment referrals, local support groups, and resources tailored to your needs; be a listening ear through your or your loved ones' journey; provide encouragement through a difficult time; and share their own story responsibly to offer hope for recovery.

The range of experience among the Navigators is diverse, and when you request to be connected with a Navigator, we can match you with someone who has been through a similar set of challenges and can share their experiences in a helpful,

responsible way. You can request to speak with someone who's dealt with co-occurring conditions such as depression, substance abuse or self-harm; shares an aspect of your identity such as ethnicity, gender, religion or sexual orientation; or has the same relationship to the person struggling, such as a fellow dad, mom, partner/spouse, sibling or friend.

Email us at pffnetwork@myneda.org and we'll get you connected. For more information about the NEDA Navigators, visit the Navigators homepage at www.myneda.org.

* Navigators are not mental health professionals or treatment providers. They are PFN volunteers who have been through an eating disorder themselves or with a loved one and are now in strong recovery. Navigators are trained to help you identify resources, treatment options and be a source of support in your journey.



BOOK REVIEW



Ed Says U Said: Eating Disorder Translator

Book written by June Alexander and Cate Sangster

Published by Jessica Kingsley Publishers

REVIEW SUBMITTED BY Neena Rinaldi, NEDA Helpline Volunteer, New York

two identities, the individual struggling and Ed, are one and the same.

At the start of nearly every chapter, June and Cate provide short, but thorough insight into the mind and language of Ed, which, they illustrate so descriptively that you eventually begin to picture Ed as a completely separate identity (for me, as a little mean elf!) They lay out Ed's fears, thoughts, beliefs, rules, and strategies. They describe what triggers Ed to make his move, and all the lies Ed tells the person struggling, so that they won't let him go. They show the destructive hold Ed has over the individual. Fortunately, though, June and Cate also offer a section on how to combat Ed for all – sufferers, caregivers and loved ones.

Every topic ranging from early signs and symptoms to what caregivers could do to facilitate the recovery process can be found in this book. Focused primarily on understanding what is going on within the mind of the sufferer, June and Cate lay out their information in a way that reflects just this. In every chapter, they reveal true conversations amongst parents, friends, family members, doctors, and of course, the individuals themselves. To help illustrate, they add input from Ed. That way, you can see all the background workings of the eating disorder.

A naturally heavy topic, it can be hard to talk about eating disorders in a lighter way – but rest assured, June and Cate are

able to do just that. Parallel to the social media site Twitter, June and Cate create a conversation style novel in 'tweet' form, using the @ sign to show each character's role and avatars to visually display each speaker. Surely, this allows for such a heavy subject to be talked about in a lighter and playful way. And, all of the conversations in the book are real. Through compiling real conversations from real sufferers, caregivers, and loved ones, June and Cate provide truth: true misconceptions, true realities, and true words.

You don't have to have a superpower to understand your loved one's mind when it comes to eating disorders. If you want to truly understand from an almost first-hand point of view, pick up this book. Providing tons of information and facts on eating disorders, what to say and what not to say to a sufferer, encouragement and hope, this book is nothing less than an informational success. With *ED Says U Said*, you can lighten the feelings of distress that often accompany trying to understand the complexity of these illnesses. ■

* Book reviews are provided by individual PFN members to share with others what they have gained from reading a book that served as a resource to the reviewer. NEDA does not endorse any specific book or author, but rather provides a space for our constituents to share resources with one another.

Submit a Book Review

Have you read a book recently that offered you insights, tools or helpful information? Write a review for the newsletter!

All you have to do is submit a 1-page article to pffnetwork@myneda.org that includes:

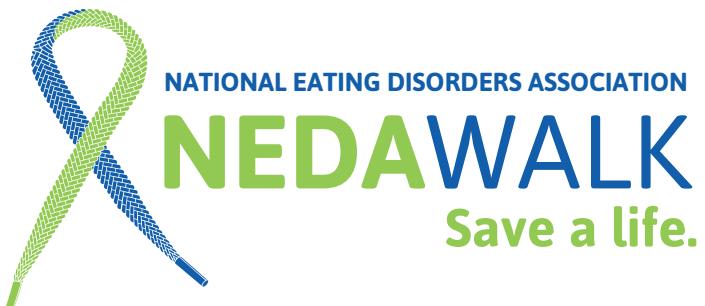
- Your name and contact information
- Title of book, author, publisher and copyright date
- A brief summary of the content of the book
- What you gained from the book: Hope, tools for recovery, strategies for self-care, encouragement, educational information, etc.

NEDA reserves the right to edit book review submissions prior to publication. If your review is selected for publication, you will be provided the updated version for your approval prior to publication.

If your loved one is struggling with an eating disorder, then there has surely been a time when you have wished for the ability to read their mind. Perhaps you couldn't understand their disordered eating habits, or why they have seemingly endless food rules. To make up for it, you've probably tried as hard as you could to put yourself in their shoes, eventually using all of your mental energy to try and understand their complex thought process. If this is you, then you know how difficult this can ultimately be, especially when it comes to the understanding of eating disorders. Thankfully, this doesn't have to be as difficult any longer. Written by two survivors of eating disorders, June Alexander and Cate Sangster, *Ed Says U Said* provides nothing less than insight, understanding, and information into the daily life and inner dialogue of someone struggling with such a devastating disorder that is often misunderstood and hard to understand.

Many people don't realize that the sufferer is not their disorder. Most loved ones can't see that their loved one is still there; often they only see a 'new' individual, filled with lies, manipulations, and plots. Luckily, June and Cate do a fantastic job of bringing to light these two separate identities: the sufferer and the malicious voice of the eating disorder. (They call the voice Ed.) Creatively, by just naming the disorder's voice, they are able to successfully break the common myth—that these

NEDA Walks bring communities together to increase eating disorders awareness and raise funds for NEDA in a fun way. They not only work to support the mission of NEDA, but also work to bring awareness and education to the local communities in which they take place. NEDA Walks that are coordinated by NEDA Network Members return a majority of the funds back to the local community, and 2013 has been the first year of the NEDA Walks scholarship program, which sends Walk Coordinators and local families to the NEDA Conference free of charge. Help NEDA support individuals and families affected by eating disorders in local communities around the country by registering for a walk near you! ■



NEDA Walk Volunteer Spotlight

By Scott Tabakin, NEDA Walk Coordinator, Illinois

I am the father of three adult children and lucky to be married to the love of my life for the past 33 years.



Normally, and without much thought, I express my bio in terms of a career — the jobs I have had, career accomplishments, education, etc. Yet this simple task of composing this bio got me thinking about how we often create an identity for ourselves by focusing on

the things in our lives that are not the most meaningful, enduring or sustaining. And for those struggling with an eating disorder, issues related to self-identity are often among the most complicated and difficult.

Because of our own family's experiences, my wife and I are passionate about raising awareness of eating disorders and promoting help-seeking behaviors among college-aged women and men. Too often, young people are not prepared for the

challenges associated with this stressful time of life and the transition to college conspires with other factors to exacerbate an eating disorder.

We were thrilled to help the University of Illinois at Urbana-Champaign kick off its inaugural NEDA walk. It was inspiring to see the great turnout. The walk raised over \$20,000, exceeding a goal of \$5,000. More importantly, it went a long way to help raise awareness around campus. ■

Upcoming 2014 NEDA Walks:

Orlando, FL NEDA Walk

(Lake Eola)
Saturday, February 15, 2014

San Diego, CA NEDA Walk

(Mission Bay in De Anza Cove)
Saturday, February 22, 2014

Savannah, GA NEDA Walk

(Daffin Park)
Saturday, February 22, 2014

Athens, GA NEDA Walk

(University of Georgia Health Center)
Saturday, March 1, 2014

Reno, NV NEDA Walk

(Gateway Plaza—University of Nevada, Reno)
Saturday, March 1, 2014

Los Angeles, CA NEDA Walk

(Crescent Bay Park)
Saturday, March 8, 2014

Phoenix, AZ NEDA Walk

(Phoenix Zoo)
Saturday, March 15, 2014

Biloxi, MS NEDA Walk

(Tradition Mississippi)
Saturday, March 22, 2014

Nashville, TN NEDA Walk

(Centennial Park Bandshell)
Saturday, March 22, 2014

Ann Arbor, MI NEDA Walk

(Nichols Arboretum)
Saturday, March 29, 2014

Boston, MA NEDA Walk

(Newton North High School)
Sunday, April 6, 2014

Abilene, TX NEDA Walk

(Grover Nelson Park)
Saturday, April 12, 2014

Waco, TX NEDA Walk

(Baylor University, Fountain Mall)
Saturday, April 12, 2014

Columbus, OH NEDA Walk

(Fred Beekman Park)
Sunday, April 13, 2014

Washington, DC NEDA Walk

(National Mall)
Sunday April 27, 2014

Philadelphia, PA NEDA Walk

(Philadelphia Zoo)
Sunday, June 1, 2014

Kansas City, MO NEDA Walk

(Berkeley Riverfront Park)
Saturday, June 14, 2014



Network Spotlight



Network Spotlight: The Elisa Project

The Elisa Project (TEP) is nestled in North Texas amid the hustle and bustle of the Dallas/Fort Worth Metroplex. As a 14 year-old non-profit we were originally founded—by a mom and dad who lost their precious daughter to an eating disorder—at a time when the eating disorder (ED) world wasn't nearly as sophisticated or well-organized as it is today.

Since our inception, technology has connected ED professionals and ED treatment has progressed. Fortunately, those who suffer from ED illnesses have been the beneficiaries. It has been our honor to be TEP, an active participant in the ED Revolution and to witness such positive changes.

However in Texas, there is still work to be done and many opportunities still exist. In 2014, TEP is proactively taking advantage of these opportunities. Like you, we have several events this year including our annual Life Lessons Luncheon—*Waves of Change* in March, a local NEDA Walk in April, and our 14th Annual Symposium, *Building Bridges* in October. In addition to events, we are implementing three new prevention and awareness curriculums that are evidence and researched based, with quantifiable outcomes. We've also formed a local coalition with industry professionals who are committed to educating our local officials and governmental entities with a goal of furthering systemic change that results in access to care for those in need of recovery.

And lastly, we've committed to a renewed plan of increasing disordered eating education to pediatricians, coaches and parents; promoting healthy life-styles that addresses self-esteem, positive body image and balanced nutrition. It truly takes a village and in 2014, our mission is to bring the village together for the good of all those who are suffering from ED illnesses and their loved ones. We wish you a happy and prosperous New Year, as together we continue the battle against eating disorders! ■

Kimberly Martinez
The Elisa Project
kmartinez@theelisaproject.org
214-369-5222
10300 N. Central Expressway, Suite 330
Dallas, Texas 75231



Staff Spotlight

Julie Steinberg has been with NEDA since May 2013 and is loving her job as the National Walk Coordinator.

NEDA currently has over 60 walks this year throughout the country, all coordi-



nated by generous volunteers and NEDA Network Members. Julie works with each walk coordinator, providing guidance on everything from sponsorship to reaching local communities, to ensure that each coordinator is supported in their efforts.

Originally from Atlantic City, NJ, Julie has a passion for mission-based work, and has been a volunteer with the Marine Mammal Stranding Center in Brigantine,

Meet the NEDA Staff! Julie Steinberg NEDA National Walk Coordinator

NJ since 2008. Julie also serves as the NYC Events Chair for the Ralph Verde Foundation.

Julie is a graduate of the George Washington University where she majored in political science and minored in film studies. ■



Making Connections offers a place for our members to share their personal experiences and insights to support others. While we value these contributions, please note that the views, beliefs and perspectives expressed do not necessarily represent those of the organization.

Call for Submissions: "Hope"

On the road to recovery from an eating disorder, hope can be a motivating feeling that sustains you through difficult times. Hope comes from many sources, and can function differently in the many stages of the eating disorder journey. It could be hope that carries you through into a strong place in your recovery, makes you stand by your loved one who is struggling, provides the encouragement to support someone through a relapse, or shows you that life does not have to include an eating disorder. We are calling for submissions from you, the readers, to tell us about where you have found hope, how you sustained hope in the face of challenges, and how hope has played a role in your family's journey. Email us at pffnetwork@nationaleatingdisorders.org. ***Making Connections*** is by parents, family, and friends for parents, family, and friends!



National Eating Disorders Association
165 W. 46th Street, Suite 402
New York, NY 10036
PHONE: 212.575.6200 FAX: 212.575.1650

HELPLINE: 800-931-2237
info@nationaleatingdisorders.org
www.NationalEatingDisorders.org

Thank you to our generous Sustaining Sponsors for helping to make our programs and services possible.

PLATINUM: Rader Programs

GOLD: Eating Disorder Center of Denver and Remuda Ranch

SILVER: Rogers Memorial Hospital

STEEL: Center for Eating Disorders at Sheppard Pratt, Eating Recovery Center, McCallum Place, The Renfrew Center, Timberline Knolls

BRONZE: Center for Change, Columbus Park Collaborative, CRC Health Group, Fairwinds Treatment Center, Laureate Eating Disorders Program, Oliver-Pyatt Centers, Rosewood Centers for Eating Disorders, Tapestry, University Medical Center of Princeton at Plainsboro, Veritas Collaborative