Intimacy

Navigating Dating, Relationships and Support Systems on the Road to Recovery

PLUS

Tips for Partners Supporting a Loved One
Ilene Fishman, LCSW

Enhancing Personal Intimacy Post Treatment
Brittany Lacour, LCSW, DAACS

For Families: Understanding the Affordable Care Act

Learning from Loss: Q & A with Michael Falk
Claire Mysko, MA
Hello Everyone,

As we embark on each issue of Making Connections, the Steering Committee thoughtfully discusses topics we feel will resonate with and be helpful to our readers. Each issue has a specific focus in order to best explore a spectrum of perspectives and insights, providing support, empowerment and encouragement. This issue explores a most personal subject – intimacy, and the added challenges that an eating disorder can present while navigating dating and long-term relationships.

The mere thought of dating may very well be scary to some people; it takes great courage to so openly share one’s journey with someone special. Trust is paramount, and the core values of respect, kindness, honesty and openness – cornerstones of any good relationship – are solid steps to stand on as you build your bridge toward a meaningful, intimate relationship. Acceptance without judgment allows us to feel safe, happy and loved, giving both the individual and the couple the opportunity to grow. If you are feeling a bit timid about taking steps toward dating I hope the articles within these pages provide comfort and reassurance.

As this issue is being published we are saying goodbye to Susie Roman, Director of Programs for NEDA. Susie has been a tremendous guiding light for the PFN, providing valuable insights, resources and connections; her spirit, energy and enthusiasm are without equal. It has been my privilege to work with Susie, and on behalf of the PFN Steering Committee I want to thank her for giving structure, and ultimately a voice, to our ideas; for her constant willingness to brainstorm and explore possibilities with us; and for supporting our efforts at every turn. It is due in large part to Susie that Making Connections has become the valuable resource that it is today. Making Connections, in tandem with the webinar series, helps us connect and communicate with others who have been touched by an eating disorder. Susie has helped us to make a positive difference in the lives of so many.

We are excited to welcome NEDA’s new Director of Programs, Kristen Snow, who will undoubtedly bring her own knowledge, enthusiasm and curiosity to NEDA and Making Connections. As always, while we explore the experiences and perspectives of families and friends with a loved one affected by an eating disorder, we welcome your ideas and questions for future issues of Making Connections.

With thanks and gratitude,
Deborah and the PFN Steering Committee

For more information on NEDA’s Leadership Councils, please visit www.nationaleatingdisorders.org/leadership-councils
**Editor’s Note**  |  **By Susie Roman, Director of Programs**

Dear Readers,

It is with gratitude to the PFN Steering Committee and to you, the many insightful readers and authors of *Making Connections*, that I say goodbye as the magazine’s editor. It has been such a wonderful experience to learn from all of you, and I am delighted to welcome, and introduce you to, Kristen Snow, current editor and NEDA’s new Director of Programs! She is thrilled to be collaborating with you to continue to educate and offer hope to the many families navigating the complexity of providing support to a loved one struggling with an eating disorder. I know that in my years at NEDA I have learned more than I ever could have imagined from the thoughtful submissions and conversations that I have been lucky enough to have with so many of you.

Together, we have given a voice to many diverse experiences with, and perspectives on, eating disorders. Talking about eating disorders is so important – we know that those who feel alone and isolated are able to feel more connected to, and gain insight from, those who share aspects of their journey. Social support and learning from one another are critical functions of NEDA’s Parent, Family and Friends Network, and I feel so privileged to have had the opportunity to work with you to expand resources for those who need them.

I am excited about this issue of *Making Connections*, as it explores often overlooked aspects of the recovery process – sexuality, dating and navigating intimacy while dealing with an eating disorder or while working towards recovery. The contributing writers offer such valuable insight as they candidly talk about the struggles and successes of refusing to let their new and long-term relationships be defined by an eating disorder. For those who are struggling to navigate romantic relationships in the recovery process – either as a partner or person who has been affected – I hope you will find the lessons learned by your fellow PFN members helpful and inspiring.

Sincerely,

Susie Roman

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**Research Summary:** Understanding and Assisting Couples Affected by an Eating Disorder  
**BY** Carina H. Dick, MEd, LPC, Community Counselor and Susan L. Renes, PhD, Associate Professor, School of Education, University of Alaska Fairbanks, Alaska

Although focus is often on eating disorders as they occur in adolescents and young adults, eating disorders can affect men and women of any age (Gagne et al., 2012), and they are increasingly affecting women who are married or in committed partnerships (Huke & Slade, 2006). The goal of our literature review, published last year in the *American Journal of Family Therapy*, was to assess the impact of eating disorders on couples’ relationships. The paper focused specifically on heterosexual couples in which the female partner was affected by either anorexia nervosa or bulimia nervosa.

The review of the literature revealed four main areas of couples’ relationships that may be impacted by the presence of an eating disorder: communication, sexuality, boundary issues and emotional health.

Communication problems for couples affected by an eating disorder are frequently linked to difficulties in resolving conflict (Van den Brouke et al., 1997). When conflict does occur, it tends to revolve around issues of emotional intensity, such as the level of affection displayed within the relationship. Communicating about the eating disorder itself is often difficult, owing in part to the sense of secrecy that frequently accompanies an eating disorder (Root, 1995).

Sexuality may be impacted in a number of ways. Women with eating disorders may experience low libido (Root, 1995), and negative feelings about their bodies, such as feelings of shame or uncleanness, which may hinder the ability to enjoy sexual interaction (Pryor, 2009). Partners of women with eating disorders may also express discontentment with the sexual relationship (Huke & Slade, 2006).

Problems with relationship boundaries can be expressed, for example, when one or both partners depend too heavily on their family-of-origin to meet their emotional needs, which can interfere with the development of intimacy within the couple (Van den Brouke et al., 1997). Both the woman with the eating disorder and her partner may experience a variety of negative emotions that can affect emotional health. The female partner may experience emotions such as anxiety, feelings of inferiority and fear of failing (Belangee, 2007), whereas male partners may desire to help solve the problems associated with the eating disorder, yet feel helpless to do so (Huke & Slade, 2006). Male partners may also feel worried, frustrated and angry.

In addition to shedding light on the many ways an eating disorder can affect a couple, our review of the literature revealed a number of interventions that clinicians can use to assist these couples. Partners can be profoundly affected by an eating disorder, and their involvement in the treatment process can play a key role in the recovery of their loved one (White, 1995). Many of the following interventions assume the active participation of the partner, and clinicians are encouraged to involve the partner in the treatment process and to help the partner understand that his support is both beneficial and needed (Van den Brouke et al., 1997). Education about eating disorders is an important primary intervention when working with couples. Many male partners want and need to understand the illness in order to be optimally supportive (Van den Brouke et al., 1997). It is also necessary to help partners understand how body-focused comments can affect their partners. Body-focused conversations, such as engaging in a discussion about whether or not the woman experiencing the eating disorder is “fat,” should be avoided (Costin, 2007).

Social support and community involvement are two other areas that can have a positive impact on couples. Women with eating disorders are often lacking in social support (Costin, 2007). Their partners, who may also experience a sense of isolation, have expressed the need to share their experiences with others (Winn et al., 2004). Improvements in these domains can ease the weight of caring for an ill loved one (Dimitropoulos et al., 2008).

Finally, couples, and the male partner in particular, need to be aware of what constitutes a medical emergency and what to do if such a situation were to arise (Heaton & Strauss, 2005). Partners need to know that symptoms such as suicidal thoughts, irregular heartbeats, and difficulty breathing are serious warning signs that require immediate medical attention.

Couples affected by an eating disorder can be challenged in many ways. Addressing these challenges improves the likelihood that relational problems will be resolved and will not continue after the recovery from the eating disorder (Evans & Wertheim, 2005). With proper support and treatment, couples affected by an eating disorder can remain hopeful, knowing that effective interventions are available, and that these issues can be overcome.

**References**

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Intimacy

Allowing Trust and Building Relationships
By Teresa Henry, NEDA Navigator, Washington

Life is all about relationships. Relationships come in all forms: through friendship, family, a job, or with a partner. Relationships allow us to share goals, dreams and interests; form social groups; and support each other through life experiences. Part of being in a relationship involves allowing another person to get to know you. This means letting someone into your world, letting someone know the real you...maybe even parts you don’t want revealed. My eating disorder spanned 20 years of my life in the form of anorexia, bulimia and binge eating. I went to treatment for anorexia, so not many people know that I have also struggled with binge eating many different times throughout my life. I put up a barrier, keeping most of my relationships at the surface level and most people at an arm's length.

Relationships can bring a lot of fear to a person with an eating disorder. The potential for someone to find out about secret parts of your life can be scary. With an eating disorder, every bite can lead to fear, guilt, shame, defeat and often disgust. Who wants to reveal that part of their life? The actual act of eating with someone is another source of fear in relationships. Throughout the duration of my eating disorder, no matter which stage I was in, eating with anyone other than myself was one of the most stressful times of my life. I avoided meeting at any restaurant, going to events that involved meals, or even dating, because that most likely included food. I avoided having people over to my house even though I loved to cook for others. Avoiding these social situations left me no room to build real depth in my personal relationships, out of a fear of revealing how the very thought of eating affected me.

I binged mostly at night after everyone was in bed. I often wanted my kids to go to bed out of my desperation to eat. When one of my kids wanted to keep talking at bedtime, I would rush the conversation. I had been planning what I was going to eat for hours. My thoughts were on saying goodnight, closing the door and getting the food. In the morning, I felt shameful for the binging and again had a hard time fully engaging with my kids—or anyone else, for that matter. My thoughts were on how weak, disgusting or stupid I felt. How could I be a mom or a friend when I was consumed by food, by fear and by shame?

As recovery begins, an element of trust begins to build. In my experience, the shame associated with food lessens, and allowing someone into your world becomes easier and less stressful. When the binge eating routine is eliminated (yes, this is possible), then those personal moments that were stolen are now open, relaxed and available to share with others. It is almost as if you had an appointment every day with binge eating (or any other ED) and those appointments are over. Those times open up for something else...someone else.

As I walked through the process of recovery (because recovery is not one moment but a process) I was able to share my world with good friends and family. I let people into my life. People who love us, who believe in us, who care about our well-being, will accept us for who we are. And, we begin to accept ourselves for who we are.

NEDA’s Helpline is available to direct you to support group options in your area, whether you are a family member, friend or pursuing recovery. Call us at 800-931-2237 or search online: www.nationaleatingdisorders.org/support-groups-research-studies
The prospect of someone being close, as we prepared for our wedding, I finally knew when I told him that he wouldn’t pretend anymore in front of the man I loved. I felt a little freer. And so I did.

Moving from dating to engagement was difficult for me...every time we went out to eat, I’d pretend not to have issues with food and weight. I hated feeling like a liar, but I was scared that he’d reject me if he knew the truth. What man in his right mind looks for all of this mess in a mate? I knew when I told him that he wouldn’t want me anymore. It bothered me constantly. He sensed something was wrong, of course, and asked me about it. What could I tell him?

As we prepared for our wedding, I finally mentioned to him that I had a secret I wasn’t ready to share with him yet. Of course, he was curious and wanted to know right then and there, but he displayed patient understanding. He told me that he loved me and that it didn’t matter what it was. He didn’t pressure me to tell him. He knew there was a secret and left it at that. Even though his response helped me feel freer and safer, I still felt guilt pulling at me. I began wanting to tell him. After all, he’d been so incredible with everything else I’d told him. He knew about my family secrets. He knew all about my weaknesses, aside from the eating disorders. He knew about all of that, and he chose to love me anyway. Still, I kept thinking, ‘don’t press your luck...’

The time for truth came a couple of weeks after we were married. It was our first Thanksgiving together, and we had been married for only twelve days... Russ and I did the cutest newlywed couple ‘this is the first mashed potatoes we’ve made together’ and ‘this is our first stuffing and cranberry sauce’ thing. We both ate our holiday feast, and I tried not to think about all of the calories.

True to form, however, I proceeded to exercise after the meal... Russell thought this was strange and unnecessary; it was a holiday, after all. He told me to just relax and enjoy the day. I, of course, repeatedly told him that I couldn’t until I had exercised. The conversation continued while I was on the stair stepper for two hours. But I saw a new look on his face—hurt. I was forfeiting my time with him, my brand-new husband, to climb steps that weren’t going anywhere. I was so tired of keeping this secret, and I wanted him to understand me. The only way I could explain it was to tell him the whole story from the beginning. First, I played an alternative rock song, an anthem, a coping mechanism for me to deal with the eating disorders. It was an angry, loud song of rage, and I thought that it would tell him clearly what I’d been through. It didn’t. He did not understand it. I took a deep breath, realizing, ‘No, Sheryle, the song isn’t going to tell him. You are.’ And so I did.

And the worst did not happen. He didn’t leave me, throw me out in the street, call me worthless and tell me how much he hated me. No. He looked at me, asked me, ‘This is the big secret?’ He hugged me, told me he loved me and that I was beautiful. I didn’t have to lie, hide and pretend anymore in front of the man I loved. I felt a little freer.

Since then, Russell has been an incredible support as I’ve continued my journey in dealing with my food, weight and body image issues. It sounds so cliché, but it’s true: he loves me just as I am. His response is the comforting ideal. I wish everyone could experience that loving reaction. Years later, he has been with me as I’ve gone through therapy, issues and all manner of ugly, painful truth concerning “this excruciating business of food.” His support has been eye-opening and empowering.

Relationships certainly are a part of life. And yes, people with disordered eating patterns and “outsiders,” like my husband Russell, fall in love and get married. There is wonderful hope out there. But these support systems are not issue-free. I’ve been approached by not only concerned parents and siblings, but also worried husbands and boyfriends feeling fear, confusion and powerlessness over their loved ones’ conditions. The eating disorder reality can be quite alarming.

Because of that, I’ve asked Russell to offer his perspective, as my husband, dealing with the eating disorder from the outside. The dilemma, of course, is that you are never truly outside when you love the person who is affected by the disorder(s).

Nevertheless, Russell has some words of encouragement for the partners, boyfriends, girlfriends, fathers, mothers, brothers, sisters, sons, daughters and friends out there.

Sheryle: What did you know about eating disorders before you and I got involved?

Russell: I knew about them peripherally, but had no real knowledge about them. I’d heard of anorexia and bulimia but knew little about what they were.

Sheryle: What are the “do’s” in dealing with a loved one who has eating disorders of any kind?

Russell: Be supportive; be understanding and open to listening to them if they talk to you about it. Do seek help for both yourself and your loved one. Educate yourself on what is going on because having an idea of what you are dealing with is a good thing.
**Tips from a Spouse continued**

**Sheryle:** What are the “don’ts” in dealing with a loved one who has eating disorders of any kind?

**Russell:** Don’t assign blame, don’t bargain or try to coerce the person into eating: it doesn’t work. Don’t allow the person’s illness to become the overwhelming force in your life because that helps no one. Don’t be judgmental.

**Sheryle:** What’s the most frustrating thing about living with or loving someone who struggles with disordered eating?

**Russell:** Knowing there is nothing you can do, but try to be supportive and understanding in the face of their continued practices. Additionally, not being able to enjoy certain things without fear of triggering their disordered eating patterns.

**Sheryle:** What would you tell partners and loved ones about eating disorders?

**Russell:** First: It has nothing to do with you. Your role is to help and be supportive of attempts to get help. Second: There is no way you can “fix” this. Only when the person struggling chooses to get help for their illness can any progress be made.

**Sheryle:** Any other advice?

**Russell:** Always let the person know you love them, no matter what. I think it’s important they know they are loved.

**Sheryle:** How do you feel about Leonard’s quote?

**Russell:** I believe it was said out of frustration and not understanding Virginia’s problems, whatever they may have been.

**Sheryle:** What’s the most frustrating thing about living with or loving someone who struggles with bulimia nervosa?

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**Author and speaker Sheryle Cruse lives in Minnesota with her husband, Russell, writing articles for faith-based and recovery magazines. She is the author of “Thin Enough: My Spiritual Journey Through the Living Death of an Eating Disorder,” a self-help book on eating disorder recovery and her personal journey.**

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**Research Summary continued from page 4**


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**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!**

EDA Navigators® 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, 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.
Enhancing Personal Intimacy Post Treatment

By Brittany Lacour, LCSW, DAACS, Colorado

Editor’s Note: The article below contains mature information regarding sexual behavior and health.

Question: Does anyone out there feel like they received a comprehensive and compassionate sexual education that addressed human development, relationships, personal skills, sexual behavior, health, society and culture?

Anyone? …Darn.

Your relationship with yourself is the longest-term relationship you will experience. For many of us, however, sexuality and building an intimate relationship with ourselves is left out of the equation. Even in the treatment and recovery process, sexuality seems to remain as private and fear-filled as ever.

As a culture, we are all too familiar with seeing sex in movies or hearing about it in songs, but we’re not so comfortable with seeing sex in couples therapy with… yourself. Try to approach yourself with the same curiosity, compassion and openness that you may another!

Sometimes, enhancing intimacy requires learning more about sexuality and our physical body. We may be faced with dismantling the messages we receive about sex as it relates to power, control and pleasure — whichever reasons resonate with you, here are some steps to begin your exploration:

Self-Commitment
Enhancing personal intimacy is your choice. Choosing to appreciate and invest energy in ourselves is the way we create value and meaning in our lives. Identifying and affirming your commitment to the value behind this process (be it wholeness, sexuality, self-expression, freedom, etc.) is important; it will serve as your port in the storm during challenging moments.

Self-Awareness
“I am willing to feel whatever is happening inside me, throughout the day, during sex or when thinking about sex. I’m willing to reflect on myself and to meet whatever is hiding. I do not have to like it, but in this moment I can observe it.” (Adapted from Heiman & LoPiccolo, 1988)

When you approach your experience with curiosity, what do you notice? When we aren’t fighting with or avoiding our minds, we may gain a different perspective or create a new relationship with an old experience. Taking this stance, begin to review your beliefs about sexuality: what assumptions have I made about my sexuality? Are these based on actual experiences or on beliefs? Do I follow these beliefs in order to avoid or prevent something? To gain something?

Pay particular attention to where your standards are coming from and whose image you might be buying. Sexual socialization may impact the way you approach yourself and the formation of your current sexual values. This includes how you were raised to feel about sex, and the role sex plays in your life and relationships.

Move Toward Yourself
“Try closing your eyes and visualizing a fantasy in which you have a high desire for sexual intimacy. Does this fantasy make you frightened or uncomfortable? Ask yourself what would be risky or different about having a desire for sex and this type of self-connection. This may get you in touch with internal experiences that inhibit your desire.” (Adapted from Heiman & LoPiccolo, 1988)

If emotions arise, try to label them specifically: as anxiety, joy, resentment and so on. Next, identify where the emotions come from; do these beliefs make sense given the context you are in now? Or are these feelings irrational, gut-level residues of negative experiences? What are your beliefs and values about your sexuality now, as an individual in recovery, as opposed to what you may have uncritically accepted in the past? Questioning yourself in this way can allow you to interact with your emotions in a different way. What you have or have not experienced is less important than how you felt or continue to feel about these experiences. Impact is determined by how we interpret our experiences, what we decide they mean and to what degree we believe they are good, bad or insignificant.

Developing affirmations can also reconnect you with your values and your ability to choose in the here and now. You can try modifying this affirmation to fit your needs:
Reflect on the following:
Growing in your connection to another, if you are feeling curious about dating or moving toward the life that you want? Where would it leave you? Would you be able to accept touch from a partner? Give loving touch to yourself, you are more able to experience your emotional life. I've let them decide for a long time, now I am ready to decide for myself.

Learn to be aware of your individual sexual feelings, which exist separately from a partner. Tune in to when you are feeling sexual and what serves as a bridge to that feeling. Use your senses for guidance! For example, does the warm sensation of the sun create a certain feeling? How about colors, words, sounds, materials? Everyone has their own sexual template (Zilbergeld, 2000), and noticing what correlates to you feeling sexual and how your body reacts allows you to say yes and no to certain experiences.

We come together with another, and our beliefs, can increase our relational flexibility by introducing different ways to express connection, love and caring. Flexibility may act as potential barriers to you moving in this valued direction; we know that shame grows in silence and secrecy. However, do not feel the need to rush to divulge every detail; this can be tempting since it may feel like a way to create “intimacy,” or quick-start a connection. You are more than a series of struggles, stories or accomplishments; if you can tune into the present moment and observe what is happening in the here and now (and not get lost in your head or history), you will be in a better position to decide when and how to talk about any aspect of yourself.

Whatever you are feeling right now, you should be confident that it is natural to have mixed emotions about this process. Remember your values and your reasons for wanting to connect to yourself or someone else; remember that you are challenging a long history of viewing intimacy in a certain way and that change may feel difficult or uncomfortable; remember that you have the power to create a safe space to talk about sexuality by providing understanding and encouragement without pressure or criticism.

Brittany Lacour is a licensed clinical social worker, Board-certified sex therapist and a diplomat to the American Academy of Clinical Sexology. She is a Primary Therapist in Eating Recovery Center’s Adult Services, and specializes in intimacy and sexuality issues in the eating disordered patient population.

References

What do you want out of dating?
Sometimes we carry the belief that in a relationship certain things about ourselves will be “fixed,” – for example, the idea of “If someone else likes me then I will no longer hate myself.” To clarify your dating intentions, try answering the following questions:

How do I feel about myself when I am in a relationship vs. not in a relationship? Do I want to date for companionship? Security? To learn? To be sexual? To receive affection? To eliminate or avoid certain feelings? To take care of others or to distract myself?

As a culture, we are all too familiar with seeing sex in movies or hearing about it in songs, but we’re not so comfortable with making it personal.

What stops me or hinders me?
Risk is involved whenever you initiate an activity, suggest a cup of coffee or ask someone on a date. If you are interested in dating, you may want to think about how willing you are to take risks and to allow yourself to experience your emotions.

What internal experiences come up for you as you move towards an intimate connection with someone else? What feelings, thoughts, beliefs, memories or judgments may act as potential barriers to you moving in this valued direction? What skills or resources can you access to support you?

What have I learned about myself?
Recovery encourages us to expand our perspective on ourselves and our relationships. Talking to others about their dating experiences, as well as processing our beliefs, can increase our relational flexibility by introducing different ways to express connection, love and caring.

You may discover that your own dating or relational preferences have changed while in treatment or since your last relationship. You may also decide to reinvent yourself in terms of how you want to show up in relationships, but be cautious of changing simply because you think you’ll attract more people. Loneliness, judgment and anxiety can push us to make choices that aren’t in service of our values.

How do I talk about therapy?
When you start dating (again or for the first time), you are bound to wonder how many details you should disclose to the person you are seeing. Expressing ourselves and being curious about a potential partner is a wonderful stance; we know that shame grows in silence and secrecy. However, do not feel the need to rush to divulge every detail; this can be tempting since it may feel like a way to create “intimacy,” or quick-start a connection. You are more than a series of struggles, stories or accomplishments; if you can tune into the present moment and observe what is happening in the here and now (and not get lost in your head or history), you will be in a better position to decide when and how to talk about any aspect of yourself.

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Bringing the Eating Disorder Out of the Shadows Together

By Stephanie Smykal, NEDA Navigator, Massachusetts

I do not have typical memories of my first date with my husband. I have no idea what he wore, what I wore, or even what we talked about. What I do remember is exactly what he ate, what I ate and what we both drank. I remember sitting, chatting, laughing and eating pizza, while a war waged in my head with every bite I took. I felt like a fraud and I hated it.

That is the thing about having an eating disorder—it robs you of simple joys and experiences. The excitement of a first date was completely overshadowed by my fear and anxiety about eating pizza for the first time in years. I was 27 years old, and I had been sick with my eating disorder for more than half my life. Despite countless hospitalizations and residential programs, my eating disorder was so ingrained in me that my first date jitters had nothing to do with the guy and everything to do with the food.

When our relationship quickly became serious, I knew that if we were going to build a future together I needed to be completely honest with him. I just needed a way to tell him about my eating disorder. Unfortunately, I carry a permanent and visible scar from my battle. At one point I had a gastric feeding tube, and as a result I have a deep scar on my stomach. What I ate and everything we talked about.

Once we became aware of what was going on, I quickly entered a hospital program. The idea of postponing our wedding was soon a very hot topic between my treatment team, my husband and I. My husband dragged my eating disorder into the light, and once it was there, it didn’t stand a chance of surviving.

Five months before our wedding, I began to relapse. It happened slowly, and snuck up on both of us. Once we became aware of what was going on, I quickly entered a hospital program. The idea of postponing our wedding was soon a very hot topic between my treatment team, my husband and me. My husband told me that he would have no problem postponing the wedding if I did not follow my treatment team’s plan to the letter. I was horrified, but not surprised. Needless to say, I worked incredibly hard and we got married as planned.

Despite not having to postpone our wedding, I was angry at my eating disorder, and at myself, for even having to discuss it. Leading up to a wedding, most couples have bridal showers and bachelor and bachelorette parties and do last-minute wedding planning. We, however, were attending family therapy and were focused on my eating disorder, my meal plan and my weight. My eating disorder had robbed us of our pre-marital bliss.

My eating disorder interfered in our relationship again six months later when we started talking about having a baby. I was eager to start trying immediately, but my husband wanted me to gain some more weight, and to make sure I was strong in my recovery. My husband, my therapist and I agreed on a month when I had to reach before that time. I was upset that we couldn’t just make our own decision to have a baby. I was upset that a therapist had to be involved in such a personal decision, and that my eating disorder was once again a big focus in our lives.

I did everything I was supposed to do, and my recovery was strong when the date arrived. Unfortunately, we were unable to get pregnant: we were infertile. It was heartbreaking news. Several rounds of fertility drugs and intrauterine inseminations were unsuccessful. Aside from my eating disorder, infertility is the hardest thing we’ve ever had to deal with. We were fortunate, however, that our first round of in vitro fertilization was successful, and we are the proud parents of an incredible 17-month-old little boy.

My eating disorder will always be the third wheel in our relationship. We hope it continues to sit on the back burner, but we know we need to be vigilant and on the lookout for signs of relapse. I have been in strong recovery for the past two and a half years, and we both hope it remains that way for the rest of our lives, but we are not naïve and know that relapse happens. We have so much we want to do with our lives — including having more children — and we both refuse to let my eating disorder stand in our way.
Intimacy is a connection; a sense of silent knowing of the thoughts and feelings of another which radiates from deep in the heart.

This winter was a never-ending request for patience. Mother Nature’s relentless cast of wicked weather caused many in my neighborhood to stay indoors and fall prey to the drying effects of recycled heat.

Each night during our somewhat forced hibernation, I applied lotion to my moisture-deprived hands. One such evening my husband asked if I’d apply some of the healing salve to his hands to help relieve dry skin and some tension. I smiled in agreement as I carefully removed his wedding band from his finger to our nightstand, as lotion can play havoc on jewelry.

The next morning I noticed his ring was still there. In split second timing, I felt an immediate rush of emotion race through my heart. The pang I felt was not for the day I slid the gold band on his finger, but the day he slid the ring off.

Aside from me, the person who suffered severe consequences of the eating disorder was my husband. After thousands of second chances and promises I’d eat better, in 2008 he told me very calmly yet clearly that I needed to leave our house and get help. Although I tried to peer through his emotionless eyes, I could not see the compassion I’d relied on for years. He had had enough of my lies and, in my mind, me.

So at the age of 46 I entered a residential treatment facility hundreds of miles from home. One of the recommendations was to engage my husband in family therapy. Knowing he was not one to talk about his feelings as well as his less-than-enthusiastic thoughts about me, I suggested including him would be a rather bad idea.

I realized there was nothing I could do other than commit to my healthy recovery. Every day, I followed the suggestions of my nutritionist and therapist, while staying connected to like-minded people striving for a similar transformation.

In time, my consistently healthy actions spoke louder than any words I could have strung together. The circle of trust our wedding rings represent re-emerged, leading to the replacement of the precious gold band on my husband’s finger.

Coming back to where I sat on the edge of my bed, a tear fell slowly down my cheek as my eyes opened. I grabbed the ring from the nightstand and walked to where my husband was reading the morning paper. When I gently slid the gold band back on his finger he turned to me and said, “I knew something was missing. I’m so glad it’s not you.”

I cherish the intimate connection we share, offering words spoken in silence through things like the touch of a hand, or a circle of gold.

The Ring
By Alison Smela, Illinois
Michael Falk: It was an unbelievable contrast. It was literally like two different people. I would be open and tell her. When she was struggling, she was quiet, reserved, really easily angered, and compulsive. She’s one of the most laid-back people normally, but she would just snap on the littlest things. She would become very manipulative. And when she wasn’t struggling, she was one of the most outgoing people. She cares about other people more than she cares about herself. She laughed like a little kid. One of the things she taught me—I’m a fairly serious person—and she would show me that it was okay to just be a kid and have fun. And none of that was there when she was struggling. She would just want to sit in the room by herself, lie down and sleep, just do anything to get away from the world, isolate herself, and push people as far away from her as she could. Throughout the five years we were together, I never really figured out how to get through to her when she was struggling. I never figured out what to say or what to do. I would try to be there to support her and ride it out and wait for the good times. She knew it because when she would come out of it, she’d be like, “Sometimes I feel like I’m bipolar. I know I’m not because I told them that when I was in the hospital, and they checked me for that, and I’m not.” But, that’s honestly how she would feel. She would feel like two different people.

Claire: That’s such a hard thing to deal with. You know it’s the eating disorder, but of course, you still feel the frustration and anger. What kind of support did you have for yourself?

Michael: I never really had any support. I talked to her parents some, but the whole time we were together, she was very rarely home, maybe a little bit over the Christmas break or the summer, but we ended up spending most of our time together. We’d travel together or whatever the case may be. It was kind of “us.” Obviously, I had my family. They would listen, but they had no real advice. I didn’t know where to go for help. Sometimes I’d try to get a hold of her therapist and talk to him, but nobody ever really engaged me on that level. When she was...
at the treatment center, I’d go to visit her and I’d ask, “what do I need to be doing?” but nobody ever really told me. I don’t know if it was that I was always the boyfriend and never a family member or a husband or whatever. I never really got anybody to engage me in a conversation about what to do, how to help her and how to get through.

Claire: Yes, and how to take care of yourself. It’s such an all-consuming process for the person struggling with the eating disorder, but also for the people who are closest.

Michael: Right. And, I’ve kind of realized it now after the fact that, as I said, when she was struggling, she’d kind of try to isolate herself from me and everyone else. And I’m not really sure if it was conscious or not, but she, the disease, kind of isolated us from everything else. We could never go out and eat with other couples. If we’d go on a double date, it would have to be short and not anything involving meals. We couldn’t do anything late at night because we couldn’t miss the night snack. So there were all these things that really kind of cut us off from friends and life at times. Everything had to be planned and usually alone because having other people around would be stressful. I didn’t really realize it at the time because for me I was just hanging out with my best friend, so I guess I didn’t notice. But now I’m like, “Man, I didn’t realize how much I’d missed and how I’d fallen out of touch with people.”

Claire: One of the other things I thought we could talk about is how the lack of resources on campus factored into your story. What changes would you like to see?

Michael: To this day I think that our school’s mind was in the right place and they were trying to help. But the whole process felt more like a punishment than that they were there to help. The way that Kayla got involved at school was after she had voluntarily gone into treatment. So she missed 10 days or two weeks of school — an extensive amount of the semester. Everything was kind of always followed by this threat of, “If you don’t do this, you’re going to be kicked out.” And that was constantly there. Kayla loved school. That was her dream. It was like somebody threatening to take her dream away. And I think that they were trying to make sure that she had motivation to keep working, but it kind of backfired. What she needed was for the school to work with her to make sure she could get treatment without having her academic future compromised.

Claire: There’s a lack of understanding, expertise and resources on so many campuses. And eating disorders are far too common on college campuses.

Michael: It’s like a breeding ground. With Kayla, there was a distinct tie between her schoolwork and her eating disorder that I don’t think anybody figured out and helped her to address. She was always aware of it but she could never fix it on her own. From her previous hospital stays she had been diagnosed with OCD and perfectionism. The amount of time she put into her schoolwork was unbelievable. She was a 4.0 student throughout high school and college. But when the stress of school picked up, and the schoolwork picked up, it was an immediate tie to the eating disorder showing up again. Once I was aware of it, I was able to help her watch it a little bit. In college, the pressure of all the classes, the time, being away from home, and you’re in a dorm eating dorm food. You can’t cook your own meals. You may not even have a fridge to keep food that you enjoy eating. It was really tough for her.

Claire: What have you learned in the grieving process?

Michael: The first thing I would say is that I’ve never really allowed myself to go back and blame myself for what I could have done differently. I’m trying to look at it in a way that I can hopefully help other people. But, I’ve never put the blame of what happened on myself. I’ve learned a little bit about what led up to her ending up in a coma. She was never honest with me about what was going on with her for really the past year. I had tried to confront her and express my concern and encouraged her to seek help and make changes, and she was never honest with me about how sick she was. That was one of the hardest things for me — looking through some of her things and seeing the dishonesty. It was really hard initially. This was a person I had loved, and we had lived together for almost a year. It goes back to that idea of dealing with those two separate people. That’s how I’ve managed to get past that initial feeling of betrayal, that level of dishonesty she had with me. I’ve been really trying to focus on remembering the good times we had together. And I’m trying to do what she would want me to do, and remember her in the way that she would want to be remembered, and try to make something positive out of this. I know that nothing I do is going to bring her back. No matter how many people I help, it’s not going to make what happened to her make sense to me. She was always someone who would help anybody else before she would help herself. That was how she lived her life. So, as part of a fundraiser, I’ve been growing a mustache for 18 weeks. I’ve raised almost $28K for a scholarship where she worked at the Boys & Girls Club. It will go to help kids pay for college. We’ll have an endowed scholarship there in her name. And I’ve been focusing on trying to work with NEDA and tell the story. She was such an incredible person. This doesn’t make sense. She fought all the way to the end. That’s part of why it’s important for me to tell this story. She never gave up.

Note from the NEDA team: As illustrated by this interview, navigating a relationship with someone who is struggling with an eating disorder can be complex and confusing. It is often beneficial for partners to be engaged in their loved one’s treatment and it is essential for them to practice self-care, including seeking out their own support networks. The impulse to put others before oneself, whether on the part of the individual suffering or the partner, can be symptomatic of the eating disorder dynamic and serve to obscure the individual’s own need for support and care.

LOSS SUPPORT NETWORK

Volunteers in the NEDA Loss Support Network know the unique type of grief experienced by those who have lost a loved one to an eating disorder, and they are available to help support those who have lost someone. If you would like to become a volunteer to support others or request support from a Loss Support Network member visit www.myneda.org/loss-support-network
Tips for Partners Supporting a Loved One

By Ilene V. Fishman, LCSW

Eating disorders are extremely complicated which means recovery is not easy to achieve. And if you love someone with an eating disorder, the challenges can sometimes seem overwhelming. The more you understand the issues involved both generally and specifically in the case of your loved one, the more you will be able to offer your support during treatment and long term recovery.

Do not avoid the elephant in the room – instead, name it, but do so with loving attunement. This means understanding how difficult it is for the person who is struggling, every step of the way. The more you understand about how the eating disorder works in your loved one’s head, the better attuned you can be in offering help.

Eating disorders defy logic and to some degree, nature. Knowing this, you can see how dealing with them personally and professionally requires specialized education. Try to understand how your loved one believes she or he needs the eating disorder to function. Try to understand the conflict between the disorder and the person who has it. That struggle causes your loved one to feel awful about hurting you and the family. Remember that eating disorders are not a choice and they exist for some very important need and purpose.

Communication is key, so don’t forget to do it! Communicate, don’t lecture or judge. Even if you think this is not your strong suit, try. And if it doesn’t seem to be working, keep trying. Listen carefully to what your loved one says and how she or he responds to what you say. For example, if you tell your loved one: “You look healthy,” they may hear: “You look fat.” Understand that you are interacting not only with your loved one but with their eating disorder, which is real and valid and worthy of your attention. You may hit a great deal of resistance but your loved one will appreciate your efforts, even if they are unable to say as much in the moment. It is great role modeling to show how you can stretch and rise to the challenge of this eating disorder with them. Full recovery requires ongoing stretching. As you stretch yourself along with them, you may be surprised how this uncomfortable process can lead to growth for both of you.

Therapy can be very helpful in this regard. You can always ask to attend therapy sessions with your loved one’s treatment provider or team. Try to respectfully offer your thoughts and perspective while always trying to better understand your loved one’s struggle and emerging self. I sometimes hear partners and families say that the sufferer’s problem is not theirs. Even if you have never sought professional help out before, once you are dedicated to helping your loved one, specialized help, even briefly, can be quite beneficial.

Boundaries are a very significant issue for individuals and families with eating disorders. Learn about the balance of giving your help while also listening carefully and understanding the lines that should not be crossed. Sensitivity to their needs, even when we may not agree or even understand those needs, is essential. You also have the right to your own boundaries and to be understood. Getting your feelings and even disagreement and conflict out in the open can be extremely helpful. We often make the mistake of not wanting to say “it” for fear of making things worse. The opposite is generally true: better to risk saying it than having it brewing and living hidden under the surface.

Take care of yourself. Just like on an airplane where we are reminded to put on our own masks first in the case of an emergency, you can’t take proper care of someone else if you are not taking care of yourself. Your loved one may feel worse seeing your pain and suffering in response to their eating disorder. Guilt only complicates the sufferer’s feelings of low self-esteem. Low self-esteem always underlies these disorders.

There are more helpful resources available in our field than ever before. Keep your eye on full recovery and please get the support you need to successfully weather the storm. There is hope and there is recovery – for all of you.

Ilene V. Fishman, LCSW, ACSW, has been specializing in the treatment of eating disorders for 30 years. Ilene helped found NEDA, is currently serving on the Board of Directors and is also a Clinical Advisor of the NEDA Navigator program, Loss Support Network and NEDA Support Group Program. Ilene is an Adjunct Professor at the Wurzweiler School of Social Work, Yeshiva University and is in private practice in New York City and Montclair, NJ. She speaks widely on the subject of eating disorders.
Understanding the Affordable Care Act for Families Seeking Treatment for an Eating Disorder

Navigating and understanding treatment options and insurance rights for eating disorders can be difficult. While we still have much to accomplish in order to ensure the best coverage for eating disorders, the federal government has made some progress in improving care through the passage of the Mental Health Parity and Addiction Equity Act of 2008 and the Affordable Care Act. The expanded coverage for pre-existing conditions will help many individuals in need. As some of these changes have recently taken effect, many questions may arise about what these laws mean in terms of coverage for eating disorders.

The Affordable Care Act and Mental Health Parity Act involve regulatory changes that affect most health plans, but not all. For example, TRICARE for military families is exempt from the provisions within the Mental Health Parity Act. It is important for all of us to know how our plans are structured and covered. The Final Parity rule requires plans to provide clear disclosures around the parameters of insurance coverage.

The guidance from these regulations has facilitated the following changes in the system:

Mental Health Parity Act

- The limits on visits and/or days for behavioral health services must be similar to any restrictions on day and/or visit limits placed on predominantly and substantially medical services. This creates an obligation for commercial health plans to offer expanded coverage of medically necessary services for chronic illnesses, including eating disorders.

- Some behavioral health intermediate care services are now included in coverage if the medical benefit covers intermediate medical services like skilled nursing services and/or rehabilitation center-based care.

- Parity provisions have been expanded to individual and small plans, which are regulated to offer essential benefits.

The Affordable Care Act

- 18-26-year-old dependents living with their parents are now covered. This includes those dependents with behavioral health illnesses that have prevented them from functioning independently.

- Performance-based reimbursement or incentives will now be facilitated.
  - Initiatives to demonstrate the effectiveness of the system of care servicing chronic care populations are focusing on readmission rates into higher levels of care.
  - There will be a long-term engagement in lower levels of care for stabilization and maintenance of functionality.

- The provider’s population will be measured against appropriate benchmarks, including severity rated plan reimbursement of populations for Health Information Exchange plans. This will provide assurance that plans are reimbursed based on the true severity of the population, and discourage plans from attracting low-risk members.

While these changes lay the groundwork for expanding care services for eating disorders, the ACA-based laws and the interpretation of compliance to the federal Parity Act still vary by state, as states have the jurisdiction to regulate insurance coverage. We will continue to work on the early detection and prevention of eating disorders to ensure that all those suffering from eating disorders receive effective treatment as early as possible.

With the regulatory changes and the movement toward pay-for-performance standards, the health care field is motivated to develop guidelines by which eating disorders are diagnosed, evaluated and treated. These include generally accepted measurements of successful clinical outcomes to help the shift to performance-based ratings for consumer choice and provider reimbursement; a clear designation of evidence-based treatments for eating disorders; and severity stratification methodologies for eating disorders that differentiate the subpopulation by service cost and utilization for reimbursements. It will be important that those personally affected by eating disorders be at the table, and bring their lived experiences to this important discussion, as we advocate for the advancement of appropriate coverage.
Interview with Filmmaker Tchaiko Omawale

Tchaiko Omawale is a filmmaker, producer and director. Her short film solace is inspired by her experiences with compulsive overeating and self-harm. She is currently working on the feature version of the film. For more information, please visit solacefilm.com.

NEDA: You mentioned that the inspiration for your current efforts to raise awareness about eating disorders — particularly among people of color — came from the experience of showing your short film and being approached by so many different people who wanted to talk to you about their own struggles with eating disorders and/or self-harm. What have you learned through all of these conversations?

Tchaiko Omawale: I’ve learned that we all feel like we’re the only one, and I want to be clear that both folks of color and also white folks came to me to talk about their personal struggles with eating disorders or with someone they knew who had an ED. The amazing thing for me was that even though my film had a black cast, there was a clear universality of the pain that comes along with having an ED. How we as humans at a base level feel pain equally is a beautiful thing to remember how horribly lonely and dark it was before I knew how to get help, and whenever someone gets help and gets better, it just makes me happy.

NEDA: What are the challenges you have encountered as you are trying to generate more conversations and resources around an illness that has historically been associated with white women? Where do you see opportunities to improve outreach and access to support and treatment?

TO: I really think the media is a great outreach tool; storytelling is historically the way we’ve learned. I have really great dreams for the dialogue that my film can initiate; we’ve never seen a black girl on TV dealing with an eating disorder.

I wanted to work with several organizations while making this film, so that when the film is released there is a structure in place for making information and resources available to audiences. When I have approached organizations that work with young girls of color to work with me, I have not gotten very open responses. Some people responded that they were not working with mental health issues in their program. Some people literally couldn’t understand how what I was doing was connected to what they were doing. The responses from those organizations shocked me, and then it motivated me.

I like to think in terms of what ifs. What if on my film’s website, there was a page that had these resources so anyone who happened upon the film could also happen upon how to get help? It makes me smile thinking about that because I remember how horribly lonely and dark it was before I knew how to get help, and whenever someone gets help and gets better, it just makes me happy.

NEDA: There is little research on the prevalence of eating disorders among men of color, but we know that overall, the prevalence of eating disorders among males is as high as 1 in 3 or 4 — much higher than what was previously believed to be the ratio. In your experience, are there men of color who are struggling with these issues, but feel less able to access help and resources than women? Have men reached out to you?

TO: I’ve met men of color on my path to recovery; there was one gentleman who spoke with me after one of my screenings. He had just gotten out of an inpatient recovery center – and he told me a story about a man who had approached him ages ago to do a play about men with EDs. The man who approached him disappeared, and he found it out it was because he had committed suicide. I had forgotten how serious this disease can be, and the invisibility of those suffering from it. The disease can be invisible, especially if you’re not physically showing as overweight or underweight. It can be hard in general for people to understand that there is a range of eating disorders that physically look different on people.

NEDA: What do you hope to accomplish through the feature-length version of your film, which you mentioned is currently a project in progress? How do you intend to use it as an outreach tool?

TO: Filmmaking is a spiritual and cathartic process for me, whether it is a fantasy film about fairies, or a coming-of-age drama about two girls whose friendship teaches them about their self-harming behaviors. So I hope to heal in making this into a feature-length film, and I hope to have fun. I hope to engage the actors in a world that increases their compassion for their own struggles and for the struggles of others who they might not have known were it not for my film. I hope to have audiences of all ethnic backgrounds see this film as their own, see themselves through the young black characters in my film. I’m

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Shining a Light for Awareness
By Lana Kasunic, NEDA Navigator, Ohio

For the past few years, I have noticed the Empire State Building lit up in green and blue for National Eating Disorders Awareness Week. What a great way to spread awareness about eating disorders—lighting a landmark building blue and green for the world to see!

When NEDA announced this year that the Empire State Building would once again be lit in blue and green on February 24th, the Monday of NEDAwareness Week. To my surprise, the application was approved! That was quite an accomplishment to me, so I figured, why stop there? I wanted to see how much awareness could be spread this way in the short amount of time I had before the start of NEDAwareness Week.

I contacted friends in other cities across the United States and asked if they knew of buildings or landmarks in their area that change colors to raise awareness. I also checked organizations that commissioned landmarks all over the world, compiled a list of participating companies and organizations and contacted as many as I could. None of the organizations said “no” to me unless it was due to cost or time constraints. Even the Space Needle in Seattle, WA was sympathetic to our cause. They called to let me know they were disappointed they couldn’t get the needle lit, but they would be happy to light it for our cause as soon as LED lights are installed. I was so surprised by all the supportive responses, whether they were “yes” or “no” and find them to be very encouraging for 2015!

In all, the Terminal Tower in Cleveland, OH; the SunTrust building in Tampa, FL; the Miami Tower in Miami, FL; and the Duke Energy/Wells Fargo Tower in Charlotte, NC were lit up in blue and green for the 2014 NEDAwareness Week.

I learned a lot about how effective lighting landmarks can be. Each organization with a lit tower posted on social media the reason for the colors, linked to myneda.org or displayed NEDAwareness Week signage inside the building. They also posted additional information about the effects of eating disorders and a link to the NEDA website. Not only were the buildings being lit, but they also gave a call to action! I learned that it is never too early to start getting on the calendars for buildings and landmarks, and as an advocate for eating disorders awareness, one person really can make a difference. If I was able to secure four buildings in major cities in less than three weeks, just imagine how much awareness we could spread by getting an earlier start!

Interested in shining a light in your area? Contact Lana Kasunic at lanak@pfn.nationaleatingdisorders.org and help shine a light on eating disorders.

Interview with Tchaiko Omawale continued

an idealist; I grew up in several different countries around the world and I have always wanted everyone to see how much more similar we are than different. It’s so important to me to stay connected to community organizations around the country so that they know about the film, so that their communities see it. I really want to have social media, which I enjoy on a compulsive level, be a tool for change, and have conversations about the film pop up on Vine, Instagram, Twitter and Facebook in a fun and informative way. What if talking about eating disorders was normative?

NEDA: What has the experience of creating this film and becoming a more visible activist around the issues of eating disorders and self-harm been like for you? How can others join you in your efforts?

TO: It has been scary, painful and fun. It has been a long process; I first conceived the idea ten years ago. I wrote the short film, then I wrote it as a feature, then I went back to the short and decided to make it. I did a Kickstarter, which was successful and so much fun. It was so exciting to see how many people wanted to be a part of the conversation. I shot it in New York in the summer of 2010, and I made amazing new friends through that process. I’m impatient and I always want to go at a faster pace, so it felt painfully slow. Then, the scary part is when the film is done, and you show it to people, and you realize, “Oh my God, I am basically outing myself to the world about this thing that I used to do in private, by myself, in my own hell.” Then it becomes fun and exciting again when I share more stories and open up the conversation even more.

I love activists, but I can’t think of myself as an activist; somehow for me, it blocks my ability to let the creativity flow. It’s more comfortable for me to say I’m sharing my story with others and I know change will come from that openness. I hope that the more I share, then maybe those who are activists and community organizers will use me and my story for their work.

We’re faced with so many images of how we should look, how we need more of this or that to be better, that I know there are so many people who can identify with not feeling good enough, with feeling like they need something to feel better about themselves. I want to involve bloggers, teachers, community organizers, chefs, yogis, parents, everyone. My film is really about dealing with the universal need to ease the pain of struggling to be seen and heard, and I want that struggle — that dialogue — out in the open.
The 2014 Annual NEDA Conference, *Thinking Big: Uniting Families & Professionals in the Fight Against Eating Disorders*, brings together professionals, researchers, educators, individuals in recovery and their families, to connect and learn from one another in a warm, welcoming environment. This year’s theme, focusing on collaboration, will highlight the wealth of knowledge that comes from sharing our experiences and expertise to advance the understanding and treatment of eating disorders. It’s an ideal opportunity to meet others, share stories and foster connections. For more information, or to register, please visit [www.nedaconference.org](http://www.nedaconference.org).

What previous conference attendees are saying:

*Attending the 2013 NEDA conference was both intense and uplifting for me. I knew our family was not alone in our struggle, but I never realized how many other families there are with young children suffering from an ED. From top to bottom, every person at the conference was approachable, encouraging and willing to share insights.*

— Parent

*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

*I appreciated the approachability of the NEDA staff, as well as all the conference participants. It felt like everyone was there to work together to fight eating disorders.*

— Attendee in Recovery

*I came home with excellent information that I could share with my daughter. I also met some amazing people that gave me such hope. I also feel that all the folks that work and involved with NEDA are so approachable. Thank you for your hospitality. I never felt alone the entire weekend.*

— Parent

*It was all new to me and I thought it was fabulous. I was blown away by all the experts attending and grateful for their willingness to share information. All experts and professionals were approachable and willing to talk.*

— A Family Member

*The atmosphere at the conference was exceptionally supportive and warm. That’s something to be proud of.*

— Professional colleague
#NEDAwareness
2014 PROGRAM OUTCOMES

What impact does #NEDAwareness Week have on help-seeking behavior? Turns out, it makes a big difference. | www.NEDAwareness.org

- 23,515 people took the I had no idea online eating disorder quiz
- 88 partner orgs.
- 155 trained speakers
- 233 online event listings
- 44 participating countries

Outreach + media exposure = more people seeking help

We're here to help

Help-seeking behavior
The most important outcome of NEDAwareness Week? More people taking a step toward recovery.

- 67% increase in helpline traffic
- 157% increase in click-to-chat
- 143% increase in online eating disorder screenings
- 87% increase in NEDA Navigator requests

2014 vs 2013

83% increase in NEDA website visitors

233% increase in NEDAwareness Week website visitors

- 23.7 million reach
- 63.3 million impressions
- 12,400 tweets
- 7,000 contributors

- 602,969 reach
- 2,123,847 impressions
- 2,273 new likes

- 2,115 photos posted on Instagram under the #capturehope hashtag
Breaking Myths
By Matt Wetsel, Virginia

Eating disorders don’t discriminate. I have known this for a long time, but 11 years after I first became sick, eating disorders are still widely misunderstood. Stories about eating disorders in people who don’t fit the common narrative (white, middle-class, cisgender females) are still treated as though they are breaking headlines.

So, it is with a touch of irony that some of the attention my writing and activism receives is due to the fact that I am not female. As is demonstrated time and again, though, the eating disorders population has always been a diverse crowd. I think sometimes there’s so much focus on our differences that people forget there is a great deal of commonality in our experiences. The idea that eating disorders are a feminine issue is so ingrained that I see many people automatically referring to boys and men as “male eating disorder patients” instead of just “eating disorder patients.” Heck, I’ve done it myself.

Without recognition that eating disorders are not just a white female illness, it can be difficult to talk about the experiences of those who do not fall into that group without reinforcing the misconception that there is something odd, different or strange about someone with an eating disorder who happens to be male. To me, this is a truly tragic state of affairs, and it reinforces all of the reasons that I feel compelled as an activist to engage communities and advocate for health policy reforms. The eating disorders field as a whole cannot properly move forward if we don’t consistently acknowledge the entire eating disorders population. Eating disorders are not a uniquely women’s health issue so much as they are a public health issue that happen to affect women with more frequency than they affect men. Unfortunately, recovery resources are still often produced with only women in mind. My own recovery frequently involved squeezing into spaces that never anticipated someone “like me” to need them.

That’s why I was happy to accept the invitation to speak on a NEDA panel, I Had No Idea: What Everyone Should Know about Eating Disorders, for the 2014 NEDAwareness Week. The theme I Had No Idea is entirely fitting, because somehow there are still plenty of people who have no idea of the diversity among those who suffer from eating disorders. We know eating disorders are serious and sometimes deadly. We therefore have an obligation to make sure there is always acknowledgment and equal representation of that diversity: in research, in activism and in treatment. And, most importantly, to convey that no matter who you are, an eating disorder is nothing to be ashamed of.

Matt Wetsel is an eating disorder and body image writer and advocate. Having suffered from anorexia in college, he focuses on the intersection of gender constructs, mental health and body acceptance. Matt has degrees in Psychology and Religious Studies, and holds a Post-Baccalaureate Certificate in Gender, Sexuality & Women’s Studies from Virginia Commonwealth University. You can check out Matt’s blog at http://arenomore.wordpress.com and follow him on Twitter @MattWestel.

Untold Truths: The Marginalized Voices Project

What is the Marginalized Voices Project?
The Marginalized Voices Project is a collaboration between the National Eating Disorders Association and feminist activist and editor of Everyday Feminism, Melissa A. Fabello. Together, we’re calling for stories that focus on underrepresented experiences and communities in order to create a platform for people to share what it means to suffer (and recover) from an eating disorder. Our goal is to create a collection of stories that tells the whole truth — by spanning the entire spectrum, highlighting stories from people of marginalized identities and that challenge misconceptions — so that we can present the world with what the reality of most eating disorders look like.

Why the Marginalized Voices Project?
Mainstream media often portray eating disorders as a “young, privileged white woman’s disease.” We know this is simply not true — eating disorders affect people from all different backgrounds, ethnicities, gender identities, sexuality and ages. It is our hope that this project will dispel these myths and misconceptions about eating disorders. We’re also organizing this project because it’s dangerous for people to believe that their eating disorder “doesn’t count” or that they’re “not that sick.” Through these stories, we hope to spread the message that everyone’s experience is as equally valid and equally deserving of care and recovery.

How to Participate
Submissions should be written in personal narrative, creative non-fiction, or memoir style and be between 1,500 and 2,500 words. Submissions are due by Friday, August 13th. To submit your story, or for more information, please visit www.nationaleatingdisorders.org/marginalized-voices.
**NEDA Walk Volunteer Spotlight**

By Christyn Enser, NEDA Walk Coordinator, Washington, D.C.

This month I graduated with a bachelor’s degree in journalism from American University. It was at college that I first learned about NEDA and began volunteering at NEDA walks, including the district’s inaugural 2011 walk. In four years, I went from a team captain to a committee member to the walk coordinator. It was a huge responsibility to plan one of NEDA’s largest walks as a college senior, and I wanted so desperately for it to be the best DC NEDA Walk yet.

Whenever I needed extra help with walk planning, I turned to my family for support. They have always been there for me, especially when I was battling anorexia nervosa as a preteen. Back then, we didn’t know what NEDA was, and an eating disorder was hard to address in a small town where I felt like the “only one” with anorexia.

Visiting Washington DC for a 2005 youth leadership conference saved my life. I was at the lowest point in my struggle, and the city was an open door to the future, making me realize I deserved the life that my eating disorder was trying to deny me. The 2014 DC NEDA Walk raised more than $45,000 to support NEDA in the city where my recovery has come full circle.

This year marks 10 years since anorexia entered my life and changed me forever. But despite the challenges I faced, my experience with an eating disorder can be a positive thing. It motivates me to help others who are struggling and give living proof that recovery is possible.

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**Upcoming 2014 NEDA Walks:**

- **St. Louis, MO NEDA Walk**
  (Tilles Park- Gloria Rogers Pavillion, St. Louis, MO)
  Saturday, July 19, 2014

- **Greater Cincinnati, OH NEDA Walk**
  (Dearborn Trails, Dearborn, IN)
  Saturday, September 6, 2014

- **Mt. Pleasant, MI NEDA Walk**
  (Chip-A-Waters Park)
  Saturday, September 6, 2014

- **Albany, NY NEDA Walk**
  (The Crossings of Colonie, Albany, NY)
  Saturday, September 27, 2014

- **Wilmington, NC NEDA Walk**
  (Hugh MacRae Park)
  Saturday, September 27, 2014

- **New York City, NY NEDA Walk**
  (Foley Square)
  Sunday, October 5, 2014

- **Asheville, NC NEDA Walk**
  (Pack Square Park)
  Saturday, November 8, 2014

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**Upcoming: PFN Webinars Series**

**Obtaining Treatment Authorization in the Complex World of Insurance**

Thursday, July 10, 2014, 5:30 to 7 PM EST

Recently Archived Webinars

- **Males & Eating Disorders**
  Recorded live on Tuesday, June 3, 2014, 11 to 12:30 PM EST

- **Eating Disorders Among Members of the Military**
  Recorded live on Tuesday, May 13, 2014 2 to 3:30 PM EST

- **Mirror, Mirror: Standards of Beauty, Body Image and the Media**
  Recorded live on Thursday, March 6, 2014, 5 to 6 PM EST

- **Neurobiology & Disordered Eating: How our brains guide our forks**
  Recorded live on Tuesday, February 25, 2014, 12 to 1:30 PM EST

- **Eating Disorders At & Beyond Mid-Life**
  Recorded live on Thursday, February 20, 2014, 1 to 2:30 PM EST
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.

Honey Does This Make My Butt Look Big? A Couple’s Guide to Food & Body Talk
Written by Lydia Hanich, MS, LMFT. Published by Gurze Books 2005.

REVIEW SUBMITTED BY Liana Fernez, PFN Intern, New York

Honey Does This Make My Butt Look Big? A Couple’s Guide to Food & Body Talk, humorously addresses how to start a dialogue. Hanich, who specializes in eating disorders and body image issues, writes a book that grapples with the difficulty of dealing with your partner’s eating disorder and/or physical insecurities. Her book is formulaic: she asks a question or provides a potentially inflammatory declaration that one might receive from a partner on a bad day (or a good day, or a day that might be about to turn from bad to good). Then she teases some comforting, neutral and downright careless ways one’s significant other might respond.

The questions Hanich poses stem from a place of vulnerability and insecurity (the title of her book being the most basic example). Her comic approach to body image conversation starters can relieve some of the tension implicit in broaching this very personal topic with your partner. However, her book falls into the heteronormative gender binary that eating disorders awareness fights against so vehemently; only one chapter of seven is specifically dedicated to male pronouns, address body image as a whole and then save a chapter to address biological-sex-specific issues, such as pregnancy and menstrual bloating?

Despite Hanich’s heteronormative approach, her analysis of the best and worst ways to handle an uncomfortable conversation with one’s significant other is all-encompassing. Her best-case-answer always encourages one to stop, think and try not to “fix” one’s significant other. Showing care, concern and a willingness to understand your partner (even if you don’t, or can’t yet) requires patience — and, as Hanich shows, investment.

When things get serious, take them seriously. Despite its jokes, Hanich’s book shows that the best answer is almost never the funny one. Frivolity and cleverness have their places in a relationship, but when it comes to a partner’s emotions, pay attention. Do not assume you understand what she means if she hasn’t explained it herself. And, even if this isn’t Hanich’s desired pronoun, don’t tell him his butt looks big.

* 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.
Network Spotlight: Maudsley Parents

Maudsley Parents is dedicated to supporting families who are helping a child overcome an eating disorder. Founded in 2006, we are a volunteer organization of parents who have helped their children recover from eating disorders through the use of Family-Based Treatment (FBT). Also known as the Maudsley approach, FBT is an evidence-based treatment that many believe should be the first-line treatment for children and teens with eating disorders. Our mission is to offer hope and help to other families confronting these illnesses. We offer information on eating disorders and Family-Based Treatment via our website www.maudsleyparents.org, along with family stories of recovery, supportive parent-to-parent advice, a collection of helpful videos and a treatment provider list.

Maudsley Parents has been an invaluable resource for thousands of families in over 100 countries seeking guidance on how best to help their children through the treatment process. Along with practical tips and a popular recipe section, our website includes a helpful “Ask the Expert Index,” where we’ve collected the most commonly asked parent questions, along with responses from a panel of leading experts and advisory board members.

Maudsley Parents also publishes quarterly newsletters highlighting recent events and news from the eating disorders community. Finally, Maudsley Parents organizes annual conferences and FBT workshops where we bring parents, clinicians and treatment providers together to hear from panels of eating disorders experts on the most current research within the field.

Are you a Maudsley Parent? Visit our site at www.maudsleyparents.org and learn more about becoming one today.
Join the NEDA Forums!

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, Eating Recovery Center, Monte Nido and Affiliates, 4Girls Foundation

**SILVER:** Remuda Ranch at the Meadows, Rogers Memorial Hospital

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

**BRONZE:** Canopy Cove, Center for Change, Columbus Park Collaborative, CRC Health Group, Fairwinds Treatment Center, Laureate Eating Disorders Program, Oliver-Pyatt Centers, Rosewood Centers for Eating Disorders, Veritas Collaborative

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**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.

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**Share Your Thoughts**

If you have an idea for an article, a question you’d like us to research, or would simply like to share your story — we’d love to have you participate! Email us at pffnetwork@myneda.org. Be sure to include your full name, email address, and daytime phone numbers so we can contact you.

**Making Connections** is by parents, family and friends for parents, family and friends!

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**Information & Referral**

**HELPLINE**

800.931.2237

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