

Transcript for Episode 402: “Eating Disorders: What We’re Not Talking About Is Killing Us”

Please note: This transcript has been lightly edited to remove filler words or sounds.

JOHANNA KANDEL: So currently in the US, about 28.8 million Americans will experience an eating disorder in their lifetime. And actually, every 52 minutes someone will die as a direct result of their eating disorder in this country. It is the second highest lethality rate of all psychiatric disorders just under opioid addiction.

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LINDSAY KOLSCH: You’re listening to the To Write Love on Her Arms podcast, a show about mental health and the things that make us human. Each episode we’ll be talking about the things that can often feel hard to talk about, like depression, addiction, self-injury, and suicide. We’ll be sharing stories and exploring big themes like hope, healing, and recovery.

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CHAD: It’s been noted everywhere from etiquette manuals to sitcoms that there are certain topics of conversation that ought not be discussed at the dinner table. Religion, politics, and money are the big three, but everything else is understood as fair game. Everything else is on the table. But for so many people, what is literally on the table can be among the most difficult topics to discuss. And so the most needed conversations may never happen. I’m referring to food—our relationship to it and the silence that steers too much of the narrative that prevents people who live with an eating disorder from seeking the help that they deserve.

According to the National Eating Disorders Association, nearly 30 million people in the US reportedly experience a clinically significant eating disorder at some point in their lives. Eating disorders are among the deadliest mental illnesses, second only to opioid overdose. It has been found that around 26% of people with eating disorders attempt suicide. EDs can show up in a number of ways ranging from anorexia nervosa, bulimia nervosa, binge eating disorder, orthorexia, or even as what’s called an Eating Disorder Not Otherwise Specified (or EDNOS) which encompasses those who do not meet the more strict criteria for a specific diagnosis but do indeed have a significant eating disorder.

In today’s episode, we’ll be joined by four different folks. All of whom have experienced varying degrees of this mental health challenge in their day-to-day and even professional lives. First, we’re going to talk to Johanna Kandel, the CEO and founder of The Alliance for Eating Disorders Awareness—a nonprofit dedicated to the outreach, education, early intervention, support, and advocacy for all eating disorders. With Johanna’s help and expertise, we’ll explore the difference between eating disorders and disordered eating, the most common ways EDs present, and what treatment and recovery can look like. I’m your host, Chad Moses. Let’s get started.

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CHAD: Johanna, thank you so much for joining us. Would you mind just sharing a little bit about who you are?

JOHANNA: Sure, absolutely. I am the founder and CEO of the Alliance for Eating Disorders Awareness. I started the Alliance a little over 20 years ago 100% because of my personal experience with my eating disorder. I am someone of lived experience. I consider myself a very non-discriminatory eating disordered human. You name it, and I did it basically. And one thing that I learned along the way is that despite a lot of folks' assumptions that eating disorders are disorders of choice and vanity, they're not. They are biopsychosocial illnesses that have the second highest lethality rate of all psychiatric disorders. And I will tell you, I was born and raised in South Florida. I never looked out the window and said, "Hey, it's a beautiful day in sunny West Palm Beach, Florida. I think I'm going to have anorexia nervosa today." For me, it was this perfect storm of genetics, co-occurring mental health, anxiety, depression, perfectionism. I was also a professional ballet dancer, and it all just came together. Before I knew it, I went on a healthy eating plan wanting to do better. You know that quote that folks say: "The path to hell is filled with good intentions." Well, that is my story. And because of the genetics and everything else, before I knew it, my very casual diet turned into an almost deadly 10 year experience with my eating disorder. And when I started the journey of recovery, the one thing that I wanted to do is to speak to that seventh grade me who felt like she didn't deserve to take up space. And really to survive and to create conversations and smash the stigma surrounding this very real psychiatric disorder.

CHAD: You mentioned just there in the intro your desire to smash stigma. For those that have been tracking with To Write Love for any amount of time, you know that to us, stigma is whenever silence is the loudest voice in the conversation. Stigma allows our assumptions to become absolutes in how we interact with a litany of mental health challenges. So with that, we feel like it is important to define and to really draw some clear lines around what it is we're talking about. I'm wondering if you could help us, from the get-go, parse the difference between an eating disorder and what would be considered disordered eating?

JOHANNA: Disordered eating really includes unhealthy food and body behaviors that typically can start for the purpose of weight loss, health promotion, or feeling better. And eating disorders are severe and life-threatening brain-based illnesses. So that's really the difference between them. And I will tell you the way that I really was able to differentiate between what for me was disordered eating and an eating disorder is when I could no longer function. When you're experiencing an eating disorder—and I'm sure it's the first thing you think of every morning, it's the last thing you think of every night, it's every other thought in between—eating disorders are maladaptive coping mechanisms. They make sense. They are very deadly, but they make sense. And with disordered eating, you can still maintain some semblance of "normalcy" if there is such a thing. But an eating disorder, it really impairs each and every part of your essence, of your being.

CHAD: That brings me to another piece of the question. So often, our definitions are handed down to us. The way that we understand mental health challenges and eating disorders, it's been gifted to us, maybe through a family of origin, but probably more likely through pop-culture. I'm wondering if you would be able to take a step back in the timeline and kind of walk through what your initial education of eating disorders looked like. Who were the first people, or what were the first sources to inform you on what this behavior was?

JOHANNA: One thing that I have so much gratitude for living in this moment of 2021 is, I think our definitions of who develops eating disorders and what they look like has started to shift. Because we know eating disorders do not discriminate between age, gender, race, class, body shape and size, sexual orientation. They are an equal opportunist. Truly. However, there is that archaic stereotype that I feel like so many of us have been gifted this information, handed down in a sense. That eating disorders only affect females or female identifying folks. They typically happen to young individuals. They affect Caucasian humans. They affect folks that are middle to upper class. And because of that, I think a lot of people still hold those values and still believe in that. So much that it's permeated, in actuality, our healthcare system. Less than 20% of all health care providers are given any information on eating disorders and who they affect. So they're still forward facing. And when people that don't fit that specific mold will go and seek help and not look like they have an eating disorder, oftentimes, they're not diagnosed. For example, you know, when we think eating disorders, typically what comes to mind is someone that is very underweight or very small bodied, when we know that more likely than not, individuals that are experiencing eating disorders are going to be of average weight to overweight. So I think that even knowing something like that will change the conversation. Because the truth of the matter is, when I was experiencing my eating disorder, the only people that I knew that had eating disorders were Karen Carpenter. I say that sometimes and people ask me who that is and I feel very old, I will be honest with you. Or Tracy Gold who was on a show called *Growing Pains* when I was growing up. What I think is extraordinary now is that you have so many different people that are coming out and sharing that they have experienced an eating disorder as well. So again, it's chipping away at that archaic idea of who develops eating disorders and again what they look like.

CHAD: Thank you for discussing a little bit about the who. I'm wondering if you could also address *what* of eating disorders. What are the most prevalent eating disorders? And what's the most common way that they present themselves?

JOHANNA: Yeah, absolutely. I think folks are most familiar with anorexia nervosa, which is when you definitely restrict your food, you have a distorted body image, and you have an intense fear of gaining weight. That's probably the one that comes to mind when folks say eating disorders. And then there's also bulimia nervosa, when individuals will engage in cycles of binge eating and purging. And just as a reminder—I apologize for forgetting a little bit more graphic—but purging is not just self-induced vomiting. Individuals purge through means of laxatives, diuretics, exercise, anything that will “rid” your body of food that was taken in. Also there's binge eating disorder, which is binge eating without the compensatory behavior of purging. What a lot of people don't know is that binge eating is actually the most common eating disorder out there. In

fact, more individuals will experience binge eating disorders than anorexia and bulimia nervosa combined times three. So binge eating disorder is really our most common eating disorder. We also have two other types of eating disorders that individuals experience. One is called ARFID, which is Avoidant and Restrictive Food Intake Disorder. And that's a little different than like anorexia nervosa, bulimia nervosa, and binge eating disorder, because there is no distorted body image. These are disorders that are really centered around the anxiety around eating food. For example, if someone has choked on some food and then they become so fearful of choking again, so therefore they stop eating. Or they'll stop eating very many types of food. You'll also see it in individuals that might have picky eating, for example, or have issues with texture or color. So ARFID is actually something that we're seeing more and more specifically around younger children, specifically in male or male identifying kids, but can absolutely stay throughout the duration of childhood and adulthood. And some people develop ARFID in adulthood as well. And the last eating disorder that I just wanted to throw in there is called OSFED, which is Other Specified Feeding or Eating Disorder. And that's things like atypical anorexia, which is maybe where they're restricting, they have the intense fear of gaining weight, that disordered body image, but they might not be in a low-weight body. But it can be just as dangerous as someone who is in a lower-weight body.

CHAD: What you just described there, when I first entered the world of mental health advocacy, several of those definitions, several of those diagnoses, they were not part of the common vernacular. This is something that is continuing to grow. Grow with research, grow with clinicians, grow with self-reporting of behaviors. And these are definitions that have been reliant on years of research, years of treatment, years of recovery. And what we are doing in this conversation is lifting the veil a little bit, saying these are fair topics of conversation so that you don't have to go through life curious if you or someone you love has disordered eating or an eating disorder. But you can use your lived experience to talk to a professional, talk to a clinician, and see if there are pieces of your life that warrant further investigation.

JOHANNA: Absolutely. I think stigma is often the determinant of individuals being able to get access to care. Eating disorders, again, are not disorders of choice. And if you are diagnosed with an eating disorder, it's not who you are. It's not an identifier. It's what you're going through. And I've always been in the belief system that mental health is on par, it's the same as physical health. And we talk about it so often in our support groups, when we have presentations, that you would never tell someone with diabetes or cancer to just fix themselves. And if they tried hard enough, or if they had the willpower, they could fix it. It's the same thing when you're dealing with mental illness. When you're dealing with eating disorders, when you're dealing with depression, anxiety, substance use disorders. It's not a character flaw if you need access to care. So please know that you are not your disease. It's not who you are, it's what you're going through. And that we all deserve access to care. Even though sometimes it can be very hard to get access to care, that doesn't diminish that treatment is a necessity, it's not a luxury. It should not be a luxury. And it's not something that we should be able to fix on our own.

CHAD:: That's it right there. We could probably just throw the last 45 seconds on repeat, and that would be the mantra, that would be the podcast, that would be the take-home. And

Johanna, I'm just so thankful that you're here. Because not only are you proof that people care, you're not only proof that people on a cognitive level care and desire to make people less alone, but you are someone that has walked this road of diagnosis, of recovery, of finding what steps to take in order to reclaim bits of our life that we thought we had sacrificed and thought that we have given up. We know that there's over seven billion people on the planet. Thereby there's going to be over seven billion different pathways of recovery, seven billion different ways that recovery will manifest. But I'm wondering if you could offer any guidance of, what's healing And what recovery from an eating disorder can look like?

JOHANNA: First and foremost, something that has always made me laugh and also I understood at the same time is that there's no definition of recovery when it comes to eating disorder recovery, when it comes to substance use recovery. There's not one definition. And I think, to your words exactly, is that recovery looks different for many, many people. In the field of eating disorders there are some schools of thought that believe that you will always be in recovery or remission, or you'll always be recovering. And then there's a school of thought that says you can be recovered from your eating disorder. That's what feels authentic and genuine to me. I consider myself recovered from my eating disorder. Now, I am very careful that I don't use the word cured because I still have the genetics that helped create that perfect storm, I still experience anxiety. I still have perfectionistic personality traits. However, over the years in my recovery, I've been given so many helpful tools to sort of counteract the maladaptive coping techniques that the eating disorder played a part in my recovery. And so, for me, recovery means freedom. My eating disorder is not at the proverbial table anymore. It's not at the dinner table. It's not at the negotiating table. It's not the first thing that I think of every morning, and it's not the last thing I think of every night. In fact, it's really not my struggle anymore. Now, I talk about it 10 hours a day because of what I do for a living, but it's not something that I experience. And so for those of you who are listening that are in the struggle, that are in the battle, please know that you're seen, that you are heard, and that you are not alone. I also want to tell you that you're not the exception to the rule. I know that so often people will believe that, "Oh, yeah, everyone else can do it. That's great for everyone else, but not me." And to that I typically say to the individuals that I have an opportunity to work with and walk alongside is, "You know, what makes you so damn special?" We all deserve access to care, we all deserve living a life beyond our eating disorder. Please know that you're not meant to do this alone. And I will tell you, one of my favorite things to say is that you do not recover to utopia, you recover to life. Life is good, life is shitty, and everything in between. Recovery is the absolute hardest thing that I ever did. And it's painful, it's overwhelming, it makes you want to give up 25 million times during the day. You will trip and fall because it's not an abstinence-based recovery. But when you do trip and fall, pick yourself up, dust yourself off and keep on moving. Because I'm not a unicorn. There are many of us out there that are completely living beyond their eating disorders. And you deserve to do that too, one million percent. And I think that, for me and for so many others that have walked this walk, the disorder has pretty much told you that you should be able to do this on your own. And that, you know, if you wanted it enough, you could do it on your own. But it's literally denying you one of the basic needs. I have a lot of friends that are in recovery from drugs and from alcohol, and recovery is different for different things. Keeping in mind my best friend who's abstinent from drugs and alcohol, who's in recovery, he said to me very seriously, "I

know that for me, I don't ever have to take a drink again. I don't ever have to pick up drugs again." He said, "I just don't know how you face your 'drug of choice' three to six times a day, every single day." And I said, "It doesn't make it harder, it just make it different. It's just a different recovery." It's a more moderative recovery where, in a sense, the "medicine" is the thing that you fear the most. Because even if you're experiencing binge eating disorder, where you're taking in large amounts of food in a short period of time, you're still malnourished. There's still a level of malnourishment because the number one behavior that leads to bingeing is restricting. So individuals that will have binge eating disorder will go through periods of restricting, and then they'll binge eat. So when you start to recover, you really have to trust and lean into a specialized team, which is why I love how you talked about having this team of professionals. And I would even take it a step up as having a team of specialized in the treatment of eating disorders professionals that would sit there and help you navigate this journey. Because it doesn't matter what eating disorder you're experiencing, there is this fear of the actual thing that is probably going to help you the most. So even though eating disorders are not about the food, it's the mechanism in which the disorder plays with.

CHAD: Obviously, we're having this conversation with a sense of urgency. We know that there is a lot at stake. You mentioned in your introduction that eating disorders represent one of the highest lethality and mortality rates of any mental illness. Would you be able to draw out why that is? What plays into that high rate of mortality? And what do treatment options look like to combat that lethality rate?

JOHANNA: So currently in the US, about 28.8 million Americans will experience an eating disorder in their lifetime. And actually, every 52 minutes someone will die as a direct result of their eating disorder in this country. It has the second highest lethality rate of all psychiatric disorders just under opioid addiction. And the reason why is because eating disorders really have this interplay with both mental and physical. So you'll see individuals that will unfortunately lose their battle because of heart failure or cardiac arrest or organ failure. And we also see that there is an extraordinarily high level of death by suicide as well with eating disorders. In fact, if there is an eating disorder and a substance use disorder together, you actually have the highest rate of suicide amongst all individuals. So that's really where you see it play out. And unfortunately, something that I have been so passionate about since I founded the organization over two decades ago, is that when someone loses their battle to their eating disorder, they don't die because of their eating disorder, they die because of cardiac arrest or they die by suicide. And even something like working with coroners offices to make sure that the word eating disorder is on their death certificate. Because for me and our population, it just shows that we know that eating disorders kill, and the more attention and the more awareness we can bring to it, the more funding we can get around research so that all folks with eating disorders can get awareness, intervention, and treatment. So that's really what you see and why you have that very high mortality rate. And then on the flip side of treatment, what's really amazing is that there are so many treatment providers now that specialize in the treatment of eating disorders. There are so many higher levels of care—everything from an inpatient unit all the way down to intensive outpatient. I would say to our listeners, be very careful as you do research and make sure that the clinician and/or treatment provider that you are going to see actually does have a

specialty in eating disorders because for example, you would never go to an eye doctor if you had a heart issue. You want to make sure that you don't go to someone that is not specialized in the treatment of eating disorders. Because it is a separate set of skills and you deserve all the access and all the specialization that you can.

CHAD: I want you to plug your own work for a second here. Would you mind sharing a little bit about your work at the Alliance for Eating Disorders Awareness?

JOHANNA: So the Alliance for Eating Disorders Awareness is really built a lot on my personal experience of what went wrong and what could have been helpful. So some of the things that we do, for example, is on the referral end. We've created the largest and inclusive referral database system for eating disorders, actually across the globe. It's called [FindEDHelp.com](https://www.findedhelp.com). It is a website and an app, and you can go in there and search by zip code, by insurance, by level of care, to help connect you to really good resources that will help you on your journey to recovery. The other thing that was so important for me is to be in a space where people know your language, speak your words, where you can be in a space where you can say me too, or be seen and heard. And so we have a plethora of, in non-pandemic times, in-person, therapist-led eating disorder support groups. We have 21 across the country. But currently they are all virtual. And so they are for all humans that experience eating disorders that are 18 and older. We have two general eating disorder support groups. We have one eating disorder support group for the LGBTQ community. And we have two support groups for moms and for all loved ones of people who are struggling with eating disorders. And more than anything, we are here to walk next to you on your journey to recovery. We're here to help you every step of the way. And you can learn more at [AllianceforEatingDisorders.com](https://www.allianceforeatingdisorders.com) or call us at 866-662-1235.

CHAD: You spoke a little bit to the times that we're currently living through, and to timestamp this, it is 2021. I'm sure some of us would still call it March 300th of 2020. But with these diagnoses with this topic of eating disorders, that can be isolating in and of itself. And we know that this is a behavior that manifests and really takes root when you are isolated, when you are removing yourself from a lot of social interaction. I'm wondering if you have any added wisdom for people who may be struggling with their relationship with food, maybe struggling with their relationship with disordered eating and eating disorders, specifically during this time of social and physical distancing?

JOHANNA: Yeah, I mean March 300th has definitely taken a toll on all of us. And unfortunately, we know that eating disorders are never in that car alone. It's typically anxiety, depression, trauma, all that stuff. And we know as a collective group, our anxiety has never been so high or depression has never been so high. So really validating and realizing that if all you've done through this pandemic is survived, you've done a great job. This is not a vacation, you're surviving a pandemic. With that being said, we are seeing the highest level of acuties that we've ever seen, with individuals having eating disorders. The one thing that I will remind everyone is that we might be physically distanced, that does not mean that we have to be socially isolated. I think a gift of living in 2021, 2020 is just that ability to have different touch points virtually. The

more that we can be accountable and vulnerable, in a sense, to say, “Hey, will you meet me online at this time? Or maybe if you're able to take a walk?” Obviously being safe together, if you're able to do that. But really pushing yourself because I will tell you like, these are all of the things that make up that storm of exacerbating eating disorders, and we need to be very preemptive and aware.

CHAD: One thing I love about this conversation and this podcast is that there is a very tangible next step to take. And this is again a t-ball setup for you, Johanna. But would you mind sharing a little bit about what's coming up on your calendar with Not One More weekend?

JOHANNA: So Not One More weekend is a fully virtual three-day event that the Alliance is hosting to really bring all humans together. It's over the weekend of February 26th-28th. And it's built on the pillars of what the Alliance does: Help, Support, and Recovery. And so Friday, February 26, is our National Day of Help, where we're urging people to pick up the phone, to go online, to know that there is no shame. We need to break through that stigma that help is available and recovery as possible. And February 27, which is our Saturday event, is our National Day of Support, where from 8am EST to midnight, every hour on the hour, we're going to have support groups for 16 straight hours. And then Sunday, February 28, is our National Day of Recovery, where we're going to really let folks and ask folks to live their life beyond their eating disorders, to raise awareness about eating disorders, and to join us at six o'clock pm EST for our Rally for Recovery, so that we all come together, and so that not one more moment is lost to this insidious disease and not one more life is stolen.

CHAD: Excellent. I'm curious if you wouldn't mind sharing some other resources that you've found helpful. Maybe it's through song or maybe it's a book that you've found to be super helpful in taking some steps towards recovery.

JOHANNA: I'm super into podcasts right now. I'm a huge fan of Brene Brown. I'm a huge fan of Jameela Jamil and her podcast “I Weigh” that has been very helpful. As far as poems, one of my most favorite people in the world is Morgan Harper Nichols, and her poetry. And more than anything, whatever brings you joy, whatever gives you breath, that's where you should go. And also on the flip side of that, be very careful of what you're looking at and what you're consuming. So pay attention to who you're following on social media. If they're not making you feel good during this time, unfollow them, this is the time to curate your feed, and to only fill it with things that fill up your cup and not make you feel bad.

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CHAD: Next up we'll be talking to Harry Allen. Harry hails from England and in 2017, he traveled to the states to join our team for a season as an intern. As a cisgender male, Harry shares his experience with facing the lie that eating disorders are a mental illness only women can face, and how things like stigma and toxic masculinity impacted his journey. We thought it was so important to include your voice in this conversation, because for so long topics of eating disorders and disordered eating centered pretty much exclusively on the female experience. On

how this was affecting women, young women, old women, but it was focused around women. And for a long time, that was by design. It wasn't until recent editions of the DSM that clinicians were able to even allow a male to be diagnosed with an eating disorder. Fortunately, we're in an age where we can look kind of beyond gender binaries, where we can investigate that this can be a problem, and it can affect people regardless of gender presentation and identities. So that being a little bit background to the question, how has the stigma that eating disorders are gender specific, impacted you and your life?

HARRY ALLEN: I'd guess the biggest impact would be just a kind of delay in recognizing what was going on for me. And also a disqualification from me thinking that it's something that I could struggle with. As you said, for a long time, even clinically, it was only something we talked about for women. As far as the people around me and people that I knew, it certainly wasn't something that looked like exists or was something that was talked about. So I guess, for contextualizing I would look to films or TV or the media or whatever it was. I suppose not only would that be just women where that topic was explored, but it would also even then be explored in a really kind of narrow way. And even my sort of experience with an eating disorder, not only did it not fit the sort of gender binary, but also didn't really fit the experience that was being presented in films and TV where it was one very sort of strict, limited, narrow, disordered eating disorder looks like. So I think on both accounts, having that disqualification just made it difficult for me to recognize or come to terms with what was going on. I'd kind of flip between saying that there was nothing going on, I couldn't possibly have an eating disorder, to deciding that I maybe did, but I was the only guy in the entire world who had this issue. Really, it felt like there can't possibly be another guy that is struggling in this way. At the same time, I guess no one thinks that they're special enough to be like the exception to the rule. So I think that largely comes down to the sort of the issue of gender and the idea that actually it's only a certain spectrum of gender that can really struggle in this way.

CHAD: I'm wondering if you would be able to unpack a little bit about the role of toxic masculinity and how that impacted your experience?

HARRY: The unique complication, I guess, with my story as far as it relates to masculinity and toxic masculinity, is at the time of which this was maybe at its worst, let's say, from the ages of around 13 to 16, I was also a young guy who was gay, who was not out about that. So I think, as well as difficulties in disordered eating, I also had this huge fear of that part of me being exposed, and all of my energy and all of my time would be spent trying to hide those parts of me that felt sort of feminine, or that felt like people would be able to see through. I guess the complication with that when it comes to my eating disorder was that that was something that for me felt hugely feminine, because that's how it had been sort of contextualized for me. That this was something that only women struggled with. At this point I'm pretty comfortable with who I am. And I don't as much feel the need to screen my behavior through a lens of is this masculine or is this feminine? In that regard, I'm pretty content and secure with who I am and what I like and how I behave. I'll admit to some hesitation still around just hanging out with a group of guys. There is still this part of me that wants to put up a bit of defense mechanism, whether it's like playing up certain parts of my character.

CHAD: I think that's what makes the topic of toxic masculinity so insidious. That you don't have to feel actively bullied in order to be negatively affected by that culture. You kind of mentioned earlier that your earliest education in eating disorders was kind of through pop culture. And you were absorbing through TV, through the media, through movies through literature that this is a topic that affects girls because you were not given proof of the opposite side of it. So that was an early onset toxic masculinity that kept you, from what I gather, silent for longer than you had to be because you were told this is an issue that is experienced by only women. And that's something that I experienced as well with my journey of self-injury, I remember reading a book by the leading researcher on self-injurious behavior, and in the introduction of the book, it said, the self-harmer is an adolescent female. And I'm reading this as a college aged male and thinking, "Oh, God, where do I fit into this?" Like, I was effectively told I was not allowed to feel this, I was not allowed to experience this. And I know that you shared with us that the first person you shared your eating disorder with was your best friend, Oakley. You decided to reach out and share with Oakley, not because you believed that Oakley would relate on a profound level to the topic at hand, but because you trusted in the character of that friendship. Do you recall what your hope was in sharing this important but previously unshared nugget, this chapter of your life? What did you hope that the outcome of this conversation would be?

HARRY: The hope was to be able to share this part of me, and for it to be listened to and heard and not questioned. For someone to not say, "Are you sure? Because like, I don't know loads about eating disorders, but from what I know, I don't think you can have one." And in my head before I told him, I was like, there's a huge possibility that that could be the response. There's a huge risk that he could really not understand this. As I said before, there were huge times where I thought, "Oh, this can't really be something I'm going through." So at the time, it felt like it wouldn't have been at all surprising had he just said, "Ah, yeah. I'm not sure about that, mate. That's not something that I think can be going on for you." But my hope was just to be heard and not questioned, and maybe to have a little bit more reassurance for myself that this was something that was happening for me, that I wasn't just trying to make my life more difficult or more painful or more complicated, but actually, there was something that was really happening that could be explored and could be made better.

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LINDSAY KOLSCH: To Write Love on Her Arms has always sold t-shirts as a way to help fund our mission. But the products we sell in our store do so much more than help us financially. Each piece of merchandise is a conversation starter. It spreads the TWLOHA message to someone who may not have found out about us otherwise. So whether you wear our shirts, hats, hoodies, or rain jackets, we want to thank you for bringing a message of hope and help wherever you go. To see our latest styles, head to store.twloha.com now and use the promo code `PODCAST20` to receive 20% off your entire order.

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CHAD: To continue the discussion, we have Kaitlyn Mueller up next. She's a former TWLOHA intern, current social work student—who was just accepted into her MSW graduate program—and she is also someone who, starting at the age of 14, has experienced anorexia, along with bingeing and purging. We'll start the conversation by hearing how Kaitlyn personally defines an eating disorder and how it has presented itself in her life so far.

KAITLYN MUELLER: To me an eating disorder is, to put it simply, an unhealthy relationship with food in your body. But oftentimes, it's not that simple. I would say that eating disorders don't exist in a vacuum. A lot of times, there's underlying issues that accompany it, and food and weight are the easiest things to control in a lot of situations. And that's where a lot of people kind of find themselves clinging to as a coping mechanism when they're dealing with other things in their lives. I first developed an eating disorder when I was 14. And I am 26 now, so I've been in solid recovery for a while. But for me, it looked like anorexia binge purge subtype, which is restricting along with purging, and took a lot of years and an incredible amount of hard work of up and down treatment.

CHAD:: So on our last episode, we talked about recovery, we talked about relapse, we talked about resolutions, on doing better, and we talked a lot about the role of community. We talked about the role of trying again and having an adequate support network. And we feel that speaking honestly about these issues is gonna be a wrecking ball to that stigma. And you shared with us that after nearly two years of being in recovery from anorexia, that you found yourself in the midst of a relapse in 2018. How did that transpire? And how did you find ways to move forward with your recovery after that?

KAITLYN: In 2018, I had just moved. I transferred to the school I'm at now. I didn't know anyone. And I was coming off of six months of a difficult living situation with my family. But I was optimistic going into this new journey ahead for me. And it's pretty well known in the treatment and recovery world that transitions are major triggers for eating disorders. But I was very naive going into this thinking, I have two years of recovery under my belt, I've got this, nothing can tear me down. And I was humbled very quickly with that. I think the loneliness of being in a new place and not knowing anyone really impacted me. And it was kind of an old coping mechanism that I had in my back pocket for, "I'm stressed. Well, okay, I'm just gonna skip this meal or something." And it's a very slippery slope when you do kind of stray off your recovery path. And, before I knew it, I was not in a very good place. I will say that getting back on track, initially, wasn't really my idea. I was seeing a treatment team outpatient, who I'd seen for a long time, and I was also seeing some providers through my school, who essentially told me, "You can't return at the end of the semester if you don't get healthier." Which was a very big wake up call to me, because with any eating disorder. It's strange because you never feel like you're sick enough. Which is so strange, I think, for other people to hear, because with any other illness you have, you don't wait to get sicker before you get help. If you have the flu, or you're having an allergic reaction to something, you go, "Okay, I need to get treatment and get help before things get worse." But in my experience, with an eating disorder, you feel like you're not worthy of that help until you get sicker and sicker till you lose more weight, or using behaviors x many times,

things like that. So getting that push into getting more help, was really what I needed at that time.

CHAD: You said that geographic transition is part of the context in this part of your story. I'm wondering when you were reaching out for help, this wasn't your first time reaching out for help. Were you able to lean on some previous support networks, some previous therapist relationships, or was this kind of starting all over again with recovery?

KAITLYN: I was able to lean on some support I had, thankfully. Primarily with the therapist and dietitian I was seeking. But when it came to more social support or family support, I felt so much shame for being back in that spot, where I did not tell anyone what was happening, essentially, until I had to. But I think I was so in that shame in thinking, "I should be farther than this. I shouldn't be back here." Just beating myself up that I wouldn't accept any help or support that people tried to offer me.

CHAD: So often we hear from people who live with eating disorders and disordered eating, they talk a lot about this theme of perception. About what is true and what you believe to be true, what is a falsehood and what you believe to be false. So I'm wondering if you could share some wisdom that you've gained in that. How has identifying trues and lies played a role in your healing and recovery?

KAITLYN: Truths, for a long time, like I said, they were kind of just in one ear and out the other. But I worked on repeating them. My mirrors in every house I've lived in since then, are covered in affirmations, things like that where I'm reading them and physically seeing them. And I think having others remind me of those truths really helped too. When I was in residential treatment, I had some amazing therapists who I bared my soul to and talked about a few things that I was ashamed of and disgusted with myself for. Just seeing that these people who are meeting me at the lowest of the low, I am at the bottom of the barrel. If they are telling me that I'm more than what happened to me, or that there's more to my life than just cycling in and out of restricting and purging, it's kind of a bit of a wake up call.

CHAD: I've been able to see firsthand how you have encouraged others. How you have passed on some of those truths to other people to hold on to. One particular moment I'd love to go back to is at Electric Forest. The folks there have allowed us to do this really awesome art installation for the past couple years that we call the Barrier Project. We invite people to write down words or phrases or symbols or paintings on a tile wall. Things that represent barriers that come between themselves and true community, or themselves and a sense of truth, or really just themselves and a greater world that's going on around them. So we're collecting these paintings, these pictures, these words, for the entire week, eventually, just to break it all down. To dismantle it piece by piece and pass it on to someone else as a reminder that the barriers in our lives can and will come down. So when you were volunteering with us a couple years back, you wrote something super poignant. It stuck with me. It's a picture that still exists in the office, but you wrote down on a tile, "Recovery is scary, but so is living with an eating disorder." I'm

wondering if you could transport yourself back to that festival, and would you be able to share what that phrase meant to you then? And if it means anything different now?

KAITLYN: I definitely remember that moment. Making the tile, when we were tearing it down, everything. During that time, when I was helping at Electric Forest, I was in a very weird spot in between treatment days, and I was at war with myself. Do I want to continue on in recovery? Do the healthy thing, which is scary as all hell? Or do I want to just go back to what's comfortable, which is also scary. And it took a lot of questioning myself and really looking inside. And kind of weighing those fears back and forth with recovery. I knew that would be the scariness of my changing body. Simply gaining weight made me feel physically nauseous with fear. And I was convinced that I could not do it. But then I thought if I stick with my eating disorder, what is my life going to look like? I'm not going to be able to finish school, or maybe have a family someday or I'll just be cycling in and out instead of having fun with friends, graduating, starting my life. I could be crying over a piece of pizza. So I had to really dig deep and choose which fear could be worth facing. And I did choose the facing recovery fear. But thinking about what my life could look like right now, if I had not chosen to go forward in recovery seems just heartbreaking. So I'm very glad that there were two scary paths ahead of me, but I chose the one that was very beneficial in the end.

CHAD: Recovery is scary, because recovery means honesty. Recovery means a shift in perspective. Recovery means vulnerability. For you and for anyone else listening, just know that that vulnerability and that honesty and that shifting of perspective pays dividends. It will have a way of bringing people together that will tear down those walls that keep us separate. Now, I'd like to touch just briefly on a myth that comes along with conversations of eating disorders. I think, not unique among other mental health challenges, people have a mental picture of what someone looks like or the stereotypical person that struggles with issue X, Y, or Z. So often people have to rely on blogs or rumors or pop culture to inform them on what mental health looks like, what eating disorders look like. There's just so much that gets clouded. So much truth that gets kicked to the side for just the easy stereotypes. So when it comes to eating disorders, there's often this stigma that it's all about being thin or looking a certain way. What are some of the nuances that people don't see about eating disorders and how they develop?

KAITLYN: There definitely is a smidgen of truth to the wanting to be thin, but that is just the tip of the iceberg. And eating disorders can stem from anything, you know. Sometimes people start a diet and then get too carried away with it, or they use it as a coping mechanism. But no one with an eating disorder out there is doing it just to lose weight. I remember growing up, my only education on eating disorders was in health classes where they would show either a Lifetime movie from the late 90s or Gossip magazine pictures. Certain socialites and celebrities who were scary, skinny, and that's what I thought anorexia looked like for the longest time. And it really kind of caused me, when I was beginning to struggle, to not believe I was struggling at all. Because I thought, "Oh, I'm not this thin or I'm not in the hospital or XYZ." And I think those myths really play a harmful role in people who are struggling. Because with those stereotypes, so many people aren't represented and seen, and they don't think they have a problem. Like I said, I think my eating disorder developed from... I had a really extensive history of sexual

abuse growing up and I was very anxious in temperament and kind of the perfect storm for an eating disorder. But I can't think of a time when I thought that, "Well, I just want to, you know, do this to lose some weight." It was definitely more of a punishment or control thing that manifested itself in, "Okay, I'm feeling super shitty about all these things in my life. I feel out of control. But I can control what I eat, or how much weight I lose." So while wanting to look a certain way, it's definitely what people see on the outside. It's just a cover up for the list of things that are actually going on.

CHAD: One last question I have for you, Kaitlyn. We know that people listen to this podcast from a number of different contexts. And I don't think it takes a ton of imagination to believe that there's someone listening in this moment that is struggling with an eating disorder. What would you care to share to that person right now?

KAITLYN: I would let them know that they are sick enough. That they don't have to reach some goal they have set or that society thinks they should look like or be doing behavior wise to get help. If you worry that you're sick enough, you are sick enough. And I would let them know that recovery is a long journey. It's definitely not the straightforward, the sunshine and rainbows. It takes a lot of hard work and a lot of being open and vulnerable and letting yourself lean on support systems, which can be hard. But you will discover that there are so many people out there who care about you and want you to do well. And they will help you realize that you are worthy of life and happiness. And so much more than worrying about food or body or punishing yourself. Recovery is possible.

[music playing]

CHAD: Last but not least, we're going to hear from Yentl Reynders. Yentl is also a former TWLOHA intern from Belgium, who has more recently discovered patterns of disordered eating in her life that involve episodes of bingeing. She'll tell us what a binge looks like for her, how diet culture has played a harmful role in her relationship with food and her body, and the steps she's trying to heal those relationships.

YENTL REYNDERS: I was never officially diagnosed with an eating disorder, but I have gone through a lot of periods in my life where I would try to lose weight, and then be very restrictive for a long period of time. Really limit my food intake for a few months, try to lose weight, but then eventually, sort of fall off the wagon, if you will, and go completely overboard. Then those kinds of periods are usually characterized by moments of bingeing episodes. My experience has been very much tinted by diet culture. So for those who are listening, because obviously you can't see me, I would say that I am objectively someone who is overweight. And I don't say that with like a negative connotation. That's just a fact and how I can describe myself. And I have always been since I was about six or seven years old. I've always been a bigger kid. Because of how our society functions, I was also constantly being reminded of the fact that I should at least be trying to make my body smaller and trying to fit in more, literally and figuratively. And so that has largely tinted my relationship with food. On the other hand, I was often spoiled with food. From a young age, my family kind of conditioned me to see food as comfort, and conditioned me to

learn that any kind of negative emotion could be treated with food. Right now, I would say that a binge, to me, because of that background, eating beyond the point where my body is actually giving me signal that I am satisfied, that I'm full, and then continuing to eat even though I am not even enjoying it anymore. But what really feels like a binge to me, or at least, I guess in the more strictly speaking way, is when I'm all by myself. In 99% of the cases, it's triggered by any kind of negative emotion or feeling of discomfort. And so that's usually what triggers it. I am very much a person with a sweet tooth, so my binges usually consist of anything that is cookie-like or chocolate-like or things like that. Or I could just literally eat a huge bowl of cereal just half an hour after having a perfectly satisfying dinner. Anything that is an amount of food that feels extremely uncomfortable physically, actually. And in general, I would say it's largely characterized by a feeling of being completely out of control, losing control.

CHAD: I think for most of society out there that this term binge, it carries a lot of different contexts. We're familiar with folks going off to college and being warned about binge drinking, we're very familiar with quarantine situations and lockdown situations where we tend to binge on media, whether that's our favorite TV show or our favorite movies. And then of course, there's this other aspect of our relationship with food. And you kind of mentioned a binge being something where moderation is out of the driver's seat. That it can turn into a control dynamic. I'm wondering, just as we continue to wrap our minds around the language of binge, if you'd be able to walk us through the life cycle of a binge. You mentioned something starting it through a trigger. But I'm wondering from the point that it starts, where does your mind go? Where does your head go?

YENTL: I would say it's mostly an autopilot situation. I feel completely out of control. It always feels like a very, very dark moment. You can be at a party with friends, eating snacks beyond the point of your body already giving you signals, like you've had enough. But when I'm all by myself, it is a much more dark feeling and context to be in. Whenever any kind of feeling triggers a bingeing episode for me, which is usually some kind of stress or anxiety caused by work or anything else, it usually doesn't even take more than 30 seconds before I am reaching for something. I think that sometimes people confuse binge eating or overeating with this uncontrollable desire for the food itself. But right now I'm at the point where I realized that when I am bingeing, I am actually deeply craving comfort or joy or someone to hug me, for example. But because my brain has been conditioned this way, I just almost automatically turn to food and quite often I will literally catch myself after a minute and be like, "Oh my God, I've done it again, and I hardly even realized what I was doing." It's as if my body's acting faster than how my mind is catching up to it or something.

CHAD: Recently, you wrote a blog. You called it "Learning to Love My Body in a Society That's Telling Me Not To." You write about feeling immense shame following a binge eating episode. While this emotion seems common, this emotion of shame, some folks also talk about how food itself acts as a comfort or a coping mechanism. We have language of soul food and comfort food, so I'm wondering, in your experience, do you associate both shame and comfort?

YENTL: Yeah, it's very complicated. Food is indeed actually something that we just need, very objectively speaking. But throughout our culture and our society and how we are raised, food also has a very emotional value. You eat food around your friends, you might have a dinner party, or you might go out to dinner with friends, or family or your loved ones. It makes sense that it is so much tied to a feeling of joy and comfort. One of my coaches actually recently asked me that question to put it into perspective. She was like, "Would you eat a bag of chips while you were sitting on the toilet? No." Many people would say no, because you link it to something cozy, you'll link it to maybe sitting on the couch with your partner, or watching a movie. But most people wouldn't associate it with sitting on the toilet. So it's so intrinsically linked to our social lives to our emotional lives. But then I guess just like with anything in life, the scale can also tip to a more negative experience of that. To get back to your more specific question, I do associate comfort with food as a whole, but I don't associate comfort with my binges. I see comfort as the underlying need that's escalating or manifesting itself through my binges. I recently talked to my counselor about this, and she explained it to me in a way that was very helpful and helped me to sort of put this into perspective and also put some kind of visualization to what's going on and this mechanism. And so right now, I actually talked about it as my inner child being neglected. I think everyone has an inner child that wants to experience joy and wants to feel happy and taken care of, wants to experience comfort, love, and support. But in my daily life on a daily basis, I am someone who's overly conscientious, overly perfectionist. I always take everything very seriously, I want to do everything well. And so I don't leave a lot of room in my daily life for pure unadulterated joy or carelessness or comfort for that inner child. And so usually, mostly, if I have a bingeing episode, it will happen in the evenings or at night. And my counselor was like, "You know, that's basically your inner child who is protesting at the end of the day. She needs something. And you've been conditioned in such a way that your solution to that looking for attention is to comfort it with food. It's a coping mechanism that is actually being harmful to your body because, of course, there are also healthy coping mechanisms."

CHAD: You mentioned that the majority of your episodes happen when you're in solitude, happen when you are by yourself. This is a time when people have been by themselves for longer and more frequently than ever before. So I'm wondering if you would be able to share perhaps some wisdom or some guardrails that you've been able to set up in this time where we're frequently alone?

YENTL: I talked about this with a counselor that was sort of towards the end of last year. She told me or advised me to make a very tangible list of things that I can turn to when I am struggling, or when I can feel a binge coming on. Things that will distract me and comfort me in a way that is more sustainable. I mean, that's obviously a very personal thing. But for me, that could range from putting on some music and dancing to my favorite songs or going out for a walk or cuddling my dog or calling up a friend and having a conversation with them. Because, and this is what another therapist has told me, when you think of this pattern of binge eating as a form of addiction, usually that impulse or that desire to do something, you need approximately just 20 minutes to distract yourself from that. This might sound very trivial, but I compare it to whenever I feel an urge to buy something that I don't need, which is another sort of mechanism that I tend to dabble in, I try to distract myself from that impulse by 20 minutes. And then if after

those 20 minutes, I am still feeling that craving or I would still want to do whatever it was that I wanted to do, then I could maybe give into it. But then I've made a very conscious decision to do so rather than sort of giving in to my emotions. And then I recently read a book, it's called Untamed by Glennon Doyle. I don't say this lightly because I read a lot of books, but this book changed my life. And I did a very, very practical thing that... I basically now have a sheet of paper hanging at eyesight level in my workspace. And it has a list with my red buttons and my reset buttons. And so red buttons are any kind of behavior that I tend to go for when I am feeling any kind of negative emotion, which is for me, of course, turning to a binge, or like I said, buying things that I don't need. But it could also be other things like mindlessly scrolling through social media or something. And then next to that is a list with my reset buttons, which are other things that I can turn to for comfort or joy, that are more sustainable and have a more positive impact. So like I said before, for me that's going for a walk or making a cup of tea or reading a chapter in a book, things like that. Those are some very practical things that I like to apply in my daily life right now. Another thing that I find helpful is just I tend to dabble in like mindfulness a little bit, and I try to meditate sometimes and I try to do some yoga here and there. Because another consequence of my disordered history with eating is that I am very much out of tune with what my body feels like or what my body is telling me or giving me signals about, and through yoga and mindfulness, I've been trying to become more in tune with that again. So how I would describe diet culture is basically this image that's being held up by popular media, but also, especially the fitness industry and weight loss companies. Our society tends to, or just does, prefer people who are conventionally thin. And that there is an entire industry making big bank off of this idea that we are all being told all day every day from the day that we're born that... I don't want to leave other genders out of the question, but I feel like as women specifically, you're being told to be as small as possible and as thin as possible. I guess, regardless of where you are on the gender spectrum, diet culture will have an impact on you, because I absolutely want to acknowledge that for men. For example, there's also a very big pressure to be as big as you possibly can be and be very muscular and be ripped. So I guess just focusing on my own experience as a woman I was constantly being told that my body was too big, and that I was always too much of everything. And never enough. There's a big industry of weight loss companies and fitness companies that are making a lot of money. They're literally capitalizing on that insecurity that's living in so many people. But focusing on a personal level, it's impacted my entire life. It's impacted my self image, my body image, the way I view myself. It has stolen so much precious time from my life. It's taken so much time from my life that should have been carefree and joyful and happy. And it made me sort of live as a wallflower that was very unhappy, very insecure, didn't believe in herself, in so many ways. And I feel like I'm still sort of reclaiming a lot of that time that I lost. I often think about, like what I would say to myself as a 10 year old or an 11 year old or 12 year old. I would just want to remind her, you don't have to feel like this. The way your body looks is not a reason for you to feel so unhappy, and you're worthy of being loved, even though your body is not fitting into the mold of what society has made out for you.

[music playing]

CHAD: If you or someone you know is experiencing an eating disorder, we hope we can remind you that your pain is valid, you are worthy of help, and healing is possible. You are human. Messy and whole, and capable of so many good things. We encourage you to use TWLOHA's [FIND HELP Tool](#) by going to twloha.com/findhelp to locate professional, affordable resources in your area. If you reside outside of the US, please browse our growing [International Resources database](#). You can also text TWLOHA to 741741 to be connected for free, 24/7 to a trained Crisis Text Line counselor. If it's encouragement or a listening ear that you need, email our team at info@twloha.com. For links to anything that was mentioned in this episode, please visit our show notes, there you'll find resources, event details, and related blogs, plus podcast and book recommendations from our guests. Thank you again to Johanna, Harry, Kaitlyn, and Yentl for sharing a bit of your story with us. And thank you for listening. We're glad you're here.

[music playing]

LINDSAY: We hope this episode has been a reminder that your story is important, you matter, and you're not alone.

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A big thank you to our friends at Copeland for the original music on this episode. The To Write Love on Her Arms podcast is produced by Rebecca Ebert. Music assistance was provided by James Likeness and Ben Tichenor.

I'm Lindsay Kolsch, thank you so much for listening.

To Write Love on Her Arms is a non-profit movement dedicated to presenting hope and finding help for people struggling with depression, addiction, self-injury, and suicide. TWLOHA exists to encourage, inform, inspire, and also to invest directly into treatment and recovery.