Introduction: A Touch of Anorexia

EXCERPT FROM ALMOST ANOREXIC, BY JENNIFER J. THOMAS, PH.D., HARVARD MEDICAL SCHOOL, AND JENNI SCHAEFER

“I wish I had just a touch of anorexia.”

A young woman whispered this to me after I shared my eating disorder recovery story in her school’s auditorium. She had waited patiently to talk with me until most of the crowd had dissipated into the humid evening and I was packing up my guitar.

“Jenni, I never had the problem you had,” she continued before I could respond. “I’ve struggled with overeating my entire life.” Her eyes darted quickly behind her to confirm that her next statement would be out of public earshot. Then she looked back up at me: “If only I had your willpower, I know I could lose this weight.”

***

You might have heard someone say this before. Or maybe you’ve said (or thought) something like it yourself. Countless people want to “eat better” and “lose a few pounds.” But, unlike what some may think, anorexia nervosa is not simply a diet gone wrong, and it has little to do with willpower. Why, then, does a serious, life-threatening illness with one of the highest mortality rates of any psychiatric disorder inspire such cachet?

A superficial response may lie in the current high rates of obesity. With one-third of adult Americans overweight and yet another third obese, the ability to achieve a low body weight by controlling food intake is exceedingly rare. But you’ve probably never heard people say they wished they had a touch of cancer or depression, two other illnesses that can also lead individuals to eat less and lose weight.

A not-so-obvious—but perhaps more accurate—explanation of anorexia’s pseudo-prestige lies in the definition of anorexia nervosa itself. The criteria listed in DSM-5, the Diagnostic and Statistical Manual of Mental Disorders (5th edition), which health care professionals use to diagnose psychiatric disorders, are quite strictly...
defined (appendix A). For some, meeting such select criteria can feel like earning a badge of honor. Of course, developing a life-threatening eating disorder is nothing of the sort. The hallmark feature of anorexia nervosa is a significantly low body weight due to self-imposed food restriction. Accompanied by an intense fear of fatness or relentless behavior that interferes with weight gain, anorexia is also characterized by body image disturbance. Not only do individuals with anorexia typically “feel fat” despite being thin; they may also base their self-worth almost entirely on their ability to control their eating and weight.

Anorexia is not just a cry for attention; it’s a serious mental illness caused by biological, psychological, and environmental factors. A common misconception is that someone with anorexia can “just eat” but is simply choosing not to. Nothing could be further from the truth. Once a person becomes dangerously underweight, powerful psychological and neurobiological changes lock the symptoms in place. Some with anorexia nervosa even begin bingeing and purging, in part, as a result of these physiological changes. Another myth is that anorexia only affects the lives of young white females. Although research suggests that anorexia is more prevalent in females, many males also develop the disorder. Similarly, although the illness typically begins during adolescence with peaks at ages fourteen and eighteen, people of all ages struggle. As a matter of fact, eating disorders do not discriminate by age, gender, culture, ethnicity, sexual orientation, or socioeconomic status.

The truth is that the majority of people with eating disorders do not fulfill anorexia nervosa’s diagnostic requirements, nor do the countless others who loathe their bodies and struggle to eat normally. We know from clinical and personal experience that the gray area between normal eating and anorexia nervosa is home to a great deal of pain and suffering for many people. Their lives can be just as out of control, unmanageable, and miserable—if not more so—than those with anorexia. That’s why we wrote this book: to identify and provide guidance for people who struggle with forms of disordered eating that are not officially recognized and often go untreated—what some clinicians have termed “diagnostic orphans.” We call this once-overlooked category almost anorexic.

In the simplest terms, almost anorexic describes subclinical levels of eating disorder symptoms. When we say “subclinical,” we mean that key symptoms of an illness are present but not in the quantity or severity to meet criteria for an official DSM-5 diagnosis. (You will see references to “DSM” throughout this book. Again, this is a manual that clinicians use to help make diagnoses.) Subclinical illnesses like almost anorexia often sneak below the radar of clinical detection. For example, a formerly heavy man who drops pounds through extremely restrictive eating may have almost anorexia even if he does not have a significantly low weight. Similarly, an underweight woman who does not feel fat or fear gaining weight would have almost anorexia if she feels terrified to relinquish the rigid dietary rules that dominate her life.

Diagnostic criteria are just guidelines, and people whose symptoms don’t quite fit those parameters can still suffer. Forget about the key symptoms of anorexia for a minute, and just consider this: to what extent is a preoccupation with eating, shape, and weight impairing your life? If almost anorexic seems to describe you or your loved one, we hope that this book will provide help and a real path to healing.

* * *

Who are we anyway? We are two people who know eating disorders—inside and out.
Jennifer J. Thomas, PhD, is an assistant professor of psychology at Harvard Medical School, where her research focuses on enhancing eating disorder diagnostic criteria to better reflect the experience of real patients. Dr. Thomas dedicated her career to eating disorders after spending her teen years as a pre-professional ballet dancer and witnessing firsthand how much the thin ideal can impact young women’s self-esteem. Her research studies have received both federal and foundation funding, and she has published over forty articles and chapters, many of which will be described in this book. People who are familiar with Dr. Thomas know that she may love to wear pearls and do research, but she doesn’t sit in an ivory tower. As a clinical psychologist in the eating disorder programs at two Harvard teaching hospitals (Massachusetts General Hospital and McLean Hospital), she has evaluated and treated—in both inpatient and outpatient settings—hundreds of individuals of all ages with anorexia nervosa, almost anorexia, and other officially recognized eating disorders. She is also an active member of several international organizations dedicated to eating disorder research, education, prevention, and treatment.

Jenni Schaefer knows what it’s like both to have an eating disorder and to fully recover from one. She has written about her journey in two best-selling books. Happily, Jenni discovered that freedom from food and weight obsessions is so much more than just that. She also learned that getting better means getting your life back. Today, Jenni encourages others to jump into their lives, to follow their true passions, and, most of all, to never give up. A singer/songwriter living in Austin, Texas, Jenni is a regular guest on national radio and television shows and a popular speaker around the globe. Jenni doesn’t usually wear pearls; they get in the way of things like ice climbing in Alaska (her favorite place to visit).

Since we have written Almost Anorexic together, in this book we will sometimes refer to each other in third person (using “she”). Because we share the same first name, we’ll refer to Jennifer Thomas as “Dr. Thomas” and Jenni Schaefer as “Jenni.” In reality, almost all of Dr. Thomas’s patients and colleagues call her “Jenny.” So if you can keep the two of us straight, feel free to mentally replace “Dr. Thomas” with “Jenny” as you read. Jenni’s battle with almost anorexia will be highlighted throughout this book, particularly in the “Jenni’s Journey” sidebars, written by Jenni herself. Like most people who develop a full-blown eating disorder, she experienced subclinical symptoms first.

Almost Anorexia: Jenni’s Story

At four years old, I already heard a negative voice in my head saying, “You’re fat. You aren’t good enough.” I remember wearing a little yellow tutu onstage during a dance recital—feeling fat. The recital was purely for fun, not competition. But I couldn’t help but compare my size to the other little girls in my class. In elementary school, I was afraid to eat birthday cake at friends’ parties. After trick-or-treating, I carefully saved my Halloween candy in the back of my closet, only to throw it away the following October.

Looking back at my middle school years, I must have had very low self-esteem. I didn’t realize it back then, though, because I had gained a false sense of confidence from achievement and status. I remember counting the number of brand-name items in my closet from back-to-school shopping trips. I had one pair of Guess jeans. But Michelle had five. I was chosen to play basketball in sports class, but not for the “A” team. Playing on the “B” team made me feel like I was inadequate in some way. Nothing was ever enough. I
was in tier two of the social hierarchy, a great, well-liked group of kids, but not the most popular crowd. On some level, I thought that if only I were thin enough, maybe I would fit in and be okay. During these years, I was also quite confused and worried, not to mention absolutely terrified about puberty and all of the associated body changes. Trying to control my food intake made me feel like I had at least some power over my ever-changing silhouette.

In high school, I tried to control even more. I became consumed with getting perfect grades. I thought I had to get 100 percent on everything. If not, I beat myself up about it. Yes, I sometimes felt like I had failed if I scored even a 99 percent—after all, that was 1 percent of the material that I didn’t know! I also began weighing myself. I bought a little blue scale and stood on it every day. (I hid this obsession from my parents and two brothers, none of whom had ever owned such a contraption.) I constantly compared myself to the other girls in my classes to make sure I was the skinniest in the room. Once, my friend Sandi became so frustrated with how I compared my body to hers—complaining that I felt much larger—that she pulled out measuring tape to prove that I was actually thinner. That still wasn’t enough for me.

By the time I graduated from high school and stepped foot onto my college campus, I was almost anorexic. This is when my eating behaviors took a turn for the worse. All of a sudden my mom wasn’t putting dinner on the table each night at 5 o’clock., so it was easy to skip meals. Women in my dorm invited me to the dining hall, but I usually made an excuse because I wanted to eat alone—to study (in an attempt to continue my trend of perfect grades from high school). I tried diet soda for the first time from my roommate’s supply in our fridge and was instantly hooked. Why hadn’t I thought of Diet Dr. Pepper as a meal replacement before? I began to drop pounds.

At the time, I didn’t realize that the transition from high school to college had been so difficult for me. Now I can see that all of the changes were affecting me more than I knew. Instead of voicing my concerns to others or even acknowledging them to myself, I just stuffed the fears deep inside. I think the more scared I became, the less I ate.

My new college classmates often asked for my secret: “I can fit my hand around your upper arm,” one gushed. “How do you stay so thin?”

But when my longtime high school friends noticed this weight loss, they expressed concern. I had always been a normal weight, although thin, prior to starting college. I knew that I had lost weight, but I honestly believed that I was just healthy. I also felt a strange sense of pride about being able to do what some thought impossible—lose weight. And yet I felt intense pressure to maintain my now-smaller size. I fearfully wondered, How am I going to be able to stay this thin for the rest of my life? I actually thought about how I might look at age eighty. Could I still be this thin? (Yes, at eighteen years old, I was already worried about how I would look in a nursing home.)

Because my high school friends seemed so worried about me, I finally went to the student health clinic. “Do you eat?” asked the doctor. “Yes,” I replied, recalling my binge earlier that week. I had gotten so hungry from the constant self-imposed food restriction that I couldn’t stop myself from eating a party-size bag of pretzels. The embarrassment that I felt about my binge eating was so intense that I couldn’t possibly reveal the details. Since that was the only question the doctor asked, I received a clean bill of health.
Looking back, I wish people had recognized that my unhealthy eating habits were a sign of a serious problem. I was in a lot of emotional pain, but there wasn’t an avenue to get help. I don’t blame the people in my life for this. Just as I hid my devotion to the scale, I also kept secret all of my eating behaviors that I knew implicitly were “different” from the way other people ate. Even so, I didn’t realize I was struggling until much later. A thick layer of denial and shame almost always accompanies eating-disordered behaviors. Because of this, many people suffer in silence for years.

If my eating disorder symptoms hadn’t eventually developed into the specific diagnostic criteria for anorexia nervosa—which happened by the end of my first semester in college—chances are that I never would have taken my illness seriously enough to get help. I might have lived my entire life in a miserable state, expending way too much time, energy, and thought on calorie counting and body loathing. I might have never stopped listening to that voice inside that said, “You aren’t enough.”

Although it was years after my initial visit to the student health clinic, I gratefully entered treatment for anorexia nervosa at age twenty-two. In therapy, I learned to name that negative voice “Ed,” which is an acronym for “eating disorder.” I was taught to personify my eating disorder and treat it like a relationship rather than an illness or a condition. Being with Ed was similar in many ways to an abusive marriage. Ed told me that I was worthless and beat me up physically. But I couldn’t figure out how to leave “him” (even when I wanted to). The metaphor of Ed was simply a tool I used to separate from the illness and to find my own unique voice and personality.

Described thoroughly in my first book, Life Without Ed,5 this externalization technique allowed me to separate from the illness and to make room for my authentic self. In the beginning, a typical conversation with Ed went something like this:

Ed: Your legs are fat.

Jenni: I know.

Ed: You should skip lunch today.

Jenni: Okay.

Throughout recovery, I learned not only to separate from Ed, like the dialogue above shows, but also to disagree with him. Ultimately, with the support of health care professionals, friends, and family, I gained the strength to disobey too. My attitudes and behaviors with food began to improve. In this book, my recovery may appear quick and easy—it will sometimes seem like I got better in a matter of pages (or even within a paragraph). I assure you that the process was not that simple. The real pages in my life took much time and patience.

It’s important to note that on my way out of anorexia nervosa, I found myself experiencing almost anorexic symptoms again. This time, almost anorexia meant both that I was getting better and that I still had room to grow. I didn’t want to settle for living with almost anorexia when complete freedom could be a reality for me. As before, almost anorexia could have pushed me into full-blown anorexia again or, if not, into full-blown misery. I didn’t want either. So, I kept taking steps forward and finally, I “divorced” Ed completely.

* * *

Although Jenni didn’t learn about the concept of “Ed” until after she had developed severe anorexia nervosa, she believes it could have been an invaluable tool in the early stages of her illness. That is why, in this book, we introduce the concept, which is used by experts
worldwide. Do you have an “Ed” in your head? If so, it can be important to think about yourself as separate from it. You don’t have to be defined by your problem. To help distinguish yourself from the negative voice in your head, you might experiment with using the Ed metaphor. Some people we know find the metaphor useful, but they change the name from “Ed” to something that rings more true for them. For example, some use the name “Rex” for ano-rexia. Others view the voice as a female and thus refer to their eating disorders as “Ana” or “Mia,” which are short for anorexia and bulimia, respectively. It doesn’t matter what you name that voice or even if you decide to name it at all. What is significant is that you realize disordered eating does not have to define you. But remember that treating your eating disorder like a relationship is just a metaphor—a tool that may help you. In her second book, Goodbye Ed, Hello Me, Jenni clarified, “Of course, my eating disorder was never really a guy named Ed who followed me around night and day, but it sure felt like it. Ed stood for a collection of beliefs I had learned since I was born. Unlike other recovery models, I learned that Ed was not an aspect of my authentic self, so my goal was always to separate from him. Different recovery models and tools work better for different people.”

If the externalization technique works for you, keep in mind that separating from your illness is not about blaming the eating disorder: Ed made me do it. Rather, the purpose of separating from Ed is to help yourself become accountable for how you respond to him.

You might notice that Ed is already starting to talk to you about this book and the almost anorexia concept, saying things like “You are such a failure at your eating disorder because you don’t meet anorexia criteria,” or “Way to go. If you keep this up, you just might reach full-fledged anorexia soon,” as if the anorexic label were some kind of trophy. Or maybe Ed is just telling you that we don’t have any idea what we are talking about! We wouldn’t be surprised. Ed’s role is to get you to focus on anything but getting better.

**It’s Not Black and White**

Most people think that you either have anorexia or you don’t, as depicted in Figure 1.

Figure 1. The Dichotomy Model of Anorexia Nervosa

But that is not what the research shows. Eating disorders are far more complex than this simple diagram implies. The officially recognized DSM-5 feeding and eating disorders are anorexia nervosa, bulimia nervosa (binge eating with compensatory behaviors), binge eating disorder (binge eating without compensatory behaviors) avoidant/restrictive food intake disorder (inadequate nutritional intake in the absence of body image concerns), pica (repeated consumption of nonfood items such as chalk), and rumination disorder (bringing food back up into one’s mouth in order to re-chew or re-swallow it). In DSM-5, each of these eating disorders has its own set of specific criteria that can rule someone in or out of the diagnosis. See appendix A for details. In this book, the eating disorders (anorexia, bulimia, and binge eating disorder) will be discussed whereas the feeding
disorders (avoidant/restrictive food intake disorder, pica, and rumination disorder) will not.

In our experience, individuals with disordered eating usually view themselves as part of an unspoken hierarchy. One patient described it like this: “Anorexia is like Saks [Fifth Avenue], bulimia is Target, and binge eating disorder is Wal-Mart.” Indeed, anorexia nervosa has a sought-after status that people often try to move toward regardless of the nature of their specific problems with food and weight. Using this line of warped thinking, almost anorexia might be seen as a thrift store or garage sale. But this model is both flawed and damaging. We have seen that people with almost anorexia sometimes feel worse than those who actually have anorexia nervosa, because those with almost anorexia assume that they are not “sick enough” to deserve help and so, sadly, never seek it.

Because we believe that most individuals with disordered eating can relate to an “anorexic mind-set” that prioritizes extreme thinness and dietary restriction, we have called this book Almost Anorexic instead of Almost an Eating Disorder. But we will cover the broad range of abnormal behaviors that exist with food and weight—not just food restriction and weight loss. Within this book, we will talk about bingeing and purging behaviors as well as negative body image. As you will see, in Jenni’s story among others, there are many levels to almost anorexia. It’s also important to remember that eating-disordered behaviors might look different, and body shapes and sizes may vary, but a similar pain goes on inside.

You might have noticed that we use the term almost anorexic as an adjective rather than a noun. We would never label someone who suffers as being an almost anorexic. Rather, a person might struggle with almost anorexic thoughts and behaviors. Labeling is not our intent. We describe almost anorexic as a vehicle for people like you or your loved one to get much-needed help.

For simplicity’s sake, we address this book primarily to individuals who might have almost anorexia. Of course, we are also writing this book for loved ones and for professionals who treat eating disorders, which is actually another reason we chose this specific format. In numerous treatment programs, Jenni’s previous books, which are also addressed to the sufferer, have been required reading both for staff and for patients’ families. This is because the books provide a novel window into the mind of someone who experiences disordered eating. If you are worried about a loved one, Almost Anorexic will provide another source of unique and helpful insights. You will get a firsthand view of what it is like to be trapped inside almost anorexia.

We have made every effort to avoid providing details that individuals struggling with almost anorexia might find “triggering.” In other words, we don’t want this book to be used as a “how-to guide” for developing an eating disorder. Patients’ diet tips and preferred brand of laxatives will not be discussed. Of course, some specifics are necessary in order for you to make a decision about whether you (or your loved one) might have almost anorexia. You can think about it this way: if this book is “triggering,” that may be important diagnostic information. If just reading about eating, weight, and shape causes someone distress, that individual may fall into the almost anorexic group or even have a full-blown eating disorder.

While part 1 of this book describes almost anorexia in greater detail, including key symptoms, part 2 offers solutions based on empirical research, Dr. Thomas’s clinical practice, and Jenni’s personal experience. We
have included self-help exercises, as well as advice on identifying treatment resources.

We have tried to jam-pack this book with information without making it feel overwhelming. To do this, we have broken each chapter into numerous sections with subheadings. When Jenni was sick with Ed screaming in her ear, she found it difficult to concentrate on reading a lot of material at once. Relating to her experience, you might prefer to read only a section or two of this book at a time. Or you might even choose to skip certain sections. (Maybe you really don’t want to know any more about the DSM!) And that’s okay. We wrote this book so that you can take from it what you find helpful and not worry about the rest. We do hope you will keep reading, so that you can begin to tackle any problems you might have with food and weight.

As Jenni once did, you might sometimes wonder, as you review self-help strategies, Will this really work? She was surprised when Dr. Thomas told her that many of the ideas she had relied on in her own recovery were backed by science. So to answer the question, research says yes. Although different strategies work for different people, one thing is certain: something will work for you.

Jennifer J. Thomas, Ph.D., is an assistant professor of psychology in the Department of Psychiatry at Harvard Medical School and co-director of the Eating Disorders Clinical and Research Program at Massachusetts General Hospital. Visit JenniferJThomasPhD.com. Connect with her at Twitter.com/DrJennyThomas.


Download further resources from almostanorexic on the book's page of www.jennischaefer.com