UN LOCKING
THE MYSTERIES OF EATING
DISORDERS

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UNLOCKING
THE MYSTERIES OF EATING DISORDERS

A Life-Saving Guide to Your Child’s Treatment and Recovery

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To our parents: Muriel and Harry Herzog Geri and Bill Franko Marcia and Austin Cable
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Acknowledgments

Our gratitude goes back many years to the mentors and friends who have encouraged and guided us in our efforts to improve the lives of patients with eating disorders. I (Dr. Herzog) first became interested in treating patients with these illnesses back in the 1970s when I was a resident in pediatrics at the University of Wisconsin Hospitals under the superb tutelage of Richard Anderson, M.D. There was disagreement between the disciplines regarding whose role it was to treat teens with anorexia nervosa on the pediatrics unit. The medical doctors claimed that psychiatry should manage the care of this illness, while the psychiatrists believed that these patients were too physically compromised to work on their psychological issues. Neither department really “owned” responsibility for treating these individuals. I wondered what drove these adolescents to lose so much weight. Why were they starving themselves? From this curiosity grew my determination to help individuals with eating disorders and their families.

From Wisconsin, I moved to Boston and, after finishing my residencies, accepted a position at Massachusetts General Hospital (MGH) to set up a program for individuals with illnesses that affected both the mind and the body. I want to thank Tom Hackett, M.D., and Michael Jellinek, M.D., for their support in 1980 to 1981, when I founded the MGH Eating Disorders Unit, which I directed for two decades. In the early 1990s, Joseph Coyle, M.D., then chairman of the Consolidated Department of Psychiatry at Harvard Medical School, helped me create the Harvard Eating Disorders Center, which is now the Harris Center at MGH. Matina Horner, Ph.D., brought to the Center her rich and far-reaching knowledge as professor, researcher in women’s achievement motivation, college president at Radcliffe, and mentor. As such, she inspired our summer fellowship program, which provides mentoring and funds for students interested in eating disorders research.

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I began my journey into the field of eating disorders as a student at the University of Michigan, where I volunteered on an adolescent psychiatric unit in the early 1970s and felt mystified by a girl who saw herself so differently than others saw her. I’m grateful to Sherry Hatcher, Ph.D., for encouraging me to pursue my studies in psychology, which led me to McGill University in Montreal. Once there, I found no services for women with eating disorders (in 1980!) and, together with my friend Bonnie Reich Pantel, LICSW, organized the first self-help group at the local YWCA. I’m forever indebted to my dissertation advisor and friend, David Zuroff, Ph.D., who taught me the meaning of being a psychologist and has mentored me throughout my career.

My colleagues and supervisors at Beth Israel Hospital—Nicholas Covino, Psy.D.; Peter Kassel, Psy.D.; and Fred Frankel, M.D.—taught me the art of psychotherapy and were instrumental in the development of an outpatient eating disorders program. Marian Winterbottom, Ph.D.; Betty North, Ph.D.; and Bob Misch, Ph.D., mentored me from my first day as a psychology intern through my 13 years as a staff psychologist, during which time I had the opportunity to direct the eating disorders program. I thank them for their wisdom and guidance. In 1987 I had the good fortune to complete a postdoctoral fellowship at Massachusetts General Hospital with Dr. Herzog, who invited me to join the Harvard Eating Disorders Center in 1998. I will always be grateful to him—a master clinician, researcher, and teacher—for giving me an appreciation of the hard road that individuals with eating disorders and their families face as they enter treatment. I thank him for all he has taught me during our 20 years of friendship and work together.

—Debra Franko, Ph.D.

Over the years, our patients and their families have been our greatest teachers, enlightening us about eating disorders and showing us the way. We extend our heartfelt appreciation to the individuals and families who participated in this book by sharing their personal experiences of eating disorders and recovery. We were impressed with the candor and clarity with which they told their stories, with their insight, and with their eagerness to help others struggling with these illnesses. All of these individuals and families wished us to assign them pseudonyms for our book, and we were happy to respect these requests.

We are thankful to many dedicated, talented professionals for helping to make this book possible: Cynthia M. Bulik, Ph.D.; Jeanine Cogan, Ph.D.; Susan Frates, M.S., RD, LDN; Mary Gee; Mark Goldstein, M.D.; Thomas R. Insel, M.D.; Lareina La Flair; Daniel le Grange, Ph.D.; Amy Lipsey; Laurie Martinelli, Esq.; Dianne Neumark-Sztainer, Ph.D., MPH, RD; Janet Treasure, Ph.D.; W. Allan Walker, M.D.; and Nancy Zucker, Ph.D.

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—David Herzog, M.D.; Debra Franko, Ph.D.; Pat Cable, RN
“Will my child get better? How? When?” If these questions are running through your mind, you are not alone. In fact, more than 8 million people in the United States suffer from eating disorders, and many more have substantially abnormal eating habits that don’t meet the formal criteria for classification as illness. The challenges and fears you may be experiencing in coping with your afflicted child can feel overwhelming. Questions such as “Why us?” or “Why this?” lead you to search for explanations for your child’s behaviors. Most of all, you are probably wondering how she can overcome her abnormal eating habits and how you can encourage her along the way. This book will help answer your questions.

Eating disorders are complex illnesses that most often strike during adolescence or young adulthood and are more common among females than males. Contrary to popular perception, eating disorders are not just a problem of wealthy, white families. They affect the rich and the poor, cutting across all races and ethnicities. Maybe your child is suffering from anorexia nervosa, the self-starvation disease. Or perhaps she has bulimia nervosa, meaning that she engages in repeated episodes of binge eating followed by efforts to prevent the food she has just ingested from resulting in weight gain. Another possibility is that she is struggling with serious eating problems that border on anorexia or bulimia. If you were to ask a number of people what they first think of when they hear the phrase eating disorder, their answers would likely revolve around food and weight. And these responses would be accurate—but only to a point. Abnormal eating is the tangible part of each illness, the part that gives this group of disorders its name. But it is not the only part. Also important are the intangible components of these illnesses—the individual’s thought patterns and feelings.

Our decision to write this book comes from our rich clinical experience. Over three decades we have seen and supervised the care of thousands of individuals with eating disorders at Massachusetts General Hospital and Beth Israel Hospital. We have listened to our patients closely, tuning in to their thoughts and feelings, and building on their strengths. The many questions people have asked us have generated valuable research initiatives. In 1994, we created the Harvard Eating Disorders Center, which is now the Harris Center for Education and Advocacy in Eating Disorders at Massachusetts General Hospital. Through the Center, we help train future leaders in the field and conduct research to better understand these illnesses and find effective treatments and prevention strategies. As we seek new knowledge, we strive to share it with the community at large.

Based on a combination of research and clinical experience, we have made the text reader-friendly, without technical terminology. The son or daughter you have in mind when you are reading this book could be almost any age, though our main focus is on school-age children, adolescents, and young adults. For our narrative, we have mostly used feminine pronouns when referring to an individual with an eating disorder; this usage is not to minimize the importance of eating disorders in males but simply to enhance readability. You’ll also find first-person
perspectives of individuals with eating disorders and families with whom we have worked. To protect their privacy, we have not used their real names. These stories open a window into what it means and how it feels to live with and receive treatment for an eating disorder. Chances are you will identify with the challenges faced by the parents in our vignettes. As you will see, although the young people in these stories have difficulties with food and weight, they often show remarkable capabilities and strengths in other aspects of life.

One reason why eating disorders can be difficult for families to spot is that people with these conditions generally try to keep their behaviors a secret. Those with anorexia often have visible signs of the disorder, such as low weight, but they are reluctant to seek help or admit that anything is wrong. Those with bulimia nervosa are generally normal in weight and look healthy. Part I of this book addresses how to recognize if your child is suffering from an eating disorder. Although every patient is unique, some of the warning signs of these illnesses are common. We talk about the various clues that may lead you to believe that your child has a problem and offer advice about when to seek professional help. It is not unusual for parents to be unsure whether their child has an eating disorder or whether she is at risk of developing one. So we have devoted a chapter to exploring what it means to cross the line from unhealthy eating to illness.

Part II, aimed at treatment and recovery, highlights how important it is for your child to see her primary care physician for an evaluation. You’ll learn why a team approach to care is often recommended, how to find the right professionals for your child, and how to navigate the various treatment options. Although eating disturbances afflict people of all ethnic and cultural backgrounds, they may show up differently in different groups. For example, it is not unusual for an Asian woman to manifest all the characteristics of anorexia nervosa but not experience a fear of becoming fat. It is important for care to be sensitive to families’ ethnic and cultural identities. The vignette in Chapter 4 brings to life a challenge encountered by many families—arranging treatment for a child who insists she doesn’t want it. As puzzling as it is that she is resistant to getting help, this is not unusual among individuals with eating disorders. The experiences of Roberta and her family will shed light on what you can do to encourage your child to give treatment a try.

First and foremost, your child’s treatment team—her primary care doctor, her nutritionist, her therapist, and possibly a psycho-pharmacologist (psychiatrist who specializes in medication)—will strive to keep her medically safe. Perhaps you are aware that anorexia and bulimia can result in serious medical problems. We outline these and discuss how they are managed. Some—but not all—of these negative consequences resolve with the restoration of healthy nutrition, but the goal is to keep them from occurring in the first place. Your child’s primary care physician will monitor her closely, educate her about the medical risks of her illness, and encourage her to choose health. The family stories in Chapters 4 and 6 illuminate how you can work with your child’s doctor to motivate her to accept help.

What is psychotherapy? What is its purpose? How will it help your child? Will it convince her to change her eating habits? What kinds of issues does it address? If the entire notion of psychotherapy for an eating disorder feels like a mystery to you, Chapter 5 will be of help. In it, we
delineate the different schools of thought that inform psychotherapy for eating disorders and talk about the importance of an alliance between the therapist and patient. Throughout the book, the voices of patients capture the experience of talk therapy; that is, individuals describe what therapy was like and whether it helped them. In Chapter 7 we explain that many individuals with eating disorders also suffer from other mental illnesses, such as depression or anxiety disorders. Here, you’ll meet 18-year-old Paula, who took a leave of absence from college so that she could get help for her bulimia, her cutting, her dark moods, and her sense of being “not good enough.” Her story and many others portray the road to recovery as bumpy and hard to travel rather than smooth or direct.

In addition to giving you an inside look at individual therapy, our vignettes provide a glimpse into family therapy, which offers parents an opportunity to express their concerns, to work on enhancing communication with their child, and to participate in the treatment process. You will learn what kinds of topics are discussed in family therapy and how the parents in our stories used their sessions to increase their understanding of themselves and their children. Chapter 9 introduces you to family-based (Mauds-ley) therapy, a specific outpatient approach that has shown promise for adolescents who are treated early in the course of their eating disorder. Throughout the book, we offer you tools to help you open channels of communication between you and your child so that—little by little—you can establish a dialogue about her friendships, sports activities, studies, life on the home front, and maybe even about her attitudes toward her body.

Part III, “Preventing Eating Disorders and Raising Awareness,” opens with a discussion of the possible causes of eating disorders. Woven throughout the text, and explored in more depth in Chapter 10, is the theme that eating disorders are no one’s fault. It is likely that these illnesses stem not from a single influence but from a combination of factors, including biology, culture, personality, and relationships.

Exactly what causes eating disorders is among the mysteries that researchers are trying to unlock. Other questions pertain to treatment. One of our main research projects—our longitudinal study—examines what happens to individuals with eating disorders over time. Who gets better and how? To conduct this study, we are following 246 women who initially sought treatment for anorexia and bulimia. We interview them regularly to find out about their eating behaviors; their emotional health; and their participation in school, work, and social activities. This research project, now in its 19th year, has revealed that the majority of patients improve over time. All of our chapters emphasize that eating disorders are treatable and that individuals and their families can be helped.

The final chapter of the book talks about the progress that is taking place in the field of eating disorders. You will learn how professional and advocacy-based organizations have joined together and established a coalition in Washington, D.C., to call attention to eating disorders as a federal health priority. You will see how the coalition is raising awareness of eating disorders nationwide and garnering support for legislation on behalf of these illnesses. Finally, you will discover what you can do to participate in the advocacy movement.
As you travel the road to recovery with your child, we think this book will guide you, and we hope you will find inspiration in the stories our patients and their families have shared with us.
PART I

Does My Child Have an Eating Disorder?
“It was 6:00 A.M., and I woke to a familiar noise coming from my 15-year-old daughter’s bedroom. Every morning, she had been waking well before dawn to put herself through a strenuous regimen of jumping jacks and other calisthenics. The previous month, after an appointment with her pediatrician, she had discontinued the early morning workouts as advised—but only temporarily. I tried to calm myself as I threw on my bathrobe and headed down the hall to talk with Maureen, hoping she’d stop her calisthenics and rest before getting ready for school. Knocking softly on her door, I sighed at the inevitable ‘Wait a sec.’ After ‘Okay, Mom. C’mon in,’ I entered and found her sitting on her bed in shorts and a T-shirt, as sullen and unapproachable as she’d been for the last couple of weeks. My eyes took in the worn exercise shoes that she had most likely flung off only moments before she’d leapt from her exercise mat in front of the mirror to her bed. I wasn’t surprised to see a clipping from a magazine on Maureen’s dresser; it was one of many weight-loss charts she had collected since beginning her strict diet. As I gave my daughter a good-morning hug and suggested she rest for half an hour before getting dressed for school, I felt like asking her what she wanted for breakfast but thought better of it. I’d give myself a few minutes to figure out how to broach that subject, knowing that Maureen would try to leave the house without eating, just as she’d done every morning for a week.”

If you have a child with an eating disorder, chances are you can relate to this mom’s worries. Maureen suffered from anorexia nervosa and became our patient a year ago, upon referral from her pediatrician. No matter how many people you have known (or heard of) with eating disorders, the experience of having your own son or daughter in the grip of this type of illness holds an intensity like no other. Even if you have always considered yourself in the know about these conditions, when you face the possibility of such a problem in your own daughter or son, you may find yourself asking, “What is an eating disorder? What’s the best treatment? Will my child get better? How can I help?” Based on scientific research and several decades of working with many individuals with eating disorders, we will provide answers to your questions. In addition to helping the families of those who suffer from eating disorders, this book will be useful to teachers, athletic coaches, college residence advisers, youth group leaders, summer camp personnel, and anyone who interacts with vulnerable individuals.

Identifying the Different Types of Eating Disorders

Eating disorders are serious psychiatric illnesses impacting both the brain and the body. Individuals with eating disorders are afflicted with negative thoughts and intense emotions about their body size and shape; they adopt unhealthy weight control practices and other abnormal eating habits, taking these measures to a dangerous extreme. The most well-known eating disorders are anorexia nervosa and bulimia nervosa. In addition, there is a third category called eating disorders not
otherwise specified (EDNOS), which consists of binge eating disorder and other severe conditions that are akin to anorexia nervosa or bulimia nervosa but do not match the official medical definitions of these illnesses.

**Anorexia Nervosa: A Self-Starvation Disease**

Maria, the mother you met at the beginning of this chapter, had more to learn about the disease that changed her daughter from a thriving, athletic ninth grader to a shadow of her former self. Known to many as the disease of self-starvation, anorexia nervosa affects about 1 percent of the population at some point in their lives, and the vast majority of sufferers are female. Like Maureen, most individuals with anorexia first fall ill during adolescence or during their early to mid-20s; for many, the disease continues into adulthood. We often do not see people for evaluation and treatment until some time after they develop the illness.

There is a big difference between how people with anorexia nervosa view themselves and how they are viewed by others. While Maria perceived her daughter as painfully thin, Maureen experienced her body as “fat,” and in her eyes, fat was “bad.” When this 15-year-old insisted she was huge, that her thighs were too big, or that her jeans were tighter than they had been yesterday, she was not just making up the perception or faking it. “She seemed to believe what she claimed about her body,” says Maria, “and trying to convince her otherwise felt like an exercise in futility.”

Given the nature of this eating disorder, the term *anorexia*—which stems from the Greek terms *an*, meaning “without,” and *orexe*, meaning “appetite”—is misleading. Individuals with this illness are so focused on fighting hunger that it is hard for them to acknowledge that they have it; that’s where the term *nervosa* fits in. People with anorexia are afraid that if they give in to their appetites and start eating, they won’t stop. Maureen felt that her calisthenics took her mind off her hunger. Driven to lose weight and intensely afraid of gaining any, she cut way back on her food intake, first eliminating desserts and snacks, then dropping other foods that worried her, such as meat and bread. When it came to eating, exercise, and weight, Maureen had a set of harsh, rigid rules that she applied only to herself and followed to the letter—even well beyond. She measured everything she ate, checking the measuring

**Self-Starvation in Times Gone By**

Self-imposed starvation dates as far back as the early Middle Ages, when the consensus was that girls who refused to eat were possessed by demons and that exorcism was the remedy.

Medieval Europe saw fasting among female saints, one of whom was Catherine of Siena. Born around the middle of the 14th century, she was 16 when she drastically reduced her food intake as part of her religious quest to transcend biological needs. Saint Catherine also engaged in strenuous physical exercise and vomited the meager ration of food that she allowed herself to eat. So tenacious was her fast that no one, not even Church authorities, could convince her to relent. She
died of starvation when she was about 32 years old.

In learning about the religious starvation of the medieval saints, some 18th- and 19th-century girls tried to emulate them. Girls with healthy weights who abstained from food yet had no discernable medical problems were viewed as miraculous, but there were also girls whose fasting led to physical wasting and death. Doctors in the 19th century considered voluntary starvation “nervous” in origin; thus, in 1874, the condition was named *anorexia nervosa* and was much like the illness as we know it today.

cup repeatedly to make sure she was not allowing herself too much. In general undernourished individuals are disinclined to engage in sports and other physical activities; with anorexia, the opposite is true. Like Maureen, people with this illness often exercise to an extreme—mostly in the interest of losing weight.

One of anorexia’s many dangers is that no matter how many pounds the individual sheds, she is never “thin enough.” As soon as Maureen reached one weight goal, she aspired to a lower one, intensifying her self-discipline and guarding against any potential “risk” of weight gain. “At one point, Maureen dropped toast from her breakfast routine,” recalls her mom. “Then, in addition to performing her calisthenics, she tried to skip breakfast altogether.”

Many sufferers are reluctant to admit they have a problem or need help. “My biggest fear was that my daughter wouldn’t accept treatment,” says Maria. “What started as voluntary self-starvation became a force unto itself and gained momentum, creating a nightmare for the entire family.” Maria’s persistence in encouraging Maureen to come in for treatment was a critical first step on the road to recovery.

**Bulimia Nervosa: A Disease with Less Obvious Signs**

Sondra, now 23, was referred to us as a college freshman after she had visited the campus health center requesting help for an upset stomach. Initially, she’d been afraid to tell the college doctor about her eating problems. But when he asked her whether she was trying to lose weight and whether she had ever vomited a meal, she told him the truth. Ruth, Sondra’s mom, has vivid memories of the days immediately preceding her daughter’s evaluation at the college health center:

“The call came on a Tuesday, just after I returned from work. It was Celia, my 18-year-old daughter Sondra’s best friend from high school, and the news wasn’t good. Celia had visited Sondra at college and found her having difficulties with food. Sondra was going to the dormitory cafeteria at mealtimes and leaving with a huge supply of desserts, which she ate in her room when no one else was there. Celia saw what Sondra’s roommate and other students on the third floor had observed repeatedly—Sondra heading straight to the bathroom down the hall, as if nothing in the world would stop her. Celia and the roommate had urged their friend to go to the college health center, which was set up to assist students suffering from eating disturbances, but Sondra wanted no part of it. After Celia’s call, I spent the next day getting some books about eating disorders and
inquiring further about the college’s services for these disorders. Then I was on my way to visit Sondra, hoping to convince her to seek help and to do it soon.”

Bulimia nervosa affects approximately 1 to 4.2 percent of people at some time in their lives. The illness tends to begin during adolescence or early adulthood and most often plagues women.

Like individuals with anorexia nervosa, those with bulimia nervosa prize thinness and tend to measure their self-worth in terms of the size and shape of their bodies. Many times, as in Sondra’s case, they are of normal weight and show no obvious signs of the disorder. Sondra set very strict weight standards for herself, constantly thought about food, and developed a pattern of binge eating, whereby she rapidly downed a large volume of food and felt unable to stop eating. Her binges were typically high in carbohydrate and fat content, foods that she did not ordinarily allow herself to eat. She went to great lengths to hide her food habits, and in the college dormitory, that was really hard.

Individuals who have recovered tend to look back on their bingeing as temporarily numbing their emotions, shutting out everything except food. Following a binge, Sondra often felt ashamed of herself for eating with such abandon. Adding to her distress was the overwhelming fear that the food she had consumed during the binge would lead to weight gain—a fate she felt compelled to avoid no matter what the cost. In the face of these powerful emotions, she resorted to purging by inducing vomiting, usually in the bathroom of her dormitory. Sondra knew that there are other methods of purging—including the misuse of laxatives, diuretics (drugs that increase the body’s rate of urination), or enemas—but she did not try any of these. Some people with bulimia nervosa fast or overexercise after bingeing in an effort to ward off unwanted pounds. Of the various methods patients with bulimia use (often in combination) in desperate attempts to keep their binges from tipping the scale upward, the most common is self-induced vomiting.

Ruth knew from the outset that eating disturbances were serious. “As I set out for my daughter’s college,” she remembers, “I kept reminding myself not to panic as thoughts about how best to approach Sondra about the problem raced through my mind. When I arrived, I sensed that she had walled herself off from me. Although she seemed to realize she had eating difficulties, she wasn’t about to discuss them with me. After expressing my concern to her and urging her to go to the college health center for help, I returned home but was so worried about Sondra that I could barely concentrate on anything. A couple days later, I received a call from the college physician who had met with Sondra and was interested in setting up a treatment plan for her.” Ruth’s gathering of reading material, her calls to the college health center, and her overall preparedness for talking to her daughter had been instrumental in getting Sondra to come to us for help.

Eating Disorder Not Otherwise Specified

As long-winded and puzzling as the term sounds, more people who come to treatment centers for help are diagnosed with eating disorder not otherwise specified than with either anorexia nervosa or bulimia nervosa. Patients with EDNOS have various combinations of eating disorder features that