

Parents' Guide to Supporting a Child Through Eating Disorder Recovery

Parents' Guide to Supporting a Child Through Eating Disorder Recovery

As a parent, discovering that your child has an eating disorder can lead to a myriad of emotions. It is common to feel helpless, fearful, confused, and even frustrated and exhausted at times. This guide was created to offer parents or caregivers basic information, ideas, and strategies to provide support for their child with an eating disorder.

ABOUT EATING DISORDERS

Eating disorders impact millions of individuals and families. With the highest mortality rate of any mental illness, eating disorders continue to be a dangerous and insidious part of our world. According to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM V), eating disorders are classified into four major categories: anorexia, bulimia, binge eating disorder, and otherwise specified feeding or eating disorders.

Anorexia

Anorexia nervosa is a disorder in which preoccupation with restricting food intake and thinness leads to excessive weight loss. The individual typically has an intense fear of gaining weight, a distorted body image, and typically weighs below what is considered to be a minimum normal weight.

Signs and Symptoms of Anorexia:

- Refusal to maintain body weight at or above a minimally normal weight for age and height
- Restrictive eating
- Intense fear of gaining weight or becoming fat, even though underweight
- Disturbance in the way in which one's body weight or shape is experienced
- Undue influence of body weight or shape on selfevaluation
- Denial of the seriousness of the current low body weight

- Loss of period in some women who have reached puberty
- Exhibits much concern about weight
- Complaints about "feeling" fat
- Suffers from depression (including shame, anger and guilt)
- Attributes social and professional successes/failures to weight gain/loss
- Denial of hunger
- Loathing of body, hiding shape, and weight

*Please note, that although the classic diagnosis of anorexia requires the individual to weigh less than 85% of their ideal body weight, further research has shown that people of all body shapes and sizes can experience the symptoms of anorexia and is defined as atypical anorexia. Please note that there are many in the field advocating to have atypical anorexia eliminated so that all individuals experiencing these symptoms are given the diagnosis of "anorexia nervosa" regardless of body weight.

Bulimia

Bulimia nervosa involves frequent episodes of binge eating, almost always followed by purging and intense feelings of guilt or shame. The individual feels out of control and may recognize that the behavior is not normal.

- 1. Recurrent episodes of binge eating. An episode of binge eating is eating a very large quantity of food in a short period of time. The binge eating episode is often accompanied by a sense of lack of control. (e.g., the feeling that one can't moderate how much or what is consumed)
- 2. Recurrent purging/compensatory behavior. (e.g., self-induced vomiting, misuse of laxatives, diuretics, enemas, fasting, or excessive exercise)
- 3. Disturbance in the way in which one's body weight or shape is experienced
- 4. Undue influence of body weight or shape on self-evaluation
- 5. Denial of the seriousness of the current low body weight

Signs and Symptoms of Bulimia:

- Complains about "feeling" fat
- Suffers from depression, including shame, anger, and guilt
- Perfectionist personality
- Attributes social and professional successes/ failures to weight gain/loss
- Denial of hunger

- Loathing of body (e.g., hiding shape and weight)
- Increased dental caries and swollen gums
- Swollen parotid glands

Binge Eating Disorder

Those struggling with binge eating disorder experience uncontrollable eating, sometimes done in secret. The individual has feelings of disgust, depression, and guilt about binge eating and eats when not physically hungry. Individuals diagnosed with binge eating disorder may be living in all sized bodies.

Signs and Symptoms of BED:

- Eating large amounts of food when not physically hungry- bingeing or eating uncontrollably
- Unable to stop eating voluntarily
- Eating rapidly
- Eating until feeling bloated or uncomfortably full
- Eating alone
- Hoarding or stealing food
- Low self-esteem and feelings of worthlessness
- Intense guilt about eating, including self-disgust
- Depressed moods, mood fluctuations, impatience, irritability
- · Loathing or hiding of the body under baggy clothes

*Many people with BED often attempt to compensate for bingeing by subsequently restricting their food intake. This, in turn, leaves them in a self-perpetuating binge-restrict cycle.

Other Specified **Feeding and Eating Disorders**

Otherwise Specified (EDNOS) in past editions of the Diagnostic and Statistical Manual. OSFED/EDNOS is a serious, life-threatening eating disorder even though it does not receive as much focus in research or attention. Just like all other eating disorders, OSFED is treatable, and individuals who struggle with this eating disorder are capable of recovery. This category was created to encompass those individuals who did not meet the strict diagnostic criteria for anorexia nervosa or bulimia nervosa, but who still have a significant eating disorder. OSFED is one of the most common eating disorders.

Under the category of OSFED are atypical anorexia nervosa, night eating disorder, purging disorder, bulimia nervosa (of low frequency or limited duration), binge eating disorder (of low frequency or limited duration), and orthorexia.

Signs and Symptoms:

- Noticeable fluctuations in weight, both up and down
- Is preoccupied with weight, food, calories, fat grams, and dieting, and appears uncomfortable eating around others
- Refuses to eat certain foods, progressing to restriction against whole categories of food (e.g., no carbohydrates, etc.)
- Evidence of binge eating, including disappearance of large amounts of food in short periods of time or lots of empty wrappers and containers indicating consumption of large amounts of food
- Evidence of purging behaviors, including frequent trips to the bathroom after meals, signs and/or smells of vomiting, presence of wrappers or packages of laxatives or diuretics

- Develops food rituals (e.g., eats only a particular food or food group [e.g., condiments], excessive chewing, doesn't allow foods to touch)
- Any new practice with food or fad diets, including cutting out entire food groups (no sugar, no carbs, no dairy, vegetarianism/veganism)
- Drinks excessive amounts of water or non-caloric beverages
- Maintains excessive, rigid exercise regimen despite weather, fatigue, illness, or injury—due to the need to "burn off calories"
- Shows unusual swelling of the cheeks or jaw area
- Stomach cramps, other non-specific gastrointestinal complaints (constipation, acid reflux, etc.)
- Fine hair on body, and thinning of hair on head, dry and brittle hair (lanugo)
- Muscle weakness and impaired immune functioning

Avoidant Restrictive Food Intake Disorder

Avoidant Restrictive Food Intake Disorder (ARFID) is a new diagnosis in the DSM-5 and can often be confused with "picky" or "selective" eating. ARFID is a restrictive eating disorder in the sense that individuals struggling with this disorder limit the quantity and quality of food consumed, but unlike anorexia, ARFID does not involve any distress pertaining to body weight, shape, or size. It also does not involve any fear of gaining weight.*

Although many children experience stages of picky eating, a person with ARFID is severely lacking when it comes to the nutrition necessary to grow (in children) or to function (in adults). In children, this often results in a lack of weight gain or vertical growth; in adults, this often results in weight loss. ARFID can also lead to social distress, as these people often dislike eating with others or need an extended amount of time to consume a meal.

*Although strict DSM criteria states there are no body image disturbances with ARFID, many practitioners have observed body image issues in the context of ARFID.

Signs and Symptoms:

- Dramatic weight loss without body image disturbance or fear of weight gain
- Reports constipation, abdominal pain, cold intolerance, lethargy, and/or excess energy
- Reports consistent, vague gastrointestinal issues ("upset stomach", feels full, etc.) around mealtimes that have no known cause
- Dramatic restriction in types or amount of food eaten, and will only eat certain textures of food
- Fears of choking or vomiting
- Lack of appetite or interest in food
- Limited range of preferred foods that becomes narrower over time (i.e., picky eating that progressively worsens)*.

^{*}Those with sensory challenges should be screened for Sensory Processing Disorder (SPD) by an occupational therapist specifically trained in treating SPD.

Unspecified <u>Feeding and Eating Disorder (UFED)</u>

UFED encompasses situations that present with symptoms characteristic of an eating disorder and which cause clinically significant impairment in functioning and substantial distress, but do not meet the full criteria for any specific eating disorder. It is often used in situations in which there is insufficient information to diagnose a specific eating disorder. For example, someone may go to an emergency room for something unrelated and mention that they have an eating disorder. The person may not provide the specific diagnosis and thus, the physician may note "Unspecified Feeding and Eating Disorder" in the patient's chart. The diagnosis is also used when clinicians do not specify the reasons why a person does not meet diagnostic criteria for a different eating disorder.

While less common than the eating disorder classifications listed above, rumination disorder and PICA are two additional eating disorders:

Rumination Disorder

Rumination disorder involves the regular regurgitation of food that occurs for at least one month. Regurgitated food might be re-chewed, re-swallowed, or even spit out. Typically, when someone regurgitates their food, they do not appear to be making an effort to do so, nor do they appear to be stressed, upset, or disgusted by this behavior.

PICA

PICA is a disorder characterized by the ingestion of items that are not categorized as food and lack nutritional value. These items might include dirt, paper, hair, or paint chips.

General Dos and Don'ts for How to Best Support a Loved One with an Eating Disorder

DOs:

- If you suspect your child has an eating disorder, talk openly about your concerns with your child. You might find your child more withdrawn or moody which may make it difficult to talk to them, however, talking about their eating disorder is essential for recovery. Be patient with your child, as talking about emotions and emotionally charged topics may be challenging. Some tips for hard conversations:
 - Maintain a calm demeanor and prepare what you are going to say ahead of time
 - Refrain from blaming yourself or your child
 - Avoid talking about appearance, even in a positive way
 - o Use "I" statements rather than beginning statements with "You"
- Find support for your child. The first step could be to schedule an appointment with your child's pediatrician. Your pediatrician will likely draw specific labs and review your child's growth chart to ensure your child is medically stable. Once an eating disorder diagnosis/concern has been validated, the gold standard of care is to establish treatment with a multi-disciplinary team, which includes a psychotherapist, dietitian, medical provider, a family therapist, and sometimes a psychiatrist.
- Find support for yourself. Eating disorder recovery is a challenging journey and while your child might be the one struggling with the disorder, you deserve help and support for yourself, too! Seeking support from other parents/caregivers who have been through this process provides hope, inspiration, and reassurance that you are not alone. Consider joining MEDA's free Monday Night Drop in Group for Family and Friends. You can sign up at www.medainc.org/events. Ask your child's treatment team for advice on how to best support your child's recovery in the home. You may also wish to ask them for 9 information on additional parent support groups.

- Learn as much as you can about eating disorders. Because eating disorders are complex, treating them is also complex. It will be helpful to familiarize yourself with different treatment modalities used as well as the various levels of care available. The Resources and Further Reading sections of this guide provide suggestions for additional materials and information.
- Learn about diet culture, reject it, and evaluate your own biases around gaining weight and fatphobia. 'Diet culture' refers to a belief system that values and prioritizes thinness and appearance above overall well-being. The concept of 'diet culture' emphasizes calorie restriction, normalizes negative self-talk, and assigns morality to food (the belief that food is "good" or "bad" and people somehow become good or bad by eating them). Diet culture assumes that thinness and dieting are equated to health and that by pursuing health, one becomes morally superior. Diet culture is harmful to folks of all sizes. It perpetuates eating disorders and instills deep-rooted insecurities in people.
- Create your own list of "dos and don'ts" with your child. This exercise can be a helpful way to improve communication and connection and allow you to learn how to best support your child. Consider using a pencil or a white board because as recovery progresses, so will your child's needs.
- **Be a positive role model** by eating a balanced diet of foods that are fun to eat and provide nourishment. Engage in movement that is fun and non-punitive. Practice mindfulness and healthy coping. All feelings are valid and need to be expressed in healthy ways. Use your voice to communicate your thoughts and feelings clearly. This will pave the way for your child to do the same.
- Remember, recovery is possible, especially with your support.

DON'Ts:

- DON'T blame yourself. Once a parent learns or suspects that their child has an eating disorder, it is common for them to blame themselves. It's important to know that parents do not cause eating disorders. Eating disorders are a biologically based brain disorder. In short, the cause of eating disorders is multifactorial. Focusing your energy on finding treatment and support for your child will be far more helpful than chastising yourself about something for which you are not responsible.
- DON'T comment on anyone's weight or appearance, including your own. Despite what popular media has taught us, a person's weight and size tell us absolutely nothing about their physical or mental health. Additionally, weight-related comments can be triggering or upsetting to hear, which in turn may fuel eating disorder behaviors. Weight-related comments also move away from important topics of conversation, such as someone's experience, feelings or thoughts.
- DON'T discuss calories, diets, exercise, or eating habits. Rather than focusing on food, focus on feelings.
- DON'T label foods as "good" or "bad". Once you label foods as "good" or "bad," food is no longer a neutral choice and starts to have moral implications. So, if you eat a "bad" food, you might consider yourself "bad" for eating that food item. When we drop the food labels, we are better able to choose what food we want, how much we want, and when we want to eat it. We are also unlikely to feel 'out of control' when eating. Anytime we put foods in an 'off limits' category, it makes us want that particular food even more. For example, try telling yourself that you can't have chocolate cake for a month. You might not even like chocolate cake, but telling yourself you can't have it is a sure-fire way to make yourself obsess over it and eat in a way that feels out of control when you eventually do encounter it. In reality, all foods break down into glucose, amino acids, and fatty acids.

• DON'T engage in a dialogue with your child's eating disorder. Do not engage in negative self-talk, diet, or exercise in your child's presence. Do not comment on your child's body. If your child asks you how they look or if you can tell that their body has changed in some way, redirect the conversation to how they are feeling. For example, "Are you feeling insecure or anxious? It sounds like you might be. Let's talk about that."

In the Moment: Mealtime Tips

- Refrain from talking about your own eating, exercise habits, and body insecurities.
- Agree, as a family, to avoid commenting on each other's plates.
 Conversation about portion sizes, calories or anything negative about food will only increase your child's anxiety and make it more difficult for them to finish their meal.
- Refrain from negotiating with your child's eating disorder. Mealtimes are not for 'making deals.'
- Avoid serving low calorie or diet food. It reinforces diet culture while fueling your child's belief that their body cannot tolerate "normal food."
- Keep conversations light-hearted during mealtimes. Consider playing music or a structured game like Wrench or Rabbit, Bananagrams, or Would You Rather.
- Consider a family activity after the meal, such as playing a game or watching a TV show.
- Be present for your child during meals. If your child doesn't want to engage in conversation, sometimes just being present with them helps them know that you care.

Further Reading

Intuitive Eating: A Revolutionary Anti-Diet Approach

by Evelyn Tribole and Elyse Resch

This book explains the research behind this evidence-based, successful approach. It explains how to follow the ten principles of intuitive eating and integrate them into a trusting relationship with food and your body in your everyday life.

Body Respect: What Conventional Health Books Get Wrong, Leave Out, and Just Plain Fail to Understand about Weight

by Dr. Lindo Bacon and Dr. Lucy Aphramor

This book debunks common myths about weight, including the false belief that BMI accurately measures health, that fatness leads to disease, and that dieting will lead to better health. It is a must-read!

Surviving an Eating Disorder: Strategies for Family and Friends by Michele Siegel, Judith Brisman, and Margot Weinshel

This classic book for family and friends is designed to help families understand eating disorders through a psychological perspective. It was one of the first books to highlight the dangers of eating disorder while supplying strategies and suggestions for families to use. The book has been updated to include advances in the field.

Talking to Eating Disorders: Simple Ways to Support Someone with Anorexia, Bulimia, Binge Eating, or Body Image Issues by Jeanna Albronda Heaton, PhD and Claudia J. Strauss

This book offers compassionate ways to have difficult conversations related to body image, media messages, physical touch, diets, and exercise.

When Your Teen Has an Eating Disorder: Practical Strategies to Help Your Teen Recover from Anorexia, Bulimia, and Binge Eating

by Dr. Lauren Muhlheim

This book offers evidence-based strategies, including family-based treatment (FBT), you can use to help your teen heal from an eating disorder.

Body Kindness: Transform Your Health from the Inside Out – and Never Say Diet Again

by Rebecca Schritchfield

Through mind and body exercises, this anti-diet book helps you identify a sense of well-being by furthering your understanding of how to love, connect, and nourish yourself.

Health at Every Size: The Surprising Truth About Your Weight by Dr. Lindo Bacon

This book explores the Health at Every Size® approach and encourages a healthy attitude towards food and movement as a means of reaching a state of overall well-being.

Sick Enough: A Guide to the Medical Complications of Eating Disorders

by Jennifer L. Gaudiani

This book provides patients and families with easy-to-understand information regarding the medical issues that arise from eating disorders.

FAQ

1. Why was my child told to decrease physical activity/not exercise at all?

Movement has so many benefits to it that it can be challenging to imagine why anyone might be told not to do it. It can modulate anxiety, relieve stress, and benefit a host of other things. However, when someone is not taking in enough food or is engaging in compensatory behaviors, exercise itself becomes an eating disorder behavior and is detrimental to the body. Rather than relieve stress and build muscle, exercising a depleted body induces stress and breaks down muscle. It is important to remember that the heart is a muscle, and we most certainly do not want that muscle to break down and become compromised. It's also important for your child to learn that their body needs food and energy even when they are not moving. They don't yet know or trust the fact that their body knows what to do with food to convert it to energy. It's important that they learn and experience that they do not need to 'earn their food' by working out. Learning new, effective ways of coping with their feelings besides using eating disorder behaviors is a critical part of recovery. Slowing down and removing an eating disorder behavior creates space to learn and practice new skills.

2. Why does my child need to see a dietitian?

Having a treatment team in place when working on recovery is not only extremely helpful, but also necessary. Best practices for eating disorder treatment include having a multidisciplinary team consisting of a therapist, dietitian, primary care provider (PCP), and sometimes a psychiatrist and family therapist. The dietitian is integral in providing individualized nutritional counseling to help your child learn more about what their body needs in order to be adequately nourished. Many dietitians will create an individualized meal plan to help your child normalize eating patterns. Once eating patterns are normalized, your child's hunger and fullness cues will return. The dietitian also works on specific food goals. Typically, dietitians will work on adequacy first.

Once your child's intake is adequate, the dietitian will work on incorporating variety. Since your child has developed food rules and fears around foods, the dietitian will help your child challenge those rules. They will often schedule "food exposure challenges" or times when your child will eat food they are afraid of with their dietitian, who will coach them through their fears with information grounded in science.

3. Why is it important to go to therapy every week? Can't they just go once or twice a month?

It is most useful to attend therapy weekly to receive the full benefits, especially in the beginning. The therapeutic relationship is more readily and securely established when meeting weekly, especially since trust is developed over time. Weekly sessions also ensure your child is getting the appropriate amount of support in order to make appreciable progress in their recovery. When meetings are less than weekly, eating disorder behaviors tend to exacerbate between sessions, as the person will continue to use eating disorder behaviors as a primary mechanism of coping with their feelings. They need the weekly contact with their therapist in order to learn new skills and receive coaching in how to apply those skills effectively. Additionally, weekly visits ensure that the therapist can accurately monitor your child and ensure that they are moving forward.

4. Why is it important not to cancel appointments?

Every appointment kept is an opportunity for your child to move forward in their eating disorder recovery. The times when clients feel the least motivated to go to an appointment are often the times when it is most important to go! Clients often want to miss sessions when they're having challenging emotions that they would prefer to avoid. Going to the appointment allows the therapist to coach the client in using skills as well as to begin to resolve some of the underlying issues that maintain those difficult feelings. The more consistently a person maintains their appointments, the more opportunities there are for them to build rapport with their team members, stay on track with their treatment

goals, and problem-solve around issues that arise. Of course, there are understandable emergency situations where an appointment may need to be canceled. However, even these appointments should be rescheduled whenever possible to ensure continuity of care and forward movement in recovery.

5. Why should I get support for myself?

Knowing your child has an eating disorder is difficult and may bring up many different emotions. You may feel hurt, exhausted, frustrated, or scared at times. Additionally, eating disorders impact the entire family system. You will best be able to support your child, if you yourself have enough support to guide you through this challenging time.

6. Do people recover? I've heard that once you have an eating disorder, you always have one.

Recovering from an eating disorder is possible and there are nuances as to what this may look like individually, because everyone's recovery is unique and personal to them. Some may consider themselves "recovered" from an eating disorder, while others may identify as "being in recovery from an eating disorder" and still others believe they are "in remission." Once a person lives with an eating disorder, that piece of their story can never be erased. However, it does not mean they are resigned to a life shackled to their eating disorder. Rather, it is possible for a person to recover from an eating disorder and live a rich, fulfilling life that is greatly informed by their eating disorder and other lived experiences. This may look like taking care of themselves physically and mentally, making choices that are aligned with their values rather than what the eating disorder values, and consistently engaging in the right mix of skills that help them challenge certain thoughts and urges. Recovery does not mean a person is never triggered or never has to face old eating disorder demons. Instead, it means that if they are triggered or if an eating disorder thought/urge arises, they have learned how to

respond to it and cope with it in a healthy way. It is also important to underscore the inherent privilege in one's ability to work towards, achieve, and maintain recovery. Those who experience stigma, oppression, and healthcare inequities – including the BIPOC, LGBTQIA+, disabled, neurodivergent, elderly, and low SES populations – face significantly more challenges on the journey to recovery than their cisgender, white, heterosexual, middle class counterparts. This is an area that the field is currently addressing in order to bring more equity to those in marginalized communities.

7. There are waitlists everywhere, my child needs help now what do I do?

Waiting for your child to receive care is frustrating. Getting on a waitlist is a great first step. While you are waiting, it's important to connect with your child's doctor for further recommendations and medical monitoring. If your child needs immediate medical assistance, please call their doctor and go to the closest emergency department or urgent care facility. In these instances, your child may require a residential or inpatient level of care, which the emergency department can facilitate once your child is medically stable.

8. We are on a waitlist, I'm nervous my child won't get help in time! What do I do?

There are a few things you can do to be proactive while you are waiting for care to begin. Continue to prepare and monitor your child's meals and snacks. Continue to take your child for regular appointments with their pediatrician to ensure they remain medically stable. Offer to listen to your child's struggles and give them a safe space to be heard. Learn as much as you can while you wait. Check out the books listed in the Further Reading section of this guide. They will get you off to an excellent start. Additionally, consider a support group for yourself. We offer a free Family and Friends drop-in support group every Monday evening at 6pm You can sign up on our <u>calendar</u>.

Resources

Multi-Service Eating Disorders Association (MEDA):

https://www.medainc.org/

MEDA offers a free drop-in support group for all loved ones of someone with an eating disorder. Visit the calendar on our website for more information.

Association for Size Diversity and Health (ASDAH):

https://asdah.org/

F.E.A.S.T (a global community of parents and those who support parents in families affected by eating disorders):

https://www.feast-ed.org/

The Alliance for Eating Disorders Awareness:

https://www.allianceforeatingdisorders.com

The Eating Disorders Foundation:

https://eatingdisordersfoundation.org



1320 Centre St. Suite 101 Newton, MA 02459

www.MEDAinc.org www.RECOVERwithMEDA.org

office@medainc.org

(617) 558-1881 • (888) 350-4049









@RECOVERwithMEDA