

Understanding Eating Disorders:

A Guide for Parents and Families



IN APPRECIATION

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This book is dedicated to our patients and all the other adolescents and young adults who are struggling with eating disorders.

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Eating disorders affect millions of young people and adults around the world of all races and ethnic backgrounds. There are different types of eating disorders including: anorexia nervosa (AN) bulimia nervosa (BN), binge eating disorders (BED), avoidant restrictive feeding intake disorder (ARFID), and other specified feeding and eating disorders” (OSFED). Although some of the symptoms of the different categories of eating disorders overlap, a person can only have one eating disorder diagnosis at a time. Eating disorders are found everywhere, particularly in cultures that focus on weight and body image. It’s not uncommon for negative body image and unhealthy eating behaviors to go together. But eating disorders are about more than weight—stress, trauma, loss of control, and participation in certain sports can all contribute to eating disorders. The dedicated team of authors wrote this booklet for parents because eating disorders have serious health consequences that can be helped or prevented with early treatment. Fortunately, recovery is likely with the help from specially trained health care providers and a supportive family. We hope this information will help you as a parent to understand what eating disorders are, the different kinds of treatment, the recovery process, and how to help your child. This booklet also includes advice for parents written by a young woman who has recovered from an eating disorder, and reflections written by her mom.

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What are Eating Disorders?

Eating disorders are complex medical and psychiatric illnesses that affect a person's physical and mental health, involving intense emotions and disordered behaviors related to food. These are serious illnesses and can be fatal if left untreated.

There are several types of eating disorders and it's easy to get them confused because symptoms may overlap. The different types include anorexia nervosa, avoidant/restrictive food intake disorder (ARFID), bulimia nervosa, binge eating disorder, and other specified feeding and eating disorders (OSFED).

Anorexia Nervosa (pronounced: an-or-rex-e-ah nerve-o-sah) involves significant weight loss, lack of appropriate weight gain or refusal to gain weight, and a distorted body image. People with anorexia drastically limit their food intake (known as food restriction, which also involves cutting out certain foods/food groups) and have an intense fear of gaining weight, even though they may be underweight or have lost a significant amount of weight. Anorexia nervosa often presents during early adolescence (11–13 years of age) or during the later high school years (17–18 years of age), when a teen is preparing to go to college, but can occur in people of any age. Someone with anorexia may or may not binge and/or purge.

Avoidant/Restrictive Food Intake Disorder (ARFID) is a feeding and eating disorder characterized by limiting intake of food or food groups without a fear of weight gain. This eating style can lead to consequences such as weight loss, inadequate growth, or a significant nutritional deficiency. ARFID often presents during early adolescence, with the average age of onset being 12-13 years old. Unlike people with other eating disorders such as anorexia nervosa, individuals with ARFID do not have significant body image concerns.

Bulimia Nervosa (pronounced: bull-e-me-ah nerve-o-sah) (pronounced: bull-e-me-ah nerve-o-sah) involves cycles of binge eating followed by a purging behavior. People with bulimia will eat an unusually large amount of food in a short period of time and then purge by vomiting, using laxatives, enemas, or diuretics, or by exercising excessively as a way to counteract the binge and avoid gaining weight.

Binge eating disorder involves eating an unusually large amount of food in a short period of time. People with binge eating disorder feel out of control during these eating episodes and often feel intense shame or guilt afterwards. People with binge eating disorder do not purge after bingeing.

Other specified feeding and eating disorders (OSFED) involve some combination of symptoms of the other eating disorders such as an intense fear of weight gain and preoccupation with food (thinking about food or having food related thoughts most of the day) but do not meet full criteria for another eating disorder. Many individuals with OSFED have a variety of eating disorder symptoms.

Disordered eating is a term used to describe the condition when someone doesn't have all the symptoms of a specific type of eating disorder, but their eating patterns and behaviors put them at risk for developing an eating disorder. For example, extreme dieting or orthorexia (an obsession with healthy eating) can lead to an eating disorder. Prevalence rates or how often eating disorders occur varies with each disorder and are difficult to pinpoint as many people suffering may never seek treatment and/or be diagnosed. Binge eating disorder and OSFED are typically more common than anorexia nervosa and bulimia nervosa. Roughly 5.4% of adolescents age 13-18 will suffer from anorexia, bulimia, or binge eating disorder at some point, with the rate of OSFED or disordered eating likely higher.

MYTH: Only girls and women have eating disorders.

TRUTH: Although girls are more likely to have eating disorders than boys, eating disorders do affect males. Males playing sports with weight restrictions such as gymnastics, swimming, rowing, wrestling and track are at higher risk, but can occur in anyone. Guys with eating disorders are often focused on gaining muscle mass, so it might appear that they are simply "getting in shape".

Causes of Eating Disorders

There are many theories about what causes eating disorders. There is rarely one cause; most eating disorders are caused by a combination of biological, psychological, and environmental factors. Sometimes the cause may not be completely clear.

There are biological reasons that may help to explain why some young people are more likely to develop an eating disorder. Your child may be more likely to have symptoms of an eating disorder if he/she has ever been diagnosed with a mood disorder, anxiety, or depression. Some people with certain traits or temperament and/or family history of eating disorders are at a higher risk of developing anorexia, bulimia, and/or binge eating.

There are psychological reasons that may put a young person at risk such as being diagnosed with obsessive compulsive disorder (OCD), having past or current trauma such as physical, emotional, or sexual abuse, or if a young person feels the need to have more control over some aspect of their life. Personality traits such as perfectionism, extreme desire to succeed, and impulsivity can also play a role. Family values about body size, appearance, feelings about food, how people feel about themselves and their self-worth are important factors as well.

In today's society, there is an intense focus on thinness and dieting. Websites and social media feeds filled with photographs of thin models as well as articles that focus on weight loss abound. Teens might spend hours each day online, constantly looking at photos and stories, many by "influencers" who do not have an scientific background in nutrition. Even if someone or something is promoting "wellness," their ideas or message may still be influenced by diet culture. Other environmental factors such as participating in sports that place emphasis on body shape and size such as dancing, rowing, gymnastics, track, and wrestling may in some cases influence whether a young person develops an eating disorder. Finally, stress at school, in sports, with peer groups, or at home, along with cultural attitudes about how a young woman or young man perceives how they should look and behave may play a role. Keep in mind that much more research is needed to understand risks and possible causes.

Warning Signs & Symptoms

You can't tell whether a person is struggling with an eating disorder just by looking at him or her, but there are often warning signs. Warning signs or "red flags" might suggest that a young person may develop or already has an eating disorder. Below is a list of signs that are linked to some or all types of eating disorders. These signs may also mean that a person has another kind of health condition, so it's best to talk with your child's primary care provider (PCP) about your concerns before jumping to any conclusions.

- Skips meals, makes excuses not to eat, or avoids eating in front of others
- Over exercises or prioritizes exercise over other previously valued activities
- Doesn't eat certain food groups or nutrients (such as carbs or fats) or starts following a vegetarian, vegan, paleo, ketogenic, or other restrictive diet
- Has unusual behaviors around food such as organizing food, cutting food into small pieces, always finding something wrong with food, or pushing food around on the plate
- Obsessively reads nutrition information or counts calories
- Constantly weighs themselves or "body checks" (looks at their body in the mirror or feels their body with their hands)
- Chews gum constantly or drinks large amounts of water, coffee, diet soda, or calorie-free drinks
- Uses the bathroom after eating or in the middle of meals
- Consumes unusually large amounts of food at one time
- Loses control around food
- Has scars or calluses on hands and knuckles (from using fingers to vomit)
- Hides food or empty wrappers

- Diets often or eats mostly diet foods
- Eats secretly (food may be missing from cabinets at home or disappearing quickly)

If any of these behaviors are a problem for your child, call your health care provider.

MYTH: Everyone with an eating disorder is underweight.

TRUTH: Although people with anorexia nervosa are underweight, individuals suffering from bulimia, binge eating disorder, and OSFED (other specified feeding and eating disorder) can be at a normal weight, or even overweight. Also, people with eating disorders may try and hide their bodies by wearing baggy clothes or dressing differently.

Health Consequences of Eating Disorders

A “health consequence” is a general term for the many negative physical and mental health changes that can result from disordered eating. Some of the dangers may be specific to anorexia nervosa (AN), avoidant/restrictive food intake disorder (ARFID), bulimia nervosa (BN), or binge eating disorder (BED), while other health problems can be associated with more than one type of eating disorder.

If food restriction is involved, the body is unable to get the nutrients it needs to function properly. In an attempt to conserve energy, the body’s natural response is to slow down. Typical symptoms such as a significant decrease in the heart rate (pulse) and blood pressure are a direct result of this process, and bone density can be compromised, which weakens bones and can increase risk for stress fractures and future osteoporosis/osteopenia.

Purging behaviors upset the body’s normal chemical balance. This causes dangerous changes to the levels of electrolytes and subsequently can affect major body organs including the heart. The major risks associated with binge eating may include high blood pressure, high blood cholesterol, heart disease, and diabetes.

The following is an overview of the systems and organs that are affected by eating disorder behaviors. Unless specifically noted, these symptoms may affect anyone with disordered eating. You will note in parenthesis that some of the symptoms and health consequences may be more common in AN, ARFID, BN, or BED.

GENERAL

- Marked weight changes
- Weakness/fatigue
- Dehydration
- Abnormal electrolytes (AN, BN)
- Poor concentration, irritability

SKIN, HAIR, AND TEETH

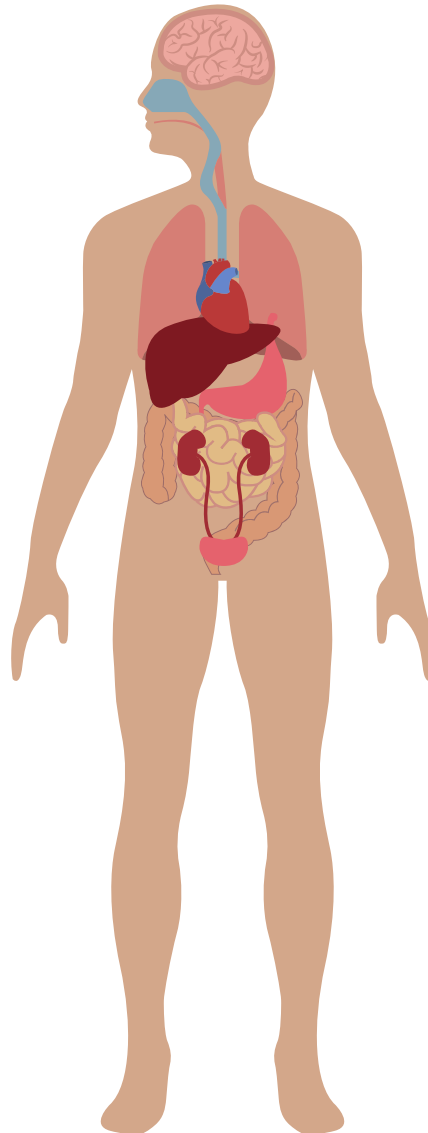
- Dry skin (AN, ARFID, BN)
- Brittle nails (AN, ARFID, BN)
- Hair loss (AN, ARFID, BN)
- Fine downy hair growth (lanugo) (AN, ARFID)
- Cold intolerance (AN, ARFID)
- Tooth decay (BN)

ENDOCRINE

- Delayed growth, short stature, delayed puberty, low hormone levels (AN, ARFID)
- Delayed onset of menses, loss of periods in females (AN, ARFID, BN)
- Abnormal thyroid levels (sick euthyroid)
- Insulin resistance of Type 2 diabetes (BED)
- Loss of libido (AN)

GASTROESOPHAGEAL

- Abdominal pain/bloating
- Constipation
- Reflux



PSYCHOSOCIAL

- Depression
- Anxiety
- Low self-esteem
- Over valuation with weight/shape
- Shame or guilt
- Withdrawal from friends/activities

CARDIOVASCULAR

- Low pulse (AN, ARFID, BN)
- Dizziness (AN, ARFID, BN)
- Low blood pressure (AN, ARFID, BN)
- High blood pressure (BN, BED)
- Arrhythmia/irregular heartbeat (AN, ARFID, BN)

MUSCULOSKELETAL

- Low bone density, osteopenia, osteoporosis (AN, ARFID)
- Stress fractures (AN, ARFID, BN)
- Decreased muscle mass (AN, ARFID)

AN = Anorexia Nervosa

ARFID = Avoidant/Restrictive Food Intake Disorder

BN = Bulimia Nervosa

BED = Binge Eating Disorder

Helping Your Child Prepare for an ED Evaluation

Young people with eating disorder behaviors or symptoms are generally referred to an eating disorder program by their pediatrician, family doctor, nurse practitioner, or physician assistant. As a parent, it's normal to feel stressed, anxious and even guilty. It's important to remember that no one is at fault. An eating disorder is an illness that requires treatment and support. For young people with restrictive intake, food is the medicine that will get your child back to a healthy weight. For young people with other types of eating disorders, normalizing food-related behaviors is essential to restoring physical and emotional health. While no two programs are exactly the same, outpatient programs usually do a complete evaluation and provide treatment for the patient with an eating disorder in addition to support for family members.

The approach is often multidisciplinary, which means that more than one health care provider trained in eating disorders will be involved in your child's evaluation and treatment plan. Team members may also involve others in your family and will meet to discuss a plan for offering the guidance and support your child will need at home. College students and young adults often see the team alone, but even they frequently work with parents or other family members. Team members in many programs include a registered dietitian, mental health and medical professionals. The roles may vary depending on if the program is family-based, if the treatment team is already in place, the age of the child, severity of the illness, and other factors.

The first visit typically includes the following:

1. **Medical Evaluation** by a health care provider who is specialized in caring for children, adolescents and young adults.

The doctor or nurse practitioner will:

- Check your child's blood pressure, pulse, temperature, height and weight
- Ask about your child's medical history and growth, as well as his/her family's medical history
- Ask for notes and growth charts to be sent for review

- Ask questions about your child’s eating habits, other behaviors, and physical symptoms
- Perform a physical exam and order tests which may include blood tests, urinalysis (to see if your child is drinking the right amount of fluids), EKG (a test which looks at the activity of the heart), or bone density test, as needed

2. **Mental Health Evaluation** by a licensed therapist experienced in eating disorder treatment. The therapist may have your child fill out a special questionnaire to assess behaviors.

Your child and the therapist may talk about:

- Eating disorder related behaviors
- Mental health history including depression and anxiety
- Body image
- The family’s concerns
- Thoughts and feelings about being evaluated for an eating disorder
- Treatment goals

Having your child work with a therapist is an important part of his/her recovery. The therapist can help your child work on his/her body image, self-esteem, and discuss any other emotional issues that may affect their eating habits.

3. **Nutrition Evaluation** by a registered dietitian experienced in working with young people with eating disorders and their parents.

The dietitian may talk mostly with your child or only with you (if the treatment is family-based) about:

- Behaviors related to food
- Health goals and concerns about changing behaviors
- Food likes and dislikes
- Common myths about food and eating disorders
- Creating a healthy eating plan

In a culture obsessed with dieting and body image, it can be challenging to have a healthy relationship with food and exercise. A specially trained dietitian can help you and your child create a personal plan for healthy eating and exercise and discuss harmful myths and confusing messages about food and dieting.

After the evaluation:

Your child's health care provider or team will talk to you and your child about a treatment plan that will likely include:

- Which level of care is most appropriate for your child right now
- Individual and family therapy
- Medical monitoring by your child's primary care provider (PCP)
- Nutritional support for you and/or your child with a dietitian
- Other adjunct therapies such as yoga, mindfulness or relaxation exercises

MYTH: People choose to have an eating disorder.

TRUTH: No one chooses to have an eating disorder. Usually a combination of risk factors will lead to a person developing an eating disorder. Recovery involves a lot of time and support from family, friends and eating disorder specialists such as a therapist, dietitian, and medical provider.

The Treatment Team

Eating disorders are both medical and psychological conditions. Therefore, treatment usually includes working with a team of specialists including: a medical doctor or nurse practitioner, licensed therapist, a registered dietitian, and sometimes a psychiatrist or family therapist. If your child will be receiving family-based treatment (FBT), the treatment team will include a specially trained FBT therapist.

MEDICAL PROVIDER

- Keeps track of your child’s physical health by checking height, weight, blood pressure, pulse, and temperature
- Orders blood or urinalysis, if necessary, to make sure the body’s chemicals including “electrolytes” are balanced
- Orders special tests such as an EKG to monitor heart rhythm, or a bone density test (DXA) to monitor bone health and to see if low bone mass or osteoporosis/osteopenia (thinning of the bones) is present or developing
- Provides recommendations on weight goals, calcium and vitamin supplements, exercise, hormone replacement, and medication for anxiety or depression
- Outlines the best treatment options for your child: The medical provider will suggest meeting with a therapist and dietitian, starting a family-based treatment program, or having your child go to a day program, the hospital or residential treatment, until medically stable

THERAPIST

- Helps your child improve self-esteem, body image, and confidence
- Involves parents and other family members in providing support, guidance, and supervision of meals
- Teaches coping skills to help your child manage emotions and stressful situations

- Addresses other emotional problems that may be related to the eating disorder such as depression, anxiety, obsessive–compulsive disorder, or substance abuse
- Creates a place where your child can (privately) discuss his or her needs, goals, and understanding of the eating disorder
- Provides a safe place for your child to talk about feelings such as sadness, anxiety, or anger
- Discusses disordered eating thinking and behaviors
- Teaches strategies to help your child become mentally and physically healthy

FAMILY–BASED THERAPIST

- Provides guidance and support around re–feeding your child
- Teaches you how to manage mealtime conflict
- Empowers you to restore your child’s weight

REGISTERED DIETITIAN

- Helps create a safe and healthy eating plan with your family and child
- Answers questions about food and nutrition
- Offers suggestions on healthy eating, weight stabilization, calcium and vitamin supplements, weight goals, and exercise
- Discusses harmful myths and confusing messages about food and dieting

It’s very important that you and your child meet with a medical provider, therapist, and a dietitian, each of whom has experience working with young people with eating disorders.

Treatment Options for Eating Disorders

Treatment for an eating disorder is a very individualized process. There are different types and different levels of treatment depending on how medically–stable a person is, how much emotional support they need, the availability of licensed therapists trained in different modalities such as family based therapy (FBT), and what you as a parent think is the best approach for your child.

What to expect at each level of treatment:

OUTPATIENT

Most young people are treated in an outpatient setting. Outpatient treatment is useful for those who are medically stable and are able to maintain their normal daily activities. The two most common approaches are multi–disciplinary and family–based treatment. The choices may vary depending upon the expertise of professionals in your community.

Multi–disciplinary: This type of treatment involves visits with a medical provider, licensed therapist, and registered dietitian. On an outpatient basis, medical providers usually schedule visits for patients who are in treatment for an eating disorder anywhere from once a week to once a month. They will check weight, blood pressure, heart rate, and a urine sample to make sure the patient is drinking enough fluids and not overhydrating to influence their weight. Dietitians help by providing information about how much food to eat and what kinds of food will be best for your child. They can offer anything from general guidelines to a structured meal plan. Therapists will assist with strategies to help young people avoid restrictive eating, binge eating, and/or purging behaviors.

Family–based treatment (FBT): This type of treatment puts parents and/or family members in charge of the recovery process. Family members control their child’s food and offer support at every meal and snack with guidance from a licensed

the family-based therapist and a medical doctor, but other health professionals may also be involved. The focus of the treatment is on weight restoration and behavioral change. Once weight is restored the therapy will focus on normal adolescent developmental issues.

How do you know if family-based treatment is right for your family?

FBT works best for adolescents who have been diagnosed with anorexia nervosa and who are living at home and who have been sick less than three years. FBT is an intensive family therapy with three phases over a period of 6–12 months and initially involves the entire family in weekly hour long sessions. Over time, families may attend the therapy every other week. The parents are coached in how to help their child eat (and/or stop purging and over-exercising) and parents are empowered to assume responsibility for their child's recovery.

FBT is a very different approach from traditional therapy and may not be right for everyone or it may not be available in your community. The focus of FBT is restoring weight and eliminating disordered eating behaviors, whereas traditional therapy focuses on understanding why the behaviors develop. In FBT the therapist does not make decisions for the family but serves as an expert consultant; most decisions are left to parents. FBT requires a long term commitment from parents and also requires families to sit with their child during and after every meal.

Whatever treatment is chosen, a strong treatment team and supportive environment is necessary so that your child will be able to restore weight, maintain their goal weight, and return to their life and age-appropriate activities.

INTENSIVE OUTPATIENT PROGRAM (IOP)

This type of treatment is for youth either transitioning back into school or work from residential treatment, or for youth who are not ready for or do not require a higher level of treatment. Intensive outpatient treatment usually involves after school group meetings 3–5 days per week for about 3 hours and includes one supervised meal and snack. Someone at this level may or may not also work with an outpatient team.

PARTIAL HOSPITALIZATION (OR DAY PROGRAM)

This type of treatment is provided for 6–8 hours during the day and patients go home at night. It includes 2–3 supervised meals and snacks, group and individual therapy. Nutrition education is provided along with various other modalities such as yoga and art therapy.

IN-PATIENT

This type of treatment is for people with severe eating disorders who are medically unstable or people who were unsuccessful with treatment at a lower level of care. Patients receive 24-hour hospital care and have a very structured schedule of meals, therapy, and groups. Once medically stable, patients often go to an intensive outpatient program, a residential treatment center, or home with close follow-up.

RESIDENTIAL

This type of treatment is for medically stable patients who need a 24 hour therapeutic environment. Patients live and sleep in a center with others who are struggling with eating disorders. Patients in residential programs have frequent meetings with their team (therapist, dietitian, nurse and/or doctor, and psychiatrist) and various kinds of group meetings. After residential treatment, patients often meet with an outpatient team, or transfer to an intensive outpatient or day program.

Treatment of eating disorders varies from person to person. Some people only receive outpatient treatment, while others may need to transition through some or all levels of care as part of their treatment.

TRANSITIONING

It's very important to support your child when he/she is transitioning from inpatient or residential to outpatient treatment as this process can be very challenging. Here are some tips to help you make this transition easier for your child:

- Before your child leaves inpatient or residential treatment, it's important to set up an outpatient team for regular visits. Ask the treatment team to help you find providers who are experts in eating disorders and who accept your family's health insurance. Usually an outpatient team consists of a therapist, dietitian, a doctor or nurse practitioner, and often a psychiatrist and a family therapist.

- Some days will be easier than others. It's okay and normal for you to have some challenging days with your child.
- You may be asked to be in charge of your child's meal plan. Don't be afraid to seek support from the team, as well as family and friends when necessary, especially around meals. It's easy to feel overwhelmed if you are supervising the meal plan. Think about one meal at a time, and try not to become discouraged if your child has a hard time once in a while.
- Encourage your child to be completely honest with their treatment team and to tell them if and when he/she has any thoughts about disordered eating or is using unhealthy behaviors.

Group Support Meetings: This type of meeting is usually held once a week and can be helpful during treatment. There are also group support meetings for parents and/or guardians who are taking care of children or young adults with eating disorders. At group meetings, parents can provide encouragement and can share stories, feelings, accomplishments, and coping methods. Group meetings can usually be found at local health centers, community agencies, or schools. Ask your child's team about support meetings in your area.

MYTH: People with anorexia don't eat anything.

TRUTH: Most people with anorexia eat, they just restrict the types and amounts of foods they allow themselves to eat. For example, they may only eat foods that are low in fat or in calories or only eat small portions of food.

Therapy for Eating Disorders

Because an eating disorder is both a medical and psychological condition, most people meet with a licensed therapist as part of treatment. Although some families worry about stigma attached to seeing a therapist, it is helpful for parents to encourage their child to keep an open mind because most young people find therapy very helpful.

What are the advantages of having your child see a therapist?

There are a lot of advantages to seeing a therapist and for each person these benefits can be different.

A therapist can:

- Provide a safe place for your child to (privately) share feelings without fear of being judged for causing problems or hurting someone else's feelings
- Give your child a place to address other emotional problems that may be related to the eating disorder such as depression, obsessive–compulsive disorder, anxiety or substance abuse
- Help your child process events in his/her life that may affect mood and can lead to disordered eating or destructive behaviors
- Help your child figure out what caused the eating disorder, what function/role the eating disorder plays in one's life, and what factors may have contributed to the use of unhealthy behaviors
- Help your child examine thoughts that might be distorted, obsessive, or destructive
- Teach your child healthy coping mechanisms to manage stress and strong emotions
- Help your child build self–confidence, self–esteem, and positive body image

"It has always been hard for me to open up even to my closest family members and friends. When I finally started opening up in therapy and sharing thoughts and feelings that I had never talked about before, I noticed a huge difference in my mood and how happy I was. Since then, my friends have told me what a huge difference they see in me and how much more open I am. I know this sounds cheesy, but there is no way this would have been possible had I not gone to therapy." Brooke, 19 yrs.

What are the types of mental health therapy?

Cognitive Behavioral Therapy (CBT): CBT is a type of therapy that teaches your child to understand how thoughts and feelings influence behaviors. CBT helps your child learn to identify and change thoughts that may not be healthy or helpful. CBT is a short term treatment and can also help manage anxiety behaviors.

Dialectical Behavioral Therapy (DBT): DBT is a type of therapy that teaches your child coping skills that are necessary to manage his/her emotions, control and decrease harmful behaviors, and improve interpersonal relationships. It is primarily a group-based therapy with weekly individual therapy. DBT emphasizes skill building and problem solving.

Family-based Therapy (FBT): FBT is a type of therapy that empowers parent(s) to play an active role in helping restore their child's weight to a normal range. This type of therapy is sometimes referred to as the "Maudsley" method. The therapist meets with the entire family on a weekly basis and supports the parent(s) in re-feeding their child. Through the process of helping parents solve problems, the parent(s) learn how to support their child through the recovery process. The goal of FBT is weight restoration and returning the child to normal physiological and psychological functioning. See page 15 for more info.

Outpatient treatments may include other types of family and group therapy.

Group therapy: Group therapy is a type of therapy that involves your child and others close in age who are experiencing similar struggles. The therapy involves meeting with a therapist as a group to gain support, share experiences, stories, and goals.

Family therapy: Family therapy is a type of therapy that involves your child and some or all other members of your family. The therapy involves meeting with a therapist as a group to discuss family relationships and how the family can best work together to support the recovery of your child.

Helpful tips to support your child make the most use of therapy:

- *Recognize that your child may feel uncomfortable at first.* It takes everyone different amounts of time before they begin to feel comfortable opening up to their therapist. If this is your child's first time seeing a therapist, it is totally normal for her/him to be shy, reserved, or even be upset about having to go to therapy.
- *Encourage your child to be honest.* Therapy gives your child a chance to share how he/she genuinely feels without being judged and without offending anyone. Also, young people with eating disorders often have difficulty seeing their weight loss or disordered eating behaviors as a problem, so the more honest your child is with the therapist, the more helpful therapy will be.
- *Make sure that your child feels comfortable with the therapist.* It may take a few sessions for both you and your child to feel that the therapist is a good match. If your child is unable to recognize that they have a problem, it can take longer to feel ready to work on the psychological aspects of their physical health. If the therapist is not a match, which is common, help your child find another therapist.

MYTH: It's almost impossible to recover from an eating disorder.

TRUTH: Complete recovery is possible, but it can take a long time for some people. Recovery can take anywhere from months to years because it requires people to change the way they think and act about food and how they cope. It also takes a team of specialists to address all the issues that led to the eating disorder and is rarely something someone can do without professional help.

What is Healthy Eating?

HEALTHY EATING: Eating nutritionally balanced meals and snacks is important for everyone’s mind and body. During the recovery process from an eating disorder, your child will work with a registered dietitian to normalize eating habits. The goal of eating is to keep your child’s body nourished, energized, and strong. Eating in a healthy, but inclusive and balanced way will help your child to concentrate and learn in school, reach and maintain a healthy weight, grow to a maximum height, and stay strong for sports and other physical activities. Healthy eating is not supposed to be a strict diet plan; it is flexible and may differ from person to person. It involves eating regular meals and snacks, along with occasional treats. To eat in a nutritionally balanced way, your child should eat foods from all of the food groups (carbohydrates, proteins, fruits, vegetables, dairy, and fats) as well as some “fun” foods because each group has different benefits for the body and the mind.

Carbohydrates: The carbohydrates in foods like grains and starchy vegetables supply the brain and muscles with energy. They help keep our minds sharp and focused and are needed for physical activity.

Dairy: Vitamin D fortified and calcium–rich dairy foods help to keep our bones strong. The protein in dairy foods also helps keep us full between meals.

Fruits/Veggies: These foods contain many important vitamins and minerals, as well as fiber which is necessary for normal digestion.

Protein: Protein has many important functions in the body from nourishing hair and nails to repairing and building muscles.

Fats: Fats found in oils (such as canola oil or olive oil), nuts, and fish are great for our heart and skin, help us make important hormones and provide energy.

MEAL PLANS: Meal plans are designed to help your child transition back to healthy eating. During treatment, your child may get a meal plan from the registered dietitian that breaks down each meal into servings of food (called “exchanges”) from the

different food groups. Each meal should include exchanges from all or most of the food groups, and the number of exchanges that your child needs (from each food group) will be based on his/her nutritional needs. The dietitian will help design meals and snacks based on the exchanges on the meal plan that fit your child's individual needs. Meal plans are not typically used if the family is participating in family-based therapy (FBT).

SNACKS: Snacks give your child energy between meals and will prevent him/her from getting overly hungry. Healthy snacks should be made of two or more food groups. In the sample list of snacks below, you can see how the snack ideas are made from different food groups such as the carbohydrate, fat, dairy, fruit, vegetable, and protein groups.

Sample Snack List

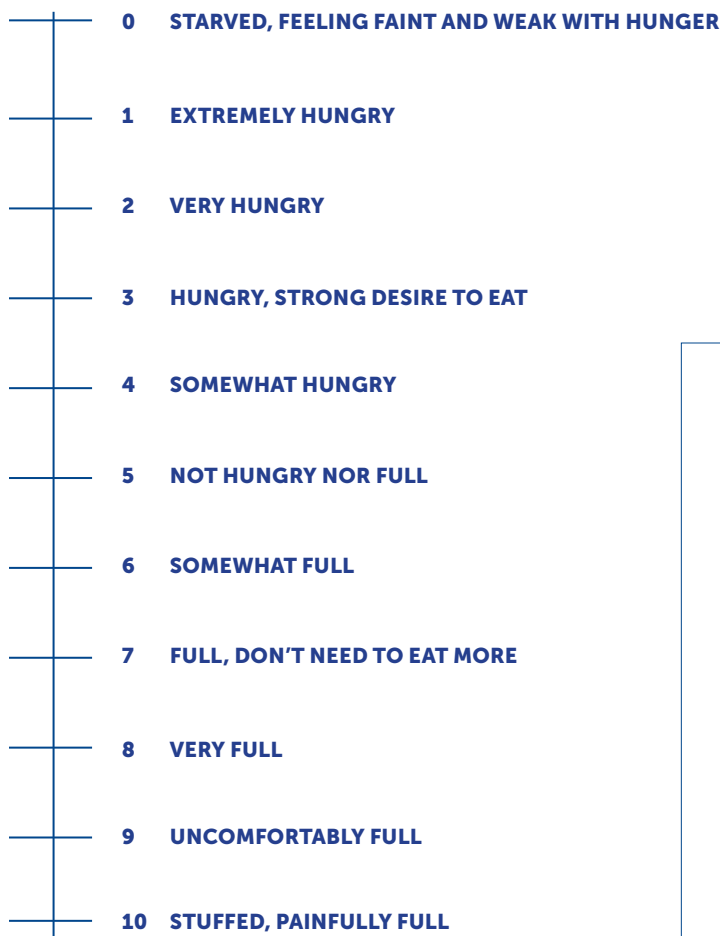
- Banana with 1 tablespoon of peanut butter (fruit/protein/fat)
- Grapes and a cheese stick (fruit/dairy/fat)
- Whole milk vanilla yogurt with strawberries (dairy/fruit/fat)
- Cheese and whole grain crackers (dairy/carbohydrate/fat)
- Hummus and baby carrots (protein/vegetable/fat)
- Nuts and dried fruit (protein/fruit/fat)

GROCERY SHOPPING: Ask your child if he/she is comfortable going grocery shopping with you. Your child may be working with a registered dietitian to set goals for trying new foods or reintroducing foods. If going to the grocery store seems stressful for your child, he/she can create a list of foods with the dietitian beforehand. Once your child is more comfortable with grocery shopping, take time to explore the entire grocery store and look for different brands or new foods to try.

COOKING: Planning your child's meals and snacks ahead of time can minimize the stress during meal preparation. The dietitian can assist with meal planning and brainstorm about ways to give the best support around meals and snacks.

HUNGER AND FULLNESS: Eating when we're hungry and stopping when we're full helps our bodies balance energy needs and keeps us comfortable. Throughout the recovery process the dietitian can help your child understand how to tune into the body's hunger and fullness cues. Learning to both listen to and understand our body's cues takes time. Using a hunger and fullness scale such as the one below can help young people better understand their bodies. A scale will help your child learn to eat when feeling like a "3" and stop eating when reaching a "7."

Sample Hunger and Fullness Scale:



MYTH: Eating disorders are just an extreme form of dieting.

TRUTH: Unlike dieting, eating disorders aren't just about losing weight. Eating disorders are psychological problems that may be used as a coping mechanism for issues such as trauma, loss of control, or abusive relationships.

Healthy Exercise

Why is exercise important?

Physical activity, or exercise, has positive effects on the body and the mind. During exercise, our heart and breathing rates increase, making those systems stronger, and insulin (the hormone that allows glucose to nourish the body's cells so they can function) works more efficiently in people who exercise. Also, our bodies make "endorphins" during exercise which are natural pain and stress reducers. Through organized sports young people can exercise while also learning new motor skills, the social skills necessary to work as a team, and, most importantly, to have fun. Research studies have shown that people who exercise have a lower risk for heart disease, obesity, and diabetes.

Exercise and healthy nutrition go together!

How much exercise is too much?

General guidelines for children up until the age of 17 years, such as those put forth by the Center for Disease Control (CDC), recommend 60 or more minutes of physical activity each day, with 3 of those days including moderate to vigorous activity and muscle strengthening. Health risks associated with exercise, such as over-use injuries, stress fractures, or menstrual irregularities in girls, become apparent when young people, parents, and/or coaches suggest that excessive exercise is better, or when the goal of exercise changes from improving health to weight loss.

When should I be concerned about the amount of exercise my child is participating in?

First, you should ask your child why they are exercising. If they are exercising to get better at a sport, to practice with a team, or because his/her health care provider recommended it, this is much more reassuring than if your child is exercising because it helps to lessen anxiety, or if the goal is to lose weight when they are already at a healthy weight or even underweight.

Examples of worrisome exercise habits. If your child:

- Exercises to the point that sleep, social interactions, or school work are affected.
- Is overly concerned with his/her physical appearance and muscle tone.
- Exercises when sick, or at an unhealthy low weight.
- Prefers to exercise rather than spend time with friends or family.
- Exercises secretly or much more than is required for sports.
- Exercises without increasing his/her caloric intake.
- Exercises despite being told by a medical provider that it's not healthy to do so because of low weight/weight loss, low blood pressure and/or low heart rate, over-use injuries, or stress fractures.
- Becomes very upset and/or anxious when he/she can't work out or go to the gym.
- Exercises before or after meals to "burn" off calories.

Menstrual irregularities or lack of menstrual periods, stress fractures, dizziness or fainting, fatigue, chest pain, recurrent injuries or extremity pain, and excessive weight loss in a young person should prompt an evaluation by a medical provider.

You may have heard of the "female athlete triad" — lack of periods, disordered eating (or insufficient nutrition for exercise leading to low energy), and low bone mass (with increased stress fractures). Medical evaluation is important to identify and address all the symptoms.

How should I talk to my child about exercise?

You might start by saying, *"I'd like to talk to you about what your health care provider mentioned during your appointment. What do you think about what he/she said regarding your weight, how much you are exercising, etc.?"* The goal is both healthy adequate nutrition and exercise. This dialogue can open the door to ongoing and honest communication. Adolescents and young adults who have a difficult time opening up to their parents may feel more comfortable talking with a teacher, therapist, coach, or school nurse. Parents can communicate their concerns to these

individuals, and their child's medical provider, working as a team to provide the optimal emotional care and advice for their child.

Remember, it is important for you as a parent to model healthy behaviors. Your child should be able to see you exercise for health and wellness. Try to avoid making comments about "earning" certain foods by "burning" enough calories.

MYTH: You can never exercise too much.

TRUTH: It's possible to over-exercise and it can actually be very dangerous. Over-exercising or "compulsive exercising" is actually a form of purging. Compulsive exercisers will make exercise their top priority, feel guilty when they don't exercise, use exercise as a way to either "earn" or "burn off" food, and exercise an excessive amount.

Yoga

Research studies have shown that yoga is helpful for some patients in treatment for and/or recovery from eating disorders. In one study, patients who practiced yoga had a decrease in eating disorder symptoms such as food preoccupation immediately after yoga sessions as compared to patients who were not exposed to yoga. Other research studies have shown that yoga can be an effective adjunct therapy to standard treatment. This may be due to the positive outcomes that your child may feel during and after a yoga session such as a deep sense of peace and relaxation, or feeling at ease in their body. For some patients with eating disorders, this may be a totally new experience, and may be uncomfortable at first.

What is yoga?

Yoga typically combines physical poses and breathing practices, with verbal commentary from the instructor to help each student focus on the present moment. There are different types of yoga; some are more physically demanding and other types are more relaxing and meditational. With regular practice, most forms of yoga can help individuals stay calm in stressful situations off the yoga mat. Yoga can even improve a person's concentration and sense of wellbeing. Yoga is meant to be an individual, non-competitive, self-paced practice.

What are common styles of yoga that might be appropriate for my child?

- **Ananda:** This style of yoga uses gentle movements, meditations, affirmations, and specific breathing exercises as a way to increase present awareness. This style is not meant to be aerobic.
- **Iyengar:** This style of yoga focuses on exact physical alignment, and may use blocks, straps or props to adapt poses for all levels. While precise focus on alignment can certainly help to ensure a safe practice, individuals with eating disorders may be prone to try to do a pose "perfectly." Here, it may help to remind students that yoga practice is just that, a practice (and no practice is perfect).

- **Integral:** This style is a combination of postures, breathing techniques, and relaxation which emphasize the purpose of the practice rather than specific postures. The practice tries to integrate the mind, body, and spirit.
- **Kripalu:** This gentle style has 3 stages. The first stage includes learning the postures and how to coordinate breath with body movement. The second stage includes meditation techniques with the postures, which are now held for a longer periods of time. During the third stage, the postures can become spontaneous and unstructured, often called “meditation in motion.” This style is known to be welcoming and individualized, making it a great starting practice for those new to yoga.
- **Sculpt yoga:** This is a newer, less traditional form a yoga that is popping up in many group fitness classes across the country. It combines vinyasa flow with cardio and resistance training. This type of class is not recommended for patients with eating disorders as it focuses on “sculpting” and “toning” the body, and it is more aerobic.
- **Vinyasa:** This style, also known as “flow yoga,” involves connecting movement with breath, balance, and intention. Vinyasa yoga is unique in the fact that the instructor has more freedom to create a series of postures, often drawing upon different styles. For individuals with eating disorders, a slow, meditative flow is encouraged over a more vigorous, aerobic flow as the latter could be used for weight loss or calorie–burning. Sometimes vinyasa yoga is offered as “hot” yoga (in a heated room); this particular type of yoga is not recommended for individuals with eating disorders as it may trigger thoughts related to weight loss or calorie–burning. “Hot” yoga may also be dangerous if your child is not properly hydrated or tends to restrict fluids.
- **Yin yoga:** This style may also be called “restorative yoga.” Yin yoga uses a series of postures that help to relax muscles (rather than poses that cause muscles to tighten). Most of the postures are done on the floor, focusing on deep stretching with intentional breathing. Postures are often held for 3–5 minutes. Yin yoga is often used to help manage stress.

What’s the connection between yoga and breathing?

Awareness of breath is the foundation of yoga practice. Different styles of yoga teach various techniques; however, the goals are ultimately the same. Breath regulation is a tool. When a person practices yoga regularly, they gain a strong awareness of how

their breath can affect their state of mind or their mood. Observing one's breath is a great way to remain focused on the present moment during yoga class; it may also help improve concentration or reduce stress outside of class.

What's the relationship between yoga and meditation?

Yoga and meditation are closely related. Just as there are many styles of yoga, there are also many different forms of meditation, all with a slightly different meaning. For example, meditation may mean practicing relaxation techniques or learning the skills to concentrate on a specific object. For some, it may be a spiritual practice; for others, it may simply mean going about their day with greater awareness and attention. The most common form of meditation in yoga occurs through focusing on the breath. Another form of meditation may include a gentle, yet focused gaze as one moves through yoga postures.

Meditation is not required in yoga, but it certainly enhances a yoga practice. In fact, research in teens has found that practicing yoga along with breathing and meditation exercises may help improve relaxation and the ability to focus.

What does my child need to know before taking a yoga class?

Before trying a yoga class, you and your child should talk to their primary care provider about the type of yoga they would like to practice to make sure the yoga style and frequency are appropriate for their recommended level of activity and their stage of recovery. They should tell their yoga instructor if they have any limitations related to duration of practice, need for rest, or even physical conditions secondary to an eating disorder.

THREE IMPORTANT POINTS ABOUT YOGA:

1. **Yoga should never hurt!** With regular practice, your child will learn to listen to his/her body. If a position hurts, they should get out of the posture. You can encourage your child to ask their yoga instructor about modifications for any posture, as they should never force a position that doesn't feel right.
2. **Different postures, different classes, different benefits.** Some postures such as "standing" poses can help strengthen and energize the body while deep stretching postures are considered passive and restorative, helping the body relax. Again, always encourage your child to view yoga as a practice, never an activity where perfect poses or a perfect body are strived for.
3. **Comfortable clothes are yoga clothes.** Your child does not need special clothing to participate in yoga.

MYTH: You can never eat too healthfully.

TRUTH: When someone becomes obsessed with only eating foods they think are "pure" or "natural" and limits their food intake to a very narrow selection of "healthy" foods, it can lead to what is called "orthorexia" and may be considered a type of eating disorder. People with orthorexia often will avoid eating "unhealthy" foods such as those with fats, preservatives, artificial ingredients, and/or processed sugar. Such extreme eating practices can lead to malnutrition.

Body Image and Self–Esteem

Young people are constantly exposed to unrealistic standards in the media, such as airbrushed images, skinny models, and overly muscular models, and thus may feel pressure to lose weight or look a certain way. Because of these pressures, many children, teens, and young adults develop poor body image and low self–esteem. Although it’s normal for young people to not feel completely content while their body is changing, it’s important for your child or teen to find ways to feel comfortable with their natural shape and size.

Body image and eating disorders are often perceived to be problems for girls and women, so there is some social stigma for boys and men who are dissatisfied with their bodies or engage in disordered eating behaviors. Generally, research shows that males report lower levels of body dissatisfaction than females; however, males do report desires to lose weight and be thin, and they may focus on muscle size, tone and definition, and maintaining low levels of body fat. Research has shown that for people who identify as gay, lesbian, or bisexual, rates of binge eating and purging by vomiting or laxative abuse were elevated, in comparison to their heterosexual peers.

The risk of eating disorder behaviors such as restricting, purging, or binge eating are more common in certain sports that require weight restrictions such as wrestling or lightweight rowing, or put an emphasis on aesthetics, such as gymnastics, dance, or skating. These behaviors are also common in endurance sports (running, swimming, cycling), as the misconception of “race weight” may drive some of these disordered eating practices. However, athletes in all sports are at risk for disordered eating behaviors and poor body image, especially since coaches and athletic trainers sometimes do not have a thorough knowledge of eating disorders and may make triggering comments about an athlete’s size or shape in relation to their performance.

Body distortion: Body distortion is when people see their body shape, size, and appearance differently from what everyone else sees. Body distortion causes a person to over–focus on flaws or imperfections and feel insecure. Most people who struggle with an eating disorder worry about how they look and what people think of them and have body distortion issues that can be hard to change.

How can I support my child?

- Buy clothes that your child likes and feels comfortable wearing and give away any clothes that make your child feel self-conscious or uncomfortable.
- Suggest relaxing activities such as listening to music, yoga, playing a game, singing, or meditating.
- Remind your child that everyone's body is different and that not everyone is meant to be the same shape or size.
- Encourage your child to spend time with positive people with whom they feels completely comfortable around.

The therapist may suggest writing exercises and activities for your child to do, such as:

- Make a list of accomplishments
- Write down 10 things he/she likes about himself/herself (caring, responsible, funny, smart, creative etc.)
- Write down things that he/she can do when feeling healthier (such as running, dancing, hiking, biking, etc.)
- Write or journal about 5 or more body parts that he/she likes and why (ears, eyes, legs, teeth, hair, etc.)
- Be critical of advertisements, magazines, and the media. Write a letter to a company if an ad is upsetting or hurtful.
- Smile when looking in the mirror. It might feel funny at first, but after a while, many people begin to see themselves in a more positive way.

MYTH: The media is the cause of all eating disorders.

TRUTH: The media's constant focus on dieting, losing weight, being thin, or being muscular can contribute to an unhealthy obsession with food and weight, but whether or not someone develops an eating disorder has a lot to do with other factors too.

Do's and Don'ts for Parents

When someone is struggling with an eating disorder, they often need a lot of help and support from family and friends. As a parent, it can be hard to know the best way to provide this support. Meal time can be very challenging during the recovery process and thus it's very important to know how to best provide both support and encouragement.

DO:

- **Eat together.** Make sure that you are eating regular meals and snacks just like your child is expected to do.
- **Keep conversations positive during meals.** Talk about things your child is interested in such as sports, hobbies, or current events. Make sure the conversation feels natural rather than fake or forced.
- **Try to reduce stress and “food talk” at the table.** You are eating with your child to normalize meal times and to ensure that they are getting the proper nutrition and restoring weight.
- **Distract after meals.** Having something to do for at least 30 minutes after meals or snacks can serve as a distraction. Distractions may prevent your child from engaging in behaviors (such as purging) or from having obsessive thoughts about what they ate.
- **Plan ahead.** As a family, agree on the structure of meals such as what time you will eat. Every family has a different style of eating, but make sure that your child has some sort of structure around meals.

DON'T:

- **Don't talk about food or treatment-related things at meals.** Avoid talking about food, calories, fat, and portion sizes. Don't talk about doctor's appointments or even progress unless your child wants you to acknowledge a specific accomplishment (such as eating a food that is challenging for them).

- **Don't use food as a reward or punishment.** Not only can this practice lead to more disordered thoughts around food, it could trigger new behaviors.
- **Don't label food as "good" or "bad".** Avoid commenting on the types of food or amount of food your child is expected to eat as part of his/her treatment.

Additional tips

- **Learn about eating disorders.** It's important to learn about the general causes and consequences about eating disorders. Also, listen when your child talks about his/her experience with having an eating disorder and thoughts and opinions about treatment.
- **Be understanding.** Although you might not agree with or understand what your child is going through, it's very important to listen and avoid saying anything that may sound judgmental.
- **Be patient.** Recovery is a long process that has its ups and downs. While some young people may be weight restored, it can take anywhere from months to years for someone to be completely recovered. Keep this in mind, because your child will need continued support.
- **Model healthy eating and exercise habits.** You can be a great role model by having a healthy relationship with food and practicing healthy, moderate exercise habits.
- **Suggest journaling.** Journaling can be a very good way to release anger or deal with intrusive thoughts. It's also a good way for people with eating disorders to examine their thinking, keep track of accomplishments and challenges, and set goals.
- **Help your child find new interests.** Suggest new activities to replace disordered behaviors such as excessive exercise, restrictive dieting, or overeating with healthy interests and new ways to cope with feelings.
- **Encourage your child to continue with long-term therapy.** Meetings with a licensed therapist and registered dietitian can be a good way for young people to check on how they are doing with thoughts and behaviors even after the symptoms are under control. There can still be challenging days even in later stages of recovery,

and therapy is a safe place to talk about other challenges your child may be facing outside of the eating disorder.

- **Avoid “health” or fashion magazines.** Most of the images have been altered to make the models look perfect, which can trigger negative body image and other negative feelings in teens struggling with an eating disorder.
- **Try to avoid diet or follow rigid exercise routines.** Remember, you are a role model of healthy living for your child. Try not to be self-deprecating or say things like “you need to eat this way but I shouldn’t because I need to lose weight”
- **Don’t make comments about exercising to “burn off” calories or “earn” food.** This will encourage exercise as a way to reduce guilt your child may feel after eating. Over time, this may lead to excessive exercise.
- **No need to purchase diet foods or products (such as protein bars or shakes) for your child that make claims about losing weight or gaining muscle.** These products suggest that certain foods can change how our bodies look.
- **Don’t make your child feel guilty.** Many people who are struggling or recovering from an eating disorder feel like they are a burden to the family. Make sure that you remind your child that you want them to get better and that their recovery and health is very important to the entire family.
- **Avoid making comments about appearance.** Statements such as “you look great,” “you look healthy”, or “you’ve gained weight,” often make people with eating disorders extremely uncomfortable. Comments like these are often interpreted as negative. For example, a statement such as “you look better” may be interpreted as “you look fat!” to someone with an eating disorder.
- **Don’t treat your child differently than you did before being diagnosed with an eating disorder.** Because there is so much focus on “the patient” during treatment, it’s important for your child to feel as normal as possible.

MYTH: Only white, upper-class teens suffer from eating disorders.

TRUTH: Eating disorders affect all races, ages, and socioeconomic groups.

What I Wish My Parents Knew

A powerful and true story as told by a patient recovering from an eating disorder

"It was never about weight. I just wanted to feel like I had some control."

I never thought I was fat. In fact, I liked the way I looked before I developed an eating disorder and liked my body less and less as I continued to lose weight. What a lot of people, including my parents, didn't understand is that an eating disorder functions as a coping mechanism for other problems in someone's life.

As I met more people who suffered from eating disorders, I realized that almost everyone had something in common. Everyone that I met felt some sort of loss of control in their life and had used their eating disorder as a reaction or way to deal with it. Although for some people bad body image did play a large role in what started their eating disorder, for a lot of people it was the feeling of losing control in their life that they discovered was the initial cause of their eating disorder.

For someone with anorexia nervosa, through extreme dieting and strict rules around food, they are able to gain control of more than one thing in their life. They can control what they eat, and eventually the shape and size of their body. Although it is an unhealthy coping mechanism for feeling like they have no power over their life, their eating disorder gives them a sense of relief that there is one thing in their life they can completely control without anyone else being able to have an influence.

Many people I met who suffered from binge eating disorder or bulimia nervosa suffered from abuse, trauma or other stressors in their life that made them feel like they had no control over themselves, or their emotions. This loss of control over their life eventually materialized into a loss of control around food, known as a binge.

I think the most common misconception about eating disorders is that they are all about weight and shape and therefore are easy to overcome with increased self-esteem and confidence. Although both of these are crucial parts of recovery,

people fail to understand that recovering from an eating disorder is a much more complicated process. It involves diving much deeper to find what function the eating disorder plays in their life, and what advantages and relief it provides that leads them to engage in behaviors that they know are extremely unhealthy, and often hate.

So, what I wish all parents knew about eating disorders is that they are not superficial diseases that are all about losing weight and wanting to be skinny; they are a coping mechanism.

What can parents do to help?

- **Listen to whatever information your child might be open to discuss.** Be sure to keep an open mind to what they are saying and to never sound judgmental, even if you can't understand what your child is going through. If your child is not ready to talk about what he/she is going through, don't force them because they might not be ready to open up. It's really important to be patient and let your child know you will be there to support them when they are ready to talk.
- **Never make your child feel guilty for what he/she is going through or how he/she feels.** No matter how much you might not understand what your child is going through, and no matter how hard and taxing the treatment process may be, make sure that you are supportive and don't make it seem like your child is a burden to you. There were a lot of young people I met who were struggling with an eating disorder who were afraid to ask for the help and support they needed from their parents because they were afraid they would be too much of a burden on their family.
- **Be open to family therapy.** Family therapy can be one of the hardest, but most useful parts of treatment for an eating disorder. It gives the family a chance to discuss what your child is going through and talk about family issues when there is someone else who can act as a problem solver. Family therapy is also a good place to figure out what are the most helpful ways to offer support.

MYTH: Someone can only ever have one type of eating disorder.

TRUTH: People with one type of eating disorder can develop symptoms of another eating disorder over time. For example, some people who restrict their food intake will go on to develop bingeing eating and/or purging behaviors.

Other things I wish my parents knew about eating disorders:

I don't want to have an eating disorder, but I am scared of what will happen if I get rid of it.

No one enjoys having an eating disorder. The two years I struggled with an eating disorder were the hardest years of my life. Having an eating disorder impacts every single part of your life and really does consume you. It impacted not only my health, but also my social life, school work, and personality. All my friends who struggled with an eating disorder agreed that as their eating disorder became more severe, the more it controlled and even ruined their life.

However, because eating disorders function as a coping mechanism, they obviously also offer a sense of relief and benefits. Many of my friends who were struggling with an eating disorder said that they couldn't picture their life without their eating disorder because it got them through some of the hardest times of their life. When a lot of them sat down to make a list of pros and cons of their eating disorder, they would find that the positives outweighed the negatives. Because of this, a lot of people find themselves struggling to find motivation to recover from their illness and to ask for the help they need.

I needed a wake up call.

Although it was obvious to my parents and friends that I was struggling with an eating disorder for over two years, no one directly approached me about having an eating disorder. Over those two years, people did express their concerns about me losing weight and how I was acting differently, but every time I would explain my way out of it and assure them that nothing was wrong. Because of this, I was even able to convince myself that I was completely fine and didn't have an eating disorder.

Looking back, if my parents and friends had been more straightforward with me about having an eating disorder, I might have gotten the wake up call that I needed to ask for help. Like I said before, because eating disorders are coping mechanisms, they serve a function and a lot of the time someone might be too scared to give it up and would benefit from a push from someone else.

Tips for parents on how to talk to your child if you are worried about an eating disorder:

- **Be direct.** *One of the most important things is for you to be completely honest about exactly what you have noticed and what you are worried about; don't avoid the issue.*
- **Don't expect a positive reaction.** *People can be very defensive when they are confronted about having an eating disorder because they go through a lot of effort to hide it, or don't want to admit that it's actually a problem. Because of this, they might have a lot of excuses to explain away your concerns about their behaviors.*
- **Be supportive.** *Make sure your child knows that you are there for them when they are ready to talk, but don't force your child to talk right away if they are not ready.*
- **Be proactive.** *Even if your child isn't ready to admit that he/she is struggling*

MYTH: Eating disorders aren't very serious.

TRUTH: Eating disorders can cause very serious medical problems. Most of these medical problems are a result of malnutrition (not getting enough nutrients) or electrolyte imbalance from weight-loss behaviors such as vomiting or laxative abuse. Eating disorders must be taken seriously and require treatment before they become too severe.

My Daughter's Journey

Looking back at my daughter's journey with an eating disorder, I wish we had known more about ways to help her when her struggle began. We were so concerned, and most of the time felt helpless.

Getting well is an uphill battle in itself– add the pressures of daily life, school, deadlines and daily tasks. Next, pile on a large serving of people who are trying to “help” and offer advice– and it all becomes completely overwhelming. It is no surprise that so many girls choose to suffer from eating disorders in silence.

I quickly realized that almost all of the people in my daughter's life didn't understand eating disorders or her well enough to be useful in her recovery. By the way, that included me, and my daughter herself. She needed someone to call her out, bring her, and all of us into reality to get the process started. Our inaction was yet another roadblock to her getting better. I am sure she thought “if no one is saying anything, things must not be that bad.” There was also the added bonus of many people around her saying things like: “she is just thin because she is an athlete,” or “it must be nice to be so thin– you look great in everything...just like a model!”

Even with my own eating disorder history around the same age, I missed many signs, which now seem so glaring. My daughter and I were then, and still are, incredibly close; she is my best friend. Many people advise that this is in the first chapter of Mothering 101: “Be her parent, not her friend”. I bring this up because so many moms I have spoken to who have daughters with an eating disorder blame themselves because they were not close enough. So, I got past blaming and started looking for solutions.

The turning point was getting a professional evaluation. We found the right specialists, listened to the hard facts, and then we all took a big sigh of relief. They understood her, and they could help her. They could help us help her too.

Once we began to better understand and empathize with the severity of our

daughter's struggle, it seemed easier for her to accept guidance and start making changes. We were wrapped up in the "when do we step in, when do we step out?" dilemma. We wanted to be there for her, but we also understood she needed space so she could develop a balance between accepting her personal responsibility for getting better and knowing when to ask for help. A friend described the parents' role as similar to driving a standard car – the fine balance between clutch and gas pedal.

As she began her inpatient treatment, my daughter developed a love/hate relationship with her doctor, therapist and nutritionist team. They were the 'truth squad' and that is what she needed. We did too. Family therapy was an essential element in creating a support system for her as she transitioned back into her regular life. We wanted to make our home a safe place she could return to with people who understood her better and knew how to help.

My daughter is educated and armed with skills to recognize when she is slipping and ask for help if needed. As she gets stronger, the 'truth squad' she has developed in her own head will be there to guide her. We love her so much and now feel she is in a safer place. She says that overcoming her eating disorder was both the most difficult and most important experience of her life.

Glossary of Terms

With an eating disorder, suggest seeing a therapist to talk about other issues and stresses. Also, make an appointment with their health care provider for a check-up.

AMENORRHEA: When a female does not get a menstrual period. Amenorrhea can be a sign that someone’s weight may be too low, the person is not eating a healthy balanced diet, or that the hormones in her body are not working properly.

ANOREXIA NERVOSA: People with anorexia drastically limit their food intake and have an intense fear of gaining weight, even though they might be significantly low weighted.

ARFID: Avoidance restrictive food intake disorder, which is marked by unhealthy weight, nutritional deficiency, and/or interference with social functioning without having a fear of gaining weight or body image concerns.

BINGE EATING DISORDER: People with binge eating disorder eat an unusually large amount of food in a short period of time and feel a loss of control during this episode. They do not purge afterwards, but feel a lot of shame or guilt about their binge eating.

BMI: Body Mass Index is a number that is calculated from someone’s weight and height. It provides a scale to determine whether or not a person is below, in, or above their healthy weight range based on their height and age. Normal values for BMI change with age. For example, the BMI of a 12-year-old girl in the 50th percentile (average range) is approximately 18. The BMI of a 15-year-old girl in the 50th percentile is about 20. For a 12 year old boy, the 50th percentile is about 19, while for a 15 year old boy it is 20. For adults, the “normal” or “healthy” BMI is 18.5–25, while younger adolescents who are of average height and weight may have a BMI that is 18–20. Although BMI can change when a child is growing or going through puberty, teens should ideally stay at about the same BMI percentile during their teen years. You can see the percentile on their growth chart at the medical provider’s office.

$$\text{BMI} = \frac{\text{Weight (in kilograms)}}{\text{Height (in meters)}^2}$$

BONE DENSITY: A measure of how dense and solid bones are. Bone density is typically measured by a DXA scan.

BULIMIA NERVOSA: Cycles of binge eating followed by a purging behavior due to fear of gaining weight. People with bulimia will eat an unusually large amount of food in a short period of time and then exercise excessively or purge by self-inducing vomiting, using laxatives, enemas, or diuretics in an attempt to avoid gaining weight.

COGNITIVE BEHAVIORAL THERAPY (CBT): A type of therapy that teaches your child how to be aware of the thoughts that occur when he/she experiences different emotions. CBT targets thoughts and behaviors that are unhealthy or unhelpful.

CHALLENGE or FEAR FOODS: Foods that people with eating disorders try to avoid because they may be considered unhealthy or because eating them may lead to bingeing or purging/vomiting. They may also be called “trigger” or “risk” foods.

DIALECTICAL BEHAVIORAL THERAPY (DBT): A type of therapy that teaches your child coping skills that are necessary to manage their emotions, control and decrease harmful behaviors, and improve interpersonal relationships. It is primarily a group-based therapy with weekly individual therapy. DBT emphasizes skill building and problem solving.

DXA SCAN: DXA (sometimes referred to as DEXA) stands for “Dual-energy X-ray Absorptiometry”. It is the most widely used method to measure bone density in the clinical setting, giving an estimate of how solid a person’s bones are. DXA provides information on whether a person has lower than normal bone mass for age, sex, and ethnicity, which would put him/her at increased risk for fractures. DXA scans are painless and involve very little radiation.

EATING DISORDER BEHAVIORS: A term used to describe habits that people develop when they have an eating disorder. Eating disorder behaviors may include purging (vomiting after meals), counting calories, exercising obsessively, binge eating, skipping meals, or eating very small meals.

EKG: A test that looks at the activity of the heart.

ELECTROLYTES: Electrolytes include sodium, potassium, chloride, and bicarbonate. Normal levels are important to keep the heart and body working properly. These levels can be affected by restricting food, laxative abuse, and self-induced vomiting.

EXCHANGES: A term used to describe servings of foods from different food groups (in specific portions). Some meal plans are based on the exchange system, meaning they are divided into main groups (such as protein, fat, starch/grain, dairy, fruit, and vegetable).

FAMILY–BASED THERAPY (FBT): A type of therapy that empowers parents to play an active role in helping restore their teen’s weight to a normal range. This type of therapy is sometimes referred to as the “Maudsley” method. The focus of the treatment is on weight restoration and behavioral change.

FAMILY THERAPY: A type of therapy usually led by a licensed therapist where some or all members of a family meet to discuss family relationships.

GOAL WEIGHT RANGE: A range of weight that a treatment team decides is a healthy weight for recovery. A goal weight range takes into account what a person weighed before having an eating disorder. A person’s goal weight range will increase as they grow and get older. The goal weight is also adjusted depending if a young woman’s menstrual period returns naturally, which often signals a minimum healthy weight.

GROUP THERAPY: A type of therapy usually led by a licensed therapist where peers struggling with similar issues share experiences and stories with each other.

HIGHER LEVEL OF CARE: Any level of care higher than outpatient which might include intensive outpatient program (IOP), partial hospital program (PHP), residential, or inpatient.

INSULIN RESISTANCE: A condition that occurs when a person has high levels of insulin because the body organs are not sensitive to normal levels of insulin, meant for keeping their blood sugar in the normal range.

MEAL PLAN: An eating plan that is designed by a dietitian. A meal plan gives recommendations about the amount and types of foods that should be eaten to achieve or maintain a healthy weight.

OSFED: Other specified feeding or eating disorder, which is some combination of symptoms of eating disorders such as an intense fear of weight gain and a preoccupation with food (thinking about food or having food related thoughts most of the day) that does not meet the clinical diagnosis for another eating disorder.

PERCENT MEDIAN BMI: A number which is calculated to compare a young person's BMI to a reference population. Percent median BMI is used to establish treatment goals and monitor progress. Percent median BMI is being used in place of "ideal body weight" or "median body weight."

PURGING: A term used to describe any behavior that someone with an eating disorder uses to "get rid of" calories. Purging behaviors include vomiting, excessive exercise, and taking laxatives or diet pills.

SAFE FOODS: Foods that people with eating disorders are comfortable eating. They are often unprocessed, low-fat, or low-calorie foods, but can be different for every person.

TRIGGER: Anything that makes someone want to engage in disordered eating behaviors or have eating disordered thoughts.

VITAL SIGNS: Measurements which include body temperature, blood pressure, pulse, and respiratory rate. In girls, menstrual periods are also often called a "vital sign."

MYTH: Eating disorders are rare.

TRUTH: A recent study showed that 0.3% of US teenagers between the ages of 13–18 suffer from anorexia, 0.9% from bulimia and 1.6% from binge eating disorder. An even higher percentage of young people use unhealthy weight control strategies such as extreme dieting and fasting.

Resources

Every effort has been made to ensure that the URLs listed in the Helpful Websites are as accurate and up-to-date as possible. We realize that the internet is constantly changing, and we can only guarantee that the links are accurate as of the most recent update of this guide.

CYWH HEALTH GUIDES:

Available at youngwomenshealth.org

HELPFUL WEBSITES:

Maudsley Parents: A Site for Parents of Eating Disordered Children.

www.maudsleyparents.org

This website, created by parent volunteers, provides helpful information about family-based treatment (FBT or the Maudsley approach) and stories of recovery, hope, as well as parent-to-parent advice.

NEDA Feeding Hope.

www.nationaleatingdisorders.org

This national website provides information and resources for patients, families, schools and professionals that can be helpful when searching for treatment, support groups and research studies.

Eating Disorder Hope.

www.eatingdisorderhope.com

A comprehensive and informational website that offers education, support, and inspiring stories for patients with eating disorders, their families, and health care providers.

Eating Disorder Referral and Information Center.

www.edreferral.com

This website provides visitors with referrals to eating disorder specialists and treatment centers nationwide.

MEDA: Multi-Service Eating Disorders Association

www.medainc.org

A Massachusetts based website that provides information for patients, parents, and professionals about eating disorders and treatment options. MEDA is a nonprofit organization dedicated to the prevention and treatment of eating disorders.

The Joy Project: Where Joy Takes Root.

www.joyproject.org

This website is sponsored by The Joy Project, a non-profit organization that aims to provide information, support, and resources for people affected by eating disorders at little to no cost.

F.E.A.S.T: Families Empowered and Supporting Treatment of Eating Disorders.

www.feast-ed.org

This website is sponsored by a non-profit organization for parents and caregivers to help loved ones recover from eating disorders by providing information and mutual support, promoting evidence-based treatment—primarily Family Based Treatment (FBT).

Recover Warriors

www.recoverywarriors.com

A multimedia resource hub for hope and healing from an eating disorder; includes an app, podcast, and articles.

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