

Parent TOOLKIT



NEDA TOOLKIT for Parents

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The NEDA Educational Toolkits Story

The Background

When a friend or family member is diagnosed with an eating disorder, it's often terrifying and confusing. *How did this happen to our family? Is my child going to be okay? Will my friend ever get better?* It's all too easy to get tangled in these questions and become mentally trapped, paralyzed with fear and unable to help yourself — or your loved one.

Helping your loved one recover from an eating disorder will take a lot of work from everyone involved. As with many jobs, having the right tools is crucial. Eating disorders have a steep learning curve, and you and your family member will need to develop lots of tools to work towards recovery.

The NEDA Parent Toolkit was created to provide some of these tools that can be used in critical moments in your search for help, hope and healing. As one parent told us, "this toolkit was exactly the resource we needed when we started the journey for our family, we needed real resources, reassurance that we were not the only family with the challenge and that there would be light at the end of that tunnel." The toolkits are designed to put crucial information at your fingertips and offer your family a range of ideas on how to best help your loved one recover from an eating disorder. Some of the questions you might find answered in the following pages are:

- What are eating disorders and how are they treated?
- What are signs of a medical or psychiatric emergency?
- How do I deal with school issues while my child is ill?
- What types of treatment are available?
- How do I know what type of treatment will work best?
- How do I get my insurance company to cover my loved one's treatment?

Of course, no toolkit, no matter how thorough, could possibly address the diverse range of issues that are unique to each individual and family. Instead, our goal is to provide a comprehensive overview of eating disorders and treatment in one easy-to-use document. We have provided resources for more in-depth information that may address these unique issues.

Our goal is to maintain the usefulness of the toolkits by treating them as ever-evolving documents. We will continue reviewing and revising them, adding the most up-to-date research and information. NEDA's clinical advisors will be the primary reviewers, along with other experts and stakeholders invited by NEDA, including families and members of professional organizations that will be disseminating the toolkits. If you have suggestions for improvement, we want to hear from you!

A Brief History of the Toolkits

In September 2007 the Board of Directors of NEDA officially approved the organization's new strategic priorities, listing educational toolkits as a new NEDA priority fitting the new mission: "To support those affected by eating disorders and be a catalyst for prevention, cures, and access to quality care."

Educational Toolkits were created to strengthen NEDA's online material offerings and provide vital information to targeted audiences. A list of audiences was prioritized by the board and serves as a reference for ongoing materials and toolkit development.

The toolkits were initially developed to combine existing information with new findings to create a complete package to assist individuals in their search for information and help. They were meant to provide guidance, not create standards of care, and would be based on the best available information at the time of development.

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The first toolkits were created with the assistance of the ECRI Institute, an organization known for its ability to translate complex healthcare research into accessible, usable information. After developing the first draft of the Parent Toolkit, NEDA and ECRI convened several focus groups of parents to review the document. Together with input from NEDA's Board of Directors and other eating disorders experts, the first Parent Toolkit was released in 2008. A revised Parent Toolkit was released two years later.

With the continuing advances in eating disorder research and treatment, NEDA realized that another more significant revision was needed. Again, the input of parents, former eating disorder sufferers, and eating disorder experts was used to further refine the draft document. In 2015, version 3.0 of the Parent Toolkit was released.

We are currently seeking funding for the ongoing development of toolkits, as well as distribution and marketing. If you or anyone you know may be interested in contributing to, sponsoring or providing a grant to support these efforts, please be sure to contact our Development Office at 212-575-6200, ext. 307; development@nationaleatingdisorders.org.

We hope you'll find these toolkits useful and will share this resource with others.

About Eating Disorders

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Eating Disorder Myths

Even for professionals who have been treating them for years, eating disorders can be baffling and confusing illnesses. Adding to this confusion is the fact that eating disorders are surrounded by a large number of myths and misconceptions. It can be difficult for some people to take an eating disorder diagnosis seriously. This section will help dispel some of the most common misunderstandings about eating disorders and those affected by them. You may wish to print out this section and share it with others (other family members, friends, teachers, coaches, physicians, etc.).

Eating disorders are a choice. I just need to tell my loved one to snap out of it.

Eating disorders (EDs) are actually complex medical and psychiatric illnesses that patients don't choose and parents don't cause. The American Psychiatric Association classifies five different types of eating disorders in the Diagnostic and Statistical Manual, 5th Edition (DSM-5): Anorexia Nervosa, Bulimia Nervosa, Binge Eating Disorder (BED), Avoidant Restrictive Food Intake Disorder (ARFID) and Other Specified Feeding or Eating Disorder (OSFED). Several decades of genetic research show that biological factors play a significant role in who develops an eating disorder. EDs commonly co-occur with other mental health conditions like major depression, anxiety, social phobia, and obsessive-compulsive disorder.

Doesn't everyone have an eating disorder these days?

Although our current culture is highly obsessed with food and weight, and disordered patterns of eating are very common, clinical eating disorders are less so. A 2007 study asked 9,282 English-speaking Americans about a variety of mental health conditions, including eating disorders. The results, published in *Biological Psychiatry*, found that 0.9% of women and 0.3% of men had anorexia during their life, 1.5% of women and 0.5% of men had bulimia during their life, and 3.5% of women and 2.0% of men had binge eating disorder during their life. The consequences of eating disorders can be life-threatening, and many individuals find that stigma against mental illness (and eating disorders in particular) can obstruct a timely diagnosis and adequate treatment.

Eating disorders are a choice.

The causes of an eating disorder are complex. Current thinking by eating disorder researchers and clinical experts holds that eating disorders are caused by both genetic and environmental factors; they are bio-sociocultural diseases. A societal factor (like the media-driven thin body ideal) is an example of an

environmental trigger that has been linked to increased risk of developing an eating disorder. Environmental factors also include physical illnesses, childhood teasing and bullying, and other life stressors. Historical data reveals that some of the earliest documented cases of eating disorders were associated with religious fasting. Additionally, they may run in families, as there are biological predispositions that make individuals vulnerable to developing an eating disorder.

I need to figure out what I did to cause my child's eating disorder.

Organizations from around the world, including the Academy for Eating Disorders, the American Psychiatric Association, and NEDA, have published guidelines which indicate that parents don't cause eating disorders. Parents, especially mothers, were traditionally blamed for their child's disorder, but more recent research supports that eating disorders have a strong biological root. Eating disorders develop differently for each person affected, and there is not a single set of rules that parents can follow to guarantee prevention of an eating disorder, however there are things everyone in the family system can do to play a role in creating a recovery-promoting environment. Psychologists have seen improvements in the speed at which children and adolescents begin to recover when including parents in the treatment process.

It's just an eating disorder. That can't be a big deal.

Eating disorders have the highest mortality rate of any psychiatric illness. Up to 20% of individuals with chronic anorexia nervosa will die as a result of their illness. Community studies of anorexia, bulimia, and eating disorder not otherwise specified (EDNOS, now called OSFED) show that all eating disorders have similar mortality rates. Besides medical complications from binge eating, purging, starvation, and over-exercise, suicide is also common among individuals with eating disorders. People who struggle with eating disorders also have a severely impacted quality of life.

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Anorexia is the only serious eating disorder.

When researchers examined the death rates of individuals with any eating disorder diagnosis who were being treated as outpatients, they found that bulimia and EDNOS (now OSFED) had mortality rates that approached the high rates seen in anorexia nervosa. During the study, roughly 1 in 20 people with eating disorders died as a result of their illness. Individuals who abuse laxatives or diuretics or force themselves to vomit are at significantly higher risk of sudden death from heart attacks due to electrolyte imbalances. Excessive exercise also can increase the risk of death in individuals with eating disorders by increasing the amount of stress on the body.

Since I don't see my loved one engaging in eating disordered behaviors, I don't need to worry about them.

Many eating disorder sufferers go out of their way to hide symptoms of their illness, either out of shame or because they are afraid someone will make them stop. It's not uncommon for loved ones to be caught off guard at how severe and pervasive the eating disorder behaviors are when a diagnosis is made or when people close to the sufferer become aware they are struggling. If you are aware a loved one is struggling it is important to express concern, with empathy and compassion, and encourage the individual to seek help.

My loved one isn't ready to recover from their eating disorder, and there's nothing I can do until they are.

Some eating disorder sufferers have difficulty recognizing that they are ill or appreciating the severity of their situation. Still others may desperately want to stop their behaviors but are afraid. While expressing a readiness and willingness to recover is a positive sign, treatment doesn't need to wait for your loved one to be ready. If your loved one is under the age of 18, and even if they aren't, it is crucial to begin treatment as soon as you are aware of the problem. Early intervention is consistently associated with higher recovery rates. If the individual struggling is an adult, family and friends should continue to express concerns about the negative impact of the eating disorder on their loved one's life and encourage him/her to seek professional help.

As a parent, there's not much I can do to help my child recover.

Research continues to consistently find the opposite is true: parental involvement in a child's eating disorder treatment can increase chances of recovery. Some forms of treatment, like Family-Based Treatment (FBT) (also known as the Maudsley Method), require that parents temporarily take control of the child's eating and monitor for purging until a healthy weight and regular eating patterns are established. Other loved ones can continue to provide support to the eating disorder sufferer by helping to reduce anxiety over eating and reminding them they are more than their illness. Even if you decide FBT isn't right for your family, there are still plenty of ways for you to be involved in your child's or loved one's treatment.

My family member won't recover until they uncover the reason they developed their eating disorder.

While some people can point to a reason or event that they believe caused their eating disorder, plenty of people with eating disorders don't have a specific reason. Nor is there any evidence that uncovering the cause of an eating disorder is correlated with recovery. Regardless of why someone may have developed an eating disorder, generally the first priorities of treatment are to restore normal eating and weight.

If my loved one insists they are fine, I should believe them.

Problems with accurate self-awareness are one of the hallmarks of EDs, so your loved one may not have the self-awareness required to recognize a problem. Thus, the individual struggling may genuinely believe they are fine when they are acutely ill. Other people may deny the presence of an eating disorder even when they know they are ill because they are afraid of treatment. Regardless of the reason, it is important to insist on treatment by a trained mental health professional and regular medical follow-up with a physician who is well-versed in eating disorders. (See page 20 for more information on medical tests.)

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Strict rules about eating or fad diets aren't a problem.

What appears to be a strict diet on the surface may actually be the beginning of an eating disorder. Even if the symptoms do not meet the criteria for a clinical eating disorder diagnosis, disordered eating can have serious medical consequences, such as anemia and bone loss. Individuals dealing with serious disordered eating may benefit from intervention and treatment to address their concerns before it becomes a full-blown eating disorder. Chronic dieting has been associated with the later development of an eating disorder, so addressing these issues right away may prevent a full-blown eating disorder.

As long as someone isn't emaciated, they are not that sick.

Most people with an eating disorder are not underweight. Although most people with eating disorders are portrayed by the media as emaciated, you can't tell whether someone has an eating disorder just by looking at them. These perceptions can perpetuate the problem and may cause distress in eating disorder sufferers for fear of not being "sick enough" or "good enough" at their disorder to deserve treatment. Additionally, you cannot determine if an individual is struggling with binge eating disorder (BED) based on their weight. It is important to remember that just because a sufferer is no longer emaciated, or has lost weight in the process of treatment for BED, it doesn't mean they are recovered; an individual can experience a severe eating disorder at any weight.

The main eating disorder symptom I have to worry about in my loved one is weight loss.

Although anorexia nervosa and other restrictive eating disorders are characterized by weight loss, many people with eating disorders don't lose weight and may even gain weight as a result of their disorder.

Eating disorder behaviors only focus on food.

Individuals with eating disorders generally have an unhealthy focus on food and weight, but the symptoms of an eating disorder can extend far beyond food. Numerous scientific studies have shown links between eating disorders, perfectionism, and obsessionality, which can lead to a fixation on grades, sports performance, etc. Although many sufferers report that eating disorder behaviors initially help them decrease

depression and anxiety, as the disorder progresses, the malnutrition caused by eating disorder behaviors can ultimately increase the levels of depression and anxiety that can affect all aspects of life.

My loved one doesn't claim to feel fat. Can they still have an eating disorder?

Absolutely. Body image distortions are very common in eating disorders, but they are far from universal. Clinical reports indicate that young children are much less likely to have body image disturbance, and plenty of teens and adults also don't report this symptom.

Since eating disorders are linked to biology, my loved one doesn't have much hope for recovery.

It's important to remember that biology isn't destiny. There is always hope for recovery. Although biological factors play a large role in the onset of EDs, they are not the only factors. The predisposition towards disordered eating behaviors may reappear during times of stress, but there are many good techniques individuals with eating disorders can learn to help manage their emotions and keep behaviors from returning.

I have a son. I don't have to worry about eating disorders because they're a "girl thing."

Eating disorders can affect anyone, regardless of their gender or sex. Although eating disorders are more common in females, researchers and clinicians are becoming aware of a growing number of males who are seeking help for eating disorders. A 2007 study by the Centers for Disease Control and Prevention found that up to one-third of all eating disorder sufferers are male. It's currently not clear whether eating disorders are actually increasing in males or if more males who are suffering are seeking treatment or being diagnosed. Because physicians don't often think that eating disorders affect males, their disorders have generally become more severe and entrenched at the point of diagnosis. There may be subtle differences in eating disorder thoughts and behaviors in males, who are more likely to be focused on building muscle than on weight loss. They are also more likely to purge via exercise and misuse steroids than females are. Although gay, bisexual, and transgender males are more likely to develop an eating disorder than straight males, the vast majority of male eating disorder sufferers are heterosexual.

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My child is too young to develop an eating disorder.

Eating disorders can develop or re-emerge at any age. Eating disorder specialists are reporting an increase in the diagnosis of children, some as young as five or six. Many eating disorder sufferers report that their thoughts and behaviors started much earlier than anyone realized, sometimes even in early childhood. Picky eating is common in young children, but doesn't necessarily indicate an eating disorder. Although most people report the onset of their eating disorder in their teens and young adulthood, there is some evidence that people are being diagnosed at younger ages. It's not clear whether individuals are actually developing eating disorders at younger ages or if an increased awareness of eating disorders in young children has led to improved recognition and diagnosis.

Now that my loved one is no longer a teenager, I don't have to worry about an eating disorder. They'll grow out of it.

People can struggle with an eating disorder regardless of their age. Research literature has identified a subset of people with eating disorders who seem to recover spontaneously, without treatment. However, many people who struggle with eating disorders and disordered eating in their teens continue to struggle into adulthood unless they receive treatment. Men and women at midlife and beyond are being treated for eating disorders, either due to a relapse, ongoing illness from adolescence or young adulthood, or due to the new onset of an eating disorder.

I'm not worried about my friend because everyone eats too much ice cream sometimes. Everyone must have binge eating disorder.

Binge eating disorder only affects 3.5% of women, 2% of men and up to 1.6% of adolescents, and it is not the same thing as occasionally eating more than is comfortable. Those who are struggling with binge eating disorder engage in recurring episodes – at least once per week over three months – in which they eat significantly more food in a short space of time than most people would, and experience a sense of loss of control over their eating behavior. The frequency and severity of the disorder have a significantly negative impact on the individual's life, with many sufferers experiencing co-occurring conditions such as major depression and anxiety.

My son has bulimia, so he won't develop another type of eating disorder.

Many with eating disorders will suffer from more than one disorder before they ultimately recover. Roughly half of all people with anorexia will go on to develop bulimia. Some individuals show signs of both anorexia and bulimia simultaneously, regularly binge eating and they may also purge while at a low weight (this is clinically classified as anorexia, binge/purge type). Still others transition from one diagnosis to another, a process known as diagnostic cross-over. All may involve life-threatening consequences.

Purging only involves self-induced vomiting.

Purging includes any method of removing food from the body before it is fully digested. Many times, an individual is driven to purge to compensate for what was perceived as excessive food intake. While self-induced vomiting is one of the most common ways that an individual will purge, it's far from the only method. Individuals can also use laxatives and enemas, as well as use non-purging compensatory behaviors, such as abusing insulin, fasting, and excessive exercising. Individuals can also purge by using more than one method. Each method carries its own particular risks, but all involve potentially life-threatening electrolyte imbalances.

Once my daughter with anorexia gains weight, she will be fine.

Weight and nutritional restoration are only the first steps to anorexia recovery. Once an anorexia sufferer has returned to a weight that is healthy for them, they can usually participate more fully and meaningfully in psychotherapy. Other psychological work usually needs to be done so the person can manage difficult emotions without resorting to anorexic behaviors. Weight recovery alone does not mean the eating disorder is cured.

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Risk Factors for Eating Disorders

Eating disorders are complex conditions that can arise from a combination of long-standing behavioral, biological, emotional, psychological, interpersonal, and social factors. Once started, however, they can create a self-perpetuating cycle of physical and emotional destruction.

Although scientists are still investigating the factors that can contribute to the development of an eating disorder, they have identified some risk factors for the development of an eating disorder.

Psychological Risk Factors

- Perfectionism
- Anxiety
- Depression
- Difficulties regulating emotion
- Obsessive-compulsive behaviors
- Rigid thinking style (only one right way to do things, etc.)

Sociocultural Risk Factors

- Cultural promotion of the thin ideal
- Size and weight prejudice
- Emphasis on dieting
- “Ideal bodies” include only a narrow range of shapes and sizes

Biological Risk Factors

- Having a close family member with an eating disorder
- Family history of depression, anxiety, and/or addiction
- Personal history of depression, anxiety, and/or addiction
- Presence of food allergies that contribute to picky or restrictive eating (e.g. celiac disease)
- Presence of Type 1 Diabetes

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Emotional and Behavioral Signs of an Eating Disorder

Those struggling with an eating disorder may have some, but not all, of the following emotional and behavioral signs. Presence of any of the signs that your loved one may be struggling is cause for serious concern and you should encourage them to seek professional help.

- Intense fear of gaining weight
- Negative or distorted self-image
- Frequent checking in the mirror for perceived flaws
- Self-worth and self-esteem dependent on body shape and weight
- Fear of eating in public or with others
- Preoccupation with food
- Eating tiny portions or refusing to eat
- Avoiding eating with others
- Hoarding and hiding food
- Eating in secret
- Disappearing after eating — often to the bathroom
- Unusual food rituals (cutting food into small pieces, chewing each bite an unusually large number of times, eating very slowly)
- Any new practice with food or fad diets, including cutting out entire food groups (no sugar, no carbs, no dairy, vegetarianism/veganism)
- Little concern over extreme weight loss
- Obsessive interest in cooking shows on television and collecting recipes
- Consumption of only “safe” or “healthy” foods
- Social withdrawal
- Making excuses for not eating
- Cooking elaborate meals for others, but refusing to eat them themselves
- Eating strange combinations of foods
- Elaborate food rituals
- Withdrawing from normal social activities
- Hiding weight loss by wearing bulky clothes
- Flat mood or lack of emotion
- Irritability
- Mood swings
- Hyperactivity and restlessness (unable to sit down, etc.)
- Rigidity in behaviors and routines, and experience of extreme anxiety if these are interrupted
- Excessive exercising
- Exercising even when ill or injured, or for the sole purpose of burning calories

Individuals with eating disorders may be at risk for co-occurring conditions such as mood and anxiety disorders, substance abuse (alcohol, marijuana, cocaine, heroin, methamphetamines, etc.), self-harm (cutting, etc.) and suicidal thoughts and behaviors.

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Physical Signs and Symptoms of an Eating Disorder

Those struggling with an eating disorder may have some, but not all, of the following physical signs and symptoms. Presence of any of the signs that your loved one may be struggling is cause for serious concern and you should encourage them to seek professional help.

- Noticeable fluctuations in weight, both up and down
- Stomach cramps, other non-specific gastrointestinal complaints (constipation, acid reflux, etc.)
- Menstrual irregularities — missing periods or only having a period while on hormonal contraceptives (this is not considered a “true” period)
- Difficulties concentrating
- Abnormal laboratory findings (anemia, low thyroid and hormone levels, low potassium, low blood cell counts, slow heart rate)
- Dizziness
- Fainting/syncope
- Feeling cold all the time
- Sleep problems
- Cuts and calluses across the top of finger joints (a result of inducing vomiting)
- Dental problems, such as enamel erosion, cavities, and tooth sensitivity
- Dry skin
- Dry and brittle nails
- Swelling around area of salivary glands
- Fine hair on body
- Thinning of hair on head, dry and brittle hair (lanugo)
- Cavities, or discoloration of teeth, from vomiting
- Muscle weakness
- Yellow skin (in context of eating large amounts of carrots)
- Cold, mottled hands and feet or swelling of feet
- Poor wound healing
- Impaired immune functioning

Signs of Anorexia Nervosa

- Dramatic weight loss
- Dresses in layers to hide weight loss or stay warm
- Is preoccupied with weight, food, calories, fat grams, and dieting
- Refuses to eat certain foods, progressing to restrictions against whole categories of food (e.g., no carbohydrates, etc.)
- Makes frequent comments about feeling “fat” or overweight despite weight loss
- Complains of constipation, abdominal pain, cold intolerance, lethargy, and excess energy
- Denies feeling hungry
- Develops food rituals (e.g., eating foods in certain orders, excessive chewing, rearranging food on a plate)
- Cooks meals for others without eating
- Consistently makes excuses to avoid mealtimes or situations involving food
- Maintains an excessive, rigid exercise regimen — despite weather, fatigue, illness, or injury, the need to “burn off” calories taken in
- Withdraws from usual friends and activities and becomes more isolated, withdrawn, and secretive
- Seems concerned about eating in public
- Has limited social spontaneity
- Resists maintaining a body weight appropriate for their age, height, and build
- Has intense fear of weight gain or being “fat,” even though underweight
- Has disturbed experience of body weight or shape, undue influence of weight or shape on self-evaluation, or denial of the seriousness of low body weight
- Postpuberty female loses menstrual period
- Feels ineffective
- Has strong need for control
- Shows inflexible thinking
- Has overly restrained initiative and emotional expression

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Signs of Bulimia Nervosa

- In general, behaviors and attitudes indicate that weight loss, dieting, and control of food are becoming primary concerns
- 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
- Appears uncomfortable eating around others
- Develops food rituals (e.g. eats only a particular food or food group [e.g. condiments], excessive chewing, doesn't allow foods to touch)
- Skips meals or takes small portions of food at regular meals
- Steals or hoards food in strange places
- Drinks excessive amounts of water
- Uses excessive amounts of mouthwash, mints, and gum
- Hides body with baggy clothes
- Maintains excessive, rigid exercise regimen—despite weather, fatigue, illness, or injury, the need to “burn off” calories
- Shows unusual swelling of the cheeks or jaw area
- Has calluses on the back of the hands and knuckles from self-induced vomiting
- Teeth are discolored, stained
- Creates lifestyle schedules or rituals to make time for binge-and-purge sessions
- Withdraws from usual friends and activities
- Looks bloated from fluid retention
- Frequently diets
- Shows extreme concern with body weight and shape
- Has secret recurring episodes of binge eating (eating in a discrete period of time an amount of food that is much larger than most individuals would eat under similar circumstances); feels lack of control over ability to stop eating
- Purges after a binge (e.g. self-induced vomiting, abuse of laxatives, diet pills and/or diuretics, excessive exercise, fasting)
- Body weight is typically within the normal weight range; may be overweight

Signs of Binge Eating Disorder

- 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
- Develops food rituals (e.g., eats only a particular food or food group [e.g., condiments], excessive chewing, doesn't allow foods to touch)
- Steals or hoards food in strange places
- Hides body with baggy clothes
- Creates lifestyle schedules or rituals to make time for binge sessions
- Skips meals or takes small portions of food at regular meals
- Has periods of uncontrolled, impulsive, or continuous eating beyond the point of feeling comfortably full
- Does not purge
- Engages in sporadic fasting or repetitive dieting
- Body weight varies from normal to mild, moderate, or severe obesity

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Eating Disorder Statistics

How many people will struggle with an eating disorder during their lifetime?

It sounds like an obvious, easy-to-answer question, but it's more complicated than you might think. Since the vast majority of people with eating disorders either never seek formal treatment for their disorder or are never formally diagnosed ([Hart et al., 2011](#)), researchers can't just search medical records. Still, scientists in the US and around the world are trying to gather data to give sufferers, loved ones, and the general community more information about how many people have eating disorders.

Researchers calculate the frequency of eating disorders using two main measurements:

- **Incidence** – the number of people who first develop an eating disorder during a specific period of time (usually one year)
- **Prevalence** – the total number of people who have an eating disorder during a specific period of time

Population-Wide Statistics

NEDA has gathered data on the prevalence of eating disorders from the US, UK, and Europe to get a better idea of exactly how common eating disorders are. Older data from other countries that use more strict definitions of anorexia and bulimia give lower prevalence estimates:

- In a study of 31,406 Swedish twins born from 1935-1958, 1.2% of the women had strictly defined anorexia nervosa during their lifetime, which increased to 2.4% when a looser definition of anorexia was used ([Bulik et al., 2006](#)).
- For twins born between 1975 and 1979 in Finland, 2.2-4.2% of women ([Keski-Rahkonen et al., 2007](#)) and 0.24% of men ([Raevuori et al., 2009](#)) had experienced anorexia during their lifetime.
- At any given point in time between 0.3-0.4% of young women and 0.1% of young men will suffer from anorexia nervosa, 1.0% of young women and 0.1% of young men will suffer from bulimia, with similar rates for binge eating disorder ([Hoek & van Hoeken, 2003](#)).

Several more recent studies in the US have used broader definitions of eating disorders that more accurately reflect the range of disorders that occur, resulting in a higher prevalence of eating disorders.

- A 2007 study asked 9,282 English-speaking Americans about a variety of mental health conditions, including eating disorders. The results, published in *Biological Psychiatry*, found that:

- 0.9% of women and 0.3% of men had anorexia during their life
- 1.5% of women and 0.5% of men had bulimia during their life
- 3.5% of women and 2.0% of men had binge eating disorder during their life ([Hudson et al., 2007](#)).
- When researchers followed a group of 496 adolescent girls for 8 years ([Stice et al., 2010](#)), until they were 20, they found:
 - 5.2% of the girls met criteria for DSM-5 anorexia, bulimia, or binge eating disorder.
 - When the researchers included nonspecific eating disorder symptoms, a total of 13.2% of the girls had suffered from a DSM-5 eating disorder by age 20.
- Combining information from several sources, Eric Stice and Cara Bohon ([2012](#)) found that
 - Between 0.9% and 2.0% of females and 0.1% to 0.3% of males will develop anorexia
 - Subthreshold anorexia occurs in 1.1% to 3.0% of adolescent females
 - Between 1.1% and 4.6% of females and 0.1% to 0.5% of males will develop bulimia
 - Subthreshold bulimia occurs in 2.0% to 5.4% of adolescent females
 - Between 0.2% and 3.5% of females and 0.9% and 2.0% of males will develop binge eating disorder
 - Subthreshold binge eating disorder occurs in 1.6% of adolescent females

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Based on the Hudson et al., 2007 study of 9,282 people, approximately 20 million females and 10 million males in the US have a clinically significant eating disorder at some point in their lifetime.

Eating Disorder Diagnosis Over Time

Have these numbers changed over time? The answer isn't clear. It does appear that, at least for the last two decades, the rates of new diagnoses of anorexia and bulimia have remained relatively stable.

- An ongoing study in Minnesota has found incidence of anorexia increasing over the last 50 years only in females aged 15 to 24. Incidence remained stable in other age groups and in males (Lucas et al., 1999).
- A Dutch study published in the *International Journal of Eating Disorders* found that new diagnoses of anorexia and bulimia remained relatively steady in the Netherlands from 1985-1989 to 1995-1999 (van Son et al., 2006).
- An analysis of many studies from Europe and North America revealed that rates of anorexia increased sharply until the 1970s, when they stabilized.
- Rates of bulimia increased during the 1980s and early 1990s, and they have since remained the same or decreased slightly (Smink, van Hoeken, & van Hoek, 2012).
- A British study also found stability in new anorexia and bulimia diagnoses in both males and females, although rates of EDNOS diagnoses increased in both groups (Micali et al., 2013). (Please note that in the new DSM-5, EDNOS is no longer recognized and a new term of OSFED has been added, meaning Other Specified Feeding or Eating Disorder).
- Eating disorder symptoms are beginning earlier in both males and females, which agrees with both formal research (Favaro et al., 2009) and clinical reports.

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Supporting a Loved One

NEDA TOOLKIT for Parents

Encouraging a Loved One to Seek Help

Recovery from an eating disorder requires professional help, and chances of recovery are improved the sooner a person begins treatment. It can be frustrating to watch a loved one suffer and refuse to seek help. Parents of children under 18 can often require that their child's eating disorder be treated, even if the child doesn't buy in to the idea that treatment is necessary.

For parents of older sufferers, and other loved ones of sufferers of any age, encouraging a reluctant eating disorder patient to seek help can be a delicate task. It's crucial to their future well-being, however, to seek recovery, and encouraging proper treatment of their eating disorder can help them move towards that goal.

Although every discussion with an eating disorder sufferer will be slightly different, here are a few basic points to keep in mind:

- **Taking the first step towards recovery is scary and challenging.** Although the act of seeking help might seem straightforward to you, it can be very stressful and confusing. Keeping that in mind will help you empathize with what the other person is going through.
- **Ask if they want help making the first call or appointment.** Some individuals may find it less anxiety-provoking if someone else sets up the appointment or goes with them to discuss a potential eating disorder.
- **Don't buy the eating disorder's excuses.** It's easy enough to promise to see a doctor or a therapist, but the sufferer needs to follow through with making the appointment and seeing a professional on a regular basis. Yes, everyone's busy, treatment can be expensive, and the eating disorder might not seem like a big deal. Don't make eating disorder treatment the only thing you talk about with your loved one, but follow up on their promise to see someone.
- **If the first professional isn't a good match, encourage them to keep looking.** Finding the right therapist isn't easy, and someone may have to interview several potential candidates before finding one that works. Sometimes it takes several tries before a person identifies the right clinician.
- **Make sure they get a medical check-up.** Eating disorders cause a wide range of medical issues, and sufferers need to see a physician regularly to make sure their health isn't at immediate risk. Remember that lab work may remain stable even if someone is close to death, so don't rely on blood tests alone.
- **Ally with the part of them that wants to get well.** Often, eating disorder sufferers are hesitant to change their behaviors. Some people have found it easier to focus on some of the side effects of the eating disorder that the sufferer may be more willing to acknowledge and tackle, such as depression, social isolation, anxiety, insomnia, fatigue, or feeling cold. This can help get them in the door, where the eating disorder can begin to be addressed.
- **Remind the person of why they want to get well.** What types of goals does your loved one have? Do they want to travel? Have children? Go to college? Start a new career? Helping them reconnect with their values and who they want to be can help them stay focused on long-term recovery and not the short-term benefits of the eating disorder.
- **Find a middle ground between forcing the issue and ignoring it.** If you become overly insistent and combative about your loved one seeking help, they may start to avoid you. On the other hand, you don't want to ignore a potentially deadly illness. It's not easy to find a middle ground between these two extremes, but regularly checking in with your loved one about how they're doing and if they are willing to seek treatment can help nudge them in the right direction.

NEDA TOOLKIT for Parents

Encouraging Your Child to Seek Treatment

The following guidance presumes that the situation is not immediately life-threatening. If you are unsure, seek immediate emergency medical care or dial 911.

Eating disorders can be fraught with secrecy and shame for sufferer and family alike. Many with eating disorders will deny they have a problem. Sometimes they are embarrassed and ashamed of their behaviors. Other people are afraid that if they admit they have a problem, they will have to stop their eating disorder behaviors, which can be extremely frightening and anxiety-provoking. Still other sufferers truly do not believe they have a problem and can be extremely reluctant to seek treatment.

Despite this, many sufferers later say that they were ultimately glad when someone stepped in and encouraged them to seek treatment. Often sufferers desperately want to get well, even as they are ambivalent about giving up eating disorder behaviors.

As a parent, it can be tempting to believe your child when they insist that they are fine. But when it comes to an eating disorder, your child may not always be the best judge of their physical and mental state. By insisting on a thorough evaluation by an eating disorder expert, the worst thing that can happen is you find out you made a big deal out of nothing.

Clear both of your schedules and set up a quiet place to talk.

The goal of this discussion should be to express your concerns to your loved one and to explain any steps you might be taking (e.g. setting up a doctor's appointment or requesting they get evaluated for a possible eating disorder). Don't worry about convincing them they have a problem. What you need to do as a parent won't necessarily depend on their ability to believe there is something wrong.

Be calm, caring, and non-judgmental. Express your observations with minimal emotion and use specifics. Try using a formula like "I am concerned when I see you running to the bathroom after dinner." Share your concerns about other changes you may have noticed, such as an increase in depression, anxiety, or isolation.

Be prepared for denial and anger.

Many eating disorder sufferers feel threatened or exposed when someone confronts them about their behavior. Not infrequently, they react with denial and anger. *Don't take this personally.* It isn't because you didn't do a good job talking to them, but because they are likely very afraid and uncertain. Try to stay off of their emotional wave as best you can. Your ability to stay calm and tolerate their distress is one of the most powerful tools you can muster against their eating disorder.

Don't expect insight or buy-in.

Your child may be one of those with an eating disorder who can recognize that something is wrong and expresses a willingness to participate in treatment. If so, great! If not, don't worry. It's normal for a young person with an eating disorder to have limited insight into the seriousness of their illness. It doesn't mean they won't get better. Sometimes insight doesn't happen until long into recovery.

Stay focused on what you need to do.

One of the biggest gifts you can give your child is to stay focused on their long-term needs and their health. Even if they don't think it's necessary, insist on a medical check-up and evaluation by an eating disorder expert. Go to the appointment with your child if you can. If not, make sure the physician knows ahead of time about your concerns and potential tests to run. Also require that your child sign all waivers and forms so that you can speak directly to their medical providers. The age at which this happens varies by state: in some places, the age is 18, but it can be as young as 13.

Seek a second opinion.

Not all eating disorder treatment providers are created equal. There are no rules as to who can call themselves an expert at treating eating disorders. Talk to several therapists and physicians until you find one you can feel confident will treat your child well. Get several ideas about treatment options and determine which one will work best for your child and family.

NEDA TOOLKIT for Parents

Remind your child that life will be there after recovery.

Taking time off of school or college can seem like a deal-breaker to many young people. What can be hard to realize in the moment is that school and life will still be waiting after they are more stable in their recovery. Plenty of people can seek treatment for their eating disorder with minimal disruption in their life, but others need more intensive support. When making your decisions about treatment, remember that recovery comes first. Everything else can wait.

If your child is over 18, you may be more limited in what you can legally require your child to do. However, don't despair. You have love on your side, and that really helps. Here are some other things that also might help:

Use whatever leverage you have.

Even some of the most successful young adults aren't completely financially independent, especially while at college or if they have recently graduated. Require them to seek an eating disorder evaluation and seek appropriate treatment (including signing any waivers). Make these actions contingent on your providing any financial or practical assistance, such as paying for college, car, cell phones, etc. It sounds cruel on the surface, but you are really prioritizing their health and their life above anything else.

Set your own boundaries.

Know what behaviors you will and won't tolerate in your home. Every family will draw the lines somewhat differently. Try framing it like drug abuse. You probably wouldn't allow your child to do heroin in their bedroom if you could stop it. Make it clear to your loved one what behaviors are out of bounds and what the consequences are, and then calmly, clearly, and consistently follow through. This will help reinforce in their minds what is and isn't okay, and will hopefully help to encourage them to seek treatment.

Seek to be involved with their treatment.

Yes, they're over 18 and they're legally adults. But an eating disorder often causes a regression in maturity, so although they might be 25 in years, they may only be able to function at the level of a 14-year-old. Add to that the fact that the eating disorder is a master manipulator and feels threatened when others are involved in treatment. Regardless of how your child feels about you being involved in their treatment, you can provide valuable insights to clinicians that your child might miss.

Keep lines of communication open.

If your child initially rejects your pleas that they seek help, don't give up. If they are financially independent, you may have less leverage to encourage them to seek care, but you can still play an important role in their life. It may take time for the message that you love them and you want them to live a full and complete life without an eating disorder in the way to sink in. Hopefully, with time and love and lots of open communication, they will receive your message.

NEDA TOOLKIT for Parents

First Steps to Getting Help

These steps are intended for use in a nonemergency situation. If the situation is a medical or psychiatric emergency and the person is at risk of suicide or is medically unstable, call 911 immediately.

Early detection, initial evaluation, and effective treatment are important steps that can help an eating disorder sufferer move into recovery more quickly, preventing the disorder from progressing to a more severe or chronic state. The following assessments are recommended as the first steps to diagnosis and will help determine the level of care needed for your family member. Receiving appropriate treatment is the first step towards recovery.

Patient Assessment

- Patient history, including screening questions about eating patterns
- Determination of medical, nutritional, psychological and social functioning (if possible, an eating disorder expert should assess the mental health of your child)
- Attitudes towards eating, exercise, and appearance
- Family history of eating disorder or other psychiatric disorder, including alcohol and substance use disorders
- Family history of obesity
- Assessment of other mental health conditions, such as depression and anxiety

Medical Exam

- Physical examination including height, weight, body mass index (BMI), growth chart assessment for children and adolescents, cardiovascular and peripheral vascular function, skin health, hair loss, evidence of self-injurious behaviors
- Measurement of body temperature and pulse
- Orthostatic blood pressure
- Laboratory tests (see below)
- Dental exam if self-induced vomiting is known or suspected
- Establishment of diagnosis and recommendations for appropriate level of care

Laboratory Testing

- Complete Blood Count (CBC) with differential urinalysis
- Complete Metabolic Profile: sodium, chloride, potassium, glucose, blood urea nitrogen
- Creatinine, total protein, albumin, globulin, calcium, carbon dioxide, aspartate transaminase (AST), alkaline phosphatase (ALP), total bilirubin
- Serum magnesium, phosphate
- Thyroid screen (T3, T4, TSH)
- Electrocardiogram (ECG)

Special Circumstances

If uncertain of diagnosis

- Erythrocyte sedimentation rate
- Radiographic studies (computed tomography or magnetic resonance imaging of the brain or upper/lower gastrointestinal system)

If patient has been without her menstrual period for six or more months

- Urine pregnancy, luteinizing and follicle-stimulating hormone, and prolactin tests

For individuals with persistent low weight, especially females who sustain amenorrhea, a work-up should include a Dual Energy X-ray Absorptiometry (DEXA) to assess bone mineral density.

NEDA TOOLKIT for Parents

How to Support a Loved One with an Eating Disorder

- Educate yourself on eating disorders; learn the jargon
- Learn the differences between facts and myths about weight, nutrition, and exercise
- Ask what you can do to help
- Listen openly and reflectively
- Be patient and nonjudgmental
- Offer to help with practical tasks (laundry, transportation to and from appointments)
- Avoid discussions about food, weight, and eating, especially your own habits or those of others
- Model a balanced relationship with food, weight, and exercise
- Ask how they are feeling
- Remember that recovery is a marathon, not a sprint
- Focus on the emotional aspects of an eating disorder, not just the physical ones
- Encourage the sufferer to follow through with treatment recommendations
- Distract your loved one during and after meals to help with anxiety
- Refrain from telling the person what they should do
- Continue to reach out—individuals with eating disorders may find it hard to socialize and may push people away
- Arrange activities that don't involve food or eating so your loved one can continue to take part
- When in doubt, ask. They can't read your mind, and you can't read theirs
- Validate their feelings and their emotional pain, especially when they share something difficult or reveal that they have kept a secret
- Focus on positive personality traits and other qualities that have nothing to do with appearance
- Express any concerns that arise
- Don't take their actions personally
- Set boundaries to preserve your own emotional well-being

NEDA TOOLKIT for Parents

How to Talk to a Loved One about an Eating Disorder

Friends and family are often key to encouraging someone with an eating disorder to seek help. Whether the eating disorder sufferer is unaware that there is a problem, they are afraid or ashamed to seek help, or they are ambivalent about giving up eating disorder behaviors, many sufferers find it difficult to seek help for their eating disorder. Family and friends can play an important role in identifying worrying symptoms to the sufferer and encouraging them to seek help.

Raising concerns about the presence of an eating disorder

It's not always easy to discuss eating disorders, especially with someone you are close to. However, many individuals now in recovery from an eating disorder say the support of family and friends was crucial to them getting well.

- **Set a private time and place to talk.** No one wants to have personal issues dissected in front of a crowd, so make sure you find a time and place where you will have time to discuss your concerns without being rushed or in front of a crowd.
- **Use "I" statements.** Focus on behaviors that you have personally observed, such as "I have noticed that you aren't eating dinner with us anymore," or "I am worried about how frequently you are going to the gym." It's easy to sound accusatory ("You're not eating! You're exercising too much!"), which can cause a person to feel defensive. Instead, stick to pointing out what you've observed. If you can, also point out behaviors not related to eating and weight, which may be easier for the person to see and accept.
- **Rehearse what you want to say.** This may help reduce your anxiety and clarify exactly what you want to say. Other people have found writing out their main points helpful.
- **Stick to the facts.** Raising concerns about a potential eating disorder can bring up lots of emotions, and it's important not to let those run the show. Instead, talk about behaviors and changes you have observed and calmly point out why you are concerned ("I have seen you run to the bathroom after meals and that makes me worried you might be making yourself throw up.").
- **Remove potential stigma.** Remind your loved one that there's no shame in admitting you struggle with an eating disorder or other mental health problem. Lots of people will be diagnosed with these issues during their lifetimes, and many will recover.
- **Avoid overly simplistic solutions.** Being told "Just stop" or "Just eat" isn't helpful. It can leave the sufferer feeling frustrated, defensive, and misunderstood.
- **Encourage them to seek professional help.** Many eating disorder sufferers require professional help in order to get better. Offer to help the sufferer find a physician or therapist if they don't have one, or attend an appointment where the eating disorder is discussed. Getting timely, effective treatment dramatically increases a person's chances for recovery.
- **Be prepared for negative reactions.** Some eating disorder sufferers are glad that someone has noticed they are struggling. Others respond differently. Some may become angry and hostile, insisting that you are the one with the problem. Others may brush off your concerns or minimize potential dangers. Both of these responses are normal. Reiterate your concerns, let them know you care, and leave the conversation open.

Even if you don't feel the discussion was well-received or that you got through to your loved one, don't despair. You shared your concern and let them know that you care and you are there for them. You may also have planted a seed that they should seek help. The seed may not take root immediately, but over time, the concern of friends and family can help move an individual towards recovery.

Note: If you suspect a medical or psychiatric emergency, such as threats of suicide or medical complications from eating disorder behaviors (such as fainting, heart arrhythmias, or seizures), seek medical attention or call 911 immediately.

NEDA TOOLKIT for Parents

Talking to Young Children About Eating Disorders

Whether in a sibling, friend, or parent, eating disorders can be frightening and stressful for loved ones to understand. When the loved one is a young child, the issue can become even more complicated. The goal of this section is to provide some basic information on eating disorders to help explain to young children what is happening to their friend or family member.

What to tell a young child?

This will depend on their age and where they are in their emotional, social, and cognitive development. There are no formal guidelines on what is best to tell a child and when, so use your best judgment and knowledge of the child.

It might be tempting to avoid saying something altogether with a very young child, since it can seem that they are unaware of the issue. However, children are often more observant than adults realize and frequently see what is going on, even if they cannot verbalize it. Acknowledging that something is going on with their loved one's behavior can validate their emotions and help them feel more safe and secure.

Some brief statements that might help very young children understand an eating disorder in a friend or family member:

- “Mom/Dad/Sibling has trouble eating properly. We are all working together to help him/her learn to eat better to get healthy. We all need food to help our bodies function properly.”
- “Mom/Dad/Sibling gets very frightened and upset at mealtimes. THIS IS NOT YOUR FAULT. We hope that this will get easier for them with treatment.”
- “Having an eating problem can be very scary. It can also be scary when a parent/sibling has an eating problem. Do you have any questions about eating problems? Is there anything you would like to talk about?”
- “Your parent's/sibling's eating problem is being helped by grown-ups and doctors. Your job is to be yourself.”
- “Your parent/sibling is not choosing to act this way. This isn't their fault. It's not your fault. We're all doing the best we can to help them get better.”

What to tell an older child?

Older children may have heard of eating disorders and be better able to understand the complexities of what is happening to their loved one. Psychologists

recommend keeping the discussions brief and matter-of-fact, while also giving the child a chance to express his/her emotions and concerns about their family member or friend.

Some Common Questions from Children

Children may have questions about eating disorders, just like adults do. Here are some common questions with some sample answers.

What is an eating disorder?

Eating disorders are illnesses that make somebody eat too much or too little for a long period of time. Lots of us might eat a little more one day and a little less the next. That's perfectly normal. People with eating disorders do this day after day, and they can't stop even though it's making them sick. That's why your mom/dad/sibling is seeing a doctor: to help get better.

Are eating disorders serious?

They can be. But most people with eating disorders do get better. Your mom/dad/sibling is working on getting well and is seeing a doctor to make sure they stay healthy.

Will I get an eating disorder?

I don't know. I hope not. The best thing you can do to stay healthy is eat enough to keep growing and tell an adult if you start to get worried about food or what you weigh.

What causes an eating disorder?

No one knows for sure. What doctors do know is that people don't choose to have eating disorders.

Will mom/dad/sibling have to go away to get better?

Many people with eating disorders can stay at home while they are working on getting better. Some people need extra help and may go to a special hospital to get better.

Do other people have this problem?

Yes — you and your family member are not alone. Lots of people also have eating problems and there are lots of good doctors out there who are helping them get well.

NEDA TOOLKIT for Parents

When Your Loved One is Over 18 and Refusing Treatment

Many of those with eating disorders are ambivalent about recovery. They may not believe there is a problem or that the problem is serious. The thought of not engaging in eating disordered behaviors is often tremendously anxiety-provoking, which can also lead someone to turn away from treatment. Regardless of why, it is important to encourage your loved one to seek appropriate treatment, since an eating disorder can be fatal.

Identify your leverage

Many young adults still rely on their parents for financial and other types of support. Some parents have found that requiring their child to engage in treatment as a condition for certain types of support (car, cell phone, housing, paying for college) has been enough to convince the sufferer to seek help. Other parents and loved ones use different tactics, including seeking professional help for their own well-being. You will know which approach will work best for your loved one and your situation.

The expectation that they will receive treatment and recover from their disorder is powerful medicine for a sufferer. Oftentimes, a person with an eating disorder stops believing that recovery is possible. Having supportive friends and family who believe that for them can be a very strong message.

When leverage isn't enough

Sometimes, a loved one is financially independent. Other times, leverage simply isn't effective. Although the parents of minors can often seek treatment on behalf of their child, it becomes exponentially more difficult to require a loved one to seek care once they have turned 18 and have the legal authority to refuse treatment. Although your options are substantially more limited if your loved one is over 18 and refusing treatment, you have several legal options you can pursue. These options are generally exercised as a last resort, but can be effective and potentially life-saving.

Guardianship

Seeking medical guardianship gives you the legal authority to make decisions about a person's physical and psychological care. It doesn't allow you to sign an adult into a treatment program, but it does allow you to be closely involved in the decision-making process. To be granted, a judge must decide that a person isn't capable of making these decisions on his or her own.

To obtain guardianship, you will need to seek a court order. As laws, definitions, and regulations vary by state, contact a family law attorney in your state for more guidance.

Conservatorship

Conservatorship gives you the authority to manage another person's finances. It can be useful in eating disorders to reduce access to funds that are fueling the disorder and allowing a seriously ill individual to go untreated. There may also be other circumstances in which conservatorship is warranted. To be granted, a judge must decide that a person isn't capable of making these decisions on his or her own.

To obtain conservatorship, you will need to seek a court order. As laws, definitions, and regulations vary by state, contact a family law attorney in your state for more guidance.

Note: both conservatorship and guardianship are governed under state law, and only effective in the particular state where it is granted. If your loved one seeks care in a different state, the guardianship or conservatorship doesn't automatically transfer, and you may need to seek additional legal advice and court orders in this situation.

Other legal actions

- "72-hour hold" or an emergency hold can be given if a person is deemed an immediate danger to themselves or others. This gives a hospital the order to hold and treat a person until a judge can evaluate the patient's status and what should happen next. This must occur within 72 hours.
- Longer-term holds are granted after an initial hearing in which a person is found incompetent to make their own medical decisions due to their current mental or physical state. An individual can be transferred to a county or state facility to receive treatment for a certain period of time, after which their case must be reviewed.

At these hearings, your loved one with an eating disorder will be granted an attorney to represent their cause and help look out for their best interests.

NEDA TOOLKIT for Parents

The definition of incapacitated and non-competent will vary from area to area and judge to judge. Although these orders are granted for individuals with eating disorders, they can be difficult to obtain, especially since some eating disordered individuals genuinely do not believe there is a problem. This can convince some judges that the person is fine. For all of these types of actions, the advice of lawyers and of the medical community is paramount to a successful outcome.

Often, knowing that a loved one is able and willing to require treatment is enough to get the eating disordered person to back down and enter treatment themselves. Studies have shown that many eating disorder sufferers who felt coerced into treatment ultimately acknowledged that the treatment was necessary and life-saving.

Treatment Information

NEDA TOOLKIT for Parents

Level of Care Guidelines for Patients

Medical necessity criteria continue to change over time and can differ between insurance companies. This American Psychiatric Association chart will give you a good sense of the levels of care, but consumers should be aware that weight, co-occurring conditions, and motivation for change are all considered when clinical programs and insurance consider level of care.

These guidelines are intended for use by treatment professionals in determining appropriate level of care. Please feel free to print and distribute to clinicians, insurance officials, and others involved in these decisions with your loved one.

American Psychiatric Association Level of Care Guidelines for Patients with Eating Disorders

	Level One: Outpatient	Level Two: Intensive Outpatient	Level Three: Partial Hospitalization (Full-day Outpatient Care)	Level Four: Residential Treatment	Level Five: Inpatient Treatment
Medical Status	Medically stable to the extent that more extensive medical monitoring, as defined in levels 4 and 5, is not required			Medically stable to the extent that intravenous fluids, nasogastric tube feedings, or multiple daily laboratory tests are not needed	<p>For adults: Heart rate <40 bpm; blood pressure <90/60 mmHg; glucose <60 mg/dl; potassium <3 mEq/L; electrolyte imbalance; temperature <97.0°F; dehydration; liver, kidney, or cardiac compromise requiring acute treatment; poorly controlled diabetes</p> <p>For children and adolescents: Heart rate near 40 bpm; orthostatic blood pressure changes (>20 bpm increase in heart rate or >10 mmHg to 20 mmHg drop); blood pressure <80/50 mmHg; low potassium, phosphate, or magnesium levels</p>

NEDA TOOLKIT for Parents

	Level One: Outpatient	Level Two: Intensive Outpatient	Level Three: Partial Hospitalization (Full-day Outpatient Care)	Level Four: Residential Treatment	Level Five: Inpatient Treatment
Suicidality	If suicidality is present, inpatient monitoring and treatment may be needed depending on the estimated level of risk				Specific plan with high lethality or intent; admission may also be indicated in patient with suicidal ideas or after a suicide attempt or aborted attempt, depending on the presence or absence of other factors modulating suicide risk
Weight as percentage of healthy body weight	Generally >85%	Generally >80%	Generally >80%	Generally <85%	Generally <85%; acute weight decline with food refusal even if not <85% of healthy body weight
Motivation to recover, including co-operativeness, insight, and ability to control obsessive thoughts	Fair-to-good motivation	Fair motivation	Partial motivation; cooperative; patient preoccupied with intrusive, repetitive thoughts >3 hours/day	Poor-to-fair motivation; patient preoccupied with intrusive repetitive thoughts 4–6 hours a day; patient cooperative with highly structured treatment	Very poor to poor motivation; patient preoccupied with intrusive repetitive thoughts; patient uncooperative with treatment or cooperative only in highly structured environment
Co-occurring disorders (substance use, depression, anxiety)	Presence of comorbid condition may influence choice of level of care				Any existing psychiatric disorder that would require hospitalization (i.e., severe depression, addiction, self-harm)
Structure needed for eating/gaining weight	Self-sufficient	Self-sufficient	Needs some structure to gain weight	Needs supervision at all meals or will restrict eating	Needs supervision during and after all meals or nasogastric/special feeding modality
Ability to control compulsive exercising	Can manage compulsive exercising through self-control	Some degree of external structure beyond self-control required to prevent patient from compulsive exercising; rarely a sole indication for increasing the level of care			

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	Level One: Outpatient	Level Two: Intensive Outpatient	Level Three: Partial Hospitalization (Full-day Outpatient Care)	Level Four: Residential Treatment	Level Five: Inpatient Treatment
Purging behavior (laxatives and diuretics)	Can greatly reduce incidents of purging in an unstructured setting; no significant medical complications, such as cardiac or other abnormalities, suggesting the need for hospitalization			Can ask for and use support from others or use cognitive and behavioral skills to inhibit purging	Needs supervision during and after all meals and in bathrooms; unable to control multiple daily episodes of purging that are severe, persistent, and disabling, despite trials of outpatient care, even if routine laboratory test results reveal no obvious abnormalities
Environmental stress	Others able to provide adequate emotional and practical support and structure		Others able to provide at least limited support and structure	Severe family conflict or problems or absence of family so patient is unable to receive structured treatment in home; patient lives alone without adequate support system	
Geographic availability of treatment program	Patient lives near treatment setting			Treatment program is too distant for patient to participate from home	

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Finding Treatment for Your Loved One's Eating Disorder

Getting a diagnosis is only the first step towards recovery from an eating disorder. Once you have a diagnosis, the next step involves identifying availability of clinical resources for treatment. Several major factors will likely play a role in determining the best type of treatment for your family member:

- Specific eating disorder diagnosis
- Medical/psychiatric status
- Location in the country
- Availability of local experts and programs
- Insurance coverage
- Ability to pay in the absence of insurance
- Family/patient preferences on the most appropriate type of treatment
- Likelihood of recovery in outpatient treatment

Many people utilize a treatment team to treat the multi-faceted aspects of an eating disorder. Treatment teams commonly include the following types of providers:

- Physician (primary care physician, pediatrician, cardiologist, etc.)
- Psychotherapist
- Dietitian
- Psychiatrist
- Additional therapists as required (yoga therapist, art therapist, etc.)
- Case manager at your insurance company (if needed)

For more information on different types of treatment, see the glossary on page 41 at the end of this section.

A large portion of eating disorder sufferers can be treated as outpatients, so make sure that your physician has experience with these conditions. Needing to seek a higher level of care is fairly common and not a sign that recovery is impossible. A primary care physician, such as a pediatrician, internist, or family doctor, may have referrals to local therapists and dietitians who have experience in treating eating disorders, as might other specialists like adolescent medicine physicians and gynecologists. Not all areas have such clinicians available, nor are all physicians familiar with eating disorder treatment.

If you can't get any referrals from your physician, there are still some ways to find good treatment providers. The following websites have lists of outpatient therapist and treatment programs that address eating disorders:

- National Eating Disorders Association (NEDA) <http://www.nationaleatingdisorders.org/find-treatment>
- Academy for Eating Disorders (AED) <http://aedweb.org>
- Local chapters of IAEDP professionals <http://www.iaedp.com/overview%2017%20Chapters.htm>
- Certified Family-Based Treatment providers <http://train2treat4ed.com/>
- ED Referral.com <http://www.edreferral.com>

Local colleges and universities may have lists of nearby therapists for students with eating disorders, so it might be worthwhile to call their counseling or health center to ask for a referral. Larger treatment programs in your state or bordering states may also have a network of therapists and treatment providers who work with eating disorders.

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Types of psychotherapy

Perhaps one of the most important considerations when you and your loved one select a psychotherapist is the type of therapy they provide. Different therapies work differently for different people, and some may be more helpful than others for where your loved one currently is in their recovery. Reducing eating disorder behaviors is generally considered to be the first goal of treatment, and the following therapies currently have the most evidence for effectiveness.

Family Based Therapy (FBT). Also known as the Maudsley Method or Maudsley Approach, this is a home-based treatment approach that has been shown to be effective for adolescents with anorexia and bulimia. FBT doesn't focus on the cause of the eating disorder but instead places initial focus on refeeding and full weight restoration to promote recovery. All family members are considered an essential part of treatment, which consists of re-establishing healthy eating, restoring weight and interrupting compensatory behaviors; returning control of eating back to the adolescent; and focusing on remaining issues.

Cognitive behavioral therapy (CBT) and Enhanced Cognitive behavioral therapy (CBT-E). A relatively short-term, symptom-oriented therapy focusing on the beliefs, values, and cognitive processes that maintain the eating disorder behavior. It aims to modify distorted beliefs and attitudes about the meaning of weight, shape and appearance, which are correlated to the development and maintenance of the eating disorder.

Interpersonal Psychotherapy (IPT). This is a short-term individual psychotherapy. It is premised on the theory that interpersonal difficulties contribute to the onset and maintenance of eating disorder symptoms, and that their resolution will promote recovery. It has predominately been applied to treatment of bulimia nervosa and binge eating disorder, and focuses on interpersonal difficulties rather than behavioral aspects of disordered eating.

In addition to the above evidence-based treatments, the following (listed in alphabetical order) are commonly used to help eating disorder sufferers move towards recovery.

Acceptance and Commitment Therapy (ACT). The goal of ACT is focusing on changing your actions rather than your thoughts and feelings. Patients are taught to identify core values and commit to creating goals that fulfill these values. ACT also encourages patients to detach themselves from emotions and learn that pain and anxiety are a normal part of life. The goal isn't to feel good, but to live an authentic life. Through living a good life, people often find they do start to feel better.

Behavioral Systems Family Therapy (BSFT). Parents are coached to help the sufferer restore adequate nutrition and eat regular meals and snacks. BSFT also broadens the focus of treatment to include cognitions and problems in "family structure" while the parents are still in charge of the re-feeding process.

Cognitive Remediation Therapy (CRT). CRT aims to develop a person's ability to focus on more than one thing. CRT targets rigid thinking processes considered to be a core component of anorexia nervosa through simple exercises, reflection, and guided supervision. CRT is currently being studied to test effectiveness in improving treatment adherence in adults with anorexia; it has not currently been tested in other eating disorders.

Conjoint Family Therapy (CFT). This is a therapeutic approach that treats the entire family, including the eating disordered member, simultaneously. The premise of CFT is that the client exists within a family and spends most of their time with them. Focus is on improving family dynamics that may be contributing to maintaining the eating disorder.

Dialectical Behavior Therapy (DBT). A behavioral treatment supported by empirical evidence for treatment of binge eating disorder, bulimia nervosa and anorexia nervosa. DBT assumes that the most effective place to begin treatment is with changing behaviors. Treatment focuses on developing skills to replace maladaptive eating disorder behaviors. Skills focus on building mindfulness skills, becoming more effective in interpersonal relationships, emotion regulation, and distress tolerance. Although DBT was initially developed to treat borderline personality disorder, it is currently being used to treat eating disorders as well as substance abuse.

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Family Systems Therapy (FST). FST emphasizes family relationships as an important factor in psychological health. Therapy interventions usually focus on relationship patterns and communication rather than on analyzing impulses or early experiences that may have contributed to development of the ED. Family Systems Therapy is different from FBT in that it focuses on the interactions between family members as a way to improve eating disorder behaviors.

Psychodynamic Psychotherapy. The psychodynamic approach holds that recovery from an eating disorder requires understanding its root cause. Psychodynamic psychotherapists view behaviors as the result of internal conflicts, motives and unconscious forces, and if behaviors are discontinued without addressing the underlying motives that are driving them, then relapse will occur. Symptoms are viewed as expressions of the patient’s underlying needs and issues and are thought to disappear with the completion of working through these issues.

Separated Family Therapy (SFT). In SFT, the adolescent is seen on his or her own and the parents are seen in a separate session by the same therapist. This differs from Conjoint Family Therapy (CFT) where the patient and family are seen together. Both are effective, but the separate parallel sessions in SFT are favored in cases where there is a high degree of hostility or parental criticism.

(some definitions adapted from FEAST’s Glossary of Eating Disorders.)

It is important to note that while all of these therapies are frequently used to treat individuals with eating disorders, they have varying levels of efficacy and research supporting their use. Many professionals now recommend the use of evidence-based treatment, which is “the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients.” In eating disorder therapies, evidence-based treatment usually means that the therapy has been used in a research study and found to be effective in reducing eating disorder symptoms, encouraging weight restoration in underweight patients, and decreasing eating disorder thoughts.

Some trials of eating disorder psychotherapies are small and are not necessarily compared to other forms of psychotherapy, which can make it difficult to compare the efficacy of various treatments. Other factors that

make testing ED therapies difficult include the relative rarity of eating disorders, high patient drop-out rates, and large costs. Generally speaking, CBT, DBT, ACT, and FBT are currently some of the best-studied commonly-used eating disorder treatments supported by several different studies around the world.

It’s important to remember that just because a therapy is classified as “evidence-based” doesn’t mean that it automatically works for everyone; just that it works for many patients. Do some research and evaluate which types of treatments would best target the symptoms and psychological issues being faced by your loved one. Also keep in mind that not all therapists who say they utilize a type of treatment actually use it in all of their sessions. Some CBT therapists, for example, might have a primarily psychodynamic approach and only occasionally use CBT principles. So be sure to ask about how strictly the therapist adheres to treatment guidelines, what a typical session might consist of, how much training the therapist has received in this particular treatment modality, the rough percentage of patients who they treat using this form of psychotherapy, and how current their ED knowledge base is.

Selecting a psychotherapist

Just as not all psychotherapies are created equal, not all therapists are created equally either. It matters less how long a specific therapist has been practicing and more on how skilled they are at treating eating disorders and how up-to-date their knowledge is.

Although there may be exceptions, eating disorder treatment generally addresses the following factors in roughly this order:

1. Correct life-threatening medical and psychiatric symptoms
2. Interrupt eating disorder behaviors (food restriction, excessive exercise, binge eating, purging, etc.)
3. Establish normalized eating and nutritional rehabilitation
4. Challenge unhelpful and unhealthy eating disorder and ED-related thoughts and behaviors
5. Address ongoing medical and mental health issues
6. Establish a plan to prevent relapse

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Questions to ask when interviewing a therapist

- How long have you been treating eating disorders?
- What are your training credentials? Have you received specialized training in eating disorders?
- Are you a member of any eating disorder professional organizations?
- What do you think causes eating disorders?
- What do you think needs to happen in order for my loved one to get well?
- How will I be involved in my loved one's treatment?
- How would you describe your treatment style?
- What forms of psychotherapy do you use?
- What happens during a typical psychotherapy session?
- How will you evaluate my loved one and develop a treatment plan?
- What are the goals of treatment?
- When can I start to expect seeing progress?
- When will I be notified if my loved one is not making progress?
- How often will progress be communicated?
- What are the criteria you use to determine whether a treatment is working?
- How long will you give a treatment to start working before you re-evaluate?
- If my loved one doesn't respond to the first form of treatment, what steps would you recommend?
- What kind of medical information do you need about my loved one before treatment begins and as therapy is ongoing?
- How will you work with other members of the treatment team? How frequently will you share information? How will you do this (email, phone, etc)?
- Are you able to communicate with my loved one's school should the need arise?
- What are your thoughts on psychotropic medication?
- What is the best way to communicate with you between sessions?
- Do you charge for phone calls or emails between sessions? How is that billed?
- How do you handle medical or psychiatric emergencies?
- What are some warning signs of immediate danger that I should be aware of?
- What are your criteria for moving a person to a higher level of care?
- What is your appointment availability? Do you have evening or weekend appointments?
- How long does each session last?
- How frequently will you need to see my loved one?
- How often will you meet with me/us as parents?
- Do you accept my insurance? If not, what do you charge?
- Do you deal directly with the insurer or do I need to do that?
- Do you have a sliding scale?
- When is payment due?

The availability of eating disorder therapists can vary widely depending on location, as can an individual's insurance benefits. It may take a bit of persistence to find a treatment provider who will work well with your family, provide effective treatment, and also accepts insurance or is otherwise affordable. Many families have found that they need to travel a bit to find good treatment, but that excellent care is worth the hassle.

Medication for Eating Disorders

Besides psychotherapy, medication is probably one of the most commonly used forms of eating disorder treatment. It is rarely used as a stand-alone treatment, but generally is meant to help relieve symptoms of co-occurring disorders like depression and anxiety, as well as reduce the discomfort (physical and mental) caused by normalizing eating. Only one medication has been

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approved by the FDA to treat bulimia nervosa, and very few have been approved for weight management in overweight individuals. Nevertheless, medications are commonly tried in combination with psychosocial interventions for patients with the range of eating disorders.

Medication names: Generic (Brand)

Frequently prescribed for eating disorder patients

▶ Selective Serotonin Reuptake Inhibitors (SSRIs)

- Fluoxetine (Prozac, Sarafem) ***This is currently the only FDA-approved medication to treat an eating disorder, and is approved for the treatment of bulimia*
- Citalopram (Celexa)
- Escitalopram (Lexapro)
- Fluvoxamine (Luvox)
- Paroxetine (Paxil)
- Sertraline (Zoloft)

▶ Serotonin and Noradepinephrine Reuptake Inhibitor

- Duloxetine (Cymbalta)
- Venlafaxine (Effexor)
- Desvenlafaxine (Pristiq)

▶ Aminoketone

- Bupropion (Wellbutrin, Zyban): Now contraindicated for treatment of eating disorders because of several reports of drug-related seizures among individuals with bulimia nervosa.

▶ Benzodiazepines

- Alprazolam (Xanax)
- Chlordiazepoxide (Librium)
- Clonazepam (Klonopin)
- Diazepam (Valium)
- Lorazepam (Ativan)

▶ Atypical Anti-psychotic Medications

- Aripiprazole (Abilify)
- Olanzapine (Zyprexa)
- Quetiapine (Seroquel)
- Risperidone (Risperdal)
- Ziprasidone (Geodon)

Less frequently prescribed for eating disorder patients

▶ Tricyclics

- Amitriptyline (Elavil)
- Clomipramine (Anafranil)
- Desipramine (Norpramin, Pertofrane)
- Imipramine (Janimine, Tofranil)
- Nortriptyline (Aventyl, Pamelor)

▶ Modified Cyclic Antidepressants

- Trazodone (Desyrel)

▶ Monoamine Oxidase Inhibitors

- Brofaromine (Consonar)
- Isocarboxazide (Benazide)
- Moclobemide (Manerix)
- Phenelzine (Nardil)
- Tranylcipromine (Parnate)

▶ Tetracyclic Antidepressants

- Mianserin (Bolvidon)
- Mirtazapine (Remeron)

▶ Mood Stabilizers (also used for anti-binge properties, especially those at higher weights)

- Lithium carbonate (Carbolith, Cibalith-S, Duralith, Eskalith, Lithane, Lithizine, Lithobid, Lithonate, Lithotabs): Used for patients who also have bipolar disorder, but may be contraindicated for patients with substantial purging.

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► Mood Stabilizers (*continued*)

- Carbamazepine (Equetro, Tegretol)
- Divalproex (Depakote)
- Lamotrigine (Lamictal)
- Oxcarbazepine (Trileptal)
- Topiramate (Topamax)
- Calproate (Depakene syrup)

Other therapies to consider

Some people with eating disorders find benefit from alternative or adjunct therapies. Many of these types of therapies don't have a lot of research supporting them, but many sufferers report finding them useful. Consult with your treatment providers and your family member to determine whether any of these might be helpful for your loved one.

- Art therapy
- Biofeedback
- Coaching
- Emailing for support or coaching
- Equine-assisted psychotherapy
- Eye movement desensitization (EMDR)
- Exercise
- Hypnotherapy
- Journaling
- Massage
- Meditation
- Movement therapy
- Psychodrama
- Relaxation training
- Yoga

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Questions to Ask a Treatment Provider Privately

You may have some questions for a treatment provider that you may prefer to ask privately, without your family member nearby. The following are some questions that other parents and loved ones have found useful to ask when the eating disorder sufferer is out of earshot. Be aware that the clinician may not be able to provide you with an answer on the spot and may need time to get back to you. If you are not satisfied with their answers, ask the treatment provider to clarify their responses, or find another clinician. Do not let a treatment provider push you to the background or be dismissive of your concerns.

- How can I support my loved one's recovery?
- Which books, websites, and other resources should I read about eating disorders?
- How often will I be updated on his/her progress?
- What is the best method to use to contact you with concerns I might have between sessions?
- What should I do if my child is unable or unwilling to participate in treatment?
- Can my loved one be admitted to treatment involuntarily? What are the criteria for making those decisions? What steps would need to be taken?
- What will happen if my loved one needs a higher level of care? How will that decision be made?
- (if a loved one is temporarily living at a facility) How should I prepare for my loved one's return home?
- What are common signs of self-harming behavior?
- How do I prevent self-harming in my loved one?
- What are signs that my family member is purging? Exercising in secret? Hiding/throwing away food?
- How do I prevent purging at home and at school/elsewhere?
- What steps should I take if I discover my loved one is purging?
- How do I prevent excessive or compulsive exercise?
- What steps should I take if I discover my loved one exercising?
- How can I help my child tackle his/her "fear foods"? How can I help expand the foods he/she is willing to eat?
- What happens if my loved one refuses a meal or snack? What happens next?
- What should I do if I discover my loved one is binge eating? If I interrupt them mid-binge?
- How do I respond if I discover eating disorder paraphernalia (scales, diet pills, measuring tapes, etc.) that my loved one has hidden or is using?
- Should I monitor my child's computer usage? What sites should I be on the lookout for?
- What should I do if my family member does not want to discuss his/her eating disorder or treatment with me?
- What should I do if my loved one says they want to pursue recovery their own way, or that they will eat when they are ready? How can I help them work towards recovery and keep them safe?
- If my family member is obsessed with food, cooking, or fitness, how can I best limit these activities?
- What can I do if my family member wants to dictate the family's eating or food habits? How do I set appropriate boundaries?
- Is it a good idea for my loved one to have a job related to food or exercise while they are recovering?
- Should my family member be involved at all in grocery shopping, or meal planning and preparation?
- If my loved one needs to gain weight, approximately how much weight should they gain per week?
- What kind of support should I provide to my family member during refeeding?
- What treatment provider will be responsible for weighing my family member? If you want me to weigh my child at home, what procedures should I follow?
- How do I provide support during mealtimes?
- What should I do if my loved one experiences aggressive or impulsive behavior during treatment?
- What are signs of a medical or psychiatric emergency? Who should I call? When should I take my loved one to the emergency room or call 911?

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Selecting a Treatment Center for Your Loved One

If your loved one is struggling with outpatient treatment or needs a higher level of care, you will need to consider several different options. Finding a program or physician that has expertise in treating all aspects of eating disorders is crucial.

Determining level of care

Several types of treatment centers and levels of care are available for treating eating disorders. Knowing the terms used to describe these is important because insurance benefits (and the duration of benefits) are tied not only to a patient's diagnosis, but also to the type of treatment setting and level of care.

Treatment is delivered in hospitals, residential treatment facilities, and private office settings. Levels of care consist of acute short-term inpatient care, partial inpatient care, intensive outpatient care (by day or evening), and outpatient care. Acute inpatient hospitalization is necessary when a patient is medically or psychiatrically unstable. Once a patient is medically stable, he/she is discharged from a hospital, and ongoing care is typically delivered on an outpatient basis or at a subacute residential treatment facility, where the individual lives in a home or dormitory setting. The level of care in such a facility can be full-time inpatient, partial inpatient, intensive outpatient by day or evening, and outpatient. There are also facilities that operate only as outpatient facilities. Outpatient psychotherapy and medical follow-up may also be delivered in a private office setting.

The level of care your loved one needs will depend on a variety of factors. The most important factor is medical and psychiatric safety, which may require hospitalization before selecting a more specialized program. Hospitalization may be required for complications of the disorder, such as electrolyte imbalances, irregular heart rhythm, dehydration, severe underweight, or acute life-threatening mental breakdown. Partial hospitalization may be required when the patient is medically stable, and not a threat to him/ herself or others, but still needs structure to continue the healing process. Partial hospitalization programs last between 3 and 12 hours per day, depending on the patient's needs. As the patient improves, they will typically move to less intensive and less structured programs.

Other factors influencing level of care are the goals of treatment. Generally, the following issues are typically treated in this order:

- medical and psychiatric stabilization
- stopping destructive behaviors (i.e., restricting foods, binge eating, purging/nonpurging)
- addressing and resolving any coexisting mental health problems that may be triggering the behavior

Be aware that normalization of eating patterns can take months to establish themselves in the patient's day-to-day life. It is important to remember that seeking intensive eating disorder treatment is only the first step towards recovery. Recovery from an eating disorder is an active, ongoing process, and they will continue to need lots of support at mealtimes and elsewhere long after discharge. This is why family involvement in treatment is so important: you need to learn how to help manage your loved one's eating disorder after they are discharged. High levels of support, whether through a step-down program, family involvement, or both, can help stop a revolving door of admissions and discharges.

Selecting an appropriate eating disorder treatment program

First, you will need to find a treatment program that meets your loved one's needs. Consulting with your family member's treatment providers and recommendations should give you a good idea of what level of care is most appropriate and what aspects of the eating disorder most need addressing.

Second, determine whether a particular level of care and specific treatment center is covered by your insurance carrier, and whether the treatment facility accepts insurance. If the treatment center is not part of the health insurer's system (out-of-network), the insurer may pay a percentage of the treatment costs, with the patient responsible for the remainder. It is best to negotiate this percentage with the insurer before starting treatment. If your insurance does not provide any coverage, you need to determine whether you and/or your loved one will be able to pay for treatment without insurance. A small number of treatment centers offer financial assistance; but most do not. However, inquiring whether a facility is able to work with your current financial situation may

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be worth investigating if the patient does not have financial resources or insurance. If you are having trouble obtaining insurance coverage for your loved one's eating disorder treatment, see page 45 for more information.

Thirdly, determine the philosophy of the treatment facility and the type of care they provide. Is the center's view of eating disorders supported by up-to-date research? Does it support ideas of eating disorder causes and recovery that are congruent with your family's situation? Does it encourage or require a high level of family involvement?

In addition, "evidence-based treatment" is increasingly emphasized, meaning that many eating disorder programs advertise that they use these types of treatments. It's important to check how frequently these therapies are used, and the qualifications of the therapists providing them. Many facilities have also begun advertising their efficacy via outcome studies. However, residential treatment hasn't been studied for efficacy in randomized control trials, and long-term outcomes have not been followed. Some treatment centers will only evaluate people who were not discharged prematurely, or they may only assess individuals who returned surveys, which could be biased towards individuals who are doing well. The eating disorder community also does not have a standard definition of what recovery looks like, which can make interpreting these studies even harder. Don't ignore these data, but interpret them with caution.

Lastly, think about what will happen after discharge. Does the program have a step-down program or is there another one that you intend to use? Discharge plans can be complicated and require much coordination of care among different healthcare providers. That takes time. Effective discharge planning needs to start much earlier than a day or two before the patient is expected to be discharged from a facility.

Other factors to consider when selecting a treatment center include religious affiliation (if any), multidisciplinary approach to care, distance from home, staff/patient ratio, professional qualifications of staff, their experience in treating eating disorders, and adjunct therapies offered. Some treatment centers provide therapies in addition to psychiatric counseling and pharmacotherapy, like equine therapy,

massage, dance, or art therapy. These therapies may be appealing, although there is no evidence for these being essential to treatment response, and they may not be covered by your health insurance.

Determining Quality of Care

Determining the quality of care offered by a center is difficult at this time. No organization yet exists to specifically accredit treatment centers for the quality and standard of eating disorder-specific care. Leaders within the national eating disorders community organized in mid-2006 to develop care standards and a process for accrediting eating disorder centers. That effort is ongoing. One national organization, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), provides generic accreditation for healthcare facilities, and some eating disorder centers advertise "JCAHO accreditation." JCAHO accreditation does not link directly to quality of care for treatment of eating disorders; it assesses safety and credentials of staff. Another issue regarding quality of care is that much care is delivered on an outpatient basis. For individual psychotherapists in private practice, no special credentialing or specialty certification exists regarding treatment of eating disorders. Thus, any mental healthcare professional can offer to treat an eating disorder whether or not he/she has experience or training in this specific area. Therefore, it is important to ask a prospective therapist about his/her knowledge about eating disorders and years of experience treating them.

Professionals in a Multi-disciplinary Care Team

- Primary care physician (i.e., family doctor, internal medicine doctor, pediatrician, gynecologist)
- Psychiatrist
- Nutritionist
- Clinical psychologist
- Social worker
- Claims advocate for reimbursement
- Other professionals who administer supplemental services such as massage, yoga, exercise programs, and art therapy

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Questions to Ask When Seeking a Treatment Center

- Does the center accept the patient's insurance? If so, how much will it cover?
- Does the center offer help in obtaining reimbursement from the insurer?
- Does the center offer financial assistance?
- How long has the center been in business?
- What is its treatment philosophy?
- Does the center have any religious affiliations and what role do they play in treatment philosophy?
- Does the center provide multidisciplinary care?
- Who will be coordinating my loved one's treatment?
- Is the location convenient for the patient and his/her support people who will be involved through recovery?
- If family cannot participate in treatment in-person, what alternatives are there?
- What security does the facility have in place to protect my loved one?
- How quickly will you complete a full assessment of my child?
- Prior to traveling to the treatment center: what are your specific medical criteria for admission and will you talk with my insurance company before we arrive to determine eligibility for benefits?
- What is expected of the family during the person's stay?
- Anorexic-specific: Please describe your strategy for accomplishing refeeding and weight gain, and please include anticipated time frame.
- How are target weights determined?
- How do you handle food refusal?
- What steps do you take to prevent purging? Compulsive exercise?
- What happens if my child needs a higher level of care? How do you make that decision?
- If my child does not start to make progress, what will happen?
- Who is the best person to whom I should fax my loved one's treatment history and medical records?
- What are the visiting guidelines for family or friends?
- What levels of care does the center provide? Please define criteria for each level mentioned.
- What types of professionals participate on the care team and what is each person's role?
- What are the credentials and experience of the staff?
- How many hours of treatment are provided to a patient each day and week?
- Which professional serves as team leader?
- What types of therapy does the center consider essential? Optional?
- What is the patient-staff ratio?
- What is the rate of turnover (staff resigning) for clinical staff?
- How is that handled with patients?
- Who will the patient have the most contact with on a daily basis?
- What is the mealtime support philosophy?
- Who will update key family or friends? How often?
- How is care coordinated for the patient inside the center and outside if needed?
- How does the center communicate with the patient's family doctors and other doctors who may routinely provide care?
- What are your criteria for determining whether a patient needs to be partially or fully hospitalized?
- What happens in counseling sessions? Will there be individual and group sessions?
- Will there be family sessions?
- How will family be prepared for the patient's discharge?
- How does the care team measure success for the patient?
- How do you decide when a patient is ready to leave?
- How is that transition managed with the patient and family?
- What after-care plans do you have in place and at what point do you begin planning for discharge?
- What follow-up care after discharge is needed and who should deliver it?
- Does the patient have a follow-up appointment in hand before being discharged? Is the follow-up appointment within 7 days of the discharge date?
- When is payment due?

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Treatment Glossary

- **Antidepressants** Prescription medications that are FDA-approved for the treatment of major depression, anxiety, or obsessive-compulsive disorder. They are also used to treat eating disorders with the goal of alleviating the depression and anxiety that often coexist with an eating disorder.
- **Behavior Therapy (BT)** A type of psychotherapy that uses principles of learning to increase the frequency of desired behaviors and/or decrease the frequency of problem behaviors. Subtypes of BT include dialectical behavior therapy (DBT) and exposure and response prevention (EXRP).
- **Cognitive Therapy (CT)** A type of psychotherapeutic treatment that attempts to change a patient's feelings and behaviors by changing the way the patient thinks about or perceives his/her significant life experiences. Subtypes include cognitive analytic therapy and cognitive orientation therapy.
- **Cognitive Analytic Therapy (CAT)** A type of cognitive therapy that focuses its attention on discovering how a patient's problems have evolved and how the procedures the patient has devised to cope with them may be ineffective or even harmful. CAT is designed to enable people to gain an understanding of how the difficulties they experience may be made worse by their habitual coping mechanisms. Problems are understood in the light of a person's personal history and life experiences. The focus is on recognizing how these coping procedures originated and how they can be adapted.
- **Cognitive Behavior Therapy (CBT)** CBT is a goal-oriented, short-term treatment that addresses the psychological, familial, and societal factors associated with eating disorders. Therapy is centered on the principle that there are both behavioral and attitudinal disturbances regarding eating, weight, and shape.
- **Cognitive Remediation Therapy (CRT)** Since patients with anorexia nervosa (AN) have a tendency to get trapped in detail rather than seeing the big picture, and have difficulty shifting thinking among perspectives, this newly investigated brief psychotherapeutic approach targets these specific thinking styles and their role in the development and maintenance of an eating disorder. Currently, it's usually conducted side by side with other forms of psychotherapies and has only been tested in individuals with anorexia nervosa.
- **Dialectical Behavior Therapy (DBT)** A type of behavioral therapy that views emotional deregulation as the core problem in eating disorders. It involves a structured, time-limited therapy teaching people new skills to regulate negative emotions and replace dysfunctional behavior. (See also Behavioral Therapy.)
- **Equine/Animal-assisted Therapy** A treatment program in which people interact with horses and become aware of their own emotional states through the reactions of the horse to their behavior.
- **Exercise Therapy** An individualized exercise plan that is written by a doctor or rehabilitation specialist, such as a clinical exercise physiologist, physical therapist, or nurse. The plan takes into account an individual's current medical condition and provides advice for what type of exercise to perform, how hard to exercise, how long, and how many times per week.
- **Exposure with Response Prevention (EXRP)** EXRP is a type of behavioral therapy effective at treating Obsessive Compulsive Disorder (OCD). The treatment strategy emphasizes graded exposure to anxiety-provoking situations, such as feared foods, and interruption of maladaptive anxiety-reducing behaviors such as purging. (See also Behavioral Therapy.)
- **Expressive Therapy** A nondrug, nonpsychotherapy form of treatment that uses the performing and/or visual arts to help people express their thoughts and emotions. Whether through dance, movement, art, drama, drawing, painting, etc., expressive therapy provides an opportunity for communication that might otherwise remain repressed.
- **Eye Movement Desensitization and Reprocessing (EMDR)** A nondrug and nonpsychotherapy form of treatment in which a therapist repetitively moves an object in front of the patient and asks them to focus on the item while also recalling a traumatic event. It is proposed that the act of tracking while concentrating allows a different level of processing

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to occur in the brain so that the patient can review the event more calmly or more completely than before.

- **Family Therapy** A form of psychotherapy that involves members of an immediate or extended family. Some forms of family therapy are based on behavioral or psychodynamic principles; the most common form is based on family systems theory. This approach regards the family as the unit of treatment and emphasizes factors such as relationships and communication patterns. With eating disorders, the focus is on the eating disorder and how the disorder affects family relationships. Family therapies may also be educational and behavioral in approach.
- **Interpersonal Therapy (IPT)** IPT (also called interpersonal psychotherapy) is designed to help people with eating disorders identify and address their interpersonal problems, specifically those involving grief, interpersonal role conflicts, role transitions, and interpersonal deficits. In this therapy, no emphasis is placed directly on modifying eating habits. Instead, the expectation is that the therapy enables people to change as their interpersonal functioning improves. IPT usually involves 16 to 20 hour-long, one-on-one treatment sessions over a period of 4 to 5 months.
- **Light therapy (also called phototherapy)** Treatment that involves regular use of a certain spectrum of lights in a light panel or light screen that bathes the person in that light. Light therapy is also used to treat conditions such as seasonal affective disorder (seasonal depression).
- **Massage Therapy** A generic term for any of a number of various types of therapeutic touch in which the practitioner massages, applies pressure to, or manipulates muscles, certain points on the body, or other soft tissues to improve health and well-being. Massage therapy is thought to relieve anxiety and depression in patients with eating disorders.
- **Maudsley Method, also called Family Based Therapy (FBT)** A family-centered treatment program with three distinct phases. During the first phase parents are placed in charge of the child's eating patterns in hopes to break the cycle of not eating, or of binge eating and purging. The second phase begins once the child's refeeding and eating is under control with a goal of returning independent eating to the child. The goal of the third and final phase is to address the broader concerns of the child's development.
- **Mealtime Support Therapy** Treatment program developed to help patients with eating disorders eat healthfully and with less emotional upset. It generally centers around mealtime itself.
- **Motivational Enhancement Therapy (MET)** A treatment based on a model of change, with focus on the stages of change. Stages of change represent constellations of intentions and behaviors through which individuals pass as they move from having a problem to doing something to resolve it. The stages of change move from "pre-contemplation," in which individuals show no intention of changing, to the "action" stage, in which they are actively engaged in overcoming their problem. Transition from one stage to the next is sequential, but not linear. The aim of MET is to help individuals move from earlier stages into the action stage using cognitive and emotional strategies.
- **Movement/Dance Therapy** The psychotherapeutic use of movement as a process that furthers the emotional, cognitive, social, and physical integration of the individual, according to the American Dance Therapy Association.
- **Nutritional Therapy** Therapy that provides patients with information on the effects of eating disorders, techniques to avoid binge eating, and advice about making meals and eating. For example, the goals of nutrition therapy for individuals with bulimia nervosa are to help individuals maintain blood sugar levels, help individuals maintain a diet that provides them with enough nutrients, and help restore overall physical health.
- **Pharmacotherapy** Treatment of a disease or condition using clinician-prescribed medications.
- **Progressive Muscle Relaxation** A deep relaxation technique based on the simple practice of tensing or tightening one muscle group at a time followed by a relaxation phase with release of the tension. This technique has been purported to reduce symptoms associated with night eating syndrome.

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- **Psychoanalysis** An intensive, nondirective form of psychodynamic therapy in which the focus of treatment is exploration of a person’s mind and habitual thought patterns. It is insight-oriented, meaning that the goal of treatment is for the patient to increase understanding of the sources of his/her inner conflicts and emotional problems.
- **Psychodrama** A method of psychotherapy in which patients enact the relevant events in their lives instead of simply talking about them.
- **Psychodynamic Therapy** Psychodynamic theory views the human personality as developing from interactions between conscious and unconscious mental processes. The purpose of all forms of psychodynamic treatment is to bring unconscious thoughts, emotions and memories into full consciousness so that the patient can gain more control over his/her life. Whereas psychoanalysis views human behavior as resulting from drives for sex and food, psychodynamic psychotherapy focuses on the human need for attachment and belonging.
- **Psychodynamic Group Therapy** Psychodynamic groups are based on the same principles as individual psychodynamic therapy and aim to help people with past difficulties, relationships, and trauma, as well as current problems. The groups are typically composed of eight members plus one or two therapists.
- **Psychotherapy** The treatment of mental and emotional disorders through the use of psychological techniques designed to encourage communication of conflicts and insight into problems, with the goal being symptom relief, changes in behavior leading to improved social and vocational functioning, and personality growth.
- **Psychoeducational Therapy** A treatment intended to teach people about their problem, how to treat it, and how to recognize signs of relapse so that they can get necessary treatment before their difficulty worsens or recurs. Family psychoeducation includes teaching coping strategies and problem-solving skills to families, friends, and/or caregivers to help them deal more effectively with the individual.
- **Self-guided Cognitive Behavior Therapy A** modified form of cognitive behavior therapy in which a treatment manual is provided for people to proceed with treatment on their own, or with support from a nonprofessional. Guided self-help usually implies that the support person may or may not have some professional training, but is usually not a specialist in eating disorders. The important characteristics of the self-help approach are the use of a highly structured and detailed manual-based CBT, with guidance as to the appropriateness of self-help, and advice on where to seek additional help.
- **Self Psychology** A type of psychoanalysis that views anorexia and bulimia as specific cases of pathology of the self. According to this viewpoint, people with eating disorders cannot rely on human beings to fulfill their self-object needs (e.g., regulation of self-esteem, calming, soothing, vitalizing). Instead, they rely on food (its consumption or avoidance) to fulfill these needs. Self psychological therapy involves helping people with eating disorders give up their pathologic preference for food as a self-object and begin to rely on human beings as self-objects, beginning with their therapist.
- **Supportive Therapy** Psychotherapy that focuses on the management and resolution of current difficulties and life decisions using the patient’s strengths and available resources.
- **Telephone Therapy** A type of psychotherapy provided over the telephone by a trained professional.

Insurance Issues

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Understanding Insurance Issues for Eating Disorders Treatment

One of the most common questions received at the National Eating Disorders Association is about issues with insurance. Whether for outpatient therapy, inpatient hospitalization, or anything in between, understanding your policy's benefits and obtaining authorization for the appropriate level of care can be confusing and frustrating. This section of the toolkit will provide an introduction to some of the basic steps involved in utilizing your insurance benefits to help pay for a loved one's treatment.

Note: If your loved one is under 18, a parent/guardian can legally act on their behalf without prior approval. If your loved one is over 18, they will need to sign a document letting you work with the insurance company on their behalf, even if you are the parent/guardian and the policy is in your name. A customer care representative at the insurance company should be able to tell you or your loved one what documents need to be submitted to allow another person to act on his/her behalf.

Proper treatment of an eating disorder must address both the psychological and physical aspects of the disorder. Many insurance companies have mental health benefits (also known as behavioral health benefits) under a separate umbrella from their physical health benefits. The recent passage of mental health parity means that, legally, mental health must be covered on par with physical health. However, the separation can still exist, and behavioral health coverage may even be contracted out to a separate company under the supervision of the insurer. All of this combines to create a confusing patchwork array of coverage and rules that can make obtaining proper care for your loved one difficult.

For example, when a service is provided by a doctor or facility, a billing code is needed to obtain reimbursement for services. Certain rules and regulations govern how services must be coded and who can perform those services. Different types of facilities and different healthcare professionals must use codes that apply to that type of facility and health professional. Also, if codes don't exist for certain services delivered in a particular setting, then facilities and health professionals have no way to bill for their services. Codes used for billing purposes are set up by various entities, such as the American Medical

Association, U.S. Medicare program, and the World Health Organization's International Classification of Diseases. Thus, even a patient with good health insurance may face barriers to care simply because of the way our healthcare system is set up.

Given that appropriate well-integrated treatment for eating disorders can easily cost more than \$30,000 dollars per month, even with insurance, an insured individual is usually responsible for some portion of those costs.

The first-line of decision making about health plan benefits is typically made by a utilization review manager or case manager. These managers review the requests for benefits submitted by a healthcare provider and determine whether the patient is entitled to benefits under the patient's contract. These decision makers may have no particular expertise in the complex, interrelated medical/mental healthcare needs for an eating disorder. Claims can be rejected outright or approved for only part of the recommended treatment plan. Advance, adequate preparation on the part of the patient or the patient's support people is the best way to maximize benefits. Prepare to be persistent, assertive, and rational in explaining the situation and care needs. Early preparation can avert future coverage problems and situations that leave the patient holding the lion's share of bills.

The rest of this section will contain tips to help you obtain the insurance benefits your loved one needs and deserves so that they have the best chance possible to recover from an eating disorder.

Educate yourself

Read the other information in the Parent Toolkit to learn about eating disorders, treatment, current clinical practice guidelines, and how you can best advocate for and support the family member who has an eating disorder. Refer to the latest evidence-based clinical practice guidelines in this toolkit and have them in hand when speaking to your health plan about benefits. Be prepared to ask your health plan for the evidence-based information they use to create their coverage policy for eating disorders.

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Read your plan

Obtain a copy of the full plan description from the health plan's member's website (i.e., the specific plan that pertains to the insured), the insurer, or, if the insurance plan is through work, the employer's human resources department. This document may be longer than 100 pages. Do not rely on general pamphlets or policy highlights. Read the detailed description of the benefits contract to find out what is covered and for how long. If you can't understand the information, try talking with the human resources staff at the company that the insurance policy comes through, with an insurance plan representative (the number is on the back of your insurance identification card), or with a billing/claims staff person at facilities where you are considering obtaining treatment. If hospital emergency care is not needed, make an appointment with a physician you trust to get a referral or directly contact eating disorder treatment centers to find out how to get a full assessment and diagnosis. The assessment should consider all related physical and psychological problems (other documents in this toolkit explain the diagnostic or assessment process and testing). The four main reasons for doing this are:

- To obtain as complete a picture as possible about everything that is wrong
- To develop the best plan for treatment
- To obtain cost estimates before starting treatment
- To obtain the benefits the patient is entitled to under his/her contract for the type of care needed. For example, many insurers provide more coverage benefits for severe mental disorder diagnoses. Some insurers categorize anorexia and bulimia nervosa as severe disorders that qualify for extensive inpatient and outpatient benefits, while others may not.

Medical benefits coverage also often comes into play when treating eating disorder-associated medical conditions, so diagnosing all physical illnesses present is important. Other mental conditions often coexist with an eating disorder and should be considered during the assessment, including depression, trauma, obsessive compulsive disorder, anxiety, social phobias, and chemical dependence. These coexisting conditions can affect eligibility for various benefits (and often can mean more benefits can be accessed) and eligibility for treatment centers.

Document everything

If you don't document it, it didn't happen. It's a saying frequently used in the legal and insurance fields alike. Insurance attorneys recommend documenting every single contact you have with your loved one's insurer, including the time and date of the call, the name of the person with whom you spoke and their contact information, and what was discussed during the conversation. Experts also recommend keeping copies of all written communication you receive from your insurance companies, such as denial or approval letters, explanations of benefits, and more. Some loved ones have found it useful to organize everything in a folder, a binder, or electronically.

If you decide to tape record any conversation, you must first inform and ask the permission of the person with whom you are speaking.

Confirm with the insurer that the patient has benefits for treatment. Also ask about "in-network" and "out-of-network" benefits and the eating disorder facilities that have contracts with the patient's insurance company, because this affects how much of the costs the patient is responsible for. If the insurer has no contract with certain treatment facilities, benefits may still be available, but may be considered out-of-network. In this case, the claims will be paid at a lower rate and the patient will have a larger share of the bill.

You may also want to consider having an attorney in mind at this point in case you need to consult someone if roadblocks appear; however, avoid an adversarial attitude at the beginning. Remember to keep complete written records of all communications with every contact at your insurance company. Other things to remember:

- Thank and compliment anyone who has assisted you.
- You're more likely to receive friendly service when you are polite while being persistent.
- Send important letters via certified mail to ensure they can be tracked and signed for at the recipient location.
- Set a timeframe and communicate when you would like an answer. Make follow-up phone calls if you have not received a response in that timeframe.

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- Don't assume one department knows what the other department is doing. Copy communications to all the departments, including health, mental health, enrollment, and other related departments.
- Don't panic when and if you receive the first denial. Typically, a denial is an automatic computer-generated response that requires a "human override." Often you need to go up at least one level, and perhaps two levels, to reach the decision maker with authority to override the automated denial.
- Your insurance company only knows what you and the treating professionals tell them. Make sure they have all information necessary to make decisions that will be of most benefit to you or your loved one.
- Make no assumptions. Your insurance company is not the enemy – but may be uninformed about your case. Treat each person as though he/she has a tough job to do.

Be aware that if the patient is a college student who had to drop out of school to seek treatment and was covered by school insurance or a parent's insurance policy, the student may no longer be covered if not a full-time student. While many people will continue working or attending school, some cannot. If this is the case, it's important to understand what happens with insurance. Most insurance policies cover students as long as they are enrolled in 12 credit hours per semester and attend classes. Experts in handling insurance issues for patients with eating disorders caution that patients who have dropped out of school should avoid trying to cover up that fact to maintain benefits, because insurance companies will usually find out and then expect the patient to repay any benefits that were paid out.

If coverage has been lost, the student may be eligible to enroll in a Consolidated Omnibus Budget Reconciliation Act (COBRA) insurance program. COBRA is an Act of

Congress that allows people who have lost insurance benefits to continue those benefits as long as they pay the full premium and qualify for the program. See www.cobrainsurance.com for more information. A person eligible for COBRA has only 30 days from the time of loss of benefits to enroll in a COBRA plan. It is critical that the sign up for COBRA be done or that option is lost. Be sure to get written confirmation of COBRA enrollment from the plan. If the student is not eligible for COBRA, an insurance company may offer a "conversion" plan for individual coverage.

Obtain a case manager

A case manager will be a single person at your insurance company who will handle your loved one's case. This can make it easier to contact your insurance company with questions and other issues, since you will only have to make one phone call. As well, this individual will become familiar with your loved one's case, facilitating decision making.

Obtaining Insurance Benefits for Higher Levels of Care

Many of the issues discussed in the previous section will be relevant to treatment at any level of care, but more intensive treatment often brings up separate issues. Before an insurance company will cover eating disorder treatment, they will conduct a utilization review. A utilization review occurs when your insurance company reviews the insured's benefits to make sure that the services being requested are both covered and "medically necessary."

A utilization review generally consists of several steps:

1. **Precertification** – After completing a face-to-face assessment with the patient, the assessing clinician will call the insurance company to request authorization of services before the patient begins treatment. The reviewers generally ask for the five-axis diagnoses, height, weight, recent behaviors, treatment history, goals for treatment, and estimated length of stay. A case manager (CM) is usually assigned to the case during this initial call, several days are usually authorized, and the next review is scheduled.
2. **Concurrent Review** – Several days are usually authorized at a time and the insurance companies request scheduled clinical updates in order to authorize additional days. These updates and requests for additional days are called concurrent reviews. They are usually done with the same care manager every time. The CM generally asks for the following information: current weight, vitals, lab/bloodwork results, behaviors/struggles, progress in treatment (individual work, family work, insight development, etc.), mood/affect, participation/motivation, discharge plan, coordination with outpatient team, and estimated length of stay.
 - a) It is very important to explain this process to the patient as some patients may be overwhelmed when they initially hear that their insurance company has authorized 5 or 6 days and they plan to be in treatment for weeks or months.
3. **Discharge Summary** – Some insurance companies request notification of the patient's discharge. The discharge summary usually includes the following information: Five-Axis diagnoses upon discharge (any changes?), medications upon discharge, follow-up appointments (names of providers, dates and times of appointments), total number of days used. This is usually a pretty quick call and it's not always required by insurance.

Other steps:

1. **"Clinical Case Consultation"** – Occasionally reviewers need to consult with other clinicians or doctors before determining how many days they will authorize. This generally happens after the patient has been in treatment for a while, appears to meet the criteria for medical necessity, but may be getting close to requiring a "doc-to-doc" review. This is not a denial. After consulting with either the clinical team at the insurance company or with the treating doctor at the facility/clinic, the reviewer will call back with an authorization and usually a few additional questions for the next review.
2. **"Doc-to-Doc" or "Peer-to-Peer" Review** – Cases are usually sent for a "doc-to-doc" for one of the following reasons:
 - a) The patient has been in treatment for long enough that the reviewer is unable to authorize additional days without involving a doctor from the insurance company.
 - b) The patient does not clearly meet the criteria for medical necessity and a doctor must use his or her clinical expertise/discretion to determine if the level of care being requested is warranted.
 - c) If this happens, it is fairly indicative of an upcoming denial within the next few reviews.
 - d) Although the insurance company may not always honor the request, it is perfectly acceptable (and recommended) to specifically request for the reviewer to be a doctor who specializes in eating disorders.
3. **Appeal** – If authorization is denied, a facility/provider has the right to file an appeal and conduct a review with a different doctor.

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Common Reasons for Denying Further Care

The most common (and frustrating) reason for a denial is “the patient does not meet the criteria for medical necessity.” The specific criteria will vary from insurance company to insurance company, but some of the most common criteria include:

1. Weight — usually not low enough
2. Treatment History (mainly applies to precertification requests)
 - a) Patient has not tried a lower level of care prior to requesting a higher level of care
 - b) Patient’s condition is chronic and past treatments at the requested level of care have been ineffective
3. Lack of Progress in Treatment
 - a) Patient is not restoring weight
 - b) No reduction in behaviors
 - c) Lack of motivation in treatment
 - d) Inconsistent attendance
4. Absence of Behaviors (i.e. someone is doing too well in treatment and may be appropriate for a step-down)
5. No medical complications

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Steps to Take When Determining Coverage Allowances

Determining how much coverage your loved one has can seem like figuring out a complicated series of math problems. By breaking the task down into simpler, more manageable tasks, you can get the job done so that your loved one gets the care they need and you don't get overwhelmed.

1. Obtain insurance info from patient. It is best to get a copy of the actual insurance card.
 - a) Name of insurance company
 - b) ID #
 - c) Group #
 - d) Phone number (often labeled "MH/SA" or "provider services" on back of card)
 - e) Subscriber's name, date of birth, and relationship to patient (This is the policyholder's info)
 - f) Employer (if it is a group policy)
 - g) Patient's SSN and date of birth
 - h) Subscriber's home address
2. Call insurance company to verify benefits. It is best to record the call for future reference. Be sure to inform the other person you are recording. Verify the following:
 - a) Eligibility
 - i. Active policy?
 - ii. Effective date?
 - iii. Benefit year? This may be different than the calendar year and it will affect when the benefits renew.
 - b) Benefits
 - i. Does the member have benefits for the services he or she is requesting?
 - ii. What is the copayment or coinsurance for each type of service/level of care (check whatever is relevant)
 - iii. Is there a limit? If so, how many sessions have been used to date?
 - iv. Do the sessions cross-accumulate? (i.e. Do OP or IOP days accumulate towards total IP or PHP days allowed?)
- c) Deductible and Out-of-Pocket (OOP) Maximum
 - i. What are the limits and how much of each has the patient met to date?
 - ii. Is the deductible included in the OOP max?
 - iii. Do copayments and coinsurance apply to the deductible and OOP max?
3. Discuss benefits and estimated cost of treatment with patient.
4. Keep track of benefit utilization throughout treatment and plan accordingly with patient.
5. DOCUMENT all communication with the insurance company. It is amazing how many times records need to be produced in order for the claims to be paid accordingly.
 - a) Record phone calls if possible
 - b) Keep records of written correspondence (faxes, e-mails, etc.)
 - c) Document the date and time of a call as well as the name of the person you spoke with. Also ask for a reference number if possible.

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Strategies for Providers for Fighting Insurance Denial

Although this next section may be most useful for clinicians and treatment facilities to use directly, knowing common strategies can help you formulate appeals for your loved one.

1. **Weight** — not low enough

- a) Patients with severe EDs are often within the normal weight range, especially with Bulimia Nervosa and EDNOS
- b) If the patient has dropped a significant amount of weight or has fluctuated a lot within the past few months or one year, a higher level of care can be justified in order to stabilize the behaviors. Basically if you can show that the patient is on a steep downward trajectory, the insurance companies will often let you “catch” the patient before he or she hits rock bottom.
- c) The brain does not function at an optimal level below about 90% IBW, so if a patient meets the criteria in every other way but his or her weight is “not low enough,” you can make the argument that the patient will actually be able to use program more effectively than if he or she were at a lower weight because the brain is nourished. They will be in a better position to learn and to implement the skills taught in program.

2. **Treatment History** (mainly applies to precertification requests)

- a) Patient has not tried a lower level of care prior to requesting a higher level of care
 - i. *Emphasize the severity of behaviors and risks of continuing behaviors (i.e. “This is so severe that we have to stop it now. Patient is likely to fail at a lower level of care. This failure will waste valuable resources such as time, money, and patient’s hope/motivation for recovery.”)*
 - ii. Outpatient providers who have been working with patient for X length of time are recommending this level of care (if applicable)
 - iii. Availability of programs (some areas have scarce resources for treating eating disorders, may not have many treatment options available)

- b) Patient’s condition is chronic and past treatments at the requested level of care have been ineffective
 - i. Emphasize any changes and give concrete reasons why this treatment will be different
 - 1) Patient’s motivation, development of insight (ex: Last time patient was forced into treatment by family/spouse. This time patient requested treatment and wants to change for himself/herself)
 - 2) Changes in support system
 - 3) Changes on Axis IV
 - 4) Different treatment approach
 - 5) Different goals for treatment
 - ii. Financial benefits – If left untreated, patient will end up in a higher, more expensive, level of care

3. **Lack of Progress in Treatment**

- a) Patient is not restoring weight
 - i. Weight restoration may not be the focus of treatment (bulimia, BED, ED NOS)
 - ii. Identify the reasons (usually behaviors) and the planned intervention strategies. This is usually enough to get a few extra days to see if patient can start to restore.
- b) No reduction in behaviors
 - i. Highlight progress in other areas and explain how this progress will lead to a reduction in behaviors.
 - ii. Have a plan ready for interventions moving forward to reduce behaviors. For example, we discovered that a patient had been exercising in her room at night, so we created a protocol for staff to check on the patient every X minutes and required her to keep her door slightly open. The reviewer understood that the protocol would likely disrupt the patient’s behaviors so she authorized additional days.

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- c) Lack of motivation in treatment
 - i. Discuss external influences on the patient’s motivation (i.e. stress within family) and emphasize the need for ongoing support during this difficult time. Also emphasize the triggering effects of these external influences and the likelihood of relapse if patient is stepped down too soon.
 - ii. Highlight *anything* patient has said or done which would indicate patient wants recovery
 - iii. Change something (medications, structure, schedule, therapeutic approach, anything that could spark a change)
 - d) Inconsistent attendance
 - i. If absences were planned or for legitimate reasons, the explanation should be enough. However, it always helps to discuss the reasons in clinical terms related to the patient’s recovery. (Ex: The patient’s schedule was modified to allow her to work a few shifts per week. This was discussed with the treatment team and will alleviate some of the financial burdens that have distracted her from focusing 100% on recovery. She has worked with her dietary team to plan meals and structure outside of treatment).
 - ii. If absences were not planned or were not for legitimate reasons, discuss the next steps the treatment team plans to take in order to encourage attendance. It is important to convey that the treatment team takes absences very seriously. It is also important to emphasize the patient’s need for extra support during this time. It does not hurt to speculate about the costs of terminating treatment while the patient is struggling.
 - iii. Frame it as “struggling with the ED” and discuss interventions moving forward
4. **Absence of Behaviors** (i.e., patient is doing too well in treatment and may be appropriate for a step-down)
- a) Continued weight restoration is imperative for a successful recovery. Stepping down now would slow or stop restoration altogether. (This argument is especially effective with patients who have previously failed at restoring weight on an outpatient or IOP basis.)
 - b) The patient has been using the program very effectively and is learning healthy coping skills. The patient is challenging herself with new skills and will benefit from additional time to practice these skills in a structured environment.
 - c) The patient will have several meals off within the next week. The patient must complete several successful meals off before we can determine that a step-down would be appropriate. If the patient struggles with the meals off, he or she will benefit from the continued structure of program in order to identify and address the issues that arise.
 - d) Emphasize the emotional/MH issues that contribute directly to the ED and the patient’s need for continued structure and support while beginning to address these issues.
5. **No medical complications**
- a) Emphasize the medical issues that the patient will likely develop if the behaviors continue. Serious, internal, long-term damage is not always apparent right away.
 - b) Dig for more information from the patient and/or medical providers. Patients often minimize or deny medical issues out of embarrassment and may be more forthcoming once they understand the benefits of disclosing the information.
 - c) Check the medical necessity criteria. Sometimes this is cited as a reason for denial even if it is not a criterion. In that case you have a pretty simple rebuttal.

How to Manage an Appeals Process

The arguments for appeals will be similar if not identical to the arguments provided in the above section. So, in addition to the arguments already given, here are some tips for filing appeals:

1. Request the specific reason for denial in the first place. Many reviewers will just cite “does not meet criteria for medical necessity” as a reason. This is not good enough. Ask for specific criterion that is not being met in the reviewer’s opinion. This will help you formulate a more concise argument for the appeal.
2. Request a copy of the medical necessity criteria being used to make the determination. If they direct you to the website, ask them to guide you to the correct page over the phone (It can be very difficult to find online and I have spoken to plenty of reviewers who struggle to find it themselves). Having the exact terminology and wording at your disposal will also help you to formulate a counter-argument.
 - a) Make sure they are using ED-specific criteria if they have it. If they are not, you can make plenty of arguments as to why it is not an appropriate measure for ED treatment.
3. Request for the next reviewer to be an ED specialist. They may not always grant the request, but it does imply that a non-ED doc may not fully understand the clinical factors involved in determining the appropriate course of treatment.
4. Request an expedited appeal. This will speed up the process and reduce the risk of financial loss if additional treatment is not authorized.
5. Believe yourself and believe in the patient. It will come across in your tone.

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Sample Letters to Use with Insurance Companies

This section provides seven sample letters to use for various circumstances you may encounter that require you to communicate with insurance companies. These letters were developed and used by families who encountered these situations. Keep in mind that a cordial, business communication tone is essential as discussed in *Understanding Insurance Issues for Eating Disorders Treatment*.

Remember:

- Follow up on letters with phone calls and document with whom you're speaking.
- Don't assume one insurance department knows what the other is doing.
- Don't panic! Your current issue or rejection can be a computer generated "glitch."
- Copy letters to others relevant to the request. Also, if you are complimenting someone for the assistance they've provided, tell them you'd love to send a copy to their boss to let him/her know about the great service you've received.
- Supply supporting documents.
- Get a signed delivery receipt — especially when time is of the essence.

Sample letters begin on the following page.

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Sample Letter #1

Request that the copay for the psychiatrist from the patient be changed to a medical copay rate instead of the higher mental health copay, because the psychiatrist was providing medication management, not psychotherapy.

Outcome

Adjustments can be made so that the family is billed for the medical copay. Remember, the psychiatrist must use the proper billing code.

Date:

To: Name of Clinical Appeals Staff Person

INS. CO. NAME & ADDRESS

From: YOUR NAME & ADDRESS

Re: PATIENT'S NAME

DOB (Date of Birth)

Insurance ID#

Dear [obtain and insert the name of a person to whom you'll address the letter — avoid sending to a generic title or "To Whom It May Concern"];

Thank you for assisting me with my [son's/daughter's] medical care. As you can imagine, this process is very emotionally draining on the entire family. However, the cooperation of the fine staff at [INSURANCE COMPANY NAME] makes it a little easier.

At this time, I would like to request that [INS. CO.] review the category that [Dr. NAME's] services have been placed into. It appears that I am being charged a copay for [his/her] treatment as a mental health service when in reality [he/she] provides [PATIENT NAME] with pharmacologic management for [his/her] neuro-bio-chemical disorder. Obviously, this is purely a medical consultation. Please review this issue and kindly make adjustments to past and future consultations.

Thank you in advance for your cooperation and assistance.

Sincerely,

[YOUR NAME]

Cc: [list the people in the company you are sending copies to]

NEDA TOOLKIT for Parents

Sample Letter #2

The need to flex hospital days for counseling sessions. Remember, just because you are using outpatient services does not mean that you cannot take advantage of benefits for a more acute level of care if your child is eligible for that level of care. The insurance company only knows the information you supply, so be specific and provide support from the treatment team!

Outcome

10 Hospital days were converted to 40 counseling sessions.

Date:

To: Name of an individual in the Ins. Co. Management Dept

INS. CO. NAME & ADDRESS

From: YOUR NAME & ADDRESS

Re: PATIENT'S NAME

DOB (Date of Birth)

Insurance ID#

Case #

Dear [insert name]:

This letter is in response to [insurance company name's] denial of continued counseling sessions for my [daughter/son]. I would like this decision to be reconsidered because [insert PATIENT NAME] continues to meet the American Psychiatric Association's clinical practice guidelines criteria for Residential treatment/Partial hospitalization. [His/Her] primary care provider, [NAME], supports [his/her] need for this level of care (see attached – Sample Letter #3 below provides an example of a physician letter). Therefore, although [he/she] chooses to receive services from an outpatient team, [he/she] requires an intensive level of support from that team, including ongoing counseling, to minimally meet [his/her] needs. I request that you correct the records re: [PATIENT NAME'S] level of care to reflect [his/her] needs and support these needs with continued counseling services, since partial hospitalization/residential treatment is a benefit [he/she] is eligible for and requires.

I am enclosing a copy of the APA guidelines and have noted [PATIENT NAME'S] current status. If you have further questions you may contact me at: [PHONE#] or [Dr. NAME] at: [PHONE#].

Thank you in advance for your cooperation and prompt attention to this matter.

Sincerely,

[YOUR NAME]

Cc: [Case manager]

[Ins. Co. Medical manager]

NEDA TOOLKIT for Parents

Sample Letter #3

Letter to a managed care plan to seek reimbursement for services that the patient received when time was insufficient to obtain pre-authorization because of the serious nature of the illness and the need to deal with it urgently. Remember: you need to research the professionals available through your plan and local support systems. In this case, after contacting their local association for eating disorders experts, the family that created this letter realized that no qualified medical experts were in their area to diagnose and make recommendations for their child. Keep in mind that you need to seek a qualified expert and not a world-famous expert. Make sure you provide very specific information from your research.

Outcome

Reimbursement was provided for the evaluating/treating psychiatrist visits and medications. Further research and documentation was required to seek reimbursement for the treatment facility portion.

DATE

To: Get the name of a person to direct a letter to

INS. CO. NAME & ADDRESS

From: YOUR NAME & ADDRESS

Re: PATIENT'S NAME

DOB (Date of Birth)

Insurance ID#

Case #

Dear [insert name]:

My [son/daughter] has been under treatment for [name the eating disorder and any applicable co-existing condition] since [month/year]. [He/she] was first seen at the college health clinic at [UNIVERSITY NAME] and then referred for counseling that was arranged through [INS. CO.]. At the end of the semester I met with my [son/daughter] and [his/her] therapist to make plans for treatment over the summer. At that time, residential treatment was advised, which became a serious concern for us. We then sought the opinion of a qualified expert about this advice. I first spoke to [PATIENT NAME'S] primary physician and then contacted the local eating disorders support group. No qualified expert emerged quickly from the community of our [INS. CO.] network providers. In my research to identify someone experienced in eating disorder evaluation and treatment, I discovered that [insert Dr.NAME at HOSPITAL in LOCATION] was the appropriate person to contact to expedite plans for our child. Dr. [NAME] was willing to see [him/her] immediately, so we made those arrangements.

As you can imagine, this was all very stressful for the entire family. Since continuity of care was imperative, we went ahead with the process and lost sight of the preapproval needed from [INS. CO.]. I am enclosing the bills we paid for those initial visits for reimbursement. [PATIENT NAME] was consequently placed in a residential setting in the [LOCATION] area and continues to see Dr. [NAME] through arrangements made by [INS. CO.].

Also, at the beginning of [his/her] placement, some confusion existed about medications necessary for [PATIENT NAME] during this difficult/acute care period. At one point payment for one of [his/her] medications was denied even though the treatment team recommended it, and it was prescribed by [his/her] primary care physician, Dr. [NAME]. I spoke to a [INS. CO.] employee [insert name] at [PHONE #] to rectify the situation; however, I felt it was a little too late to meet my timeframe for visiting [PATIENT NAME], so I paid for the Rx myself and want reimbursement at this time. If you have any questions, please speak to [employee name].

Thank you in advance for your cooperation. I'd be happy to answer any further questions and can be reached at: [PHONE]

Sincerely,
[YOUR NAME]

NEDA TOOLKIT for Parents

Sample Letter #4

To continue insurance while attending college less than full-time so that student can remain at home for a semester due the eating disorder. Note: When a student does not register on time at the primary university at which he/she has been enrolled, insurance is automatically terminated at that time. Automatic termination can cause an enormous amount of paperwork if not rectified IMMEDIATELY. The first letter informs the insurance company of the student's current enrollment status in a timely fashion, and the second letter responds to the abrupt and retroactive termination. Students affected by an eating disorder may be eligible for a medical leave of absence from college for up to one year — so you may want to inquire about that at the student's college.

Outcome

The student was immediately reinstated as a less than full-time student.

DATE

To: NAME OF CONTACT PERSON

INS. CO. NAME & ADDRESS

From: YOUR NAME & ADDRESS

Re: PATIENT'S NAME

DOB (Date of Birth)

Insurance ID#

Case #

Dear [NAME]:

We spoke the other day regarding my [son's/daughter's] enrollment status. I am currently following up on your instructions and appreciate your assistance in explaining what to do. [Dr. NAME] is sending you a letter that should arrive very soon about [PATIENT NAME's] medical status that required [him/her] to reduce the number of classes [he/she] will be able to take this fall. When [he/she] completes re-enrollment at [UNIVERSITY NAME] (which is not possible to do until the first day of classes, [DATE]), [he/she] will have the registrar's office notify you of her status. At this time, [NAME] plans to be a part-time student at [UNIVERSITY] for the [DATE] semester and plans to return to [UNIVERSITY] in [DATE], provided [his/her] disorder stabilizes. If all goes well; [he/she] may be able to graduate with [his/her] class and complete [his/ her] coursework by the [DATE] in spite of the medical issues. Please feel free to get answers to any questions regarding these plans from [PATIENT NAME'S academic advisor Mr./Ms. NAME], whom [PATIENT NAME] has given written permission in a signed release to speak to you. This advisor has been assisting my [son/daughter] with [his/her] academic plans and is aware of [his/her] current medical status. The advisor's phone number and email are: [PHONE #/ email].

Please feel free to contact me at [PHONE #] if you have any questions or need any further information. Thank you for your assistance.

Sincerely,
[YOUR NAME]

Cc:

NEDA TOOLKIT for Parents

Sample Letter #5

Follow-up letter to enrollment department after coverage was terminated retroactively to June 1st by the insurance company's computer.

DATE

To: NAME OF CONTACT PERSON

INS. CO. NAME & ADDRESS

From: YOUR NAME & ADDRESS

Re: PATIENT'S NAME

DOB (Date of Birth)

Insurance ID#

Case #

Dear [NAME]:

I am sure you can imagine my shock at receiving the attached letter [copy of the letter you received] that my [son/daughter] received about termination of coverage. [NAME] has been receiving coverage from [INSURANCE COMPANY] for treatment of serious medical issues since [DATE]. We have received wonderful assistance from [NAME], Case Manager [PHONE#]; [NAME], Mental Health Clinical Director [PHONE#]; and Dr. [NAME], [INS. CO.] Medical Director [PHONE #]. I am writing to describe the timeline of events with copies to the people who have assisted us as noted above.

In [DATE], [PATIENT NAME] requested a temporary leave of absence from [UNIVERSITY 1 NAME] to study at [UNIVERSITY 2 NAME] for one year. [He/she] was accepted at [UNIVERSITY 2 NAME] and attended the [DATE] semester. At the end of the spring semester [PATIENT NAME'S] medical issues intensified and [PATIENT NAME] returned home for the summer. The summer of [YEAR] has been very complicated and a drain on our entire family. The supportive people noted earlier in this letter made our plight bearable but we were constantly dealing with one medical issue after another.

At the beginning of August [PATIENT NAME] and the treatment team members began to discuss [PATIENT NAME'S] needs for the fall semester of [YEAR]. As far as our family was concerned, all options [UNIV. 1, UNIV. 2, & several local options full and part-time] needed to be up for discussion to meet [patient name's] medical needs. We hoped that with the help of [his/her] medical team we could make appropriate plans in a timely fashion.

During [PATIENT NAME'S] appointments the first two weeks of August, the treatment team agreed that [PATIENT NAME] should continue to live at home and attend a local university on a part-time basis for the fall semester. This decision was VERY difficult for [PATIENT NAME] and our family. [PATIENT NAME] still hopes/plans to return to [UNIV. 1] in [date] as a full-time student. [He/she] has worked with [his/her] [UNIV. 1] advisor since [date] to work out a plan that might still allow [him/her] to graduate with [his/her] class even if [he/she] needed to complete a class or two in the summer of [YEAR]. This decision by [NAME] was difficult but also a major breakthrough/necessity for [his/her] treatment.

After a workable plan was made, I called the enrollment department at [INS. CO. NAME] to gain information about the process of notification regarding this change in academic status due to [his/her] current medical needs. [INS. EMPLOYEE NAME] communicated to me that I needed to have my child's primary care physician write a letter supporting these plans. This letter is forthcoming as we speak. As soon as [PATIENT NAME'S] fall classes are finalized on [date]' that information will also be sent to you.

NEDA TOOLKIT for Parents

In summary, [PATIENT NAME] intended to be a full-time student this fall until [his/her] treatment team suggested otherwise in the early August. At that time I began notifying the insurance company. Please assist us in expediting this process. I ask that you immediately reinstate [him/her] as a policy member. If [his/her] status is not resolved immediately it will generate a GREAT DEAL of unnecessary extra work for all parties involved and, quite frankly, I'm not sure that our family can tolerate the useless labor when our energy is so depleted and needed for the medical/life issues at hand.

I am attaching 1) my previous enrollment notification note; 2) [PATIENT NAME'S] acceptance from [UNIV. 2]; 3) a copy of [PATIENT NAME'S] apartment lease for the year; and 4) [his/her] recent letter to [UNIV. 2] notifying them that [he/she] will be unable to complete the year as a visiting student for medical reasons. Please call me TODAY at [PHONE #] to update me on this issue. This is very draining on our family. Thank you for your assistance.

Sincerely,

[YOUR NAME]

Cc: [CASE MANAGER, MENTAL HEALTH CLINICAL DIRECTOR, MEDICAL DIRECTOR]

NEDA TOOLKIT for Parents

SAMPLE LETTER #6

Letter from doctor describing any medical complications your child has had, the doctor's recommendations for treatment, and the doctor's prediction of outcome if this treatment is not received. This is a sample physician letter that parents can bring to their child's doctor as a template to work from.

DATE

To: [Get the name of a medical director at the insurance company]:

INS. CO. NAME & ADDRESS

Re: PATIENT'S NAME

DOB (Date of Birth)

Insurance ID#

Dear [NAME]:

We are writing this letter to summarize our treatment recommendations for [patient name]. We have been following [patient name] in our program since [DATE]. During these past [NUMBER years], [patient name] has had [NUMBER] hospitalizations for medical complications of [insert conditions, e.g., malnutrition, profound bradycardia, hypothermia, orthostasis]. Each of the patient's hospital admissions are listed below [list each and every one separately]:

- Admission Date – Discharge Date [condition]

In all, [patient] has spent [NUMBER] days of the past [NUMBER years] in the hospital due to complications of [his/her] malnutrition. [Patient name's] malnutrition is damaging more than [his/her] heart. [His/Her] course has been complicated by the following medical issues:

- List each issue and its medical consequence [e.g., secondary amenorrhea since DATE, which has the potential to cause irreversible bone damage leading to osteoporosis in his/her early adult life.]

Despite receiving intensive outpatient medical, nutritional and psychiatric treatment, [patient name's] medical condition has continued to deteriorate with [describe symptoms/signs, e.g., consistent weight loss since DATE] and is currently 83% of [his/her] estimated minimal ideal body weight (the weight where the nutritionist estimates [he/she] will regain regular menses). White blood cell count and serum protein and albumin levels have been steadily decreasing as well, because of extraordinarily poor nutritional intake.

Given this history, prior levels of outpatient care that have failed, and [his/her] current grave medical condition, we recommend that [patient name] urgently receive more intensive psychiatric and nutritional treatment that can be delivered only in a residential treatment program specializing in eating disorders. We recommend a minimum 60- to 90- day stay in a tiered program that offers: intensive residential and transitional components focusing on adolescents and young adults with eating disorders (not older patients). [Patient] requires intensive daily psychiatric, psychologic, and nutritional treatment by therapists well-trained in the treatment of this disease. Such a tiered program could provide the intensive residential treatment that [he/she] so desperately needs so [he/she] can show that [he/she] can maintain any progress in a transitional setting. We do not recommend treatment in a non-eating disorder-specific behavioral treatment center. [Patient]'s severe anorexia requires subspecialty-level care. Examples of such programs would include [name facilities].

NEDA TOOLKIT for Parents

Anorexia nervosa is a deadly disease with a 10% to 15% mortality rate; 15% to 25% of patients develop a severe lifelong course. We believe that without intensive treatment in a residential program, [patient name's and condition], and the medical complications that it causes, will continue to worsen causing [him/her] to be at significant risk of developing lifelong anorexia nervosa or dying of the disease. We understand that in the past, your case reviewers have denied [patient] this level of care. This is the only appropriate and medically responsible care plan that we can recommend. We truly believe that to offer a lesser level of care is medically negligent. We trust that you will share our grave concern for [patient's] medical needs and approve the recommended level of care to assist in [his/her] recovery.

Thank you for your thorough consideration of this matter. Please feel free to contact us with any concerns regarding [patient's] care.

Sincerely,
[PHYSICIAN NAME]

Cc: [YOU]

NEDA TOOLKIT for Parents

SAMPLE LETTER #7

“Discussion” with the insurance company about residential placement when the insurance company suggests that the patient needs to fail at lower levels of care before being eligible for residential treatment. In a telephone conversation, the parents asked the insurance company to place a note in the patient file indicating the insurance company was willing to disregard the American Psychiatric Association guidelines and recommendations of the patient’s treatment team and take responsibility for the patient’s life. (SEND BY CERTIFIED MAIL!)

OUTCOME

Shortly thereafter, the parents received a letter authorizing the residential placement.

DATE

To: CEO (by name)

INS. CO. NAME & ADDRESS (use the headquarters)

From: YOUR NAME & ADDRESS

Re: PATIENT’S NAME

DOB (Date of Birth)

Insurance ID#

Case #

Dear (Pres. of INS. CO.):

Residential placement services for eating disorder treatment have been denied for our [son/daughter] against the recommendations of a qualified team of experts consistent with the American Psychiatric Association’s evidence-based clinical practice guidelines. Full documentation of our child’s grave medical condition and history and our attempts to obtain coverage for that care is available from our case manager [name]. At this time, I would like you to put in writing to me and to my child’s case file that [INS. CO.] is taking complete responsibility for my [son’s/daughter’s] life.

Respectfully,
[YOUR NAME]

Cc: [CASE MANAGER NATIONAL MEDICAL DIRECTOR (get the names for both the medical and behavioral health divisions)
NATIONAL MEDICAL DIRECTOR – Behavioral Health]

NEDA TOOLKIT for Parents

Other Steps for Loved Ones

One of the major factors insurance companies use to determine whether to continue paying for the current level of care is how the individual is responding to treatment. This can include physical signs, such as weight, vital signs, and electrolyte levels. It can also include the provider's assessments of the patient, which rely heavily on what the sufferer discloses during treatment. Not all sufferers are able and willing to disclose their internal struggles—such as hiding food, exercising in secret, and ongoing purging—during treatment, which would indicate a need for ongoing treatment at the current level of care or even the need for more intensive treatment.

However, loved ones may observe these behaviors when the eating disorder sufferer is home during the day or in the evenings, as well as when visiting at a

hospital or residential facility. Although health care providers cannot disclose information about the patient without their permission, that doesn't mean you can't open the doors of communication the other way.

If you see ongoing, worrisome eating disorder behaviors in your loved one, be sure to document them and give their providers a written copy. Not only will this help them receive better care and address issues the treatment team may not be aware of, it can give the providers additional ammunition to argue the need for ongoing care with the insurance companies.

Making Sense of Neuroscience

NEDA TOOLKIT for Parents

Appetite

For people with eating disorders, the decision of what to eat is a complicated snarl of anxiety and guilt. And it's not much less complicated for people without eating disorders. Our appetites — for *what* and *how much* we eat — are regulated by a complex array of hormones, hunger, and desire. When these systems are working properly, everything is great. We eat what we need and want, more or less. Our weight is appropriate for our genes and body type. Our diet is varied and tasty.

As in any complex system, however, things can go wrong. Research has shown us that eating disorder sufferers have problems regulating feelings of hunger and satiety that can perpetuate and perhaps even contribute to the onset of illness. Scientists have identified several key hormones and brain processes that may be malfunctioning in people with eating disorders. Leptin and ghrelin, discussed below, also interact with a variety of other hunger and satiety signals to help keep our bodies fueled properly.

Leptin is a hormone produced by fat cells that signals satiety. Researchers at Rockefeller University discovered the leptin gene almost 20 years ago (Zhang *et al.*, 1994), and researchers soon showed that leptin is one of the (many) reasons why diets don't work. As body fat stores go down, so do leptin levels. Lower leptin levels mean that it takes longer to feel full after eating, which serves to bring the body back to its original weight.

Since leptin is a key component of appetite and body weight regulation, scientists suspected that leptin might be involved in eating disorders. Researchers measured leptin levels in 67 women with eating disorders (21 had anorexia, 32 had bulimia, and 14 had binge eating disorder), and compared this to 25 healthy women (Monteleone *et al.*, 2000). As expected, leptin levels were significantly elevated in the women with binge eating disorder compared to healthy women, but they were significantly lowered in women with anorexia or bulimia.

Normally, high levels of leptin are associated with lower levels of endocannabinoids, brain chemicals that, among other things, regulate appetite (DiMarzo *et al.*, 2001). Low levels of endocannabinoids should make a person feel less hungry. This isn't the case in people with binge eating disorder; their elevated leptin levels are actually associated with high levels of

endocannabinoids, which could help promote further binge eating (Monteleone *et al.*, 2005a). It's not clear, at this point, whether these alterations are a cause or a result of regular binge eating.

When researchers compared leptin levels in women with anorexia to women who had low weights for other reasons, they found that leptin was significantly higher in the women with anorexia. This blunted leptin response could help explain why people with anorexia are hyperactive and can continue starving themselves for long periods of time. They are hungry, yes, but not as hungry as they should be (Frederich *et al.*, 2002).

In bulimia, leptin levels appeared somewhat lower than expected, and lower leptin levels were associated with more frequent binge eating (Jimerson *et al.*, 2000). A later study found that low leptin levels in women with bulimia were also associated with more chronic, severe illness (Monteleone *et al.*, 2002).

Ghrelin is secreted by the stomach and acts opposite to leptin. Whereas high levels of leptin help trigger satiety, high levels of ghrelin help trigger hunger. Ghrelin levels typically rise before a meal and decrease afterwards. The hormone is thought to work in part by helping to stimulate the brain's reward system to encourage eating. The links between ghrelin and eating disorders aren't quite as straightforward as those seen with leptin.

Scientists found that, in women with binge eating disorder, ghrelin levels were lower than in women with similar BMIs (Geliebter, Gluck, & Hashim, 2005). Other researchers have found similar results (Monteleone *et al.*, 2005b), indicating that decisions about eating aren't dictated just by hunger and fullness, but by other emotions as well.

When researchers measured ghrelin in women with bulimia, they found that levels of this hormone didn't decrease as much as it did in control women. Since women with bulimia don't feel as full after a meal, they may be more likely to binge or overeat (Monteleone *et al.*, 2003). In anorexia, ghrelin levels are elevated, as expected with someone who is starving. During the refeeding process, however, ghrelin levels drop dramatically, which could help explain why many people with anorexia struggle to put on weight: their hunger signals aren't working properly (Cano *et al.*, 2012).

NEDA TOOLKIT for Parents

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NEDA TOOLKIT for Parents

Body Image

A common feature in many eating disorders is distorted body image, and an overemphasis on the importance of weight and shape to one's value as a person. Our cultural emphasis on dieting, thin models, and digitally altered images certainly plays a role. However, if the body image distortions were only caused by media factors, nearly everyone would suffer from an eating disorder. Nor do cultural factors explain the documented existence of eating disorders in cultures and time periods without a cultural emphasis on thinness. New research is showing that individuals with eating disorders have differences in the way they perceive their own shape and size that appears to be strongly influenced by biology.

Everyone has a body image. Researchers define body image as the way we picture and perceive our bodies in our minds, and this perception is shaped by broader cultural factors, our own individual experiences, and by how our brains perceive the size of our bodies and how they move through space. Only in more recent years have scientists begun to tease apart how these neurological factors can affect the development of body image in eating disorders.

It appears that several regions of the brain are involved in this body image distortion. In a neuroimaging study of women recovered from binge/purge anorexia, researchers found that higher serotonin receptor activity in the left parietal cortex was associated with lower drive for thinness (Bailer *et al.*, 2004). A separate study also found abnormal activation of the parietal cortex when individuals with anorexia were asked to look at pictures of themselves (Wagner *et al.*, 2003). The parietal cortex helps to create a map of the body using the sensory information it processes, and researchers have hypothesized that problems with creating this body map may at least in part underlie body image distortions in eating disorders (Titova *et al.*, 2013). This hypothesis is supported by research that showed patients currently ill with anorexia had problems retrieving accurate information about their body shape that caused them to overestimate their current body size (Mohr *et al.*, 2010).

These distortions also appear to involve the brain's fear circuitry. Scientists in Germany asked three adolescents currently hospitalized for anorexia to view pictures of their own body that had been digitally altered to appear larger and thus simulate the teens' actual body image. When the teens with anorexia looked at the

digitally altered images of their bodies, the activity in their fear circuits increased significantly when compared to the activity when these teens viewed digitally altered images of healthy teen bodies (Seeger *et al.*, 2002).

Although more research has been done looking at the neurobiology of body image in people with anorexia, it appears that many of the same processes may occur in people with bulimia. When researchers asked 13 women with anorexia, 16 women with bulimia, and 27 healthy controls to view pictures of their own bodies in a bikini, the activity in the parietal cortex was similar in both groups of eating disordered women (Vocks *et al.*, 2010).

Studies have found that body image dissatisfaction plays a role in binge eating disorder (Grilo & Masheb, 2005), as does body image distortion (Mussell *et al.*, 1996); however, no neurobiological studies have been completed to determine the nature of these body image issues.

In adolescent girls without eating disorders, scientists have found that the extent to which a teen girl believes that her body should conform to the cultural ideal of extreme thinness (known as thin ideal internalization) appears to be somewhat heritable (Suisman *et al.*, 2012). The authors of the study believe that perfectionism may play a role in this, as highly perfectionistic people may likely express the need or desire to have a "perfect" body. Indeed, independent studies have found that, in individuals without eating disorders, people who have higher levels of perfectionism also experience higher levels of body dissatisfaction (Wade & Tiggemann, 2013). It's also not yet clear how thin ideal internalization interacts with the neurobiological differences discussed above to alter a person's risk for an eating disorder.

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Neurotransmitters

Although eating disorders result from the interplay of a variety of cultural and biological factors, the brain is central to understanding why some people develop eating disorders, why people stay ill, and how they can recover. In recent years, scientists have made tremendous strides in understanding the brain science of eating disorders.

Based on evidence from hundreds of studies, it appears that one of the factors that make a person more likely to develop an eating disorder is how their brain functions. Researchers have identified specific neurobiological differences in the brains of people with anorexia, bulimia, or binge eating disorder. These differences affect how we eat, as well as things like mood, anxiety, personality, and decision-making.

This section will introduce you to the basics of eating disorder neurobiology, and how various neural systems work together in individuals with eating disorders.

Neurons

Neurons send signals to each other using chemicals known as neurotransmitters. The type and amount of neurotransmitters released will tell neighboring neurons whether to become active or to stay silent.

The body produces an array of neurotransmitters and their receptors, which are proteins on the surface of the cell that recognize a specific neurotransmitter and relay the signal from the outside to the inside of the cell. Small variations in the shape and number of receptors, as well as the amount of neurotransmitter produced — known as polymorphisms — exist in the population, which increase or decrease the amount of neurotransmitter in the synapse (the small space between a neuron and its neighbors) and our sensitivity to it. These variations have been linked to a variety of mental illnesses, including eating disorders.

For eating disorders, there are two primary neurotransmitters you need to know about: serotonin and dopamine. Each of these neurotransmitters has an influence in how we think and behave, our personalities, and even perhaps our risk for developing an eating disorder.

Serotonin

Given that serotonin (sometimes referred to as 5-hydroxytryptophan) helps control everything from memory and learning to sleep, mood, and appetite,

researchers quickly began to look for potential relationships between polymorphisms in serotonin receptor genes and eating disorders.

A variety of studies have found alterations in the serotonin system in individuals currently ill with anorexia nervosa and those recovered from the disorder. Researchers found that people who are currently suffering from anorexia have significantly lower levels of serotonin metabolites in their cerebrospinal fluid than individuals without an eating disorder. This is likely a sign of starvation, since the body synthesizes serotonin from the food we eat. After long-term recovery from anorexia, however, individuals have significantly elevated serotonin levels (Kaye *et al.*, 1991). In this study, the researchers found that higher levels of serotonin correspond with levels of anxiety and obsessive behavior. Geneticists have also found that individuals with anorexia are slightly more likely to carry a particular variant of the 5HT2A serotonin receptor, which is thought to increase the amount of serotonin in the brain during the non-starved state (Gorwood *et al.*, 2002).

In an article published in 2009 in *Nature Neuroscience*, leading eating disorder researcher Walter Kaye hypothesizes that starvation actually makes people with anorexia feel better by decreasing the serotonin in their brains (Kaye, Fudge, & Paulus, 2009). As they continue to starve themselves, however, the brain responds by increasing the number of serotonin receptors to more efficiently utilize the remaining serotonin. So in order to keep feeling better, the person needs to starve themselves further, creating the illness's vicious cycle. When someone with anorexia starts eating again, however, serotonin levels spike, causing extreme anxiety and emotional chaos, which makes recovery difficult without adequate support.

Individuals with bulimia also have dysfunctions in their serotonin circuitry. Those with bulimia, however, appear to have somewhat different alterations than those with anorexia. When going without food for longer periods of time (such as during sleep), those with bulimia had a larger drop in serotonin levels than women without eating disorders, which led to binge eating and increased irritability (Steiger *et al.*, 2001). Researchers also found that women with bulimia who carried a particular variant of a serotonin receptor were also significantly more impulsive (Bruce *et al.*, 2005). Abnormalities in the serotonin system were also found to persist after recovery, hinting that these

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differences may have been present before the onset of the disorder (Kaye *et al.*, 2001).

Serotonin alterations in binge eating disorder appear fairly similar to those found in bulimia, although the research is more limited in this area. Researchers generally believe that individuals with BED also suffer from chronically low serotonin levels, which is thought to contribute to binge eating in an attempt to relieve the depressed mood caused (in part) by this low serotonin (Haedt-Matt & Keel, 2011). Genetics studies have supported this idea, as variants in a serotonin transporter gene were associated with increased binge eating severity in the general population (Akkermann *et al.*, 2010). Further studies found an association between impulsivity and strict dieting with serotonin receptor genes and binge eating in young women (Racine *et al.*, 2009).

Dopamine

Dopamine is commonly thought of as the “pleasure” chemical, due to its links with rewarding behaviors and drugs of abuse. Although dopamine is involved in reward-motivated behavior (such as studying to get good grades, or going to work early to get a raise), it also helps regulate movement, memory, hormones and pregnancy, and sensory processing (Beaulieu & Gainetdinov, 2011). Like serotonin, the overlap of processes controlled by dopamine and eating disorder-related symptoms caused researchers to investigate potential associations.

In anorexia, the leading hypothesis is that the disorder is associated with an over-production of dopamine, leading to anxiety (Bailer *et al.*, 2012a), harm avoidance (Bailer *et al.*, 2012b), hyperactivity and the ability to go without pleasurable things like food (Kontis & Theochari, 2012). Research has shown that bulimia is associated with lower levels of both dopamine and certain of its receptors, and that binge eating is significantly associated with dopamine release in certain parts of the brain (Broft *et al.*, 2012). Binge eating disorder has been linked to a hyper-responsiveness to rewards such as food, which makes eating more rewarding and pleasurable than in people without this disorder (Davis *et al.*, 2012) and leads to a continuation of compulsive overeating (Bello & Hajnal, 2010).

You can read more about the effects of dopamine in the section on Reward.

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Reward

In eating disorders, scientists have identified problems not only with the physical sensations of hunger and fullness, but also with how rewarding food is. If an animal doesn't eat enough, it will die, so necessities like eating are generally quite pleasurable to ensure that we stay alive. This pleasure helps reinforce the behaviors, thoughts, and memories that lead to eating. Alternately, the brain usually perceives hunger as being uncomfortable to motivate us to go eat something. Research has shown us that the brain's reward pathways are altered in individuals with eating disorders, making them more or less able to perceive and respond to pleasurable things.

Normally, when we are hungry, food is more rewarding than when we are full (Bragulat *et al.*, 2010), as evidenced by the increased release of dopamine in the nucleus accumbens, which is known to play a role in pleasure, reward, addiction and fear (Avena, Rada, & Hoebel, 2008). Given that food restriction frequently accompanies binge eating behavior (Stice *et al.*, 2000), the binge becomes even more rewarding in these individuals than the normal satiation of hunger. The post-binge guilt leads to further food restriction, which serves to maintain the high reward of binge eating (Carr, 2011).

Neuroimaging studies in women with bulimia revealed that their brain's reward pathways are significantly more active than in healthy controls when they viewed pictures of food (Brooks *et al.*, 2011). Women with the binge/purge type of anorexia also showed significantly higher reward sensitivity (Harrison *et al.*, 2010).

Despite increased awareness and diagnosis of binge eating in males, the disorder is still significantly more common in females. Some researchers believe that female sex hormones may help increase reward sensitivity (Klump *et al.*, 2013). Scientists are currently testing this idea.

In bulimia, purging appears to be rewarding as well. One study found a significant association between higher reward sensitivity and frequency of purging in women with bulimia (Farmer, Nash, & Field, 2001). One potential explanation for this is that purging decreases the amount of acetylcholine in the brain, high levels of which have been found to be unpleasant (Avena & Bocarsly, 2012).

This altered reward system in individuals who binge eat is evident in areas besides food. Studies have found that high school students who reported regular binge eating were much more likely to report use of drugs, alcohol, or tobacco than non-binge eaters. Those students who also engaged in compensatory behaviors like fasting or purging were most likely to use these substances (Ross & Ivis, 1999).

In anorexia, a large number of studies have instead found significantly decreased reward sensitivity, as well as an over-response to punishment (Harrison *et al.*, 2010). Neuroimaging studies also revealed unusually high levels of cognitive processing when individuals with anorexia viewed images of food (Cowdrey *et al.*, 2011). Because food is less rewarding and appears to be associated with fear and punishment, people with anorexia tend to place a higher emphasis on the long-term goal of weight loss and maintaining anorexic behaviors rather than food's more immediate rewards (Kaye *et al.*, 2013). They also tend to report high levels of ascetic behaviors (Keating *et al.*, 2012).

These differences in reward processing across the eating disorder spectrum appear to persist after recovery (Wagner *et al.*, 2010; Wagner *et al.*, 2007). Because of this, some researchers believe that these results may indicate that these traits exist before disease onset and are corroborated with reports of childhood behaviors (Anderluh *et al.*, 2003). Still, it also remains possible that these post-recovery traits are scars from the illness rather than pre-illness risk factors.

In some religious and cultural traditions, the denial of pleasure is typically seen as a good thing. Thus it may seem that individuals with anorexia have a "better" way of managing reward. This isn't true. When you're truly physically hungry, it's good to focus on the immediate rewards of eating. Difficulties in shifting focus from the potential benefits of long-term goals to the more immediate benefits of feeding a starving body and pursuing recovery can keep people stuck in anorexia nervosa for years.

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Temperament and Personality

Our personalities are molded by both the genes we inherit and our life experiences. Psychologists have been trying for decades to identify the different aspects of personality or temperament that help make us tick. Over the years, scientists have found distinct personality traits in individuals with eating disorders. They appear relatively specific to each disorder and can distinguish eating disorder sufferers from healthy people.

Some studies have associated aspects of these personality traits with alterations in serotonin and dopamine signaling.

Anorexia Nervosa

People who suffer from anorexia nervosa tend to have high levels of harm avoidance, a personality trait characterized by worrying, pessimism, and shyness, and low levels of novelty seeking, which includes impulsivity and preferring new or novel things (Fassino *et al.*, 2002). The different subtypes of anorexia have slightly different personality traits, with the binge/purge subtype showing slightly higher levels of impulsivity and novelty-seeking (Bulik *et al.*, 1995). The restricting subtype had higher levels of persistence (Klump *et al.*, 2000). Researchers have linked higher levels of harm avoidance with higher levels of serotonin in the brain (Cloninger, 1985), and scientists have linked harm avoidance with specific alterations in the serotonin system in women recovered from anorexia (Bailer *et al.*, 2005).

A study measuring slightly different facets of personality found that women with either the restricting or binge/purge subtype of anorexia had higher levels of neuroticism (characterized by depression, anxiety, worry, and moodiness) than controls, and that women with restricting anorexia scored higher on measures of agreeableness and conscientiousness than those with the binge/purge type (Bollen & Wojciechowski, 2004).

Bulimia Nervosa

Individuals with bulimia nervosa have high levels of harm avoidance like anorexia sufferers, but instead it's paired with high levels of novelty seeking (Fassino *et al.*, 2002). This study found that those with the binge/purge subtype of anorexia show traits that are midway between restricting anorexia and bulimia. Other research has found high levels of impulsivity, emotion

dysregulation, and anxiety in women with bulimia, and greater impulsivity was associated with more frequent purging behaviors (Brown, Haedt-Matt, & Keel, 2011).

Scientists found that people who have trouble regulating the amount of dopamine in their brains have higher levels of novelty-seeking (Zald *et al.*, 2008), and that this also occurs in women with bulimia (Groleau *et al.*, 2012).

Anorexia and bulimia

Although some personality traits are specific to each eating disorder diagnosis, other traits are more general and appear to be shared by many or most individuals with eating disorders. Researchers at King's College London identified a set of five obsessive-compulsive personality traits (perfectionism, inflexibility, rule driven, drive-for-order and symmetry, excessive doubt and cautiousness) and found that women with anorexia and bulimia were significantly more likely to have shown signs of these in childhood (they were almost never seen in healthy controls). What's more, the presence of each of these traits increased a person's odds of developing an eating disorder by seven. A person who had all five of these traits is *thirty-five times* more likely to develop an eating disorder than someone who shows none of these traits (Anderluh *et al.*, 2003).

Separately from other obsessive-compulsive traits, individuals with eating disorders show high levels of perfectionism, especially a type known as self-oriented perfectionism, in which a person has unreasonably high standards for themselves but not others. Researchers found equally high levels of perfectionism in women with either anorexia or bulimia in two separate studies (Halmi *et al.*, 2005; Bulik *et al.*, 2003).

Binge Eating Disorder

Personality traits are less well-defined in binge eating disorder than in anorexia or bulimia. Preliminary research in *Comprehensive Psychology* found that people with binge eating disorder had higher levels of harm avoidance and novelty seeking and lower levels of self-directedness than healthy controls (Grucza, Przybeck, & Cloninger, 2007).

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