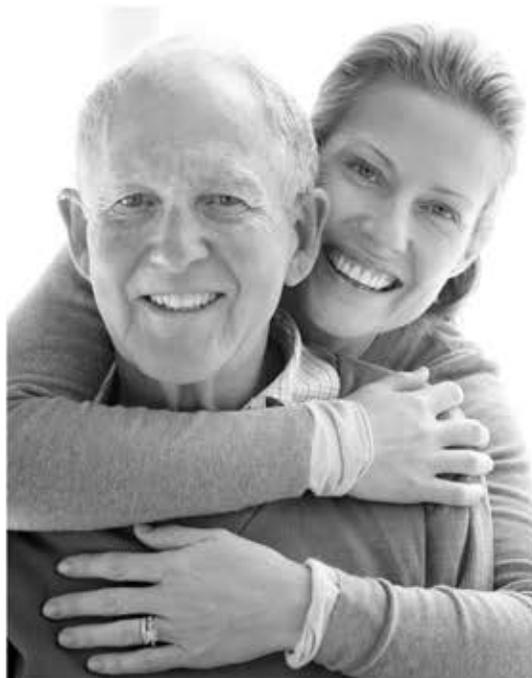




National Eating Disorders Association

# Parent TOOLKIT



**NEDA TOOLKIT for Parents**  
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## NEDA TOOLKIT for Parents

# The NEDA Educational Toolkits Story

### The background

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 existing materials and provide vital information to targeted audiences. A list of audiences was prioritized by the board and acts as a reference for ongoing materials and toolkit development.

### The toolkit concept

The initial concept of the toolkits was to tie together existing information along with the development of new materials to create complete packages that would help targeted audiences during critical moments in their search for help, hope and healing. They are intended for guidance, not for standards of care and would be based on information available at the time of development.

Creation of the toolkits took thoughtful consideration. We identified several key questions as we began working on this project. First: "What is a NEDA Educational Toolkit?" led us to ask ourselves these questions:

- Who is the audience we are trying to reach?
- How many different toolkits will we develop?
- What should a toolkit contain?
- How do we include our stakeholders in the development of the toolkits?
- How does our audience want to receive the toolkit once it's developed?
- How do we market the toolkits?
- What is the plan to revise and enhance the toolkits over time?

### Parents and Educators...the starting point

Using the core questions we decided the Parent and Educators Toolkits would be created first. Additional target audiences will include Coaches and Trainers, Health Care Providers, and Individual Patients. We then hired ECRI Institute, a recognized expert in providing publications, information and consulting services internationally for healthcare assessments. Their ability to translate work on behalf of the eating disorders community into useful, real world tools established an excellent partnership for creating the content of the toolkits.

### Parents and Educators...the process

ECRI initially created two separate toolsets with a consistent tone. We brought together two focus groups to guide us in the types of information to be included for each of the audiences – parents and educators. ECRI conducted additional interviews with interested elementary and high school teachers and families. Next, ECRI researched and revised existing NEDA educational materials and handouts (as needed) and created new materials as appropriate for each kit. The result was a draft set of "tools" for each toolkit. Some basic information is common to each; other tools are unique to each toolkit. As with all our materials, we want to increase the outreach and support to our constituents while providing reliable information to the general public about the unique and complex nature of eating disorders.

All focus groups agreed that an electronic toolkit, accessible via the NEDA website, would be the easiest, most up-to-date way to make the toolkits available. NEDA researched and reviewed several online toolkits, looking for the best elements of each that could be used to inform the design concept. The final design plan for the organization of each kit was created by designer, David Owens Hastings. ECRI then produced the final documents that are the body of each of the first toolkits. The focus groups reviewed materials one more time and made suggestions for revisions. Their excellent edits and useful comments were integrated into the drafts. Joel Yager, MD, and additional clinical advisors were final reviewers on all documents. ECRI then submitted the Toolkit documents to NEDA.

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### Beyond parent and educators toolkits

We fully recognize that not all the information within each toolkit will be able to address the diversity and the nuances of each person's and/or families unique circumstances. Our intent is to provide a one-stop place for a comprehensive overview relating to eating disorders for each audience. We have included resources for further information and will be going deeper as funding permits with each audience. We are imagining at this point in the project Parent and Educator toolkits version 1.0, then version 2.0 and so on. The lifecycle of the toolkits is an important aspect in managing this strategic priority for the organization. Our goal is to maintain the usefulness of the toolkits by reviewing and revising each at two-year intervals and including the most up-to-date research and information. NEDA's clinical advisors will be primary reviewers, along with others invited by NEDA, including members of professional organizations that will be disseminating the toolkits.

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](mailto:development@nationaleatingdisorders.org). We hope you'll find these toolkits useful and will share this resource with others.

# Basic Information for Parents

## NEDA TOOLKIT for Parents

# Common myths about eating disorders

This information is intended to help dispel all-too-common misunderstandings about eating disorders and those affected by them. If your family member has an eating disorder, you may wish to share this information with others (i.e., other family members, friends, teachers, coaches, family physician).

### Eating disorders are not an illness

Eating disorders are a complex medical/psychiatric illness. Eating disorders are classified as a mental illness in the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Health Disorders (DSM-IV)*, are considered to often have a biologic basis, and co-occur with other mental illness such as major depression, anxiety, or obsessive-compulsive disorder

### Eating disorders are uncommon

They are common. Anorexia nervosa, bulimia nervosa, and binge-eating disorder are on the rise in the United States and worldwide. Among U.S. females in their teens and 20s, the prevalence of clinical and subclinical anorexia may be as high as 15%. Anorexia nervosa ranks as the 3rd most common chronic illness among adolescent U.S. females. Recent studies suggest that up to 7% of U.S. females have had bulimia at some time in their lives. At any given time an estimated 5% of the U.S. population has undiagnosed bulimia. Current findings suggest that binge-eating disorder affects 0.7% to 4% of the general population.

### Eating disorders are a choice

People do not choose to have eating disorders. They develop over time and require appropriate treatment to address the complex medical/psychiatric symptoms and underlying issues.

### Eating disorders occur only in females

Eating disorders occur in males. Few solid statistics are available on the prevalence of eating disorders in males, but the disorders are believed to be more common than currently reflected in statistics because of under-diagnosis. An estimated one-fourth of anorexia diagnoses in children are in males. The National Collegiate Athletic Association carried out studies on the incidence of eating-disordered behavior among athletes in the 1990s, and reported that of those athletes who reported having an eating disorder, 7% were male. For binge-eating disorder, preliminary research suggests equal prevalence among males and females. Incidence in males may be underreported

because females are more likely to seek help, and health practitioners are more likely to consider an eating disorder diagnosis in females. Differences in symptoms exist between males and females: females are more likely to focus on weight loss; males are more likely to focus on muscle mass. Although issues such as altering diet to increase muscle mass, over-exercise, or steroid misuse are not yet criteria for eating disorders, a growing body of research indicates that these factors are associated with many, but not all, males with eating disorders.

### Men who suffer from eating disorders tend to be gay

Sexual preference has no correlation with developing an eating disorder.

### Anorexia nervosa is the only serious eating disorder

All eating disorders can have damaging physical and psychological consequences. Although excess weight loss is a feature of anorexia nervosa, effects of other eating disorders can also be serious or life threatening, such as the electrolyte imbalance associated with purging.

### A person cannot die from bulimia

While the rate of death from bulimia nervosa is much lower than that seen with anorexia nervosa, a person with bulimia can be at high risk for death and sudden death because of purging and its impact on the heart and electrolyte imbalances. Laxative use and excessive exercise can increase risk of death in individuals who are actively bulimic.

### Subclinical eating disorders are not serious

Although a person may not fulfill the diagnostic criteria for an eating disorder, the consequences associated with disordered eating (e.g., frequent vomiting, excessive exercise, anxiety) can have long-term consequences and requires intervention. Early intervention may also prevent progression to a full-blown clinical eating disorder.

## NEDA TOOLKIT for Parents

### **Dieting is normal adolescent behavior**

While fad dieting or body image concerns have become “normal” features of adolescent life in Western cultures, dieting or frequent and/or extreme dieting can be a risk factor for developing an eating disorder. It is especially a risk factor for young people with family histories of eating disorders and depression, anxiety, or obsessive-compulsive disorder. A focus on health, wellbeing, and healthy body image and acceptance is preferable. Any dieting should be monitored.

### **Anorexia is “dieting gone bad”**

Anorexia has nothing to do with dieting. It is a life-threatening medical/psychiatric disorder.

### **A person with anorexia never eats at all**

Most anorexics do eat; however, they tend to eat smaller portions, low-calorie foods, or strange food combinations. Some may eat candy bars in the morning and nothing else all day. Others may eat lettuce and mustard every 2 hours or only condiments. The disordered eating behaviors are very individualized. Total cessation of all food intakes is rare and would result in death from malnutrition in a matter of weeks.

### **Only people of high socioeconomic status get eating disorders**

People in all socioeconomic levels have eating disorders. The disorders have been identified across all socioeconomic groups, age groups,

### **You can tell if a person has an eating disorder simply by appearance**

You can't. Anorexia may be easier to detect visually, although individuals may wear loose clothing to conceal their body. Bulimia is harder to “see” because individuals often have normal weight or may even be overweight. Some people may have obvious signs, such as sudden weight loss or gain; others may not. People with an eating disorder can become very effective at hiding the signs and symptoms. Thus, eating disorders can be undetected for months, years, or a lifetime.

### **Eating disorders are about appearance and beauty**

Eating disorders are a mental illness and have little to do with food, eating, appearance, or beauty. This is indicated by the continuation of the illness long after a person has reached his or her initial ‘target’ weight. Eating disorders are usually related to emotional issues such as control and low self-esteem and often exist as part of a “dual” diagnosis of major depression, anxiety, or obsessive-compulsive disorder.

### **Eating disorders are caused by unhealthy and unrealistic images in the media**

While sociocultural factors (such as the ‘thin ideal’) can contribute or trigger development of eating disorders, research has shown that the causes are multifactorial and include biologic, social, and environmental contributors. Not everyone who is exposed to media images of thin “ideal” body images develops an eating disorder. Eating disorders such as anorexia nervosa have been documented in the medical literature since the 1800s, when social concepts of an ideal body shape for women and men differed significantly from today—long before mass media promoted thin body images for women or lean muscular body images for men.

### **Recovery from eating disorders is rare**

Recovery can take months or years, but many people eventually recover after treatment. Recovery rates vary widely among individuals and the different eating disorders. Early intervention with appropriate care can improve the outcome regardless of the eating disorder. Although anorexia nervosa is associated with the highest death rate of all psychiatric disorders, research suggests that about half of people with anorexia nervosa recover, about 20% continue to experience issues with food, and about 20% die in the longer term due to medical or psychological complications.

## NEDA TOOLKIT for Parents

### Eating disorders are an attempt to seek attention

The causes of eating disorders are complex and typically include socio economic, environmental, cultural, and biologic factors. People who experience eating disorders often go to great lengths to conceal it due to feelings of shame or a desire to persist in behavior perceived to afford the sufferer control in life. Eating disorders are often symptomatic of deeper psychological issues such as low self-esteem and the desire to feel in control. The behaviors associated with eating disorders may sometimes be interpreted as 'attention seeking'; however, they indicate that the affected person has very serious struggles and needs help.

### Purging is only throwing up

The definition of purging is to evacuate the contents of the stomach or bowels by any of several means. In bulimia, purging is used to compensate for excessive food intake. Methods of purging include vomiting, enemas and laxative abuse, insulin abuse, fasting, and excessive exercise. Any of these behaviors can be dangerous and lead to a serious medical emergency or death. Purging by throwing up also can affect the teeth and esophagus because of the acidity of purged contents.

### Purging will help lose weight

Purging does not result in ridding the body of ingested food. Half of what is consumed during a binge typically remains in the body after self-induced vomiting. Laxatives result in weight loss through fluids/water and the effect is temporary. For these reasons, many people with bulimia are average or above-average weight.

### You're not sick until you're emaciated

Only a small percentage of people with eating disorders reach the state of emaciation often portrayed in the media. The common belief that a person is only truly ill if he or she becomes abnormally thin compounds the affected individuals' perceptions of body image and not being "good" at being "sick enough." This can interfere with seeking treatment and can trigger intensification of self-destructive eating disorder behaviors.

### Kids under age 15 are too young to have an eating disorder

Eating disorders have been diagnosed in children as young as seven or eight years of age. Often the precursor behaviors are not recognized until middle to late teens. The average age at onset for anorexia nervosa is 17 years; the disorder rarely begins before puberty. Bulimia nervosa is usually diagnosed in mid-to-late teens or early 20s, although some people do not seek treatment until even later in life (30s or 40s).

### You can't suffer from more than one eating disorder

Individuals often suffer from more than one eating disorder at a time. Bulimarexia is a term that was coined to describe individuals who go back and forth between bulimia and anorexia. Bulimia and anorexia can occur independently of each other, although about half of all anorexics become bulimic. Many people suffer from an eating disorders not otherwise specified (EDNOS), which can include any combination of signs and symptoms.

### Achieving normal weight means the anorexia is cured

Weight recovery is essential to enabling a person with anorexia to participate meaningfully in further treatment, such as psychological therapy. Recovering to normal weight does not in and of itself signify a cure, because eating disorders are complex medical/psychiatric illnesses.

## Eating Disorder Signs, Symptoms, and Behaviors

### Anorexia Nervosa

- Dramatic weight loss
- Dresses in layers to hide weight loss
- 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 body weight at or above a minimally normal weight for age and height
- 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

## **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

### **Binge Eating Disorder (Compulsive 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

### **Other Eating Disorders**

- Any combination of the above

## NEDA TOOLKIT for Parents

# How to be supportive

### Recommended Do's

- 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
- Talk with the person in a kind way when you are calm and not angry, frustrated, or upset
- Have compassion when the person brings up painful issues about underlying problems
- Let him/her know you only want the best for him/her
- Remind the person that he/she has people who care and support him/her
- Suggest professional help in a gentle way
- Offer to go along
- Be flexible and open with your support
- Be honest
- Compliment the person's personality, successes, and accomplishments
- Encourage all activities suggested by the treating care team, such as keeping appointments and medication compliance
- Encourage social activities that don't involve food
- Encourage the person to buy foods that he/she will want to eat (as opposed to only "healthy" foods)
- Help the person to be patient
- Help with the person's household chores (e.g., laundry, cleaning) as needed
- Remember: recovery takes time and food may always be a difficult issue
- Remember: recovery work is up to the affected person
- Show care, concern, and understanding
- Ask how he/she is feeling
- Try to be a good role model
- Understand that the person is not looking for attention or pity

### Recommended Don'ts

- Accuse or cause feelings of guilt
- Invade privacy and contact the patient's doctors or others to check up behind his/her back
- Demand weight changes (even if clinically necessary for health)
- Insist the person eat every type of food at the table
- Invite the person out for social occasions where the main focus is food
- Invite the person to go clothes shopping
- Make eating, food, clothes, or appearance the focus of conversation
- Make promises or rules you cannot or will not follow (e.g., promising not to tell anyone)
- Threaten (e.g., if you do this once more I'll...)
- Offer more help than you are qualified to give
- Create guilt or place blame on the person
- Put timetables on recovery
- Take the person's actions personally
- Try to change the person's attitudes about eating or nag about food
- Try to control the person's life
- Use scare tactics to get the person into treatment, but do call 911 if you believe the person's condition is life-threatening

## NEDA TOOLKIT for Parents

# Ways to start a discussion with a loved one who might have an eating disorder

The following guidance presumes that the situation is serious, that it is not immediately life threatening, and that it does not require emergency medical care or a call to 911.

### Learn all you can about eating disorders

Then, prepare yourself to listen with compassion and no judgment. Have a list handy of the resources to offer if asked.

### Remember that even though you are informed about the eating disorder, only a professional trained in diagnosing eating disorders can make a diagnosis

Avoid using your knowledge to nag or scare the person. The goal of a discussion should be to express your concerns about what you've observed and persuade, but not force, the person to accept help.

### Plan a private, uninterrupted time and place to start a discussion

Be calm, caring, and nonjudgmental. Directly express, in a caring way, your observations and concerns about the person's behavior. Use a formula like "I am concerned about you and what's going on for you when I see you [fill in the blank]." Cite specific days/times, situations, and behaviors that have raised your concern. Share your wonder about whether the behavior might indicate an eating disorder that requires treatment. Share what you've observed about the person's mood, depression, health, addiction recovery, or relationships. Avoid words and body language that could imply blame. Avoid discussing food and eating behavior, which can lead to power struggles. Leave those issues for the therapist to handle. Comments like "You're putting on weight" or "You look thinner," may be perceived as encouraging disordered eating.

### Explain the reasons for your concerns, without mentioning eating behavior

The person may deny the situation because of overwhelming feelings, such as shame and guilt. Avoid expressing frustration with the person. Stay calm. Be gently persistent as you go on expressing your concerns. Ask, "Are you willing to consider the possibility that something is wrong?" Be prepared with resources to offer if the person seems to be listening—or leave a list of resources behind for the person to look at on his/her own. Expressing your concerns may be awkward at first, but such efforts can provide the bridge to help the person. Even if the person does not acknowledge a problem during your discussion, you have raised awareness that you are paying attention, are concerned, and want to be a support.

### Ask if he/she is willing to explore these concerns with a healthcare professional who understands eating disorders

Remember that only appropriately trained professionals can offer appropriate options and guide treatment. Your job is to express concern and offer support. Ask if he/she will share the feelings that come from the behavior you've observed. Does it provide a sense of control, relief, satisfaction, or pleasure? Let your loved one know there are other ways to feel better that don't take such a physical and emotional toll.

### Remind your loved one that many people have successfully recovered from an eating disorder

Offer to help find a treatment center and offer to go along to a therapist or intake appointment. Offer encouragement and support, but, understand that in the long run, recovery is up to the person.

## **NEDA TOOLKIT for Parents**

### **Take a break if your loved one continues to deny the problem**

Revisit the subject again soon, but not in a confrontational way. It's frustrating and scary to see someone you love suffering and be unable to do much about it. Remember that control is often a big issue. You cannot successfully control another person's behavior. Many patients and families interviewed about these issues discussed "control" as a key issue they had to come to terms with. If your child is older than 18, treatment cannot be forced or discussed with any health professional without written permission from your child. Even if your child is younger than age 18 years of age, he/she must be willing to acknowledge the problem and want to participate in treatment. In some cases, enlisting the support of others whom the person likes and respects may help—like a teacher, coach, guidance counselor, or other mentor who can share your concerns.

### **Lastly, being a good support means that you also have to take good care of yourself and attend to the stresses you feel from the situation**

This is important not only for your wellbeing, but also to serve as a model of healthy behavior for the person you are trying to support. Don't let your loved one's eating disorder completely rule your life.

## 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 in which the patient is at risk of suicide or is medically unstable, call 911 immediately.

Early detection, initial evaluation, and ongoing management can play a significant role in recovery and in preventing an eating disorder from progressing to a more severe or chronic state. The following assessments are recommended as first steps to diagnosis and will help determine the level of care needed for your family member. Receiving appropriate treatment at the earliest opportunity can aid in long-term recovery. The following assessments are recommended as first steps to diagnosis and will help determine the level of care your child or family member needs.

### **Patient assessment by a physician experienced in eating disorders should include the following:**

- Patient history, including screening questions about eating patterns
- Medical, nutritional, and psychological and social functioning (if possible, an eating disorder expert should assess the mental health of your child)
- Attitudes toward eating, exercise, and appearance
- Family history of eating disorders or other psychiatric disorders, including alcohol and other substance use disorders
- Family history of obesity
- Assessment of how the patient interacts with people regarding food-related feelings and behaviors
- Assessment of attitudes toward eating, exercise, and appearance

### **Medical assessment should include the following:**

- Physical exam including weight, height, body mass index (BMI), cardiovascular and peripheral vascular function, dermatologic symptoms (e.g., health of skin, hair growth), and evidence of self-injurious behaviors
- Laboratory tests (see list below)
- Dental examination if a history of purging behaviors exists
- Establishment of the diagnosis along with a determination of eating disorder severity

### **Laboratory Testing Used for Diagnosis of Eating Disorders and Monitoring Response to Treatment**

#### **Standard Work-Up**

- 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, asat, alkaline
- Phosphates, total bilirubin
- Serum magnesium
- Thyroid Screen (T3, T4, TSH)
- Electrocardiogram (ECG)

## NEDA TOOLKIT for Parents

### Special Circumstances

If uncertain of diagnosis:

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

If patient has been amenorrheic for 6 months:

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

If patient is 15% or more below ideal body weight (IBW):

- Chest x-ray
- Complement 3 (C3)
- 24 Creatinine Clearance
- Uric Acid

If patient is 15% or more below IBW lasting 6 months or longer at any time during course of eating disorder:

- Dual Energy X-Ray Absorptiometry (DEXA) to assess bone mineral density
- Estradiol Level (or testosterone in male)

If patient is 20% or more below IBW or any neurologic sign:

- Brain Scan

If patient is 20% or more below IBW or sign of mitral valve prolapse:

- Echocardiogram

If patient is 30% or more below IBW:

- Skin Testing for Immune Functioning

### Level of Care

Once a diagnosis is made, a level of care will be recommended based on the physical, psychiatric, and laboratory findings. Pursue the level of care that is recommended for your child. This may include inpatient, outpatient, intensive outpatient, partial hospital, or residential treatment.

## NEDA TOOLKIT for Parents

# Advice from other parents: What to expect and how to respond

Well-meaning people who have no idea about what your family is going through can sometimes say insensitive things. Others who need to be part of the care and communication plan—like schools, coaches, other family members—need to know certain things. Avoid responding to intrusive questions that are none of the asker's business. On the other hand, some questions provide an opportunity to educate and enlighten if you feel so inclined. Some days you may just feel too drained to respond to questions—let the asker know it's not a great day to be asking questions. Parents of adolescents and young adults with an eating disorder offer the advice below about possible ways to respond to questions, based on their own experience.

### **Aren't eating disorders just the new disease fad? I hear about them all over the media.**

Not at all. An eating disorder is not a "fad" or a "phase." People don't just "catch" it and get over it. Eating disorders are complex and devastating conditions that can have serious consequences for physical and emotional health, quality of life, and relationships.

### **An eating disorder? That's not really an illness is it? It's just dieting gone bad [anorexia]. It's just an excuse to get sympathy for being overweight [bulimia; binge eating disorder].**

It's a recognized and real illness, identified by the National Institute of Mental Health. It's also serious – anorexia is the largest cause of death among teenage girls.

### **He's/she's only in middle school. Isn't that too young to have an eating disorder?**

No. Eating disorders are diagnosed in people as young as 7.

### **Can I give you some advice?**

I appreciate your thoughtfulness and desire to help, and it's good to know I have your support. I'd really prefer to rely on the advice of our care team right now. We are getting lots of input from lots of directions and it's really a little overwhelming. Thanks for caring.

### **Why do you think he/she has an eating disorder?**

No one knows exactly what causes eating disorders. Right now I'm concerned with supporting my child through treatment and not focusing on the how and whys.

### **How can he/she be sick? He/she doesn't look sick.**

Individuals with bulimia nervosa typically are within the normal weight range, and some may be underweight or overweight. Individuals with anorexia may not look it outwardly until the disorder becomes so severe that it is life threatening.

### **Why did he/she tell a teacher [coach, nurse, counselor—any other adult] first?**

Kids often are hesitant to tell their parents something they feel really bad about. We're happy and relieved that he/she at least told someone who then told us so we can get him/her the care he/she needs.

### **What are you doing to help your child?**

We're listening to our child, educating ourselves about it, and getting the best, most comprehensive care possible to address all the aspects of a really complex illness. It's exhausting.

## NEDA TOOLKIT for Parents

### Can't you just make her eat?

Like many behavioral problems, it is hard to make changes unless there is a consistent, persistent, and clinically informed way of going about it. Although you can't just "make them eat," you can, as parents working with a professional who supports your efforts, find effective ways to disrupt starvation and over exercise. In fact, studies in the UK and US suggest that putting parents in charge of weight restoration is effective for most adolescents with anorexia nervosa.

### Will he/she be cured after treatment?

We're hopeful for a full recovery over time. It can be a very long haul. Getting the right treatment is key and that's a significant part of what I'm trying to accomplish.

### Is there a chance that he/she could die?

Eating disorders can be life-threatening. They affect a person's physical and emotional health. Some people have died from them. It's very scary, but we are hopeful and doing everything we can to make sure he/she gets care that will prevent that.

### Do you want us to help the child make-up work (flexible schedule) or should we leave him/her back a grade? Do you want us to provide a tutor?

Let's schedule a meeting with my child's therapist and the principal, key teachers, nurse, and school psychologist to create the education plan.

### What kind of support do you want the school to provide?

Have a specific list from the treatment team: Mealtime support; excuse from physical education or other activities as needed; communication expected from school and with whom.

### Why didn't you do anything sooner?

The scariest thing about eating disorders is how secretive they are and how well a person can hide the condition. Hindsight is 20/20. Had we known the signs and symptoms back then that we know now, we might have suspected it sooner and would have sought help right away. Even then, the person has to be willing to accept treatment after the initial medical crisis is over—and the nature of the illness makes that hard.

### What can I do to help?

Thanks very much for asking. Life has been very draining lately just trying to make sure my child is getting the care he/she needs. It leaves little time for the mundane. I keep my "to-do" list handy. (Pull out your list.) If you're serious, I could use help with (assign a task with a date and time that it's needed).

### Why aren't you letting me help you?

Our child's illness is serious and I'm relying on professional help to treat his/her condition. The help I need from family and friends is your continued support and ongoing friendship. I appreciate your asking. If I think of something our family needs that you can do for us, I'll let you know.

### Why didn't you tell me about this earlier?

It's private and our focus initially was on educating ourselves and getting our child the best care. We weren't even sure it would be helpful to share with others. So when we were ready, we decided that now is the right time for us to share this with friends and family.

### How are you coping with this?

Thanks for asking. It's very draining and very stressful on our entire family. We really appreciate the understanding and support coming from friends.

## **NEDA TOOLKIT for Parents**

### **Can I go with you to the support group?**

The response depends on the context: If the person is being nosy and is not close to the family or patient, it may be inappropriate to attend a support group. In that case, here is a response: The support group is intended for people who are closest to the situation. If you want to learn more about eating disorders, that's terrific. Community information seminars are given locally sometimes on eating disorders and that might be a more comfortable setting—these are often offered through local hospital outreach programs or eating disorder advocacy groups.

### **Is he/she going to have to be hospitalized?**

That depends on the progress he/she makes as an outpatient. We'll just have to see how it goes. Hospitalization is sometimes necessary with this illness because of the serious medical consequences it can have.

### **Why is he/she returning to the hospital again?**

Recovery is a hard and not always predictable road. A few steps forward and a step back. Sometimes events or stresses can trigger a relapse. But keeping a positive outlook is important and knowing that many people recover keeps us going.

### **Why can't you stop this destructive behavior?**

Recovery is ultimately up to the patient. The care team and all of us in the family are doing everything we can to give her/him the care and support needed for recovery. But no one can force or speed up treatment and recovery.

### **How much school is your child going to miss?**

That isn't entirely clear right now, but based on the treatment team's recommendation for the near term, here is what we know...

### **Can't you just make him/her go to the hospital?**

The use of hospitalization to treat anorexia nervosa varies from country to country. In the US, hospitalization for medical complications for adolescents with AN is a common intervention. Depending on individual state law, a parent may be able to admit their minor children for medical hospitalization against the minor's wishes. Laws governing psychiatric hospitalization of minors also vary from state to state, but in many, parents cannot require their minor children to stay in a psychiatric facility if a judge determines they are not a danger to themselves or others, or cannot care for themselves.

### **How long will he/she be in treatment?**

Everyone's treatment process and progress is different. It could be months; it could be years.

### **Why are you going to family therapy?**

We're hoping to better understand the problem, our role in the recovery process, how best to encourage and support our son/daughter, and how to help manage the symptoms.

### **How long will he/she be in recovery?**

Don't put timetables on recovery. Every patient progresses at his/ her own speed. Be patient with therapy, finding the right medication, and the process of the entire treatment plan.

### **Is your child on any medications that I should be aware of? What are the side effects I should be looking out for?**

The school and coaches and anyone your child spends significant time with should be given this information in case of an adverse event. Be prepared with copies of a sheet that summarizes medication names, dosing regimen, and the prescribing physician's contact information.

## NEDA TOOLKIT for Parents

# Why parent-school communications may be difficult: Regulatory constraints and confidentiality issues

This information is intended to help both parents and school staff understand each other's perspectives about communication and the factors that affect their communications.

Parents of children with an eating disorder (diagnosed or undiagnosed) sometimes express frustration about what they perceive as a lack of communication about their child's behavior from school teachers, coaches, guidance counselors, and other school administrative personnel. From the parents' perspective, feelings have been expressed that "my child is in school and at school activities more waking hours a day than they are home. Why didn't the school staff notice something was wrong? Why don't they contact us about our child to tell us what they think?"

From a teacher's perspective, feelings have been expressed that "my hands are tied by laws and regulations about what and how we are allowed to communicate concerns to parents. Also, it's often the case that a given teacher sees a student less than an hour a day in a class full of kids. So no school staff person is seeing the child for a prolonged period. Kids are good at hiding things when they want to. "

While rules vary from state to state, the Position Statement on Confidentiality from The American School Counselor Association may help both sides better understand why communications between family members and school personnel may be difficult at times. The rationale behind this position is that an atmosphere of trust is important to the counseling relationship. In addition, schools may be bound by strict protocols generated by state regulations about how teachers and staff are required to channel observations and concerns. For example, school districts in a state may be required to have a "student assistance program" team to handle student nonacademic issues. Teacher concerns are submitted on a standard form to the team that then meets to develop a "student action plan." Privacy laws can prohibit a teacher from discussing their concerns with a student without parent permission.

Teachers explain that sometimes the student considers the problem to be the parent, so contacting the parent about a concern can make a student's problem worse in the students' eyes. Conversely, a student can also prohibit a teacher from talking with parents about the teachers' concerns without evidence from direct observations of behavior.

The following link presents the position statement from the professional association of school counselors: <http://www.schoolcounselor.org/content.asp?pl=325&sl=133&contentid=133>. It states the professional responsibilities of school counselors, emphasizing rights to privacy, defining the meaning of confidentiality in a school setting, and describing the role of the school counselor. The position statement's summary is as follows:

**"A counseling relationship requires an atmosphere of trust and confidence between student and counselor. A student has the right to privacy and confidentiality. The responsibility to protect confidentiality extends to the student's parent or guardian and staff in confidential relationships. Professional school counselors must adhere to P.L. 93-380."**

## NEDA TOOLKIT for Parents

# Useful online resources for eating disorders

### Academy for Eating Disorders

[www.aedweb.org](http://www.aedweb.org)

An organization for healthcare professionals in the eating disorders field. The academy promotes research, treatment, and prevention of eating disorders. Their Web site lists current clinical trials and general information about eating disorders.

### A Chance to Heal Foundation

[www.achancetoheal.org](http://www.achancetoheal.org)

This foundation was established to provide financial assistance to individuals with eating disorders who might not otherwise receive treatment or reach full recovery due to their financial circumstances. The organization's mission also focuses on increasing public awareness and education about eating disorders and advocating for change to improve access to quality care for eating disorders.

### Anna Westin Foundation

[www.annawestinfoundation.org](http://www.annawestinfoundation.org)

This organization was founded in memory of a child who died from bulimia complications. It performs advocacy, education, and speakers, and provides resources about eating disorders, treatment, and navigating the health insurance system. The Anna Westin Foundation and Methodist Hospital Eating Disorders Institute partnered to establish a long-term residential eating disorder treatment program for women in Minnesota.

### Anorexia Nervosa and Related Eating Disorders, Inc.

[www.anred.com](http://www.anred.com)

This organization provides information about anorexia, bulimia, binge-eating disorder, and other lesser-known food and weight disorders, including self-help tips and information about recovery and prevention.

### Eating Disorders Coalition for Research, Policy & Action

[www.eatingdisorderscoalition.org](http://www.eatingdisorderscoalition.org)

A coalition with representatives of various eating disorder groups. This organization focuses on lobbying the federal government to recognize eating disorders as a public health priority.

### ECRI Institute Bulimia Resource Guide for Families

[www.bulimiaguide.org](http://www.bulimiaguide.org)

ECRI Institute, an independent, nonprofit healthcare research organization, researching the best ways to improve patient care. ECRI Institute produces evidence-based information about healthcare for patients and families, including the Web site listed above. The Institute is designated an Evidence-based Practice Center by the U.S. Agency for Healthcare Research and Quality and a Collaborating Center of the World Health Organization.

### Maudsley Parents

[www.maudsleyparents.org](http://www.maudsleyparents.org)

Maudsley Parents is an independent, nonprofit, volunteer organization of parents. The Maudsley approach is an evidence-based treatment for eating disorders. In Maudsley treatment, parents play a key role in helping their child recover.

### National Alliance on Mental Illness

[www.nami.org](http://www.nami.org)

A national grassroots mental health organization dedicated to improving the lives of people living with serious mental illness and their families.

## NEDA TOOLKIT for Parents

### **National Association of Anorexia Nervosa and Associated Disorders (ANAD)**

[www.anad.org/site/anadweb](http://www.anad.org/site/anadweb)

This organization seeks to alleviate the problems of eating disorders by educating the public and healthcare professionals, encouraging research, and sharing resources on all aspects of these disorders. ANAD's Web site includes information on finding support groups, referrals, treatment centers, advocacy, and background on eating disorders.

### **National Eating Disorders Association**

[www.nationaleatingdisorders.org](http://www.nationaleatingdisorders.org)

This organization is the largest non-profit organization in the United States dedicated to supporting those affected by eating disorders and being a catalyst for prevention, cures and access to quality care. NEDA develops support programs for a wide range of audiences, publishes and distributes educational materials, operates a toll-free eating disorders Information and Referral Helpline which links callers to vital information and treatment. The searchable database of treatment providers throughout the U.S. and Canada is also available on the website.

### **Eating Disorder Referral and Information Center**

[www.edreferral.com](http://www.edreferral.com)

This is a sponsored site with a large archive of information on eating disorders and referral information to treatment centers.

### **Perfect Illusions**

[www.pbs.org/perfectillusions/index.html](http://www.pbs.org/perfectillusions/index.html)

These Public Broadcasting System web pages are based on a NOVA television program documentary. The site provides information on eating disorders with personal stories and links.

### **Something Fishy**

[www.something-fishy.org](http://www.something-fishy.org)

This Web site gives detailed information on most aspects of eating disorders: defining them, preventing them, finding treatments, and paying for recovery. Useful links to related articles and stories are provided.

### **Voices not Bodies**

[www.voicesnotbodies.org](http://www.voicesnotbodies.org)

An all-volunteer organization dedicated to eating disorders awareness and prevention.

# Treatment Information

## NEDA TOOLKIT for Parents

# Treatments available for eating disorders

Standard treatments include medications (prescription drugs), various psychotherapies, nutrition therapy, other nondrug therapies, and supportive or adjunct interventions such as yoga, art, massage, and movement therapy. Some novel treatments are currently under research, such as implantation of a device called a vagus nerve stimulator implanted at the base of the neck. This stimulator is currently in use to treat some forms of depression, and it is under research for treating obesity.

The most commonly used treatments—psychotherapy and medication—are delivered at various levels of inpatient and outpatient care, and in various settings depending on the severity of the illness and the treatment plan that has been developed for a particular patient. Bulimia nervosa and binge eating disorders can often be treated on an outpatient basis, although more severe cases may require inpatient or residential treatment. The levels of care and types of treatment centers are discussed in separate documents in the tool kit. The treatment plan should be developed by a multidisciplinary team in consultation with the patient, and family members as deemed appropriate by the patient and his/her team.

### Medication

Biochemical abnormalities in the brain and body have been associated with eating disorders. Many types of prescription drugs have been used in treatment of eating disorders; however, only one prescription drug (fluoxetine) actually has a labeled indication for one eating disorder, bulimia nervosa. (This means that the manufacturer requested permission from the U.S. Food and Drug Administration (FDA) to market the drug specifically for treatment of bulimia nervosa and that FDA approved this request based on the evidence the manufacturer provided about the drug's efficacy for bulimia nervosa.)

Most prescription drug therapy used for treatment of the disorder is aimed at alleviating major depression, anxiety, or obsessive-compulsive disorder (OCD), which often coexist with an eating disorder. Some prescription drug therapies are intended to make individuals feel full to try to prevent binge eating. Generic and brand names of prescription drugs that have been used to treat eating disorders are listed in the chart. Some of these antidepressants also can exert other effects. Selective serotonin reuptake inhibitors

alleviate depression, but may also play a role in making an individual feel full and possibly prevent binge eating in patients with bulimia or binge eating disorder. FDA has issued a warning and labeling to prevent prescription of one particular antidepressant for eating disorders Wellbutrin, which is available in several brand and generic formulations—because it leads to higher risk of epileptic seizures in these patients.

### Psychological Therapy

Several types of psychotherapy are used in individual and group settings and with families. Patients must be medically stable to be able to participate meaningfully in any type of psychological therapy. Thus, a patient who has required hospitalization for refeeding and to stabilize his/her medical condition will ordinarily not be able to participate in therapy until after he/she has recovered sufficiently to enable cognitive function to return to normal.

A given psychologist or psychiatrist may use several different approaches tailored to the situation. The types of psychotherapy used are listed here in a chart and defined below. Cognitive behavior therapy (CBT) and behavior therapy (BT) have been used for many years as first-line treatment, and they are the most-used types of psychotherapy for bulimia. CBT involves three overlapping phases. The first phase focuses on helping people to resist the urge to engage in the cycle of behavior by educating them about the dangers. The second phase introduces procedures to reduce dietary restraint and increase eating regularity. The last phase involves teaching people relapse-prevention strategies to help prepare them for possible setbacks. A course of individual CBT for bulimia nervosa usually involves 16- to 20-hour-long sessions over a period of 4 to 5 months. BT uses principles of learning to increase the frequency of desired behavior and decrease the frequency of problem behavior. When used to treat bulimia nervosa, BT focuses on teaching relaxation techniques and coping strategies that individuals can use instead of binge eating and purging or excessive exercise or fasting.

Self-help groups are listed here because they may be the only option available to people who have no insurance. However, self-help groups can also have negative effects on a person with an eating disorder if they are not well-moderated by a trained professional.

## NEDA TOOLKIT for Parents

# Medication names: Generic (Brand)

### Antidepressants

#### Tricyclics

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

#### Modified Cyclic Antidepressants

- Trazodone (Desyrel)

#### Selective Serotonin Reuptake Inhibitors (SSRIS)

- Citalopram (Celexa)
- Escitalopram (Lexapro)
- Fluoxetine (Prozac, Sarafem)
- Fluvoxamine (Luvox)
- Paroxetine (Paxil)
- Sertraline (Zoloft)

#### Aminoketone

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

#### Monoamine Oxidase Inhibitors

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

#### Serotonin And Noradepinephrine Reuptake Inhibitor

- Duloxetine (Cymbalta)
- Venlafaxine (Effexor)

#### Tetracyclics

- Mianserin (Bolvidon)
- Mirtazapine (Remeron)

### Opioid antagonist

- Naltrexone (Nalorex) (Intended to alleviate addictive behaviors such as the addictive drives to eat or binge eat.)

### Antiemetic

- Ondansetron (Zofran) (Used to give sensation of satiety and fullness.)

### Anticonvulsant

- Topiramate (Topamax) (May help regulate feeding behaviors.)

### Other

- 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.)

## NEDA TOOLKIT for Parents

### Psychological Therapies

#### Individual Psychotherapy

- Behavior therapy
- Exposure with response prevention
- Hypnotherapy
- Cognitive therapy
- Cognitive analytic therapy
- Cognitive behavior therapy (all forms)
- Cognitive remediation therapies
- Scheme-based cognitive therapy
- Self-guided cognitive behavioral therapy
- Dialectical behavior therapy
- Guided imagery
- Psychodynamic therapy
- Self psychology
- Psychoanalysis
- Interpersonal psychotherapy
- Motivational enhancement therapy
- Psychoeducation
- Supportive therapy

#### Family therapy

- Involving family members in psychotherapy sessions with and without the patient

#### Group psychotherapy

- Cognitive behavioral therapy
- Psychodynamic
- Psychoeducational
- Interpersonal

#### Self-Help groups

- ANAD (Anorexia Nervosa and Associated Disorders)
- 12-step approaches
- Eating Disorders Anonymous
- Web-based on-line programs

### Other Adjunctive and Alternative Treatments

#### Creative Art Therapies

- Art Therapy
- Movement Therapy
- Psychodrama

#### Nutritional Counseling

- Individual, group, family, and mealtime-support therapy

#### Other Therapies

Although little research exists to support the use of the following interventions, individual patients have sometimes found some of these approaches to be useful, particularly as adjuncts to conventional treatments. However, these approaches should not be used in place of evidence-based treatments where the latter are available.

- Biofeedback
- Coaching
- Emailing for support or coaching
- Eye movement desensitization
- Exercise
- Journaling
- Mandometer
- Massage
- Meditation
- Relaxation training
- Yoga

## NEDA TOOLKIT for Parents

# Treatments Defined

**Antidepressants** Prescription drugs used for treatment of eating disorders and aimed at alleviating major depression, anxiety, or obsessive-compulsive disorder, which 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), exposure and response prevention (ERP), and hypnbehavioral therapy.

**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 Orientation Therapy (COT)** A type of cognitive therapy that uses a systematic procedure to understand the meaning of a patient's behavior by exploring certain themes such as aggression and avoidance. The procedure for modifying behavior then focuses on systematically changing the patient's beliefs related to the themes, not beliefs that refer directly to eating behavior.

**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.

**Dialectical Behavior Therapy (DBT)** A type of behavioral therapy that views emotional deregulation as the core problem in eating disorders. It involves 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 (ERP)** A type of behavior therapy strategy that is based on the theory that purging serves to decrease the anxiety associated with eating. Purging is therefore negatively reinforced via anxiety reduction. The goal of ERP is to modify the association between anxiety and purging by preventing purging following eating until the anxiety associated with eating subsides. (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.

## NEDA TOOLKIT for Parents

**Eye Movement Desensitization and Reprocessing (EMDR)** A nondrug and nonpsychotherapy form of treatment in which a therapist waves his or her fingers back and forth in front of the patient's eyes, and the patient tracks the movements while also focusing on a traumatic event. It is thought that the act of tracking while concentrating allows a different level of processing 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.

**Hypnbehavioral Therapy** A type of behavioral therapy that uses a combination of behavioral techniques such as self-monitoring to change maladaptive eating disorders and hypnotic techniques intended to reinforce and encourage behavior change.

**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).

**Mandometer Therapy Treatment** program for eating disorders based on the idea that psychiatric symptoms of people with eating disorders emerge as a result of poor nutrition and are not a cause of the eating disorder. A mandometer is a computer that measures food intake and is used to determine a course of therapy.

**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** 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.

**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.

## NEDA TOOLKIT for Parents

**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.

**Opioid Antagonists** A type of drug therapy that interferes with the brain's opioid receptors and is sometimes used to treat eating disorders.

**Pharmacotherapy** Treatment of a disease or condition using clinician-prescribed drugs.

**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.

**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.

**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.

## NEDA TOOLKIT for Parents

# The Evidence on What Treatment Works: Clinical Guidelines and Evidence Reports

If you want access to the same documents that clinicians use to guide their treatment decisions, and if you want to know what the available evidence says on what works for treatment of eating disorders, you want to look at published clinical practice guidelines and medical journal articles called systematic reviews. The information in this document provides links to that information so you can look it over and take it with you to discuss the care plan with the physicians and others who will treat your family member.

This document discusses two types of evidence-based information used by clinicians in determining appropriate care for eating disorders: clinical practice guidelines and systematic reviews. We define below what an evidence-based clinical guideline and a systematic review are and provide links to the documents. If you review this information before meeting with the care team, it can help you have informed discussions about care plans with your loved one's care team.

### Systematic Reviews of Clinical Studies

A systematic review is a comprehensive review and analysis of data from the available published clinical studies on existing methods of diagnosing and treating a disorder. Researchers start out with key clinical questions that they seek to answer, and then they perform a comprehensive search for published data to analyze to address the questions. Thus, the data for analysis are collected from as many published clinical studies as there are to address the question. The data are then pooled together statistically where possible and analyzed to figure out how well each treatment works and for whom it works best. Sometimes sufficient data are not available to conclusively answer a question. Knowing where the holes in the research are is important, because that knowledge will help in planning new research that hopefully will answer the questions about "what works?" Also, it's important to understand that some treatments may not have evidence available about how well they work. Therefore, your decisions about treatment may have to be based on considerations other than conclusive clinical evidence. A lot more research is needed about what works best in the field of eating disorders. That said, some information is available about how well some types of treatment work. Keep in mind that a lack of evidence doesn't mean that a treatment does not work—it just means no evidence is available to be able to conclude whether or not it works.

Following this section are links to two systematic reviews: one pertains to bulimia nervosa and pooled data together where possible on all the different

treatments for bulimia eating disorders in general; the other systematic review did not pool data for analysis from groups of studies, but rather looked at individual studies on their own. Both systematic reviews were performed by very reputable research organizations: two U.S. Evidence-based Practice Centers of the U.S. Agency for Healthcare Research and Quality (AHRQ). Links to the Executive Summary and full Evidence Reports are provided.

### Bulimia Nervosa: Efficacy of Available Treatments

A Systematic Review conducted by ECRI Institute Evidence-based Practice Center ECRI Institute's approach was unique in producing this evidence report and the bulimia nervosa resource guide. The focus of the work was driven by an external advisory committee of patients and family members affected by bulimia nervosa, clinicians and specialists from leading eating disorder treatment centers that treat eating disorders, scientists who conduct research on eating disorders, health insurance representatives, and others who affect patient care. ECRI Institute gratefully acknowledges the support of The Hilda & Preston Davis Foundation, which provided major funding for this evidence report and the family resource guide and Web site that emerged from the research. The approach was unique because of the intensive involvement of families and recovering patients in formulating the key questions and reviewing the family and patient information before publication.

Link to the Summary:

[http://www.bulimiaguide.org/static/report\\_summary.pdf](http://www.bulimiaguide.org/static/report_summary.pdf)

Link to the Full Report:

[http://www.bulimiaguide.org/static/report\\_complete.pdf](http://www.bulimiaguide.org/static/report_complete.pdf)

## NEDA TOOLKIT for Parents

# Management of Eating Disorders

### A systematic review conducted by RTI International, University of North Carolina at Chapel Hill Evidence-based Practice Center

This systematic review of the literature focused on key questions concerning anorexia nervosa, bulimia nervosa, and eating disorders not otherwise specified (i.e., especially binge eating disorder) to address questions posed by the American Psychiatric Association and Laureate Psychiatric Clinic and Hospital through AHRQ. Funding was provided by AHRQ, the Office of Research on Women's Health at the National Institutes of Health, and the Health Resources and Services Administration. We received guidance and input from a Technical Expert Panel. This report was also published as four separate articles in the International Journal of Eating Disorders in 2007.

Link to the Executive Summary:

<http://www.ncbi.nlm.nih.gov/books/bv.fcgi?rid=hstat1b.section.14940>

Link to the Full Report:

<http://www.ncbi.nlm.nih.gov/books/bv.fcgi?rid=hstat1b.chapter.14937>

Berkman, N.D., C.M. Bulik, and K.N. Lohr. (2007). Outcomes of Eating Disorders: A Systematic Review of the Literature. *International Journal of Eating Disorders*, 40(4): 293-309

Brownley, K.A., N.D. Berkman, J.A. Sedway, K.N. Lohr, and C.M. Bulik. (2007). Binge Eating Disorder Treatment: A Systematic Review of Randomized Controlled Trials. *International Journal of Eating Disorders*, 40(4):337-348

Bulik, C.M., N.D. Berkman, K.A. Brownley, J.A. Sedway, and K.N. Lohr (2007). Anorexia Nervosa Treatment: A Systematic Review of Randomized Controlled Trials. *International Journal of Eating Disorders*, 40(4): 310-320.

Shapiro, J.R., N.D. Berkman, K.A. Brownley, J.A. Sedway, K.N. Lohr, and C.M. Bulik (2007). Bulimia Nervosa Treatment: A Systematic Review of Randomized Controlled Trials. *International Journal of Eating Disorders*, 40(4): 321-336

### Clinical Practice Guidelines

A practice guideline is defined as a “systematically developed statement to assist practitioner and patient decisions about appropriate healthcare for specific clinical conditions.” The following four clinical practice guidelines have been published by reputable medical organizations and are available to the medical treatment team that is providing care to your child. We also provide summaries of these guidelines below. These guidelines were identified from the National Guideline Clearinghouse ([www.guideline.gov](http://www.guideline.gov))

- Identifying and treating eating disorders. American Academy of Pediatrics.  
<http://aappolicy.aappublications.org/cgi/content/full/pediatrics;111/1/204>
- Practice guideline for the treatment of patients with eating disorders. American Psychiatric Association.  
[http://www.psych.org/MainMenu/PsychiatricPractice/PracticeGuidelines\\_1.aspx](http://www.psych.org/MainMenu/PsychiatricPractice/PracticeGuidelines_1.aspx)
- Finnish Medical Society Duodecim. Eating disorders among children and adolescents.  
<http://www.guideline.gov/content.aspx?id=11035>
- U.K. National Collaborating Centre for Mental Health (National Institute for Health and Clinical Excellence [NICE]). Eating disorders. Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders.  
<http://www.nice.org.uk/guidance/index.jsp?action=byType&type=2&status=3>

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# Eating disorders among children and adolescents

### From the Finnish Medical Society Duodecim Brief Summary

#### Bibliographic Source

- Finnish Medical Society Duodecim. Eating disorders among children and adolescents. In: EBM Guidelines. Evidence- Based Medicine [Internet]. Helsinki, Finland: Wiley Interscience. John Wiley & Sons; 2007 Mar 28 [Various].

#### Major Recommendations

The levels of evidence [A-D] supporting the recommendations are defined at the end of the “Major Recommendations” field.

#### Objectives

- Remember that eating disorders are very common among adolescent girls, and especially bulimic disorders are encountered in boys as well.
- One must remember to look for signs of an eating disorder; patients seldom report it themselves.
- The diagnosis and planning of treatment are the responsibility of special personnel.

#### Basic Rules

- An eating disorder refers to states in which food and nourishment have an instrumental and manipulative role: food has become a way to regulate the appearance of the body.
- The spectrum of eating disorders is vast. The most common disorders are anorexia nervosa and bulimia nervosa. In addition, incomplete clinical pictures and simple binge eating have become more general.
- Recently the international trend has been to put more emphasis on early reaction to the symptoms.
- Even small children can have different kinds of eating disorders that relate to difficulties in the relationships between the child and his/her caretaker.

#### Aetiology

- Currently, eating disorders are considered to be multifarious. Genetic and sociocultural factors and also individual dynamics all affect eating disorders.
- The typical age of onset is adolescence, when the body changes and grows.
- Anorexia nervosa typically emerges between 14 and 16 years of age or around the age of 18 years. Bulimia appears typically at the age of 19 to 20 years.
- Eating disorders are 10 to 15 times more common among girls than boys.
- Every 150th girl between the ages of 14 and 16 years suffers from anorexia nervosa.
- There is no epidemiologic data on the occurrence of bulimia, but it is considered to be more common than anorexia nervosa.

#### Diagnostic Criteria for Anorexia Nervosa

- The patient does not want to maintain his/her normal body weight.
- The patient’s weight is at least 15% below that expected for age and height.
- The patient’s body image is distorted.
- The patient is afraid of gaining weight.
- There is no other sickness that would explain the loss of weight.

#### Diagnostic Criteria of Bulimia Nervosa

- Desire to be thin, phobic fear of gaining weight.
- Persistent preoccupation with eating and an irresistible urge or compulsive need to eat.
- Episodes of binge eating (at least twice a week); control over eating is lost.
- After the episode of binge eating, the person attempts to eliminate the ingested food (e.g., by self-induced vomiting and by abuse of purgatives and diuretics).

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### Symptoms

- Anorexia nervosa generally starts gradually.
- Losing weight can either be very rapid or very slow. Generally the patients continue to go to school; they go on with their hobbies and feel great about themselves. Therefore, the families are usually surprised to find that their child suffers from malnutrition.
- A screening questionnaire is helpful in the assessment of patients with suspected eating disorders (each positive answer gives one point; two or more points suggest an eating disorder).
  - Do you try to vomit if you feel unpleasantly satiated?
  - Are you anxious with the thought that you cannot control the amount of food you eat?
  - Have you lost more than 6 kg of weight during the last 3 months?
  - Do you consider yourself obese although others say you are underweight?
  - Does food/thinking of food dominate your life?
- Anorexic adolescents deny their symptoms, and it takes time and patience to motivate them to accept treatment.
- Somatic symptoms include the following:
  - Disappearance of menstruation
  - The slowing of metabolism, constipation
  - Slow pulse, low blood pressure
  - Flushed and cold limbs
  - Reduction of subcutaneous fat
- Bulimic adolescents are aware that their eating habits are not normal, but the habit causes so much guilt and shame that seeking treatment is not easy.
- Bulimia also causes physical symptoms, including the following:
  - Disturbances of menstruation
  - Disturbances in electrolyte and acid-alkali balances created by frequent vomiting
  - Damage to tooth enamel

### Laboratory Findings

- In anorexia nervosa:
  - anemia
  - Blood glucose levels on the lower border of normal
- In bulimia:
  - Hypokalemia
  - Increased serum amylase

### Differential Diagnosis

- Severe somatic diseases, for example, brain tumors
- Psychiatric diseases — severe depression, psychosis, and drug use

### Treatment

- If the symptoms correspond to the diagnostic criteria of anorexia nervosa, the situation should be discussed with the family before treatment is arranged.
- The adolescent and his/her family should be made aware of the seriousness of the disorder.
- Sometimes it takes time to motivate the patient to participate in the treatment.
- The treatment is divided into:
  - Restoring the state of nutrition
  - Psychotherapeutic treatment
- If the state of malnutrition is life threatening, the patient is first treated in a somatic ward, and thereafter the adolescent is guided into therapy if possible.
- The forms of psychotherapy vary: both individual and family therapy have brought results; in cases of bulimia cognitive therapy and medication (Lewandowski et al., 1997; Whittal, Agras, & Gould, 1999) [C] have been successful.
- With adolescents between the ages of 14 and 16 years, positive results have been obtained by treating the entire family. This is because the adolescent's symptoms are often connected with difficulties to "cut loose" from the family.
- With older patients, individual, supportive, and long lasting treatment has been the best way to promote recovery.
- A prolonged state of malnutrition and insufficient outpatient care are reasons to direct a patient into forced treatment.

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### Medical Treatment

- A specialist should start all drug treatment.
- Different psychopharmaceuticals, for example, neuroleptics and antidepressants, have been tried in the treatment of anorexia nervosa. Controlled studies have proved them indisputably useful only if the disorder is linked to clear depression.
- Most research on the medical treatment of bulimia has concentrated on antidepressants (Bacaltchuk & Hay, 2003) [A], particularly fluoxetine, which has been found to decrease binge eating and vomiting for about two-thirds of bulimic patients.

### Prognosis

- Early intervention improves prognosis.
- Eating disorders comprise a severe group of diseases that are difficult to treat. The prognosis for the near future of anorexic patients is good, but for the long term the prognosis is worse. The percentage of mortality is still 5% to 16%.
- Not enough follow-up research has been carried out on the prognosis of bulimia, but the disease is thought to last years.
- Bulimia can be associated with depression, self-destructiveness, alcohol or drug abuse, and other psychological problems.

### Links

Link to Full Summary:  
<http://www.guideline.gov/content.aspx?id=11035>

## NEDA TOOLKIT for Parents

# Eating disorders: Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa, and related eating disorders.

## U.K. National Collaborating Centre for Mental Health: Brief Summary

### Bibliographic Source

National Collaborating Centre for Mental Health. Eating disorders. Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders. Leicester (UK): British Psychological Society; 2004. 260 p. [408 references]

### Major Recommendations

Evidence categories (I-IV) and recommendation grades (A-C) are defined at the end of the Major Recommendations field.

## Care Across All Conditions

### Assessment and Coordination of Care

C — Assessment of people with eating disorders should be comprehensive and include physical, psychological, and social needs and a comprehensive assessment of risk to self.

C — The level of risk to the patient's mental and physical health should be monitored as treatment progresses because it may change--for example, following weight gain or at times of transition between services in cases of anorexia nervosa.

C — For people with eating disorders presenting in primary care, general practitioners (GPs) should take responsibility for the initial assessment and the initial coordination of care. This includes the determination of the need for emergency medical or psychiatric assessment.

C — Where management is shared between primary and secondary care, there should be clear agreement among individual healthcare professionals on the responsibility for monitoring patients with eating disorders. This agreement should be in writing (where appropriate using the Care Program Approach) and

shared with the patient and, where appropriate, his/her family and caregivers.

### Providing Good Information and Support

C — Patients and, where appropriate, caregivers should be provided with education and information on the nature, course, and treatment of eating disorders.

C — In addition to the provision of information, family and caregivers may be informed of self-help groups and support groups, and offered the opportunity to participate in such groups where they exist.

C — Healthcare professionals should acknowledge that many people with eating disorders are ambivalent about treatment. Healthcare professionals should also recognize the consequent demands and challenges this presents.

### Getting Help Early

There can be serious long-term consequences to a delay in obtaining treatment.

C — People with eating disorders seeking help should be assessed and receive treatment at the earliest opportunity.

C — Whenever possible patients should be engaged and treated before reaching severe emaciation. This requires both early identification and intervention. Effective monitoring and engagement of patients at severely low weight or with falling weight should be a priority.

### Management of Physical Aspects

C — Where laxative abuse is present, patients should be advised to gradually reduce laxative use and informed that laxative use does not significantly reduce calorie absorption.

C — Treatment of both subthreshold and clinical cases of an eating disorder in people with diabetes is essential because of the greatly increased physical risk in this group.

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C — People with type 1 diabetes and an eating disorder should have intensive regular physical monitoring, because they are at high risk of retinopathy and other complications.

C — Pregnant women with eating disorders require careful monitoring throughout the pregnancy and in the postpartum period.

C — Patients with an eating disorder who are vomiting should have regular dental reviews.

C — Patients who are vomiting should be given appropriate advice on dental hygiene, which should include avoiding brushing after vomiting; rinsing with a nonacid mouthwash after vomiting; and reducing an acid oral environment (for example, limiting acidic foods).

C — Healthcare professionals should advise people with eating disorders and osteoporosis or related bone disorders to refrain from physical activities that significantly increase the likelihood of falls.

### Additional Considerations for Children and Adolescents

C — Family members, including siblings, should normally be included in the treatment of children and adolescents with eating disorders. Interventions may include sharing of information, advice on behavioral management, and facilitating communication.

C — In children and adolescents with eating disorders, growth and development should be closely monitored. Where development is delayed or growth is stunted despite adequate nutrition, pediatric advice should be sought.

C — Healthcare professionals assessing children and adolescents with eating disorders should be alert to indicators of abuse (emotional, physical and sexual) and should remain so throughout treatment.

C — The right to confidentiality of children and adolescents with eating disorders should be respected.

C — Health care professionals working with children and adolescents with eating disorders should familiarize themselves with national guidelines and their employers' policies in the area of confidentiality.

### Identification and Screening of Eating Disorders in Primary Care and Non-Mental Health Settings

C — Target groups for screening should include young women with low body mass index (BMI) compared with age norms, patients consulting with weight concerns who are not overweight, women with menstrual disturbances or amenorrhea, patients with gastrointestinal symptoms, patients with physical signs of starvation or repeated vomiting, and children with poor growth.

C — When screening for eating disorders one or two simple questions should be considered for use with specific target groups (for example, “Do you think you have an eating problem?” and “Do you worry excessively about your weight?”).

C — Young people with type 1 diabetes and poor treatment adherence should be screened and assessed for the presence of an eating disorder.

### Management of Anorexia Nervosa in Primary Care

C — In anorexia nervosa, although weight and BMI are important indicators of physical risk they should not be considered the sole indicators (as they are unreliable in adults and especially in children).

C — In assessing whether a person has anorexia nervosa, attention should be paid to the overall clinical assessment (repeated over time), including rate of weight loss, growth rates in children, objective physical signs, and appropriate laboratory tests.

C — Patients with enduring anorexia nervosa not under the care of a secondary care service should be offered an annual physical and mental health review by their GP.

### Psychological Interventions for Anorexia Nervosa

The delivery of psychological interventions should be accompanied by regular monitoring of a patient's physical state including weight and specific indicators of increased physical risk.

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### Common Elements of the Psychological Treatment of Anorexia Nervosa

C — Therapies to be considered for the psychological treatment of anorexia nervosa include cognitive analytic therapy (CAT), cognitive behavior therapy (CBT), interpersonal psychotherapy (IPT), focal psychodynamic therapy, and family interventions focused explicitly on eating disorders.

C — Patient and, where appropriate, carer preference should be taken into account in deciding which psychological treatment is to be offered.

C — The aims of psychological treatment should be to reduce risk, to encourage weight gain and healthy eating, to reduce other symptoms related to an eating disorder, and to facilitate psychological and physical recovery.

### Outpatient Psychological Treatments in First Episode and Later Episodes

C — Most people with anorexia nervosa should be managed on an outpatient basis, with psychological treatment (with physical monitoring) provided by a health care professional competent to give it and to assess the physical risk of people with eating disorders.

C — Outpatient psychological treatment and physical monitoring for anorexia nervosa should normally be of at least 6 months' duration.

C — For patients with anorexia nervosa, if during outpatient psychological treatment there is significant deterioration, or the completion of an adequate course of outpatient psychological treatment does not lead to any significant improvement, more intensive forms of treatment (for example, a move from individual therapy to combined individual and family work or day care or inpatient care) should be considered.

C — Dietary counseling should not be provided as the sole treatment for anorexia nervosa.

### Psychological Aspects of Inpatient Care

C — For inpatients with anorexia nervosa, a structured symptom-focused treatment regimen with the expectation of weight gain should be provided in order to achieve weight restoration. It is important to carefully monitor the patient's physical status during refeeding.

C — Psychological treatment should be provided which has a focus both on eating behavior and attitudes to weight and shape and on wider psychosocial issues with the expectation of weight gain.

C — Rigid inpatient behavior modification programs should not be used in the management of anorexia nervosa.

### Post-Hospitalization Psychological Treatment

C — Following inpatient weight restoration, people with anorexia nervosa should be offered outpatient psychological treatment that focuses both on eating behavior and attitudes to weight and shape and on wider psychosocial issues, with regular monitoring of both physical and psychological risk.

C — The length of outpatient psychological treatment and physical monitoring following inpatient weight restoration should typically be at least 12 months.

### Additional Considerations for Children and Adolescents with Anorexia Nervosa

B — Family interventions that directly address the eating disorder should be offered to children and adolescents with anorexia nervosa.

C — Children and adolescents with anorexia nervosa should be offered individual appointments with a health care professional separate from those with their family members or carers.

C — The therapeutic involvement of siblings and other family members should be considered in all cases because of the effects of anorexia nervosa on other family members.

C — In children and adolescents with anorexia nervosa, the need for inpatient treatment and the need for urgent weight restoration should be balanced alongside the educational and social needs of the young person.

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### Pharmacological Interventions for Anorexia Nervosa

C — There is a very limited evidence base for the pharmacological treatment of anorexia nervosa. A range of drugs may be used in the treatment of comorbid conditions but caution should be exercised in their use given the physical vulnerability of many people with anorexia nervosa.

C — Medication should not be used as the sole or primary treatment for anorexia nervosa. Caution should be exercised in the use of medication for comorbid conditions such as depressive or obsessive-compulsive features, as they may resolve with weight gain alone.

C — When medication is used to treat people with anorexia nervosa, the side effects of drug treatment (in particular, cardiac side effects) should be carefully considered because of the compromised cardiovascular function of many people with anorexia nervosa.

C — Health care professionals should be aware of the risk of drugs that prolong the QTc interval on the electrocardiogram (ECG) (for example, antipsychotics, tricyclic antidepressants, macrolide antibiotics, and some antihistamines). In patients with anorexia nervosa at risk of cardiac complications, the prescription of drugs with side effects that may compromise cardiac functioning should be avoided.

C — If the prescription of medication that may compromise cardiac functioning is essential, ECG monitoring should be undertaken.

C — All patients with a diagnosis of anorexia nervosa should have an alert placed in their prescribing record concerning the risk of side effects.

### Physical Management of Anorexia Nervosa

Anorexia nervosa carries considerable risk of serious physical morbidity. Awareness of the risk, careful monitoring, and, where appropriate, close liaison with an experienced physician are important in the management of the physical complications of anorexia nervosa.

### Managing Weight Gain

C — In most patients with anorexia nervosa, an average weekly weight gain of 0.5-1 kg in inpatient settings and 0.5 kg in outpatient settings should be an aim of treatment. This requires about 3,500 to 7,000 extra calories a week.

C — Regular physical monitoring, and in some cases treatment with a multi-vitamin/multi-mineral supplement in oral form, is recommended for people with anorexia nervosa during both inpatient and outpatient weight restoration.

C — Total parenteral nutrition should not be used for people with anorexia nervosa, unless there is significant gastrointestinal dysfunction.

### Managing Risk

C — Health care professionals should monitor physical risk in patients with anorexia nervosa. If this leads to the identification of increased physical risk, the frequency of the monitoring and nature of the investigations should be adjusted accordingly.

C — People with anorexia nervosa and their carers should be informed if the risk to their physical health is high.

C — The involvement of a physician or pediatrician with expertise in the treatment of physically at-risk patients with anorexia nervosa should be considered for all individuals who are physically at risk.

C — Pregnant women with either current or remitted anorexia nervosa may need more intensive prenatal care to ensure adequate prenatal nutrition and fetal development.

C — Oestrogen administration should not be used to treat bone density problems in children and adolescents as this may lead to premature fusion of the epiphyses.

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### Feeding Against the Will of the Patient

C — Feeding against the will of the patient should be an intervention of last resort in the care and management of anorexia nervosa.

C — Feeding against the will of the patient is a highly specialized procedure requiring expertise in the care and management of those with severe eating disorders and the physical complications associated with it. This should only be done in the context of the Mental Health Act 1983 or Children Act 1989.

C — When making the decision to feed against the will of the patient, the legal basis for any such action must be clear.

### Service Interventions for Anorexia Nervosa

This section considers those aspects of the service system relevant to the treatment and management of anorexia nervosa.

C — Most people with anorexia nervosa should be treated on an outpatient basis.

C — Where inpatient management is required, this should be provided within reasonable travelling distance to enable the involvement of relatives and carers in treatment, to maintain social and occupational links, and to avoid difficulty in transition between primary and secondary care services. This is particularly important in the treatment of children and adolescents.

C — Inpatient treatment should be considered for people with anorexia nervosa whose disorder is associated with high or moderate physical risk.

C — People with anorexia nervosa requiring inpatient treatment should be admitted to a setting that can provide the skilled implementation of refeeding with careful physical monitoring (particularly in the first few days of refeeding), in combination with psychosocial interventions.

C — Inpatient treatment or day patient treatment should be considered for people with anorexia nervosa whose disorder has not improved with appropriate outpatient treatment, or for whom there is a significant risk of suicide or severe self-harm.

C — Health care professionals without specialist experience of eating disorders, or in situations of uncertainty, should consider seeking advice from an appropriate specialist when contemplating a compulsory admission for a patient with anorexia nervosa, regardless of the age of the patient.

C — Health care professionals managing patients with anorexia nervosa, especially that of the binge purging sub-type, should be aware of the increased risk of self-harm and suicide, particularly at times of transition between services or service settings.

### Additional Considerations for Children and Adolescents

C — Health care professionals should ensure that children and adolescents with anorexia nervosa who have reached a healthy weight have the increased energy and necessary nutrients available in their diet to support further growth and development.

C — In the nutritional management of children and adolescents with anorexia nervosa, carers should be included in any dietary education or meal planning.

C — Admission of children and adolescents with anorexia nervosa should be to age-appropriate facilities (with the potential for separate children and adolescent services), which have the capacity to provide appropriate educational and related activities.

C — When a young person with anorexia nervosa refuses treatment that is deemed essential, consideration should be given to the use of the Mental Health Act 1983 or the right of those with parental responsibility to override the young person's refusal.

C — Relying indefinitely on parental consent to treatment should be avoided. It is recommended that the legal basis under which treatment is being carried out should be recorded in the patient's case notes, and this is particularly important in the case of children and adolescents.

C — For children and adolescents with anorexia nervosa, where issues of consent to treatment are highlighted, health care professionals should consider seeking a second opinion from an eating disorders specialist.

## NEDA TOOLKIT for Parents

C — If the patient with anorexia nervosa and those with parental responsibility refuse treatment, and treatment is deemed to be essential, legal advice should be sought in order to consider proceedings under the Children Act 1989.

### Psychological Interventions for Bulimia Nervosa

B — As a possible first step, patients with bulimia nervosa should be encouraged to follow an evidence-based self-help program.

B — Health care professionals should consider providing direct encouragement and support to patients undertaking an evidence based self-help program, as this may improve outcomes. This may be sufficient treatment for a limited subset of patients.

A — Cognitive behavior therapy for bulimia nervosa (CBT-BN), a specifically adapted form of CBT, should be offered to adults with bulimia nervosa. The course of treatment should be for 16 to 20 sessions over 4 to 5 months.

C — Adolescents with bulimia nervosa may be treated with CBT-BN adapted as needed to suit their age, circumstances, and level of development, and including the family as appropriate.

B — When people with bulimia nervosa have not responded to or do not want CBT, other psychological treatments should be considered.

B — Interpersonal psychotherapy should be considered as an alternative to CBT, but patients should be informed it takes 8-12 months to achieve results comparable with CBT.

### Pharmacological Interventions for Bulimia Nervosa

B — As an alternative or additional first step to using an evidence-based self-help program, adults with bulimia nervosa may be offered a trial of an antidepressant drug.

B — Patients should be informed that antidepressant drugs can reduce the frequency of binge eating and purging, but the longterm effects are unknown. Any beneficial effects will be rapidly apparent.

C — Selective serotonin reuptake inhibitors (SSRIs) (specifically fluoxetine) are the drugs of first choice for the treatment of bulimia nervosa in terms of acceptability, tolerability, and reduction of symptoms.

C — For people with bulimia nervosa, the effective dose of fluoxetine is higher than for depression (60 mg daily).

B — No drugs, other than antidepressants, are recommended for the treatment of bulimia nervosa.

### Management of Physical Aspects of Bulimia Nervosa

Patients with bulimia nervosa can experience considerable physical problems as a result of a range of behaviors associated with the condition. Awareness of the risks and careful monitoring should be a concern of all health care professionals working with people with this disorder.

C — Patients with bulimia nervosa who are vomiting frequently or taking large quantities of laxatives (especially if they are also underweight) should have their fluid and electrolyte balance assessed.

C — When electrolyte disturbance is detected, it is usually sufficient to focus on eliminating the behavior responsible. In the small proportion of cases where supplementation is required to restore electrolyte balance, oral rather than intravenous administration is recommended, unless there are problems with gastrointestinal absorption.

### Service Interventions for Bulimia Nervosa

The great majority of patients with bulimia nervosa can be treated as outpatients. There is a very limited role for the inpatient treatment of bulimia nervosa. This is primarily concerned with the management of suicide risk or severe self-harm.

C — The great majority of patients with bulimia nervosa should be treated in an outpatient setting.

C — For patients with bulimia nervosa who are at risk of suicide or severe self-harm, admission as an inpatient or day patient, or the provision of more intensive outpatient care, should be considered.

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C — Psychiatric admission for people with bulimia nervosa should normally be undertaken in a setting with experience of managing this disorder.

C — Health care professionals should be aware that patients with bulimia nervosa who have poor impulse control, notably substance misuse, may be less likely to respond to a standard program of treatment. As a consequence treatment should be adapted to the problems presented.

### Additional Considerations for Children and Adolescents

C — Adolescents with bulimia nervosa may be treated with CBT-BN adapted as needed to suit their age, circumstances, and level of development, and including the family as appropriate.

### General Treatment of Atypical Eating Disorders

C — In the absence of evidence to guide the management of atypical eating disorders (eating disorders not otherwise specified) other than binge eating disorder, it is recommended that the clinician considers following the guidance on the treatment of the eating problem that most closely resembles the individual patient's eating disorder.

### Psychological Treatments for Binge Eating Disorder

B — As a possible first step, patients with binge eating disorder should be encouraged to follow an evidence based self-help program.

B — Health care professionals should consider providing direct encouragement and support to patients undertaking an evidence-based self-help program as this may improve outcomes. This may be sufficient treatment for a limited subset of patients.

A — Cognitive behavior therapy for binge eating disorder (CBTBED), a specifically adapted form of CBT, should be offered to adults with binge eating disorder.

B — Other psychological treatments (interpersonal psychotherapy for binge eating disorder and modified dialectical behavior therapy) may be offered to adults with persistent binge eating disorder.

A — Patients should be informed that all psychological treatments for binge eating disorder have a limited effect on body weight.

C — When providing psychological treatments for patients with binge eating disorder, consideration should be given to the provision of concurrent or consecutive interventions focusing on the management of comorbid obesity.

C — Suitably adapted psychological treatments should be offered to adolescents with persistent binge eating disorder.

### Pharmacological Interventions for Binge Eating Disorder

B — As an alternative or additional first step to using an evidence based self-help program, consideration should be given to offering a trial of an SSRI antidepressant drug to patients with binge eating disorder.

B — Patients with binge eating disorders should be informed that SSRIs can reduce binge eating, but the long-term effects are unknown. Antidepressant drug treatment may be sufficient treatment for a limited subset of patients.

### Definitions: Evidence Categories

I: Evidence obtained from a single randomized controlled trial or a meta-analysis of randomized controlled trials

IIA: Evidence obtained from at least one well-designed controlled study without randomization

IIB: Evidence obtained from at least one well-designed quasiexperimental study

III: Evidence obtained from well-designed non-experimental descriptive studies, such as comparative studies, correlation studies, and case-control studies

IV: Evidence obtained from expert committee reports or opinions and/or clinical experience of respected authorities

## NEDA TOOLKIT for Parents

### Recommendation Grades

**Grade A** — At least one randomized controlled trial as part of a body of literature of overall good quality and consistency addressing the specific recommendation (evidence level I) without extrapolation

**Grade B** — Well-conducted clinical studies but no randomized clinical trials on the topic of recommendation (evidence levels II or III); or extrapolated from level I evidence

**Grade C** — Expert committee reports or opinions and/or clinical experiences of respected authorities (evidence level IV) or extrapolated from level I or II evidence. This grading indicates that directly applicable clinical studies of good quality are absent or not readily available.

### Patient Resources

The following is available:

Eating disorders: anorexia nervosa, bulimia nervosa and related eating disorders. Understanding NICE guidance: a guide for people with eating disorders, their advocates and carers, and the public. London: National Institute for Clinical Excellence. 2004 Jan. 44.

Electronic copies: Available in English and Welsh in Portable Document Format (PDF) from the National Institute for Clinical Excellence (NICE) Web site (<http://www.nice.org.uk:80/>).

Print copies: Available from the National Health Service (NHS) Response Line 0870 1555 455. ref: N0407. 11 Strand, London, WC2N 5HR.

## NEDA TOOLKIT for Parents

# Identifying and treating eating disorders

### American Academy of Pediatrics Brief Summary

#### Bibliographic Source

Identifying and treating eating disorders. Pediatrics 2003 Jan;111(1):204-11. [78 references] PubMed

#### Major Recommendations

- Pediatricians need to be knowledgeable about the early signs and symptoms of disordered eating and other related behaviors.
- Pediatricians should be aware of the careful balance that needs to be in place to decrease the growing prevalence of eating disorders in children and adolescents. When counseling children on risk of obesity and healthy eating, care needs to be taken not to foster overaggressive dieting and to help children and adolescents build self-esteem while still addressing weight concerns.
- Pediatricians should be familiar with the screening and counseling guidelines for disordered eating and other related behaviors.
- Pediatricians should know when and how to monitor and/ or refer patients with eating disorders to best address their medical and nutritional needs, serving as an integral part of the multidisciplinary team.
- Pediatricians should be encouraged to calculate and plot weight, height, and body mass index (BMI) using age and gender-appropriate graphs at routine annual pediatric visits.
- Pediatricians can play a role in primary prevention through office visits and community- or school-based interventions with a focus on screening, education, and advocacy.
- Pediatricians can work locally, nationally, and internationally to help change cultural norms conducive to eating disorders and proactively to change media messages.
- Pediatricians need to be aware of the resources in their communities so they can coordinate care of various treating professionals, helping to create a seamless system between inpatient and outpatient management in their communities.
- Pediatricians should help advocate for parity of mental health benefits to ensure continuity of care for the patients with eating disorders.
- Pediatricians need to advocate for legislation and regulations that secure appropriate coverage for medical, nutritional, and mental health treatment in settings appropriate to the severity of the illness (inpatient, day hospital, intensive outpatient, and outpatient).
- Pediatricians are encouraged to participate in the development of objective criteria for the optimal treatment of eating disorders, including the use of specific treatment modalities and the transition from one level of care to another.

#### Links

Link to Full Summary:

[http://www.guideline.gov/summary/summary.aspx?ss=15&doc\\_id=3589&string=](http://www.guideline.gov/summary/summary.aspx?ss=15&doc_id=3589&string=)

Link to Complete Guideline:

<http://aappolicy.aappublications.org/cgi/content/full/pediatrics;111/1/204>

## NEDA TOOLKIT for Parents

# Practice guideline for the treatment of patients with eating disorders

### Brief Summary

#### Bibliographic Sources

American Psychiatric Association (APA). Practice guideline for the treatment of patients with eating disorders. 3rd ed. Washington (DC): American

Psychiatric Association (APA); 2006 Jun. 128 p. [765 references] American Psychiatric Association. Treatment of patients with eating disorders, third edition. *Am J Psychiatry* 2006 Jul;163(7 Suppl):4-54. PubMed

### Major Recommendations

Each recommendation is identified as meriting one of three categories of endorsement, based on the level of clinical confidence regarding the recommendation, as indicated by a bracketed Roman numeral after the statement. Definitions of the categories of endorsement are presented at the end of the “Major Recommendations” field.

#### 1. Psychiatric Management

Psychiatric management begins with the establishment of a therapeutic alliance, which is enhanced by empathic comments and behaviors, positive regard, reassurance, and support [I]. Basic psychiatric management includes support through the provision of educational materials, including self-help workbooks; information on community-based and Internet resources; and direct advice to patients and their families (if they are involved) [I]. A team approach is the recommended model of care [I].

##### a. Coordinating Care and Collaborating with Other Clinicians

In treating adults with eating disorders, the psychiatrist may assume the leadership role within a program or team that includes other physicians, psychologists, registered dietitians, and social workers or may work collaboratively on a team led by others. For the management of acute and ongoing medical

and dental complications, it is important that psychiatrists consult other physician specialists and dentists [I].

When a patient is managed by an interdisciplinary team in an outpatient setting, communication among the professionals is essential to monitoring the patient’s progress, making necessary adjustments to the treatment plan, and delineating the specific roles and tasks of each team member [I].

##### b. Assessing and Monitoring Eating Disorder Symptoms and Behaviors

A careful assessment of the patient’s history, symptoms, behaviors, and mental status is the first step in making a diagnosis of an eating disorder [I]. The complete assessment usually requires at least several hours and includes a thorough review of the patient’s height and weight history; restrictive and binge eating and exercise patterns and their changes; purging and other compensatory behaviors; core attitudes regarding weight, shape, and eating; and associated psychiatric conditions [I]. A family history of eating disorders or other psychiatric disorders, including alcohol and other substance use disorders; a family history of obesity; family interactions in relation to the patient’s disorder; and family attitudes toward eating, exercise, and appearance are all relevant to the assessment [I]. A clinician’s articulation of theories that imply blame or permit family members to blame one another or themselves can alienate family members from involvement in the treatment and therefore be detrimental to the patient’s care and recovery [I]. It is important to identify family stressors whose amelioration may facilitate recovery [I]. In the assessment of children and adolescents, it is essential to involve parents and, whenever appropriate, school personnel and health professionals who routinely work with the patient [I].

## NEDA TOOLKIT for Parents

### c. Assessing and Monitoring the Patient's General Medical Condition

A full physical examination of the patient is strongly recommended and may be performed by a physician familiar with common findings in patients with eating disorders. The examination should give particular attention to vital signs, physical status (including height and weight), cardiovascular and peripheral vascular function, dermatological manifestations, and evidence of self-injurious behaviors [I]. Calculation of the patient's body mass index (BMI) is also useful (see <http://www.cdc.gov/nccdphp/dnpa/bmi/00binaries/bmi-tables.pdf> [for ages 2-20] and <http://www.cdc.gov/nccdphp/dnpa/bmi/00binaries/bmi-adults.pdf> [for adults]) [I]. Early recognition of eating disorder symptoms and early intervention may prevent an eating disorder from becoming chronic [I]. During treatment, it is important to monitor the patient for shifts in weight, blood pressure, pulse, other cardiovascular parameters, and behaviors likely to provoke physiological decline and collapse [I]. Patients with a history of purging behaviors should also be referred for a dental examination [I]. Bone density examinations should be obtained for patients who have been amenorrheic for 6 months or more [I].

In younger patients, examination should include growth pattern, sexual development (including sexual maturity rating), and general physical development [I]. The need for laboratory analyses should be determined on an individual basis depending on the patient's condition or the laboratory tests' relevance to making treatment decisions [I].

### d. Assessing and Monitoring the Patient's Safety and Psychiatric Status

The patient's safety will be enhanced when particular attention is given to suicidal ideation, plans, intentions, and attempts as well as to impulsive and compulsive self-harm behaviors [I]. Other aspects of the patient's psychiatric status that greatly influence clinical course and outcome and that are important to assess include mood, anxiety, and substance use disorders, as well as motivational status, personality traits, and personality disorders [I]. Assessment for suicidality is of particular importance in patients with co-occurring alcohol and other substance use disorders [I].

### e. Providing Family Assessment and Treatment

For children and adolescents with anorexia nervosa, family involvement and treatment are essential [I]. For older patients, family assessment and involvement may be useful and should be considered on a case-by-case basis [III]. Involving spouses and partners in treatment may be highly desirable [II].

## 2. Choosing a Site of Treatment

Services available for treating eating disorders can range from intensive inpatient programs (in which general medical care is readily available) to residential and partial hospitalization programs to varying levels of outpatient care (in which the patient receives general medical treatment, nutritional counseling, and/or individual, group, and family psychotherapy). Because specialized programs are not available in all geographic areas and their financial requirements are often significant, access to these programs may be limited; petition, explanation, and follow-up by the psychiatrist on behalf of patients and families may help procure access to these programs. Pretreatment evaluation of the patient is essential in choosing the appropriate treatment setting [I].

## NEDA TOOLKIT for Parents

In determining a patient's initial level of care or whether a change to a different level of care is appropriate, it is important to consider the patient's overall physical condition, psychology, behaviors, and social circumstances rather than simply rely on one or more physical parameters, such as weight [1]. Weight in relation to estimated individually healthy weight, the rate of weight loss, cardiac function, and metabolic status are the most important physical parameters to be considered when choosing a treatment setting; other psychosocial parameters are also important [1]. Healthy weight estimates for a given individual must be determined by that person's physicians [1]. Such estimates may be based on historical considerations (often including that person's growth charts) and, for women, the weight at which healthy menstruation and ovulation resume, which may be higher than the weight at which menstruation and ovulation became impaired. Admission to or continuation of an intensive level of care (e.g., hospitalization) may be necessary when access to a less intensive level of care (e.g., partial hospitalization) is absent because of geography or a lack of resources [1].

Generally, adult patients who weigh less than approximately 85% of their individually estimated healthy weights have considerable difficulty gaining weight outside of a highly structured program [11]. Such programs, including inpatient care, may be medically and psychiatrically necessary even for some patients who are above 85% of their individually estimated healthy weight [1]. Factors suggesting that hospitalization may be appropriate include rapid or persistent decline in oral intake, a decline in weight despite maximally intensive outpatient or partial hospitalization interventions, the presence of additional stressors that may interfere with the patient's ability to eat, knowledge of the weight at which instability previously occurred in the patient, co-occurring psychiatric problems that merit hospitalization, and the degree of the patient's denial and resistance to participate in his or her own care in less intensively supervised settings [1].

Hospitalization should occur before the onset of medical instability as manifested by abnormalities in vital signs (e.g., marked orthostatic hypotension with an increase in pulse of 20 beats per minute (bpm) or a drop in standing blood pressure of 20 millimeters of mercury (mmHg), bradycardia <40 bpm, tachycardia >110 bpm, or an inability to sustain core body temperature), physical findings, or laboratory tests [1]. To avert potentially irreversible effects on physical growth and development, many children and adolescents require inpatient medical treatment, even when weight loss, although rapid, has not been as severe as that suggesting a need for hospitalization in adult patients [1].

Patients who are physiologically stabilized on acute medical units will still require specific inpatient treatment for eating disorders if they do not meet biopsychosocial criteria for less intensive levels of care and/or if no suitable less intensive levels of care are accessible because of geographic or other reasons [1]. Weight level per se should never be used as the sole criterion for discharge from inpatient care [1]. Assisting patients in determining and practicing appropriate food intake at a healthy body weight is likely to decrease the chances of their relapsing after discharge [1].

Most patients with uncomplicated bulimia nervosa do not require hospitalization; indications for the hospitalization of such patients include severe disabling symptoms that have not responded to adequate trials of outpatient treatment, serious concurrent general medical problems (e.g., metabolic abnormalities, hematemesis, vital sign changes, uncontrolled vomiting), suicidality, psychiatric disturbances that would warrant the patient's hospitalization independent of the eating disorder diagnosis, or severe concurrent alcohol or drug dependence or abuse [1].

Legal interventions, including involuntary hospitalization and legal guardianship, may be necessary to address the safety of treatment-reluctant patients whose general medical conditions are life threatening [1].

## NEDA TOOLKIT for Parents

The decision about whether a patient should be hospitalized on a psychiatric versus a general medical or adolescent/ pediatric unit should be made based on the patient's general medical and psychiatric status, the skills and abilities of local psychiatric and general medical staff, and the availability of suitable programs to care for the patient's general medical and psychiatric problems [I]. There is evidence to suggest that patients with eating disorders have better outcomes when treated on inpatient units specializing in the treatment of these disorders than when treated in general inpatient settings where staff lack expertise and experience in treating eating disorders [II].

Outcomes from partial hospitalization programs that specialize in eating disorders are highly correlated with treatment intensity. The more successful programs involve patients in treatment at least 5 days/week for 8 hours/day; thus, it is recommended that partial hospitalization programs be structured to provide at least this level of care [I].

Patients who are considerably below their healthy body weight and are highly motivated to adhere to treatment, have cooperative families, and have a brief symptom duration may benefit from treatment in outpatient settings, but only if they are carefully monitored and if they and their families understand that a more restrictive setting may be necessary if persistent progress is not evident in a few weeks [II]. Careful monitoring includes at least weekly (and often two to three times a week) weight determinations done directly after the patient voids and while the patient is wearing the same class of garment (e.g., hospital gown, standard exercise clothing) [I]. In patients who purge, it is important to routinely monitor serum electrolytes [I]. Urine specific gravity, orthostatic vital signs, and oral temperatures may need to be measured on a regular basis [II].

In an outpatient setting, patients can remain with their families and continue to attend school or work. Inpatient care may interfere with family, school, and work obligations; however, it is important to give priority to the safe and adequate treatment of a rapidly progressing or otherwise unresponsive disorder for which hospital care might be necessary [I].

### 3. Choice of Specific Treatments for Anorexia Nervosa

The aims of treating anorexia nervosa are to 1) restore patients to a healthy weight (associated with the return of menses and normal ovulation in female patients, normal sexual drive and hormone levels in male patients, and normal physical and sexual growth and development in children and adolescents); 2) treat physical complications; 3) enhance patients' motivation to cooperate in the restoration of healthy eating patterns and participate in treatment; 4) provide education regarding healthy nutrition and eating patterns; 5) help patients reassess and change core dysfunctional cognitions, attitudes, motives, conflicts, and feelings related to the eating disorder; 6) treat associated psychiatric conditions, including deficits in mood and impulse regulation and self-esteem and behavioral problems; 7) enlist family support and provide family counseling and therapy where appropriate; and 8) prevent relapse.

#### a. Nutritional Rehabilitation

The goals of nutritional rehabilitation for seriously underweight patients are to restore weight, normalize eating patterns, achieve normal perceptions of hunger and satiety, and correct biological and psychological sequelae of malnutrition [I]. For patients age 20 years and younger, an individually appropriate range for expected weight and goals for weight and height may be determined by considering measurements and clinical factors, including current weight, bone age estimated from wrist x-rays and nomograms, menstrual history (in adolescents with secondary amenorrhea), mid-parental heights, assessments of skeletal frame, and benchmarks from Centers for Disease Control and Prevention (CDC) growth charts (available at <http://www.cdc.gov/growthcharts/>) [I].

## NEDA TOOLKIT for Parents

For individuals who are markedly underweight and for children and adolescents whose weight has deviated below their growth curves, hospital-based programs for nutritional rehabilitation should be considered [I]. For patients in inpatient or residential settings, the discrepancy between healthy target weight and weight at discharge may vary depending on patients' ability to feed themselves, their motivation and ability to participate in aftercare programs, and the adequacy of aftercare, including partial hospitalization [I]. It is important to implement refeeding programs in nurturing emotional contexts [I]. For example, it is useful for staff to convey to patients their intention to take care of them and not let them die even when the illness prevents the patients from taking care of themselves [II]. It is also useful for staff to communicate clearly that they are not seeking to engage in control battles and have no punitive intentions when using interventions that the patient may experience as aversive [I].

In working to achieve target weights, the treatment plan should also establish expected rates of controlled weight gain. Clinical consensus suggests that realistic targets are 2-3 pounds (lb)/week for hospitalized patients and 0.5-1 lb/week for individuals in outpatient programs [II]. Registered dietitians can help patients choose their own meals and can provide a structured meal plan that ensures nutritional adequacy and that none of the major food groups are avoided [I]. Formula feeding may have to be added to the patient's diet to achieve large caloric intake [II]. It is important to encourage patients with anorexia nervosa to expand their food choices to minimize the severely restricted range of foods initially acceptable to them [II]. Caloric intake levels should usually start at 30-40 kilocalories/kilogram (kcal/kg) per day (approximately 1,000-1,600 kcal/day). During the weight gain phase, intake may have to be advanced progressively to as high as 70-100 kcal/kg per day for some patients; many male patients require a very large number of calories to gain weight [II].

Patients who require much lower caloric intakes or are suspected of artificially increasing their weight by fluid loading should be weighed in the morning after they have voided and are wearing only a gown; their fluid intake should also be carefully monitored [I]. Urine specimens obtained at the time of a patient's weigh-in may need to be assessed for specific gravity to help ascertain the extent to which the measured weight reflects excessive water intake [I]. Regular monitoring of serum potassium levels is recommended in patients who are persistent vomiters [I]. Hypokalemia should be treated with oral or intravenous potassium supplementation and rehydration [I].

Physical activity should be adapted to the food intake and energy expenditure of the patient, taking into account the patient's bone mineral density and cardiac function [I]. Once a safe weight is achieved, the focus of an exercise program should be on the patient's gaining physical fitness as opposed to expending calories [I].

Weight gain results in improvements in most of the physiological and psychological complications of semistarvation [I]. It is important to warn patients about the following aspects of early recovery [I]: As they start to recover and feel their bodies getting larger, especially as they approach frightening, magical numbers on the scale that represent phobic weights, they may experience a resurgence of anxious and depressive symptoms, irritability, and sometimes suicidal thoughts. These mood symptoms, non-food-related obsessional thoughts, and compulsive behaviors, although often not eradicated, usually decrease with sustained weight gain and weight maintenance. Initial refeeding may be associated with mild transient fluid retention, but patients who abruptly stop taking laxatives or diuretics may experience marked rebound fluid retention for several weeks. As weight gain progresses, many patients also develop acne and breast tenderness and become unhappy and demoralized about resulting changes in body shape.

## NEDA TOOLKIT for Parents

Patients may experience abdominal pain and bloating with meals from the delayed gastric emptying that accompanies malnutrition. These symptoms may respond to pro-motility agents [III]. Constipation may be ameliorated with stool softeners; if unaddressed, it can progress to obstipation and, rarely, to acute bowel obstruction.

When life-preserving nutrition must be provided to a patient who refuses to eat, nasogastric feeding is preferable to intravenous feeding [I]. When nasogastric feeding is necessary, continuous feeding (i.e., over 24 hours) may be better tolerated by patients and less likely to result in metabolic abnormalities than three to four bolus feedings a day [II]. In very difficult situations, where patients physically resist and constantly remove their nasogastric tubes, feeding through surgically placed gastrostomy or jejunostomy tubes may be an alternative to nasogastric feeding [II]. In determining whether to begin involuntary forced feeding, the clinician should carefully think through the clinical circumstances, family opinion, and relevant legal and ethical dimensions of the patient's treatment [I]. The general principles to be followed in making the decision are those directing good, humane care; respecting the wishes of competent patients; and intervening respectfully with patients whose judgment is severely impaired by their psychiatric disorders when such interventions are likely to have beneficial results [I]. For cooperative patients, supplemental overnight pediatric nasogastric tube feeding has been used in some programs to facilitate weight gain [III].

With severely malnourished patients (particularly those whose weight is <70% of their healthy body weight) who undergo aggressive oral, nasogastric, or parenteral refeeding, a serious refeeding syndrome can occur. Initial assessments should include vital signs and food and fluid intake and output, if indicated, as well as monitoring for edema, rapid weight gain (associated primarily with fluid overload), congestive heart failure, and gastrointestinal symptoms [I].

Patients' serum levels of phosphorus, magnesium, potassium, and calcium should be determined daily for the first 5 days of refeeding and every other day for several weeks thereafter, and electrocardiograms should be performed as indicated [II]. For children and adolescents who are severely malnourished (weight <70% of healthy body weight), cardiac monitoring, especially at night, may be desirable [II]. Phosphorus, magnesium, and/or potassium supplementation should be given when indicated [I].

### b. **Psychosocial Interventions**

The goals of psychosocial interventions are to help patients with anorexia nervosa 1) understand and cooperate with their nutritional and physical rehabilitation, 2) understand and change the behaviors and dysfunctional attitudes related to their eating disorder, 3) improve their interpersonal and social functioning, and 4) address comorbid psychopathology and psychological conflicts that reinforce or maintain eating disorder behaviors.

#### i. **Acute Anorexia Nervosa**

During acute refeeding and while weight gain is occurring, it is beneficial to provide anorexia nervosa patients with individual psychotherapeutic management that is psychodynamically informed and provides empathic understanding, explanations, praise for positive efforts, coaching, support, encouragement, and other positive behavioral reinforcement [I]. Attempts to conduct formal psychotherapy with starving patients who are often negativistic, obsessional, or mildly cognitively impaired may be ineffective [II].

For children and adolescents, the evidence indicates that family treatment is the most effective intervention [I]. In methods modeled after the Maudsley approach, families become actively involved, in a blame-free atmosphere, in helping patients eat more and resist compulsive exercising and purging.

## NEDA TOOLKIT for Parents

For some outpatients, a short-term course of family therapy using these methods may be as effective as a long-term course; however, a shorter course of therapy may not be adequate for patients with severe obsessive-compulsive features or non-intact families [II].

Most inpatient-based nutritional rehabilitation programs create a milieu that incorporates emotional nurturance and a combination of reinforcers that link exercise, bed rest, and privileges to target weights, desired behaviors, feedback concerning changes in weight, and other observable parameters [II]. For adolescents treated in inpatient settings, participation in family group psychoeducation may be helpful to their efforts to regain weight and may be equally as effective as more intensive forms of family therapy [III].

### ii. **Anorexia Nervosa after Weight Restoration**

Once malnutrition has been corrected and weight gain has begun, psychotherapy can help patients with anorexia nervosa understand 1) their experience of their illness; 2) cognitive distortions and how these have led to their symptomatic behavior; 3) developmental, familial, and cultural antecedents of their illness; 4) how their illness may have been a maladaptive attempt to regulate their emotions and cope; 5) how to avoid or minimize the risk of relapse; and 6) how to better cope with salient developmental and other important life issues in the future. Clinical experience shows that patients may often display improved mood, enhanced cognitive functioning, and clearer thought processes after there is significant improvement in nutritional intake, even before there is substantial weight gain [II].

To help prevent patients from relapsing, emerging data support the use of cognitive-behavioral psychotherapy for adults [II]. Many clinicians also use interpersonal and/or psychodynamically oriented individual or group psychotherapy for adults after their weight has been restored [II].

For adolescents who have been ill <3 years, after weight has been restored, family therapy is a necessary component of treatment [I]. Although studies of different psychotherapies focus on these interventions as distinctly separate treatments, in practice there is frequent overlap of interventions [II].

It is important for clinicians to pay attention to cultural attitudes, patient issues involving the gender of the therapist, and specific concerns about possible abuse, neglect, or other developmental traumas [II]. Clinicians need to attend to their countertransference reactions to patients with a chronic eating disorder, which often include beleaguering, demoralization, and excessive need to change the patient [I].

At the same time, when treating patients with chronic illnesses, clinicians need to understand the longitudinal course of the disorder and that patients can recover even after many years of illness [I]. Because of anorexia nervosa's enduring nature, psychotherapeutic treatment is frequently required for at least 1 year and may take many years [I].

Anorexics and Bulimics Anonymous and Overeaters Anonymous are not substitutes for professional treatment [I]. Programs that focus exclusively on abstaining from binge eating, purging, restrictive eating, or excessive exercising (e.g., 12-step programs) without attending to nutritional considerations or cognitive and behavioral deficits have not been studied and therefore cannot be recommended as the sole treatment for anorexia nervosa [I].

It is important for programs using 12-step models to be equipped to care for patients with the substantial psychiatric and general medical problems often associated with eating disorders [I]. Although families and patients are increasingly accessing worthwhile, helpful information through online web sites, newsgroups, and chat rooms, the lack of professional supervision within these resources may sometimes lead to users' receiving misinformation or create unhealthy dynamics among users.

## NEDA TOOLKIT for Parents

It is recommended that clinicians inquire about a patient's or family's use of Internet-based support and other alternative and complementary approaches and be prepared to openly and sympathetically discuss the information and ideas gathered from these sources [I].

### iii. **Chronic Anorexia Nervosa**

Patients with chronic anorexia nervosa generally show a lack of substantial clinical response to formal psychotherapy. Nevertheless, many clinicians report seeing patients with chronic anorexia nervosa who, after many years of struggling with their disorder, experience substantial remission, so clinicians are justified in maintaining and extending some degree of hope to patients and families [II]. More extensive psychotherapeutic measures may be undertaken to engage and help motivate patients whose illness is resistant to treatment [II] or, failing that, as compassionate care [I]. For patients who have difficulty talking about their problems, clinicians have reported that a variety of nonverbal therapeutic methods, such as the creative arts, movement therapy programs, and occupational therapy, can be useful [III]. Psychosocial programs designed for patients with chronic eating disorders are being implemented at several treatment sites and may prove useful [II].

### c. **Medications and Other Somatic Treatments**

#### i. **Weight Restoration**

The decision about whether to use psychotropic medications and, if so, which medications to choose will be based on the patient's clinical presentation [I]. The limited empirical data on malnourished patients indicate that selective serotonin reuptake inhibitors (SSRIs) do not appear to confer advantage regarding weight gain in patients who are concurrently receiving inpatient treatment in an organized eating disorder program [I]. However, SSRIs in combination with psychotherapy are widely used in treating patients with anorexia nervosa.

For example, these medications may be considered for those with persistent depressive, anxiety, or obsessive-compulsive symptoms and for bulimic symptoms in weight-restored patients [II]. A U.S. Food and Drug Administration (FDA) black box warning concerning the use of bupropion in patients with eating disorders has been issued because of the increased seizure risk in these patients. Adverse reactions to tricyclic antidepressants and monoamine oxidase inhibitors (MAOIs) are more pronounced in malnourished individuals, and these medications should generally be avoided in this patient population [I]. Second-generation antipsychotics, particularly olanzapine, risperidone, and quetiapine, have been used in small series and individual cases for patients, but controlled studies of these medications are lacking. Clinical impressions suggest that they may be useful in patients with severe, unremitting resistance to gaining weight; severe obsessional thinking; and denial that assumes delusional proportions [III]. Small doses of older antipsychotics such as chlorpromazine may be helpful prior to meals in very disturbed patients [III]. Although the risks of extrapyramidal side effects are less with second-generation antipsychotics than with first-generation antipsychotics, debilitated anorexia nervosa patients may be at a higher risk for these than expected.

Therefore, if these medications are used, it is recommended that patients be carefully monitored for extrapyramidal symptoms and akathisia [I]. It is also important to routinely monitor patients for potential side effects of these medications, which can result in insulin resistance, abnormal lipid metabolism, and prolongation of the QTc interval [I]. Because ziprasidone has not been studied in individuals with anorexia nervosa and can prolong QTc intervals, careful monitoring of serial electrocardiograms and serum potassium measurements is needed if anorexic patients are treated with ziprasidone [I].

## NEDA TOOLKIT for Parents

Antianxiety agents used selectively before meals may be useful to reduce patients' anticipatory anxiety before eating [III], but because eating disorder patients may have a high propensity to become dependent on benzodiazepines, these medications should be used routinely only with considerable caution [I]. Pro-motility agents such as metoclopramide may be useful for bloating and abdominal pains that occur during refeeding in some patients [II]. Electroconvulsive therapy (ECT) has generally not been useful except in treating severe co-occurring disorders for which ECT is otherwise indicated [I].

Although no specific hormone treatments or vitamin supplements have been shown to be helpful [I], supplemental calcium and vitamin D are often recommended [III]. Zinc supplements have been reported to foster weight gain in some patients, and patients may benefit from daily zinc-containing multivitamin tablets [II].

### ii. **Relapse Prevention**

Some data suggest that fluoxetine in dosages of up to 60 mg/day may help prevent relapse [II]. For patients receiving cognitive-behavioral therapy (CBT) after weight restoration, adding fluoxetine does not appear to confer additional benefits with respect to preventing relapse [II]. Antidepressants and other psychiatric medications may be used to treat specific, ongoing psychiatric symptoms of depressive, anxiety, obsessive-compulsive, and other comorbid disorders [I]. Clinicians should attend to the black box warnings in the package inserts relating to antidepressants and discuss the potential benefits and risks of antidepressant treatment with patients and families if such medications are to be prescribed [I].

### iii. **Chronic Anorexia Nervosa**

Although hormone replacement therapy (HRT) is frequently prescribed to improve bone mineral density in female patients, no good supporting evidence exists either in adults or in adolescents to demonstrate its efficacy [II].

Hormone therapy usually induces monthly menstrual bleeding, which may contribute to the patient's denial of the need to gain further weight [II]. Before estrogen is offered, it is recommended that efforts be made to increase weight and achieve resumption of normal menses [I]. There is no indication for the use of bisphosphonates such as alendronate in patients with anorexia nervosa [II]. Although there is no evidence that calcium or vitamin

D supplementation reverses decreased bone mineral density, when calcium dietary intake is inadequate for growth and maintenance, calcium supplementation should be considered [I], and when the individual is not exposed to daily sunlight, vitamin D supplementation may be used [I]. However, large supplemental doses of vitamin D may be hazardous [I].

## 4. **Choice of Specific Treatments for Bulimia Nervosa**

The aims of treatment for patients with bulimia nervosa are to 1) reduce and, where possible, eliminate binge eating and purging; 2) treat physical complications of bulimia nervosa; 3) enhance patients' motivation to cooperate in the restoration of healthy eating patterns and participate in treatment; 4) provide education regarding healthy nutrition and eating patterns; 5) help patients reassess and change core dysfunctional thoughts, attitudes, motives, conflicts, and feelings related to the eating disorder; 6) treat associated psychiatric conditions, including deficits in mood and impulse regulation, self-esteem, and behavior; 7) enlist family support and provide family counseling and therapy where appropriate; and 8) prevent relapse.

### a. **Nutritional Rehabilitation Counseling**

A primary focus for nutritional rehabilitation is to help the patient develop a structured meal plan as a means of reducing the episodes of dietary restriction and the urges to binge and purge [I]. Adequate nutritional intake can prevent craving and promote satiety [I]. It is important to assess nutritional intake for all patients, even those with a normal body weight (or normal BMI), as normal weight does not ensure appropriate nutritional intake or normal body composition [I].

## NEDA TOOLKIT for Parents

Among patients of normal weight, nutritional counseling is a useful part of treatment and helps reduce food restriction, increase the variety of foods eaten, and promote healthy but not compulsive exercise patterns [I].

### b. Psychosocial Interventions

It is recommended that psychosocial interventions be chosen on the basis of a comprehensive evaluation of the individual patient that takes into consideration the patient's cognitive and psychological development, psychodynamic issues, cognitive style, comorbid psychopathology, and preferences as well as patient age and family situation [I]. For treating acute episodes of bulimia nervosa in adults, the evidence strongly supports the value of CBT as the most effective single intervention [I]. Some patients who do not respond initially to CBT may respond when switched to either interpersonal therapy (IPT) or fluoxetine [II] or other modes of treatment such as family and group psychotherapies [III]. Controlled trials have also shown the utility of IPT in some cases [II].

In clinical practice, many practitioners combine elements of CBT, IPT, and other psychotherapeutic techniques. Compared with psychodynamic or interpersonal therapy, CBT is associated with more rapid remission of eating symptoms [I], but using psychodynamic interventions in conjunction with CBT and other psychotherapies may yield better global outcomes [III]. Some patients, particularly those with concurrent personality pathology or other co-occurring disorders, require lengthy treatment [II]. Clinical reports suggest that psychodynamic and psychoanalytic approaches in individual or group format are useful once bingeing and purging improve [III].

Family therapy should be considered whenever possible, especially for adolescent patients still living with their parents [II] or older patients with ongoing conflicted interactions with parents [III]. Patients with marital discord may benefit from couples therapy [II].

A variety of self-help and professionally guided self-help programs have been effective for some patients with bulimia nervosa [I]. Several innovative online programs are currently under investigation and may be recommended in the absence of alternative treatments [III]. Support groups and 12-step programs such as Overeaters Anonymous may be helpful as adjuncts in the initial treatment of bulimia nervosa and for subsequent relapse prevention, but they are not recommended as the sole initial treatment approach for bulimia nervosa [I]. Issues of countertransference, discussed above with respect to the treatment of patients with anorexia nervosa, also apply to the treatment of patients with bulimia nervosa [I].

### c. Medications

#### i. Initial Treatment

Antidepressants are effective as one component of an initial treatment program for most bulimia nervosa patients [I], with SSRI treatment having the most evidence for efficacy and the fewest difficulties with adverse effects [I]. To date, fluoxetine is the best studied of these and is the only FDA-approved medication for bulimia nervosa. Sertraline is the only other SSRI that has been shown to be effective, as demonstrated in a small, randomized controlled trial. In the absence of therapists qualified to treat bulimia nervosa with CBT, fluoxetine is recommended as an initial treatment [I]. Dosages of SSRIs higher than those used for depression (e.g., fluoxetine 60 mg/day) are more effective in treating bulimic symptoms [I]. Evidence from a small open trial suggests fluoxetine may be useful for adolescents with bulimia [II].

Antidepressants may be helpful for patients with substantial concurrent symptoms of depression, anxiety, obsessions, or certain impulse disorder symptoms or for patients who have not benefited from or had only a suboptimal response to appropriate psychosocial therapy [I]. Tricyclic antidepressants and MAOIs have been rarely used with bulimic patients and are not recommended as initial treatments [I].

## NEDA TOOLKIT for Parents

Several different antidepressants may have to be tried sequentially to identify the specific medication with the optimum effect [I].

Clinicians should attend to the black box warnings relating to antidepressants and discuss the potential benefits and risks of antidepressant treatment with patients and families if such medications are to be prescribed [I].

Small controlled trials have demonstrated the efficacy of the anticonvulsant medication topiramate, but because adverse reactions to this medication are common, it should be used only when other medications have proven ineffective [III]. Also, because patients tend to lose weight on topiramate, its use is problematic for normal or underweight individuals [III].

Two drugs that are used for mood stabilization, lithium and valproic acid, are both prone to induce weight gain in patients [I] and may be less acceptable to patients who are weight preoccupied. However, lithium is not recommended for patients with bulimia nervosa because it is ineffective [I]. In patients with co-occurring bulimia nervosa and bipolar disorder, treatment with lithium is more likely to be associated with toxicity [I].

### ii. **Maintenance Phase**

Limited evidence supports the use of fluoxetine for relapse prevention [II], but substantial rates of relapse occur even with treatment. In the absence of adequate data, most clinicians recommend continuing antidepressant therapy for a minimum of 9 months and probably for a year in most patients with bulimia nervosa [II]. Case reports indicate that methylphenidate may be helpful for bulimia nervosa patients with concurrent attention-deficit/hyperactivity disorder (ADHD) [III], but it should be used only for patients who have a very clear diagnosis of ADHD [I].

### iii. **Combining Psychosocial Interventions and Medications**

In some research, the combination of antidepressant therapy and CBT results in the highest remission rates; therefore, this combination is recommended initially when qualified CBT therapists are available [II]. In addition, when CBT alone does not result in a substantial reduction in symptoms after 10 sessions, it is recommended that fluoxetine be added [II].

### iv. **Other Treatments**

Bright light therapy has been shown to reduce binge frequency in several controlled trials and may be used as an adjunct when CBT and antidepressant therapy have not been effective in reducing bingeing symptoms [III].

## 5. **Eating Disorder Not Otherwise Specified**

Patients with subsyndromal anorexia nervosa or bulimia nervosa who meet most but not all of the DSM-IV-TR criteria (e.g., weight >85% of expected weight, binge and purge frequency less than twice per week) merit treatment similar to that of patients who fulfill all criteria for these diagnoses [II].

### a. **Binge Eating Disorder**

#### i. **Nutritional Rehabilitation and Counseling**

Behavioral weight control programs incorporating low- or very-low-calorie diets may help with weight loss and usually with reduction of symptoms of binge eating [I]. It is important to advise patients that weight loss is often not maintained and that binge eating may recur when weight is gained [I]. It is also important to advise them that weight gain after weight loss may be accompanied by a return of binge eating patterns [I]. Various combinations of diets, behavior therapies, interpersonal therapies, psychodynamic psychotherapies, non-weight-directed psychosocial treatments, and even some “non-diet/health at every size” psychotherapy approaches may be of benefit for binge eating and weight loss or stabilization [III].

## NEDA TOOLKIT for Parents

Patients with a history of repeated weight loss followed by weight gain (“yo-yo” dieting) or patients with an early onset of binge eating may benefit from following programs that focus on decreasing binge eating rather than on weight loss [II].

There is little empirical evidence to suggest that obese binge eaters who are primarily seeking weight loss should receive different treatment than obese individuals who do not binge eat [I].

### ii. Other Psychosocial Treatments

Substantial evidence supports the efficacy of individual or group CBT for the behavioral and psychological symptoms of binge eating disorder [I]. IPT and dialectical behavior therapy have also been shown to be effective for behavioral and psychological symptoms and can be considered as alternatives [II]. Patients may be advised that some studies suggest that most patients continue to show behavioral and psychological improvement at their 1-year follow-up [II]. Substantial evidence supports the efficacy of self-help and guided self-help CBT programs and their use as an initial step in a sequenced treatment program [I]. Other therapies that use a “non-diet” approach and focus on self-acceptance, improved body image, better nutrition and health, and increased physical movement have been tried, as have addiction-based 12-step approaches, self-help organizations, and treatment programs based on the Alcoholics Anonymous model, but no systematic outcome studies of these programs are available [III].

### iii. Medications

Substantial evidence suggests that treatment with antidepressant medications, particularly SSRI antidepressants, is associated with at least a short-term reduction in binge eating behavior but, in most cases, not with substantial weight loss [I]. The medication dosage is typically at the high end of the recommended range [I]. The appetite-suppressant medication sibutramine is effective for binge suppression, at least in the short term, and is also associated with significant weight loss [II].

The anticonvulsant medication topiramate is effective for binge reduction and weight loss, although adverse effects may limit its clinical utility for some individuals [II]. Zonisamide may produce similar effects regarding weight loss and can also cause side effects [III].

### iv. Combining Psychosocial and Medication Treatments

For most eating disorder patients, adding antidepressant medication to their behavioral weight control and/or CBT regimen does not have a significant effect on binge suppression when compared with medication alone. However, medications may induce additional weight reduction and have associated psychological benefits [II]. Adding the weight loss medication orlistat to a guided self-help CBT program may yield additional weight reduction [II]. Fluoxetine in conjunction with group behavioral treatment may not aid in binge cessation or weight loss but may reduce depressive symptoms [II].

### b. Night Eating Syndrome

Progressive muscle relaxation has been shown to reduce symptoms associated with night eating syndrome [III]. Sertraline has also been shown to reduce these symptoms [II].

## Definitions

The three categories of endorsement are as follows:  
[I] Recommended with substantial clinical confidence  
[II] Recommended with moderate clinical confidence  
[III] May be recommended on the basis of individual circumstances

## Links

Link to Full Summary:  
<http://www.guideline.gov/content.aspx?id=9318>

Link to Information for the Public:  
[http://www.nice.org.uk/nicemedia/pdf/cg009publicinf\\_english.Pdf](http://www.nice.org.uk/nicemedia/pdf/cg009publicinf_english.Pdf)

## NEDA TOOLKIT for Parents

# How to find a suitable treatment setting

Several considerations enter into finding a suitable treatment setting for the patient. The patient's options may be limited by his/her available insurance coverage, by whether or not a particular center or therapist accepts insurance, and the ability of the patient to pay in the absence of insurance. Primary care physicians (i.e., family doctor, gynecologist, pediatrician, internal medicine doctor) may be able to play a valuable advisory role in referring patients for treatment if they have had previous experience with referring to eating disorder facilities, participating as a member of a care team for a patient with an eating disorder, or outpatient therapists. Some primary care physicians, however, don't have much or any experience in this area. Therefore, it's important to ask about their experience before asking for a referral.

In 2005 and again in 2007, ECRI Institute (a nonprofit health services research organization) sought to identify all healthcare facilities that stated that they offered treatment for eating disorders. This included hospitals, psychiatric hospitals, residential centers, and outpatient-care facilities. We surveyed treatment facilities nationwide to obtain information about their treatment philosophies, treatment approach, years of experience, and the clinical and support services they offer. The information is available in a searchable database, [www.bulimiaguide.org](http://www.bulimiaguide.org). This database focuses on facilities offering any or all levels of care (see the tool explaining Treatment setting and levels of care). It does not include a listing of individual therapist outpatient practices. For information on outpatient-only therapists, go to the "treatment referral" source at [www.nationaleatingdisorders.org](http://www.nationaleatingdisorders.org); [www.something-fishy.org/treatmentfinder](http://www.something-fishy.org/treatmentfinder); or [www.edreferral.com](http://www.edreferral.com).

## 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. 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.

## Factors Affecting Choice of Treatment Center

For insured patients, the choice of a treatment center may be dictated by the beneficiary's health insurance plan. Health insurers should provide a list of in-network (covered) treatment centers. If the treatment center is outside of the health insurer's system (out-of-network), the insurer might pay a percentage of the treatment costs leaving the patient responsible for the remainder. It is best to negotiate this percentage with the insurer before starting treatment. A small number of treatment centers offer financial assistance; but most do not. However, inquiring about treatment scholarships, as they are termed, may be worth investigating if the patient does not have financial resources or insurance.

## NEDA TOOLKIT for Parents

Costs aside, other factors may be important to the patient in selecting a treatment center: the treatment center's philosophy (or 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 you may want to consider whether they're covered by your health insurance.

Some important questions to ask treatment centers are provided at the end of this document. If you are considering traveling some distance to a center, you may want to ask these questions by phone before you invest the time and expense in traveling. Also, if the patient is going to enter some type of facility, knowing how the facility plans for discharge is important. 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.

Also important in your considerations are the type of care team a facility typically uses. Below is a list of the types of professionals that are generally recommended to be on the care team to ensure well-rounded care. Once a treatment facility decision has been made, there is another checklist of questions in a separate document in this toolkit—Questions to ask the care team—that you may want to ask the care team.

Lastly, there are some questions a family may want to ask the treatment facility and care team separately (i.e., not in the presence of the patient). We have created a separate checklist in another document in the Parent Toolkit: Questions parents may want to ask treatment providers privately. Depending on the patient's age, you may need written permission to speak about the patient with a treatment facility or member of the care team.

### Professionals in a Multi-disciplinary Care Team

- Primary care physician (i.e., family doctor, internal medicine doctor, pediatrician, gynecologist)
- Psychiatrist
- Nutritionist
- Clinical psychologist
- Psychopharmacologist (psychiatrist, clinical psychologist, or pharmacologist with special knowledge about medications used for mental disorders)
- Social worker
- Claims advocate for reimbursement
- Other professionals who administer supplemental services such as massage, yoga, exercise programs, and art therapy

## NEDA TOOLKIT for Parents

### 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?
- Is the location convenient for the patient and his/her support people who will be involved through recovery?
- If the location is far away for in-person family participation, what alternatives are there?
- What security does the facility have in place to protect patients?
- 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.
- 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 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?

#### Key Sources

ECRI Institute Bulimia Resource Guide

<http://www.bulimiaguide.org>

ECRI Institute interviews with families and treatment centers

## NEDA TOOLKIT for Parents

# Treatment settings and levels 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 at a subacute care residential treatment facility. 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 treatment setting and level of care should complement the general goals of treatment. Typically, goals are:

- to medically stabilize the patient;
- help the patient to stop destructive behaviors (i.e., restricting foods, binge eating, purging/nonpurging); and
- address and resolve any coexisting mental health problems that may be triggering the behavior.

Patients with severe symptoms often begin treatment as inpatients and move to less intensive programs as symptoms subside. 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.

Psychotherapy and drug therapy are available in all the care settings. Many settings provide additional care options that can be included as part of a tailored treatment plan. Support groups may help a patient to maintain good mental health and may prevent relapse after discharge from a more intensive program.

The intensity and duration of treatment depends on: insurance coverage limits and ability to pay for treatment;

- severity and duration of the disorder;
- mental health status; and
- coexisting medical or psychological disorders.

A health professional on the treatment team will make treatment recommendations after examining and consulting with the patient.

## Criteria for treatment setting and levels of care

### Inpatient

Patient is medically unstable as determined by:

- Unstable or depressed vital signs
- Laboratory findings presenting acute health risk
- Complications due to coexisting medical problems such as diabetes

Patient is psychiatrically unstable as determined by:

- Rapidly worsening symptoms
- Suicidal and unable to contract for safety

### Residential

Patient is medically stable and requires no intensive medical intervention.

Patient is psychiatrically impaired and unable to respond to partial hospital or outpatient treatment.

## NEDA TOOLKIT for Parents

### **Partial Hospital**

Patient is medically stable but:

- Eating disorder impairs functioning, though without immediate risk
- Needs daily assessment of physiologic and mental status

Patient is psychiatrically stable but:

- Unable to function in normal social, educational, or vocational situations
- Engages in daily binge eating, purging, fasting or very limited food intake, or other pathogenic weight control techniques

### **Intensive Outpatient/Outpatient**

Patient is medically stable and:

- No longer needs daily medical monitoring

Patient is psychiatrically stable and has:

- Symptoms under sufficient control to be able to function in normal social, educational, or vocational situations and continue to make progress in recovery

These criteria summarize typical medical necessity criteria for treatment of eating disorders used by many healthcare facilities, eating disorder specialists, and health plans for determining level of care needed. Please see Questions to Ask a Treatment Center for additional help in determining a suitable treatment setting.

## NEDA TOOLKIT for Parents

# Questions to ask the care team at a facility

Some of these questions pertain to particular eating disorders; some pertain to particular treatment settings; and some pertain to any eating disorder and all settings.

- What are the names, roles, titles, and contact information of those who will treat my family member?
- What other professionals will be involved in the treatment?
- What treatment plan do you recommend? Do you use current published clinical guidelines to guide treatment? If so, which guidelines?
- What's your prognosis for the patient's chance of a full recovery? How long might it take? How do you measure success?
- What specific goals will be set for the treatment plan?
- Is there any psychiatric diagnosis in addition to the eating disorder? How will it be treated?
- What physical/medical complications need ongoing treatment?
- What will the sequence of treatments be?
- Are there alternative or adjunct treatments you recommend?
- What benefits and risks are associated with the recommended treatments and alternatives?
- How can I best help my family member during treatment? What is my role within the treatment?
- How often will you talk to me about my family member's progress?
- What if my family member doesn't want to participate in therapy?
- What are your admissions criteria for residential, inpatient, partial hospital, intensive, and outpatient/inpatient care?
- How much weight gain should be expected in what time period for anorexia? What can I do to support my family member during a time of weight gain?
- Who should monitor refeeding and/or weight status? What procedures should we follow for weighing?
- How do family members determine whether purge behavior is occurring at home? What should we do if we notice this behavior?
- If my family member is being treated as an outpatient, how do you decide if more intensive intervention is needed?
- How often do team members communicate with each other? (Even if the team doesn't talk to each other, you can serve as a liaison to relay information.)
- When do you begin discharge planning? Do you schedule and give the patient a specific follow-up appointment date/time at discharge?
- How do you follow up if the patient does not show up for a scheduled appointment?
- What are your criteria for determining whether and when a patient needs to be hospitalized?
- What happens in counseling sessions? Will there be individual and group sessions? Will there be family sessions?
- If I become very concerned about the patient, who can I call?
- How long does each counseling session last? How many will there be? How often will they happen?
- What contact can the patient have with family and friends through the course of treatment?
- What are we permitted to bring when visiting? What are we not permitted to bring?
- How will you help us prepare for the patient's return home?
- What should we do and who should we contact in the event of a partial or complete relapse?
- What books, websites, or other sources of information would you recommend?

## NEDA TOOLKIT for Parents

# Questions to ask when interviewing a therapist

- What is your experience and how long have you been treating eating disorders?
- How are you licensed? What are your training credentials? Do you belong to the Academy for Eating Disorders (AED)? AED is a professional group that offers its members educational trainings every year. This doesn't prove that individuals are up-to-date, but it does increase the chances.
- How would you describe your treatment style? Many different treatment styles exist. Different approaches may be more or less appropriate for your child and family depending on your child's situation and needs.
- What kind of evaluation process do you use to recommend a treatment plan? Who all is involved in that planning?
- What are the measurable criteria you use to assess how well treatment is working? Can you give me a few examples?
- Do you use published clinical practice guidelines to guide your treatment planning for eating disorders? How?
- What psychotherapeutic approaches and tools do you use?
- How do you treat coexisting mental health conditions such as depression or anxiety?
- How do you decide which approach is best for the patient? Do you ever use more than one approach? When?
- What kind of medical information do you need? Will a medical evaluation be needed before my child begins treatment?
- How will you work with my child's other doctors, such as medical doctors, who may need to provide care?
- How often will you communicate with them?
- Will you work with my child's school and teachers? How often do you communicate with them?
- Will medication play a role in my child's treatment?
- Do you work with a psychopharmacologist if medication seems indicated or do I find one on my own?
- What is your availability in an emergency? If you are not available, what are my alternatives?
- What are your criteria for determining whether a patient needs to be hospitalized?
- What is your appointment availability? Do you offer after work or early morning appointments?
- What happens in counseling sessions? If a particular session is upsetting for my child, will you advise me on how best to support my child?
- How long does each counseling session last? How many will there be and how often?
- How often will you meet with me/us as parents?
- How do you involve key family members or friends?
- What specific goals will be set for treatment and how will they be communicated?
- How and when will progress be assessed?
- How long will the treatment process take? How do you know when recovery is happening and therapy can stop?
- Do you charge for phone calls or emails from patients or family between sessions? If so, what do you charge and how and to whom (insurance company or patient) is that billed?
- Will you send me written information, a treatment plan, treatment price, etc.? The more information the therapist or facility is able to send in writing, the better informed you will be.
- Do you deal directly with the insurer or do I need to do that?
- When is payment due?
- Are you reimbursable by my insurance? What if I don't have insurance or mental health benefits under my health care plan?

It is important for you to research your insurance coverage policy and what treatment alternatives are available in order for you and your treatment provider to design a treatment plan that suits your coverage.

With a careful search, the provider you select will be helpful. If the first time you meet is awkward, don't be discouraged. The first few appointments with any treatment provider can be challenging. It takes time to build trust when you are sharing highly personal information. If you continue feeling that a different therapeutic environment is needed, consider other providers.

## NEDA TOOLKIT for Parents

# Questions parents may want to ask treatment providers privately

Appropriate support from parents and family is crucial to the treatment process and recovery.

Below are some questions you can ask the treatment provider (at an eating disorder facility or private practice) to assist you in providing the best support possible for your loved one.

Remember you may need to be proactive to help ensure the communication process flows smoothly. And don't forget to find support for yourself! As a parent, family member, or friend it's easy to overlook the self-care you need as you focus on your loved one's recovery. National Eating Disorders Association's (NEDA's) treatment referral resource on the website lists family support groups, though you can ask the treatment provider helping your loved one to make a recommendation.

- How can I best support my child/family member during treatment?
- What is my role?
- How often can I discuss progress with you?
- What should be done if my child/family member does not want to participate in treatment?
- Can my child/family member be admitted to a facility against her/his will? If so, under what circumstances?
- How should I prepare for our family member's return home?
- What books, websites, or other resources do you recommend?
- How can I tell if a relapse is occurring? What should we do?
- If my family member receives outpatient treatment, how will you decide if more intensive treatment is needed?
- If I have concerns about how it's going, who should I call?
- What limits should be placed on exercise? What distinguishes compulsive from healthy exercise?
- Are there any special first-aid items such as Gatorade® or Pedialyte® that I should keep on hand to help with bulimia-related emergencies?
- How can I encourage "safe" food choices?
- What if my family member shuts me out of talking about things?
- Will my family member be in group treatment with people of similar age/sex? What kind of food-related supervision should I provide?
- If my family member is fascinated by cooking, nutrition, or fitness, should those interests be encouraged?
- Is it wise for a recovering patient to have a job related to food or exercise?
- How should I involve my family member in meal planning, preparation, and food shopping?
- How much weight gain should be expected in what time period with anorexia nervosa?
- What support can I offer during a time of weight gain?
- Is it my responsibility to monitor refeeding and/or weight? What procedures should I follow for weighing?
- How do family members determine if purge behavior is occurring in the home setting?
- What action should I take if we notice this behavior?
- If I become anxious or notice problems, who should I call?
- My family member doesn't want anyone to know about the illness. I do because it would help me to share about the illness with select, carefully chosen, discrete people in our lives. They could be supportive, but I'm afraid that my family member might see them as spies. What should I do?

If the patient is age 18, and often even younger, parents will need written permission from the patient to discuss his/her situation with a healthcare provider (professional or facility).

## NEDA TOOLKIT for Parents

# Find eating disorder treatment

Online databases and telephone referral lines are available to help families find a suitable treatment setting. Excellent resources are listed below

### Treatment Center Databases to Search

#### NEDA

[www.nationaleatingdisorders.org](http://www.nationaleatingdisorders.org)

Treatment center listings can be accessed from the NEDA homepage. This database contains listings from professionals who treat eating disorders. Simply open the treatment referral tab and agree to the disclaimer. Find an eating disorders treatment provider who will serve your state, a nationwide list of inpatient/residential treatment facilities, search for free support groups in your area or locate a national Eating Disorders Research Study.

#### Bulimia Guide

<http://www.bulimiaguide.org/>

This database focuses on U.S. centers that treat all types of eating disorders (not just bulimia) and offer various levels of care and many types of treatment from standard to alternative. On this website, you can browse center listings by state, type of treatment offered, whether or not they accept insurance, or other characteristics by selecting from the drop-down lists. Some states have no eating disorder treatment centers, and that's why no listings come up for some states. This information was compiled from detailed questionnaires sent to every center to gather information about its treatment philosophies, approaches, staffing, and the clinical and support services it offers. The amount of information centers provided varies widely among centers. This database does not contain listings for individual outpatient therapists who claim to treat eating disorders.

#### Something Fishy

<http://www.something-fishy.org/treatmentfinder/>

The database contains listings from individual therapists, dieticians, treatment centers, and other professionals worldwide who treat eating disorders. Open the "treatment finder" tab on the left, and search by category (type of treatment), country, state, area code, name, services, description, or zip code.

### What to Consider When Searching for a Treatment Center

Several considerations enter into finding a suitable treatment setting. Options may be limited by factors such as insurance coverage, location, or ability to pay for treatment in the absence of insurance. When contacting treatment centers, be sure to talk with them to find out their complete admission criteria and whether your loved one meets their criteria for treatment. That way, you can better ensure that your loved one will meet their criteria before traveling. Arriving at a center only to find out, after they take sufficiently detailed patient intake information, that they won't admit your loved one is a situation you'll want to prevent. Primary care physicians (i.e., family doctor, gynecologist, pediatrician, internal medicine doctor) may be able to assist in referring patients to appropriate treatment facilities, because they may have experience with various centers or outpatient therapists.

### Telephone Referral and Information Helplines

**NEDA Helpline** 800.931.2237

**Something Fishy** 866.690.7239

**Hope Line Network** 800.273.TALK

**National Suicide Hotline** 800.784.2433

**National Call Center for At-Risk Youth** 800.USA.KIDS

## NEDA TOOLKIT for Parents

# How to take care of yourself while caring for a loved one with an eating disorder

- Take time for yourself. Keep in mind that what you do is a much more powerful message than what you say. Being a good role model for your child or family member during the healing process means taking care of your own physical, emotional, and spiritual needs.
- If you are married or in a significant relationship, spend time on that relationship. Talk daily to your partner about your feelings and frustrations. Take time for a hug. If time allows, make a date for something you both enjoy to have fun.
- Seek support from family, friends, and/or professionals whom you find to be helpful. Allow yourself to be cared for.
- Ask for help with the mundane. It makes your friends feel useful and keeps you from becoming isolated. Make a list of things you can use help with: laundry, errands, lawn care, housecleaning, meals for the rest of the family. If someone says, “Let me know if there is anything I can help with,” show them your list of unassigned tasks. Ask what they can do.
- Remind yourself daily that you are doing the best for your child or family member. Keeping a journal can help— making a self-commitment to jot down one positive thought each day can help.
- Find support in what others are saying – join a local or online support group.
- Say “No” when you can. Give yourself a break. Don’t take on any added responsibilities at this time.
- Explore your options if you think you may need to leave work temporarily to provide full-time care. Learn about the Family and Medical Leave Act (FMLA). FMLA provides job protection for employees who must leave their job for family medical concerns.

## NEDA TOOLKIT for Parents

# Confidentiality issues

Parents of children of legal age or friends of a person with an eating disorder may want to help navigate insurance issues and finding treatment facilities, or participate in treatment, but cannot talk with health professionals or facilities on a patient's behalf without the patient's permission because of certain regulations protecting medical privacy. The Health Insurance Portability and Accountability Act of 1996, or HIPAA, protects individuals' medical records from becoming public knowledge. HIPAA states that under normal circumstances, medical records are private and that anyone with access to them, like healthcare professionals, healthcare facilities, or insurers, cannot share that medical information with anyone but the patient. HIPAA protection also extends to human resources (HR) departments at employers. If a person discloses his/her medical condition to HR personnel when talking about health insurance benefits, HR is required to maintain confidentiality. If HR divulges information without permission, the harmed party can file a civil rights complaint. HIPAA requires companies to have policies that provide for sanctions against any HR person who releases confidential medical information. The Americans with Disabilities Act may provide recourse for anyone fired from a job because of a medical condition.

If a friend or family member is helping a patient through the treatment process, the patient can give oral permission for that person to see the patient's records and participate when talking with healthcare providers or insurers. That person may also make doctors' appointments for the patient. A friend or family member cannot see a patient's medical files or transport the files or lab samples if the patient is absent, even if permission has been given orally.

To grant a friend or family member access to medical records, the patient must provide a durable power of attorney (POA) document. This document varies by state so it's best to have a lawyer create it. Anyone with a POA can sign legal documents for the patient and read or transport medical records in the patient's absence.

Other documents worth knowing about include a medical POA, which lets someone make medical decisions about the patient's healthcare if the patient is incapable of making these decisions. The rules about medical POAs vary by state and it's best to consult a lawyer to write one. Advanced directives are another set of documents that the patient authorizes for future treatment in case the patient cannot make decisions at that time. Most hospitals have forms for patients to fill out to specify instructions.

In most states parents have medical POA over their children as long as the children are younger than age 18 although the exact regulations depend on the state. Parents do not have medical or durable POA over children who are older than age 18, even if the children are covered under the parents' health insurance policy. If a child is in college, is over age 18, but is still covered by the parents' insurance, then the parents and child must go through the usual legal process to set up POA. This can be a problem if the child does not want treatment or is at odds with the parents, which is sometimes the case. Parents have no legal authority to force a legally adult child into treatment.

# Insurance Issues

## NEDA TOOLKIT for Parents

# Navigating and Understanding Health Insurance Issues

This guidance is intended to assist people looking for help when accessing care and when insurance denies coverage for treatment of eating disorders. The information here was compiled from research by ECRI Institute and the experience of parents and treatment providers who have had experience obtaining coverage for eating disorders care.

In a separate document are sample letters to adapt to various insurance situations related to obtaining appropriate care. This information has not been prepared by attorneys and is not intended as a legal document. This information does not guarantee success. If you have suggestions, feedback, or personal additions to share (e.g., submit a sample letter you've used with your insurance company with all identifying information removed), please email National Eating Disorders Association at [info@nationaleatingdisorders.org](mailto:info@nationaleatingdisorders.org) with "Insurance Issues" in the subject line.

The National Eating Disorders Association fields many questions every day that focus on how to gain access to care and navigate insurance issues. While there is little argument that early intervention offers the best chance for recovery, insurance and the healthcare system can pose barriers to accessing prompt, comprehensive treatment.

Accessing the full benefits a patient is entitled to under his/her health plan contract requires understanding a few things about all the factors that affect access to care, coverage, and reimbursement. Navigating the system to find out what the patient is entitled to receive also takes a lot of energy. While parents can legally act on behalf of children younger than age 18, they need permission from a child older than age 18 to act on his/her behalf.

Because treatment usually involves both mental healthcare and medical care aspects, a well-rounded care plan must address both types of care. The overall healthcare system has long treated medical care and mental healthcare separately. The result of that care model is that health insurer benefits plans have often followed suit by separating mental health benefits (also called behavioral health benefits) from medical benefits. This split has created great difficulty for people with an eating disorder because they need an integrated care plan. Ways to steer through these difficulties are offered here in an 8-step plan.

Another issue is the level of benefits for mental healthcare. For years, many health plans provided few or no mental health benefits. When they did, most subcontracted those benefits through "mental health carve-out" plans. Such plans are administered by behavioral health service companies that are separate from health plans. This approach made well-rounded care by a multidisciplinary team very difficult to achieve. Even when a psychotherapist and medical doctor want to integrate services and case management to treat the patient as a whole person, the healthcare delivery system in the United States poses barriers that prevent that from happening.

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.

The system is slowly changing. Sporadic improvements have come about as a result of lawsuits and state legislation prompted by individuals, legislators, clinicians, support groups, and mental health advocacy groups. The U.S. federal government and most U.S. states have passed some form of mental health parity law. Generally these laws require insurers to provide benefits for mental healthcare that are equivalent to benefits for medical care. These laws do, however, vary widely in their provisions.

## NEDA TOOLKIT for Parents

Landmark lawsuits brought by families of patients with bulimia nervosa and/or anorexia in two states—Wisconsin in 1991, and Minnesota in 2001—were watershed events that set legal precedents about what insurers should cover for eating disorders. These lawsuits also raised public awareness of the problems faced by people seeking coverage for treatment of eating disorders. Nonetheless, the system today has a long way to go to improve access to care and adequate reimbursement for care for a sufficient period for a patient with an eating disorder.

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, inter-related 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 patients' 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.

## NEDA TOOLKIT for Parents

# Steps to maximize insurance benefits

### 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.

Find out if your state has a mental health parity law or mandate and what the terms of that law or mandate are. Mental health parity simply means that your insurance company must not limit mental health and substance abuse healthcare by imposing lower day and visit limits, higher copayments and deductibles, and lower annual and lifetime spending caps than they do for medical care. The website [www.bulimiaguide.org](http://www.bulimiaguide.org) has detailed information about which states have mental health parity laws or mandates and what those laws and mandates cover. See the Eating Disorders Coalition for Research, Policy & Action web site for how to get involved in the effort to influence federal policy at: [www.eatingdisorderscoalition.org](http://www.eatingdisorderscoalition.org).

### Get organized

If a patient's first encounter with the healthcare system is admission to an emergency room for a life-threatening situation with an eating disorder, whoever is going to deal with insurance issues on the patient's behalf will need to get organized very quickly to figure out how to best access benefits. Patients who are seriously medically compromised will likely be in the hospital for a few days before discharge to outpatient care or a residential eating disorder center. Those few days are critical to negotiating reimbursement for the longer-term care. If the situation is not an acute emergency and you want to find a treatment center, consider whether you have authority to act on the patient's behalf or whether the patient must give you written authority to act on his/her behalf. If a child is 18 years of age or older, parents will need the child's written permission to act on the child's behalf. Healthcare providers have forms that require signatures to allow free flow of communication and decision making.

A spouse, partner, friend, or other person who wants to act on behalf of the patient will need to have the patient sign appropriate authorizations. Medical confidentiality is discussed later in this section.

### Read the patient's entire insurance benefits manual carefully to understand the available benefits

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.

## NEDA TOOLKIT for Parents

Medical benefits coverage also often comes into play to treat 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.

### Keep careful and complete records of communications with the insurance company and healthcare providers for future reference as needed

From the first call you make, keep a complete record of your conversation. Treatment often occurs over a long period of time. Maintaining a log book—whether computerized or in hard copy—can be important for future reference if there are questions about claims. Decide where all notes and documentation will be kept for easy access. Create a back-up copy of everything, and keep it in a safe and separate place. The record log of conversations should contain the following:

- Notes taken of each conversation with an insurer or healthcare provider
- Date, time, name, and title of person with whom you spoke
- Person's contact information

As a courtesy, you may wish to let the people you talk with know that you are keeping careful records of your conversations to help you and the patient remember what was discussed. If you decide to tape record any conversation, you must first inform and ask the permission of the person with whom you are speaking.

### Call the insurer to discuss benefits options

With documentation of the patient's diagnosis and proposed care plan in hand, it's a good idea to call the insurance company before the patient formally enters a treatment program. Quite often, preauthorization for a treatment facility or healthcare provider is needed. Ask for a case manager who has credentials in eating disorders.

This will improve your chance of getting one contact person to talk with over the longer term of treatment who better understands the complexities of treatment. 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 person you speak with 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.
- 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.

## NEDA TOOLKIT for Parents

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.cobrainurance.com](http://www.cobrainurance.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.

If the patient is in the hospital and will be discharged to a residential treatment center, discuss how the medical and behavioral health components of benefits will work. Although a patient may be "medically stable" at discharge, he/she may not be nearly well enough to participate fully in psychotherapy at the residential center. The patient's medical condition, though not life-threatening at this point, affects mental health and ability to participate in treatment. Restoring physical health may take days or weeks. Therefore, before the patient is admitted to a residential eating disorder center or placed in outpatient treatment, contact the patient's health plan or employer (if applicable and the health plan is self-funded by the employer) and ask for the early claims for psychotherapy to be paid under the medical benefits instead of the behavioral health benefits. The language to use is: "Will you intercept psychotherapy claims and pay them under medical benefits until the patient is stable enough to participate fully and assist in her treatment?"

Not all health plans will do this, but some do, so it's worth asking. Going this route can save the behavioral health benefits for the time when the patient is better able to take part in the psychotherapy.

Another way to get the most out of benefits is to find out whether chemical dependency or substance abuse benefits are included in the mental health day allotment or if it is a separate benefit. If it is separate and the patient does not really need this benefit, find out whether the insurer will "flex" the benefit to apply it for treating an eating disorder.

### **Find out the authorizations for care that the insurer requires for the patient to access care.**

Once insurance benefits are confirmed, be sure to obtain the health plan authorizations required for reimbursement for the care the patient will receive. Sometimes authorizations and referrals are sent electronically to the concerned parties. Always confirm that they have been sent and received by the appropriate parties. Ask for the level-of-care criteria the patient must meet to be eligible for the various levels of benefits. Again, keep a record of the authorizations received.

### **Communicate with key caregivers to give any needed input and devise a treatment plan.**

Obtain the names of the people who will be providing care and having daily interactions with the patient (including lower-level staff such as aides). Try to meet with, or talk by phone, to each caregiver on the team. Discuss the diagnosis (and whether there is more than one primary diagnosis) and treatments options, and ask whether there is clinical evidence to support the recommended treatment and what that evidence is.

## NEDA TOOLKIT for Parents

This information can be useful when talking to the insurance company about benefits, because insurance companies value evidence-based care. Also, ask how the treatment plan will be coordinated and managed, and who will coordinate the plan. In the case of bulimia nervosa, the patient often has close to normal body weight. However, serious, but less obvious medical conditions may also be present (e.g., osteoporosis, heart problems, kidney problems, brain abnormalities, diarrhea, reflux, nausea, malnutrition, heartburn). Tests that are used to diagnose medical symptoms and criteria for levels of care are listed in First steps to getting help in this toolkit. Ask for “letters of support” from the healthcare team. See Sample letter #6 in Sample letters to use with insurers in this toolkit. Using language that is used by insurance companies is helpful to have common ground. For example, it’s important to point out care that is considered by the doctors to be “medically necessary” for the patient’s recovery.

Documentation like this is useful to provide to the insurer when discussing reimbursement, because it gives both you and the insurer a framework for discussion. With regard to the healthcare providers, ask them how to and who can obtain copies of the patient’s medical records, who will provide progress reports, how often they will provide them, and to whom. Ask the healthcare provider (whether a facility or individual therapist) for an itemization of the estimated costs of care, which costs will likely be paid by the insurer, and which costs will be paid by the patient. Also ask how billing for reimbursement will be handled—ask whether you have to submit claims or whether the healthcare service provider submits the claims on the patient’s behalf.

### **Enlist support from family members and friends you can count on.**

Make a list of people you can count on for moral support throughout the course of treatment. Keep their names, phone numbers, and email addresses handy. For this list, identify people who can help the patient remain focused and provide helpful emotional support and encouragement while navigating the system to obtain care and while receiving care. Find out from each of them their availability (i.e., times, dates) for support and the kind of support they can offer. Also consider distributing that list among key people on the list so they know who is in your support network. Also, list key healthcare provider (facilities and healthcare providers) contact numbers on that list in the event of an emergency.

## NEDA TOOLKIT for Parents

# COBRA rights checklist

This is a list of requirements that employers must follow to inform their group health plan beneficiaries (employees, spouses, dependents) of their rights under the Consolidated Omnibus Budget Reconciliation Act (COBRA).

### Required notices

- Model general and election notices available at [www.dol.gov](http://www.dol.gov)
- General Rights Notice (must be sent within 90 days of enrollment into a group health plan - health, dental, vision, flexible spending account)
- Specific Rights Notice (Election notice - the plan administrator must provide the notice within 14 days after receiving notice of a qualifying event)
- Conversion Rights Notice (must be sent 180 days prior to the end of the maximum continuation period)
- Notice of Unavailability (must be sent when the plan administrator denies coverage after receiving notice and explain why continuation coverage is not available)
- Notice of Termination of COBRA Rights (must be sent when COBRA coverage terminates before the end of the maximum COBRA period)

### Enrollment into group health plan

- Send General COBRA notice addressed to covered employee and spouse, if applicable, to home address within 90 days of enrollment into group health plan
- Send General COBRA notice to covered spouse if added during open enrollment or qualified event

### Types of qualifying events for COBRA eligibility

- Employee Termination
- Employee Reduction in Hours
- Employee Death
- Entitlement to Medicare
- Employee Divorce or Legal Separation
- Loss of Dependent Child Status
- Length of coverage available
- 18 months (Employee Events)
- 36 months (Dependent Events)
- 29 months (Disability Extension periods)

### Payment of COBRA premiums

- Premiums are due the first of the coverage month. An administrative charge may be added to the monthly premium. There is a 30-day grace period to make payments. This begins on the second day of the coverage month. For example, September's grace period expires on October 1, not September 30.

### Reasons for terminating COBRA coverage

- The maximum continuation period has been reached.
- The Qualified Beneficiary fails to make a timely COBRA premium payment.
- The Qualified Beneficiary is covered under another group health plan AFTER the election of COBRA.
- The Qualified Beneficiary is no longer disabled after the start of the 11-month extension has begun.
- The Employer ceases to provide any group health coverage to any covered employee.
- The Qualified Beneficiary has become entitled to Medicare, part A or B (For purposes of Medicare, ELIGIBLE means the person has attained the age of 65. ENTITLEMENT means the person has actually become enrolled under Medicare).

### Open enrollment

- During open enrollment, the same information and enrollment options must be communicated to COBRA Qualified Beneficiaries as to active employees. This includes allowing Qualified Beneficiaries the ability to enroll under a new plan.

## NEDA TOOLKIT for Parents

# 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 Navigating and understanding health insurance issues. Remember:
- Follow up letters with phone calls and document whom you speak to.
- 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.

## NEDA TOOLKIT for Parents

### 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 address your letter to—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 Letters #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.

(HEADING SAME AS PREVIOUS LETTER)

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.

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#

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].

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

# How to manage an appeals process

### **Continue treatment during the appeals process.**

Appeals can take weeks or months to complete, and health professionals and facilities that treat eating disorders advise that it's very important for the patient's well-being to stay in treatment if at all possible to maintain progress in recovery.

### **Clarify with the insurer the reasons for the denial of coverage.**

Most insurers send the denial in writing. Claims advocates at treatment centers advise patients and families to make sure they understand the reasons for the denial and ask the insurance company for the reason in writing if a written response has not been received.

### **Send copies of the letter of denial to all concerned parties with documentation of the patient's need.**

Claims advocates at treatment centers state that sending documentation of an appeals request to the medical director, the human resources director of the company where the patient works (or has insurance under), if applicable can help bring attention to the situation. Presenting a professional-looking and organized appeal with appropriate documentation, including an evidence-based care plan makes the strongest case possible. Initial denials are often overturned at higher appeal levels, because higher-level appeals are often reviewed by a doctor who may have a better understanding than the initial claims reviewer of the clinical information provided, especially well-organized, evidence-based documentation.

### **Ask the insurer what evidence-based outcome measures it uses to assess patient health and eligibility for benefits.**

Some insurance companies may use body mass index (BMI) as a criterion for inpatient admission or discharge from treatment for bulimia nervosa, for example, which may not be a valid outcome measure. This is because patients with bulimia nervosa can have close-to-ideal BMIs, when in fact, they may be very sick. Thus, BMI does not correlate well with good health in a patient with bulimia nervosa. For example, if a patient with bulimia nervosa was previously overweight or obese and lost significant weight in a short timeframe, the patient's weight might approach the norm for BMI. Yet, a sudden and large weight loss in such a person could adversely affect his or her blood chemistry and indicate a need for intensive treatment or even hospitalization.

### **Ask that medical benefits, rather than mental health benefits, be used to cover hospitalization costs for bulimia nervosa-related medical problems.**

Claims advocates advise that sometimes claims for physical problems such as those arising from excessive fasting or purging, for example, are filed under the wrong arm of the insurance benefit plan—they are filed under mental health instead of medical benefits. They say it's worth checking with the insurance company to ensure this hasn't happened. That way, mental health benefits can be reserved for the patient's nonmedical treatment needs like psychotherapy. Various diagnostic laboratory tests can identify the medical conditions that need to be treated in a patient with eating disorders. Also, if a patient has a diagnosis of two mental disorders (also called a dual diagnosis), and if that diagnosis is considered by the insurance company to be more "severe" than an eating disorder, the patient may be eligible for more days of treatment.

## NEDA TOOLKIT for Parents

### **Ask the insurer whether they will “flex the benefit.”**

Flexing benefits means that the insurer applies one type of benefit for a different use. For example, medical benefits might be “flexed” to cover some aspect of mental health treatment— usually inpatient treatment. Also, inpatient benefits might be flexed (traded) to substitute intensive outpatient care for inpatient care—for example, 30 inpatient days for 60 intensive outpatient benefit days. Substance abuse (also called chemical dependency) benefits might be traded for additional benefits to treat the eating disorder if the beneficiary thinks he/she will never need the substance abuse benefits available under his/ her coverage. There is a clinical rationale for doing this: if the eating disorder is not treated appropriately from the outset, the insurer risks incurring additional and higher costs for patient care in the future because further hospitalization and treatment may be needed. By flexing inpatient medical benefits or trading inpatient days for outpatient days to obtain more days of mental health treatment, future and possibly higher healthcare expenses might be avoided. While insurers are not obligated to do flex benefits, they may respond to a sound, logical argument to do so if it makes good sense from both a business and patient care perspective in the longer term. If you can support this argument with your doctors’ recommended treatment plan and clinical evidence from practice guidelines and an evidence report, the insurer may agree.

If the patient is employed or in a union, consider asking the employer (or its human resources manager) or union representative to negotiate with the insurer about aspects of the coverage policy that seem open to interpretation. As a client of the insurance company, the employer is likely paying a lot of money to provide benefits to employees (even when employees pay part of the insurance premiums). Because insurance companies want to maintain good business relationships with their clients, the employer may have more influence than the patient alone when negotiating for reimbursement. Many patients or families of patients are afraid or embarrassed to discuss bulimia or anorexia with an employer. Remember that legally, a person cannot be fired and insurance cannot be dropped solely because of having an eating disorder (or any other health condition).

### **Negotiate with the treatment center about the cost of treatment.**

Our survey of treatment centers indicates that some treatment centers have a sliding fee scale and may adjust the treatment charges or set up a payment plan for the patient’s out-of pocket costs.

### **Discuss with the insurer how existing laws and clinical practice standards affect your situation.**

Educate yourself about how the state’s mental health parity laws and mandates apply to the patient’s insurance coverage. Also ask the insurer if it is aware of evidence reports on treatment for eating disorders and guidelines like the American Psychiatric Association’s clinical guidelines for treating eating disorders: [www.psych.org](http://www.psych.org). Ask what role the evidence plays in the decision about benefits. As a last resort, some patients or their advocates may also contact the state insurance commissioner, state consumer’s rights commission, an attorney, the media, or legislators to bring attention to the issue of access to care for patients with eating disorders.

# Additional Resources

## NEDA TOOLKIT for Parents

# Glossary

This eating disorders glossary defines terms you may encounter when seeking information and talking with care providers about diagnosis and treatment of all types of eating disorders.

It also contains some slang terms that may be used by individuals with an eating disorder.

**Alternative Therapy** In the context of treatment for eating disorders, a treatment that does not use drugs or bring unconscious mental material into full consciousness. For example yoga, guided imagery, expressive therapy, and massage therapy are considered alternative therapies.

**Amenorrhea** The absence of at least three consecutive menstrual cycles.

**Ana Slang** for anorexia or anorexic.

**ANAD (National Association of Anorexia Nervosa and Associated Disorders)** A nonprofit corporation that seeks to alleviate the problems of eating disorders, especially anorexia nervosa and bulimia nervosa.

**Anorexia Nervosa** A disorder in which an individual refuses to maintain minimally normal body weight, intensely fears gaining weight, and exhibits a significant disturbance in his/her perception of the shape or size of his/her body.

**Anorexia Athletica** The use of excessive exercise to lose weight.

**Anticonvulsants** Drugs used to prevent or treat convulsions.

**Antiemetics** Drugs used to prevent or treat nausea and vomiting.

**Anxiety** A persistent feeling of dread, apprehension, and impending disaster. There are several types of anxiety disorders, including: panic disorder, agoraphobia, obsessive-compulsive disorder, social and specific phobias, and posttraumatic stress disorder. Anxiety is a type of mood disorder. (See Mood Disorders.)

**Arrhythmia** An alteration in the normal rhythm of the heartbeat.

**Art Therapy** A form of expressive therapy that uses visual art to encourage the patient's growth of self-awareness and self-esteem to make attitudinal and behavioral changes.

**Atypical Antipsychotics** A new group of medications used to treat psychiatric conditions. These drugs may have fewer side effects than older classes of drugs used to treat the same psychiatric conditions.

**B&P** An abbreviation used for binge eating and purging in the context of bulimic behavior.

**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. When used to treat an eating disorder, the focus is on modifying the behavioral abnormalities of the disorder by teaching relaxation techniques and coping strategies that affected individuals can use instead of not eating, or binge eating and purging. Subtypes of BT include dialectical behavior therapy (DBT), exposure and response prevention (ERP), and hypnbehavioral therapy.

**Binge Eating Disorder (also Bingeing)** Consuming an amount of food that is considered much larger than the amount that most individuals would eat under similar circumstances within a discrete period of time. Also referred to as "binge eating."

**Beneficiary** The recipient of benefits from an insurance policy

**Biofeedback** A technique that measures bodily functions, like breathing, heart rate, blood pressure, skin temperature, and muscle tension. Biofeedback is used to teach people how to alter bodily functions through relaxation or imagery. Typically, a practitioner describes stressful situations and guides a person through using relaxation techniques. The person can see how their heart rate and blood pressure change in response to being stressed or relaxed. This is a type of non-drug, non-psychotherapy.

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**Body Dysmorphic Disorder or Dysmorphophobia** A mental condition defined in the DSM-IV in which the patient is preoccupied with a real or perceived defect in his/her appearance. (See DSM-IV.)

**Body Image** The subjective opinion about one's physical appearance based on self-perception of body size and shape and the reactions of others.

**Body Mass Index (BMI)** A formula used to calculate the ratio of a person's weight to height. BMI is expressed as a number that is used to determine whether an individual's weight is within normal ranges for age and sex on a standardized BMI chart. The U.S. Centers for Disease Control and Prevention Web site offers BMI calculators and standardized BMI charts.

**Bulimia Nervosa** A disorder defined in the DSM-IV-R in which a patient binges on food an average of twice weekly in a three-month time period, followed by compensatory behavior aimed at preventing weight gain. This behavior may include excessive exercise, vomiting, or the misuse of laxatives, diuretics, other medications, and enemas.

**Bulimarexia** A term used to describe individuals who engage alternately in bulimic behavior and anorexic behavior.

**Case Management** An approach to patient care in which a case manager mobilizes people to organize appropriate services and supports for a patient's treatment. A case manager coordinates mental health, social work, educational, health, vocational, transportation, advocacy, respite care, and recreational services, as needed. The case manager ensures that the changing needs of the patient and family members supporting that patient and family members supporting that patient are met.

**COBRA** A federal act in 1985 that included provisions to protect health insurance benefits coverage for workers and their families who lose their jobs. The landmark Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA) health benefit provisions became law in 1986. The law amends the Employee Retirement Income Security Act (ERISA), the Internal Revenue Code, and the Public Health Service Act to provide continuation of employer-sponsored group health coverage that otherwise might be terminated. The U.S. Centers for Medicare & Medicaid Services has advisory jurisdiction for the COBRA law as it applies to state and local government (public sector) employers and their group health plans.

**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)** A treatment that involves three overlapping phases when used to treat an eating disorder. For example, with bulimia, the first phase focuses on helping people to resist the urge to binge eat and purge by educating them about the dangers of their behavior. The second phase introduces procedures to reduce dietary restraint and increase the regularity of eating. The last phase involves teaching people relapse-prevention strategies to help them prepare for possible setbacks. A course of individual CBT for bulimia nervosa usually involves 16- to 20-hour-long sessions over a period of 4 to 5 months. It is offered on an individual, group, or self-managed basis. The goals of CBT are designed to interrupt the proposed bulimic cycle that is perpetuated by low self-esteem, extreme concerns about shape and weight, and extreme means of weight control.

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**Cognitive Orientation Therapy (COT)** A type of cognitive therapy that uses a systematic procedure to understand the meaning of a patient's behavior by exploring certain themes such as aggression and avoidance. The procedure for modifying behavior then focuses on systematically changing the patient's beliefs related to the themes and not directly to eating behavior

**Comorbid Conditions** Multiple physical and/or mental conditions existing in a person at the same time. (See Dual Diagnosis.)

**Crisis Residential Treatment Services** Short-term, round-the-clock help provided in a nonhospital setting during a crisis. The purposes of this care are to avoid inpatient hospitalization, help stabilize the individual in crisis, and determine the next appropriate step.

**Cure** The treated condition or disorder is permanently gone, never to return in the individual who received treatment. Not to be confused with "remission." (See Remission.)

**Dental Caries** Tooth cavities. The teeth of people with bulimia who using vomiting as a purging method may be especially vulnerable to developing cavities because of the exposure of teeth to the high acid content of vomit.

**Depression (also called Major Depressive Disorder)** A condition that is characterized by one or more major depressive episodes consisting of two or more weeks during which a person experiences a depressed mood or loss of interest or pleasure in nearly all activities. It is one of the mood disorders listed in the DSM-IV-R. (See Mood Disorders.)

**Diabetic Omission of Insulin** A nonpurging method of compensating for excess calorie intake that may be used by a person with diabetes and bulimia.

**Dialectical Behavior Therapy (DBT)** A type of behavioral therapy that views emotional deregulation as the core problem in bulimia nervosa. It involves teaching people with bulimia nervosa new skills to regulate negative emotions and replace dysfunctional behavior. A typical course of treatment is 20 group sessions lasting 2 hours once a week. (See Behavioral Therapy.)

**Disordered Eating** Term used to describe any atypical eating behavior.

**Drunkorexia** Behaviors that include any or all of the following: replacing food consumption with excessive alcohol consumption; consuming food along with sufficient amounts of alcohol to induce vomiting as a method of purging and numbing feelings.

**DSM-IV** The fourth (and most current as of 2006) edition of the *Diagnostic and Statistical Manual for Mental Disorders IV* published by the American Psychiatric Association (APA). This manual lists mental diseases, conditions, and disorders, and also lists the criteria established by APA to diagnose them. Several different eating disorders are listed in the manual, including bulimia nervosa.

**DSM-IV Diagnostic Criteria** A list of symptoms in the *Diagnostic and Statistical Manual for Mental Disorders IV* published by APA. The criteria describe the features of the mental diseases and disorders listed in the manual. For a particular mental disorder to be diagnosed in an individual, the individual must exhibit the symptoms listed in the criteria for that disorder. Many health plans require that a DSM-IV diagnosis be made by a qualified clinician before approving benefits for a patient seeking treatment for a mental disorder such as anorexia or bulimia.

**DSM-IV-R Diagnostic Criteria** Criteria in the revised edition of the DSM-IV used to diagnose mental disorders.

**Dual Diagnosis** Two mental health disorders in a patient at the same time, as diagnosed by a clinician. For example, a patient may be given a diagnosis of both bulimia nervosa and obsessive-compulsive disorder or anorexia and major depressive disorder.

**Eating Disorders Anonymous (EDA)** A fellowship of individuals who share their experiences with each other to try to solve common problems and help each other recover from their eating disorders.

**Eating Disorders Not Otherwise Specified (ED-NOS)** Any disorder of eating that does not meet the criteria for anorexia nervosa or bulimic nervosa.

**Eating Disorder Inventory (EDI)** A self-report test that clinicians use with patients to diagnose specific eating disorders and determine the severity of a patient's condition.

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**Eating Disorder Inventory-2 (EDI-2)** Second edition of the EDI.

**Ed Slang** Eating disorder.

**ED** Acronym for eating disorder.

**Electrolyte Imbalance** A physical condition that occurs when ionized salt concentrations (commonly sodium and potassium) are at abnormal levels in the body. This condition can occur as a side effect of some bulimic compensatory behaviors, such as vomiting.

**Emetic** A class of drugs that induces vomiting. Emetics may be used as part of a bulimic compensatory behavior to induce vomiting after a binge eating episode.

**Enema** The injection of fluid into the rectum for the purpose of cleansing the bowel. Enemas may be used as a bulimic compensatory behavior to purge after a binge eating episode.

**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 and Response Prevention (ERP)** A type of behavior therapy strategy that is based on the theory that purging serves to decrease the anxiety associated with eating. Purging is therefore negatively reinforced via anxiety reduction. The goal of ERP is to modify the association between anxiety and purging by preventing purging following eating until the anxiety associated with eating subsides. (See 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 waves his/her fingers back and forth in front of the patient's eyes, and the patient tracks the movements while also focusing on a traumatic event. It is thought that the act of tracking while concentrating allows a different level of processing 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 a nuclear 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 therapy tends to be short-term, usually lasting only a few months, although it can last longer depending on the family circumstances.

**Guided Imagery** A technique in which the patient is directed by a person (either in person or by using a tape recording) to relax and imagine certain images and scenes to promote relaxation, promote changes in attitude or behavior, and encourage physical healing. Guided imagery is sometimes called visualization. Sometimes music is used as background noise during the imagery session. (See Alternative Therapy.)

## NEDA TOOLKIT for Parents

**Health Insurance Portability and Accountability Act (HIPAA)** A federal law enacted in 1996 with a number of provisions intended to ensure certain consumer health insurance protections for working Americans and their families and standards for electronic health information and protect privacy of individuals' health information. HIPAA applies to three types of health insurance coverage: group health plans, individual health insurance, and comparable coverage through a high-risk pool. HIPAA may lower a person's chance of losing existing coverage, ease the ability to switch health plans, and/or help a person buy coverage on his/her own if a person loses employer coverage and has no other coverage available.

**Health Insurance Reform for Consumers** Federal law has provided to consumers some valuable—though limited—protections when obtaining, changing, or continuing health insurance. Understanding these protections, as well as laws in the state in which one resides, can help with making more informed choices when work situations change or when changing health coverage or accessing care. Three important federal laws that can affect coverage and access to care for people with eating disorders are listed below. More information is available at: [http://www.cms.hhs.gov/HealthInsReformforConsumers/01\\_Overview.asp#TopOfPage](http://www.cms.hhs.gov/HealthInsReformforConsumers/01_Overview.asp#TopOfPage)

- Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA)
- Health Insurance Portability and Accountability Act of 1996 (HIPAA);
- Mental Health Parity Act of 1996 (MHPA).

**Health Maintenance Organization (HMO)** A health plan that employs or contracts with primary care physicians to write referrals for all care that covered patients obtain from specialists in a network of healthcare providers with whom the HMO contracts. The patient's choice of treatment providers is usually limited.

**Hematemesis** The vomiting of blood.

**Hypno-behavioral Therapy** A type of behavioral therapy that uses a combination of behavioral techniques such as self-monitoring to change maladaptive eating disorders and hypnotic techniques intended to reinforce and encourage behavior change.

**Hypoglycemia** An abnormally low concentration of glucose in the blood.

**In-network benefits** Health insurance benefits that a beneficiary is entitled to receive from a designated group (network) of healthcare providers. The "network" is established by the health insurer that contracts with certain providers to provide care for beneficiaries within that network.

**Indemnity Insurance** A health insurance plan that reimburses the member or healthcare provider on a fee-for-service basis, usually at a rate lower than the actual charges for services rendered, and often after a deductible has been satisfied by the insured.

**Independent Living Services** Services for a person with a medical or mental health-related problem who is living on his/ her own. Services include therapeutic group homes, supervised apartment living, monitoring the person's compliance with prescribed mental and medical treatment plans, and job placement.

**Intake Screening** An interview conducted by health service providers when a patient is admitted to a hospital or treatment program.

**International Classification of Diseases (ICD-10)** The World Health Organization lists international standards used to diagnose and classify diseases. The listing is used by the healthcare system so clinicians can assign an ICD code to submit claims to insurers for reimbursement for services for treating various medical and mental health conditions in patients. The code is periodically updated to reflect changes in classifications of disease or to add new disorders.

**Interpersonal Therapy (IPT)** IPT (also called interpersonal psychotherapy) is designed to help people 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 will enable 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.

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**Ketosis** A condition characterized by an abnormally elevated concentration of ketones in the body tissues and fluids, which can be caused by starvation. It is a complication of diabetes, starvation, and alcoholism.

**Level of Care** The care setting and intensity of care that a patient is receiving (e.g., inpatient hospital, outpatient hospital, outpatient residential, intensive outpatient, residential). Health plans and insurance companies correlate their payment structures to the level of care being provided and also map a patient's eligibility for a particular level of care to the patient's medical/ psychological status.

**Major Depression** See Major Depressive Disorder.

**Major Depressive Disorder** A condition that is characterized by one or more major depressive episodes that consist of periods of two or more weeks during which a patient has either a depressed mood or loss of interest or pleasure in nearly all activities. (See Depression)

**Mallory-Weiss Tear** One or more slit-like tears in the mucosa at the lower end of the esophagus as a result of severe vomiting.

**Mandometer Therapy** Treatment program for eating disorders based on the idea that psychiatric symptoms of people with eating disorders emerge as a result of poor nutrition and are not a cause of the eating disorder. A Mandometer is a computer that measures food intake and is used to determine a course of therapy.

**Mandates** See State Mandates.

**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 an eating disorder.

**Maudsley Method** A family-centered treatment program with three distinct phases. The first phase for a patient who is severely underweight is to regain control of eating habits and break the cycle of starvation or binge eating and purging. The second phase begins once the patient's eating is under control with a goal of returning independent eating to the patient. The goal of the third and final phase is to address the broader concerns of the patient's development.

**Mealtime Support Therapy** Treatment program developed to help patients with eating disorders eat healthfully and with less emotional upset.

**Mental Health Parity Laws** Federal and State laws that require health insurers to provide the same level of healthcare benefits for mental disorders and conditions as they do for medical disorders and conditions. For example, the federal Mental Health Parity Act of 1996 (MHPA) may prevent a group health plan from placing annual or lifetime dollar limits on mental health benefits that are lower, or less favorable, than annual or lifetime dollar limits for medical and surgical benefits offered under the plan.

**Mia Slang.** For bulimia or bulimic.

**Modified Cyclic Antidepressants** A class of medications used to treat depression.

**Monoamine Oxidase Inhibitors** A class of medications used to treat depression.

**Mood Disorders** Mental disorders characterized by periods of depression, sometimes alternating with periods of elevated mood. People with mood disorders suffer from severe or prolonged mood states that disrupt daily functioning. Among the general mood disorders classified in the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)* are major depressive disorder, bipolar disorder, and dysthymia. (See Anxiety and Major Depressive Disorder)

**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.

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**Motivational Enhancement Therapy (MET)** A treatment is 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.

**Nonpurging** Any of a number of behaviors engaged in by a person with bulimia nervosa to offset potential weight gain from excessive calorie intake from binge eating. Nonpurging can take the form of excessive exercise, misuse of insulin by people with diabetes, or long periods of fasting.

**Nutritional Therapy** Therapy that provides patients with information on the effects of their eating disorder. For example, therapy often includes, as appropriate, techniques to avoid binge eating and refeed, and advice about making meals and eating. The goals of nutrition therapy for individuals with anorexia and bulimia nervosa differ according to the disorder. With bulimia, for example, goals are to stabilize blood sugar levels, help individuals maintain a diet that provides them with enough nutrients, and help restore gastrointestinal health.

**Obsessive-compulsive Disorder (OCD)** Mental disorder in which recurrent thoughts, impulses, or images cause inappropriate anxiety and distress, followed by acts that the sufferer feels compelled to perform to alleviate this anxiety. Criteria for mood disorder diagnoses can be found in the DSM-IV.

**Opioid Antagonists** A type of drug therapy that interferes with the brain’s opioid receptors and is sometimes used to treat eating disorders.

**Orthorexia Nervosa** An eating disorder in which a person obsesses about eating only “pure” and healthy food to such an extent that it interferes with the person’s life. This disorder is not a diagnosis listed in the DSM-IV.

**Osteoporosis** A condition characterized by a decrease in bone mass with decreased density and enlargement of bone spaces, thus producing porosity and brittleness. This can sometimes be a complication of an eating disorder, including bulimia nervosa and anorexia nervosa.

**Out-of-network benefits** Healthcare obtained by a beneficiary from providers (hospitals, clinicians, etc.) that are outside the network that the insurance company has assigned to that beneficiary. Benefits obtained outside the designated network are usually reimbursed at a lower rate. In other words, beneficiaries share more of the cost of care when obtaining that care “out of network” unless the insurance company has given the beneficiary special written authorization to go out of network.

**Parity Equality** (see Mental Health Parity Laws).

**Partial Hospitalization (Intensive Outpatient)** For a patient with an eating disorder, partial hospitalization is a time-limited, structured program of psychotherapy and other therapeutic services provided through an outpatient hospital or community mental health center. The goal is to resolve or stabilize an acute episode of mental/behavioral illness.

**Peptic Esophagitis** Inflammation of the esophagus caused by reflux of stomach contents and acid.

**Pharmacotherapy** Treatment of a disease or condition using clinician-prescribed drugs.

**Phenethylamine Monoamine Reuptake Inhibitors** A class of drugs used to treat depression.

**Pre-existing Condition** A health problem that existed or was treated before the effective date of one’s health insurance policy.

**Provider** A healthcare facility (e.g., hospital, residential treatment center), doctor, nurse, therapist, social worker, or other professional who provides care to a patient.

**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.

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**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 mental material and processes into full consciousness so that the patient can gain more control over his/her life.

**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.

**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.

**Psychopathological Rating Scale Self-Rating Scale for Affective Syndromes (CPRS-SA)** A test used to estimate the severity of depression, anxiety, and obsession in an individual.

**Psychopharmacotherapy** Use of drugs for treatment of a mental or emotional disorder.

**Psychotherapy** The treatment of mental and emotional disorders through the use of psychologic techniques (some of which are described below) designed to encourage communication of conflicts and insight into problems, with the goal being relief of symptoms, changes in behavior leading to improved social and vocational functioning, and personality growth.

**Purging** To evacuate the contents of the stomach or bowels by any of several means. In bulimia, purging is used to compensate for excessive food intake. Methods of purging include vomiting, enemas, and excessive exercise.

**Recovery Retreat** See Residential Treatment Center.

**Relaxation Training** A technique involving tightly contracting and releasing muscles with the intent to release or reduce stress.

**Remission** A period in which the symptoms of a disease are absent. Remission differs from the concept of “cure” in that the disease can return. The term “cure” signifies that the treated condition or disorder is permanently gone, never to return in the individual who received treatment.

**Residential Services** Services delivered in a structured residence other than the hospital or a client’s home.

**Residential Treatment Center** A 24-hour residential environment outside the home that includes 24-hour provision or access to support personnel capable of meeting the client’s needs.

**Selective Serotonin Reuptake Inhibitors (SSRI)** A class of antidepressants used to treat depression, anxiety disorders, and some personality disorders. These drugs are designed to elevate the level of the neurotransmitter serotonin. A low level of serotonin is currently seen as one of several neurochemical symptoms of depression. Low levels of serotonin in turn can be caused by an anxiety disorder, because serotonin is needed to metabolize stress hormones.

**Self-directedness** A personality trait that comprises self-confidence, reliability, responsibility, resourcefulness, and goal orientation.

**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.

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**Self Psychology** A type of psychoanalysis that views anorexia and bulimia as specific cases of pathology of the self. According to this viewpoint, for example, people with bulimia nervosa 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 bulimia give up their pathological preference for food as a self-object and begin to rely on human beings as selfobjects, beginning with their therapist.

**Self-report Measures** An itemized written test in which a person rates his/her feeling towards each question; the test is designed to categorize the personality or behavior of the person.

**State Mandate** A proclamation, order, or law from a state legislature that issues specific instructions or regulations. Many states have issued mandates pertaining to coverage of mental health benefits and specific disorders the state requires insurers to cover.

**Substance Abuse** Use of a mood or behavior-altering substance in a maladaptive pattern resulting in significant impairment or distress of the user.

**Substance Use Disorders** The fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)* defines a substance use disorder as a maladaptive pattern of substance use leading to clinically significant impairment or distress, as manifested by one (or more) of the following, occurring within a 12-month period: (1) Recurrent substance use resulting in a failure to fulfill major role obligations at work, school, or home; (2) Recurrent substance use in situations in which it is physically hazardous; and (3) Recurrent substance-related legal, social, and/ or interpersonal problems.

**Subthreshold Eating Disorder** Condition in which a person exhibits disordered eating but not to the extent that it fulfills all the criteria for diagnosis of an eating disorder.

**Supportive Residential Services** See Residential Treatment Center.

**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.

**Tetracyclics** A class of drugs used to treat depression.

**Therapeutic Foster Care** A foster care program in which youths who cannot live at home are placed in homes with foster parents who have been trained to provide a structured environment that supports the child's learning, social, and emotional skills.

**Thinspiration Slang** Photographs, poems, or any other stimulus that influences a person to strive to lose weight.

**Third-party Payer** An organization that provides health insurance benefits and reimburses for care for beneficiaries.

**Thyroid Medication Abuse** Excessive use or misuse of drugs used to treat thyroid conditions; a side effect of these drugs is weight loss.

**Treatment Plan** A multidisciplinary care plan for each beneficiary in active case management. It includes specific services to be delivered, the frequency of services, expected duration, community resources, all funding options, treatment goals, and assessment of the beneficiary environment. The plan is updated monthly and modified when appropriate.

**Tricyclic Antidepressants** A class of drugs used to treat depression.

**Trigger** A stimulus that causes an involuntary reflex behavior. A trigger may cause a recovering person with bulimia to engage in bulimic behavior again.

**Usual and Customary Fee** An insurance term that indicates the amount the insurance company will reimburse for a particular service or procedure. This amount is often less than the amount charged by the service provider.

**Vocational Services** Programs that teach skills needed for self-sufficiency.

**Yoga** A system of physical postures, breathing techniques, and meditation practices to promote bodily or mental control and well-being.

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### Why parent-school communications may be difficult: Regulatory constraints and confidentiality issues

American School Counselor Association <http://www.schoolcounselor.org/content.asp?pl=325&sl=133&contentid=133>

ECRI Institute interviews with educators and parents of children with eating disorders

### Treatment settings and levels of care

ECRI Institute Bulimia Resource Guide <http://www.bulimiaguide.org>

### Questions to ask the care team at a facility

ECRI Institute Bulimia Resource Guide <http://www.bulimiaguide.org>

### Questions parents may want to ask treatment providers privately

ECRI Institute Bulimia Resource Guide <http://www.bulimiaguide.org>

ECRI Institute interviews with parents

## **NEDA TOOLKIT for Parents**

### **How to take care of yourself while caring for a loved one with an eating disorder**

Canadian National Eating Disorder Information Centre  
[www.nedic.ca/giveandgethelp/helpforfriendsfamily.shtml](http://www.nedic.ca/giveandgethelp/helpforfriendsfamily.shtml)

University of Florida, Institute of Food and Agricultural Sciences  
<http://edis.ifas.ufl.edu/FY872>

Anorexia nervosa and related eating disorders, Inc.  
[www.anred.com/prev.html](http://www.anred.com/prev.html)

### **Confidentiality Issues**

ECRI Institute Bulimia Resource Guide  
<http://www.bulimiaguide.org>

### **COBRA rights checklist**

U.S. Department of Labor [www.dol.gov](http://www.dol.gov)

ECRI Institute Bulimia Resource Guide  
<http://www.bulimiaguide.org>

### **Sample letters to use with insurance companies**

National Eating Disorders Association member families

### **How to manage an appeals process**

ECRI Institute Bulimia Resource Guide  
<http://www.bulimiaguide.org>