Authors:

Tracie L. Pasold, Ph.D.
Assistant Professor of Counseling and Psychology
Marywood University
Scranton, PA 18509

Maria G. Portilla, M.D.
Professor of Pediatrics, University of Arkansas for Medical Sciences
Medical Director, Child and Adolescent Eating Disorder Program,
Arkansas Children’s Hospital, Little Rock, AR

We hope this guide will promote knowledge, understanding, and identification of eating disorders and ultimately provide useful guidance to patients and families.

Peer Reviewed by:

S. Todd Callahan, M.D., M.P.H
Associate Professor of Pediatrics
Medical Director, Eating Disorders Program
Vanderbilt University
Monroe Carell Jr. Children’s Hospital
Nashville, TN

Robyn Mehlenbeck, PhD
Clinical Associate Professor
Director of Center for Psychological Services
George Mason University
Fairfax, VA

2015 Revised with permission by:

Jessica Moore, MD
Professor of Pediatrics, University of Arkansas for Medical Sciences
Medical Director, Child and Adolescent Eating Disorder Program,
Arkansas Children’s Hospital, Little Rock, AR

Jen Freilino, LPC
Contents

I. Prevention…4
II. General Information About Eating Disorders…5
   Epidemiology of Eating Disorders…5
   Mortality of Eating Disorders…5
   Co-Morbidities of Eating Disorders…5
III. Contributing Factors to the Development of Eating Disorders: Major Risk Factors…6
   Gender…6
   Puberty…6
   Brain Chemistry…6
   Genetics…6
   Personality and Temperament…7
   Society and Media…8
   Race and Socioeconomic Status…8
   Dieting…8
   Sports…9
   Family Relationships/Functioning…9
   Family attitudes…9
   Peer influence…10
   Trauma…10
IV. Eating Disorder Signs and Symptoms…11
V. Making the Diagnosis…12
VI. Eating Disorders Treatment…13
   The Multidisciplinary Approach to Treatment…13
   Components of a Multidisciplinary Treatment Program…14
   Individual Psychotherapy…14
   Group Psychotherapy…14
   Parent support group…15
   The Psychotherapist…15
   Medical Monitoring and Nutritional Support…16
   The Medical Doctor…16
      Physical Signs and Symptoms – Anorexia…16
      Physical Signs and Symptoms – Bulimia…17
   The Dietitian…18
   Nutritional Vocabulary…19
   Medications/Psychiatry…20
VII. Important Information Regarding Treatment and Recovery…21
VIII. Information to Promote Understanding that May Support the Eating Disorder Recovery Process…22
      Maintain Live Outside of the Eating Disorder…22
      Do not Blame Yourself or your Child…22
      Maintain Healthy Boundaries…23
      Tips on How to Manage food in the Home…25
      Understanding the Level of Motivation for Change…26
      The Impact of Family Style…28
      Recommendations that may Promote Health Family Functioning…30
IX. The Road to Recovery…31
X. Informative Resources for Patients and Families…32
XI. References…33
Prevention

Eating disorders are very serious illnesses that have a very high death rate. They are becoming increasingly more common across the nation as well as internationally, affecting younger children, males, and all ethnic and socioeconomic groups. Efforts to prevent eating disorders have been ongoing. Below are some suggestions for parents that can aid in preventing the development of an eating disorder.

- Make every effort to model healthy eating, body acceptance, and appropriate expression of emotions
- Have family meals together that are relaxing, enjoyable, and promote communication
- **Teach maintenance of healthy boundaries (healthy limits on number of extracurricular activities and sports)**
- Engage in social activities with your child or adolescent that are both nonphysical (e.g., board games) as well as physical in nature.
- Teach critical thinking that will improve skills in analyzing messages from media, TV, magazines, etc.
- Focus on healthy self-esteem building by paying attention to personality qualities and other “inner” strengths rather than physical appearance
General Information about Eating Disorders

Epidemiology of Eating Disorders (who can get an eating disorder):
- Female to Male ratio 10 to 1 - studies show likely closer to 25%
- Anorexia: up to 4% of population
- Bulimia: up to 5% of population
- All ethnic groups
- Across Socio-economic status
- Children as young as age six

Mortality of Eating Disorders:
- Eating disorders have the *highest* death rate of all psychiatric illnesses
- Up to 22% of patients die from eating disorders
  - One out of every five people with anorexia eventually die of causes related to the disorder
  - Suicide is the most common cause of death
  - A person with anorexia is 56 times more likely to commit suicide
  - Medical complications can also result in death, most commonly due to heart problems
- Individuals at highest risk of death:
  - Significantly underweight or underweight for prolonged period of time
  - Very frequent and prolonged vomiting or laxative use
  - Prolonged illness

Co-morbidities of Eating Disorders - Eating Disorders are often accompanied by:
- Depression
- Anxiety
- Obsessive-Compulsive Disorder
- Substance abuse
- High risk behaviors
- Self-harming behaviors
- Personality disorders


Contributing Factors to the Development of Eating Disorders:

Major Risk Factors

**Gender:**
Gender is a risk factor to developing an eating disorder with females being at higher risk compared to males.
- Greater pressure on females to be thin
- Biological and hormonal factors predispose females to being more likely to develop an eating disorder
- Dieting behaviors (a risk factor) more common among females
- It is important to know that males GET eating disorders

**Puberty:**
Onset of puberty is the most common period of onset of an eating disorder with the associated changes that take place during puberty possibly triggering an eating disorder in individuals who may be at risk of developing an eating disorder.
- Emotional stress results from hormonal and physical changes in the body
- Biological changes brought about by hormonal changes can trigger onset of eating disorder
- Fears of becoming an adult; wanting to remain a child

**Brain Chemistry:**
Significant differences have been found to exist in the brains of individuals with eating disorders.
- Serotonin, which controls mood and anxiety, is low in individuals with eating disorders which suggests that this may be a risk factor or trigger for an eating disorder
- Brain research has identified differences in global and localized brain activity in specific regions of brain of those who have eating disorders

**Genetics:**
Research is illustrating a strong genetic basis for eating disorders.
- Familial history of eating disorders significantly increases risk
- Inheritance of certain personality/temperament traits or other psychiatric disorders increases risk
**Personality and Temperament:**
Research has identified certain personality traits and thinking styles to exist more frequently in patients with eating disorders.
Two groups of personality and temperament are described:

- **Anxious, fearful, harm avoidant personality/temperament**
  - Anxiety symptoms common
  - Shy – social anxiety
  - Obsessive and compulsive
  - Orderly, likes structure
  - Low self-esteem
  - Perfectionist
  - Achievement oriented, wants to be the best at everything
  - All or nothing thinking, rigid and inflexible thinking
  - People-pleasing
  - Harm avoidant, cautious, avoids risk

- **Dramatic-erratic novelty seeking personality/temperament**
  - Impulsive
  - Chaotic
  - Strong mood swings
  - Easily bored
  - Extroverted
  - Argumentative, Oppositional
  - Seeks out stimulation but is overwhelmed by it
  - Risk-taking
  - Personality Disorders common
**Society and Media:**
Society tends to communicate negative and unrealistic messages regarding standards for beauty and these messages can trigger behaviors that lead to an eating disorder in individuals at risk.

- Being thin is thought to be the same as beauty, being smart, being successful
- Being overweight is thought to be the same as being out of control, not smart, unsuccessful, lazy
- Societal messages promote dieting, especially now with social media

**Race and Socioeconomic Status (SES):**
Eating disorders affect individuals from all ethnicity and socioeconomic groups.

- Recent research demonstrates that eating disorders do not discriminate in any way with increasing numbers of patients developing eating disorders who are of different races and social classes
- Latinos living in US have higher rates of eating disorders than those living most of their lives in native country
- Binge eating and purging are more common eating disorder behaviors among Latinos
- Blacks are at increased risk for body image dissatisfaction and bulimia
- People from minority groups often do not seek treatment

**Dieting:**
Going on a diet has been found to be the greatest trigger for developing an eating disorder

- Dieting increases the chances of developing an eating disorder by 5 or more times
- Dieting leads to chemical changes in the brain that may increase the chances of developing an eating disorder
- Dieting also leads to other biological and hormonal changes that can trigger an eating disorder
**Sports as a Risk Factor:**
Participation in certain sports increases the risk of developing an eating disorder (4 to 25 times higher risk) among individuals who are at risk. The following are a few of the sports that have been identified as potential triggers for eating disordered behaviors:

- Cross Country
- Track/Running
- Wrestling
- Gymnastics
- Dance
- Cheerleading
- Ballet

**Family Relationships/Functioning:**
Poor family interactions and family stress are risk factors for developing an eating disorder. However, keep in mind that:

- Not all individuals with eating disorders come from dysfunctional families
- Family dysfunction does not automatically trigger an eating disorder

**Family Attitudes as a risk factor:**
Parents sometimes (without meaning to) focus on thinness and appearance and this can trigger eating disordered behaviors:

- Modeling negative eating behaviors (e.g., dieting, avoiding food groups)
- Expressing negative attitudes about own body and body of others
- Expressing negative attitudes towards the child’s weight, shape, appearance, and diet

Studies have found that parents of children with eating disorders:

- Often have a history of dieting themselves
- Worry much more about body shape and weight than do parents of children who do not suffer from eating problems.
**Peer Influence as a risk factor:**
The teenage years include placing high value on friends, appearances, and acceptance.

- Peer influence found to increase risk of developing an eating disorder
  - Having friends with excessive concern with body image, weight, and dieting increases risk of doing the same behaviors

**Trauma or Distressing Experiences can Trigger an Eating Disorder:**
A traumatic experience includes anything that a person finds very distressing, such as a major life-change, injury, loss of parent/friend/pet, relocation, sexual or physical abuse or neglect.

- History of teasing about how a person looks can trigger an eating disorder
  - Teasing about appearance can have long-term effects on body image
  - Teasing about appearance has been linked to dieting and weight loss, which can trigger an eating disorder
- Research shows that individuals with eating disorders are more likely to have a history of traumatic experiences
  - Trauma increases chances of developing a wide range of emotional and behavioral issues which increase risk of developing an eating disorder
Eating Disorder Signs and Symptoms

Warning Signs:

The following is a list of signs of a possible eating disorder:

- Constant thoughts about body size and weight
- Dieting, fasting, skipping meals
- Reducing portions or serving sizes of foods
- Avoiding certain food groups (fat, protein, carbohydrates)
- Excessive reading food labels, counting calories
- Avoiding foods that used to be enjoyed
- Eating the same foods, following strict diet, every day
- Avoiding eating in front of others
- Avoiding situations that may involve eating
- Isolating from family and friends
- Unusual food behaviors such as counting bites, chewing food a certain number of times, having to eat at certain times, arranging and eating foods in a certain order, pushing food around on plate and not eating it
- Feeling guilty or ashamed after eating
- Chewing food and spitting it out
- Obsessing about food (e.g., cooking a lot but not eating the food, reading cookbooks, excessive watching of food shows on T.V)
- Excessive exercise to get rid of calories
- Evidence of overeating large amounts of food (large amounts of food missing; empty boxes, cans, food packages)
- Signs of purging (soiled toilet, use of bathroom after eating, running water while using bathroom)
- Weight loss or constant focus on trying to lose weight
- Excessive fears of becoming fat
- Excessive weighing self
- Wearing baggy clothing
- Often comparing body size and shape to others
- Focusing on the eating habits of others
- Irregular menstrual periods or suddenly not having menstrual periods
- Excessive concern about size of clothing (wants to wear only certain size)
- Excessive viewing of body in mirrors or avoidance of viewing self in mirrors
- Extreme dislike/criticism of all or some body parts
Making the Diagnosis

The patient’s diagnosis is made using the diagnostic criteria for eating disorders described in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, (DSM-5). The criteria for the eating disorders treated in our clinic are listed below:

Diagnostic Criteria for Anorexia Nervosa:
All of the following criteria must be met for the diagnosis of Anorexia Nervosa to be made:
- Weight for Below normal range for age, sex, and development due to restriction of intake
- Intense fear of gaining weight or becoming fat
- Body image distortion, weight or body shape very strongly determine self-esteem, or denial of seriousness of current low weight
- May binge/purge along with restricting

Diagnostic Criteria for Bulimia Nervosa:
All of the following criteria must be met for the diagnosis of Bulimia Nervosa to be made:
- Episodes of Binge eating
- Inappropriate compensatory behavior to prevent weight gain (vomiting, laxative abuse, diuretic abuse, use of enemas or other medications, fasting, and excessive exercise)
- Binge eating and inappropriate compensatory behaviors both occur at least one time a week for a period of three months
- Body shape and/or weight very strongly determine self-esteem or self-evaluation

Diagnostic Criteria for Other Specified Eating Disorder:
Disordered eating and body image issues are present and clinically significant; however:
- Atypical Anorexia Nervosa: normal weight but all thoughts and behaviors consistent with Anorexia Nervosa
- Purging Disorder
- Sub threshold Bulimia Nervosa: Binge/purge activity occurs less than once a week or for less than three months
- There are other eating disorders without body image distortion or concerns.
Eating Disorders Treatment

The Multidisciplinary Approach to Treatment

The multidisciplinary treatment approach to eating disorders is thought to be the most effective way to help patients on the path to recovery from an eating disorder. Members of a multidisciplinary treatment team typically include a pediatrician (MD), a psychologist (PhD), master’s degree therapists, and registered dietitians. Treatment typically includes individual therapy, family therapy, group therapy, medical monitoring, and nutritional support. A comprehensive approach to wellness might include goals for healthy eating, healthy weight, a positive self esteem and body image, as well as healthy coping and a balanced lifestyle. Because an eating disorder is a mental illness, therapy is the most essential component to recovery. Frequency of medical monitoring and nutritional support appointments are decided upon at each medical visit and are based on need. With patient and family involvement and compliance with the treatment protocol, recovery from an eating disorder is possible.

The family is also a vital part of the treatment team. Parents play a crucial role in supporting their child’s recovery by helping their child to follow through with recommendations made by the physician, dietitian, and therapist. Treatment team members will engage in ongoing, collaborative, and detailed discussion with the parents and the patient about the involvement of parents in the treatment and recovery process.
Components of a Multidisciplinary Treatment Program

**Individual Psychotherapy**
Individual psychotherapy is the *most important* component of treatment of an eating disorder. Frequency of these sessions is determined by patient needs and may change with progress in treatment. Therapy focuses on thinking patterns, body image, self-esteem, and general coping skills, among other issues related to the eating disorder. Treatment interventions are typically based on research which shows what is beneficial in promoting recovery. Evidence-based practices, which are treatment interventions that have been researched to be effective in treatment of eating disorders, are recommended. Therapists may include ideas and methods from Cognitive-Behavioral Therapy, Dialectical Behavior Therapy, Acceptance and Commitment Therapy, and Family-Based Treatment (Maudsley) approaches.

**Group Psychotherapy**
Research has consistently demonstrated group therapy to be a valuable addition to individual treatment. Parents are sometimes concerned that their child will learn new or additional negative behaviors related to eating through their participation in group. Parents should be aware that the group leader provides structure and guides the group process, putting effort into maintaining healthy group activities and discussion. Group sessions typically include discussion of common issues surrounding eating disorders, support, and understanding from others who are suffering with similar issues. Planned learning activities are also part of group treatment. Group therapy helps patients learn about themselves. Unsupervised group meetings or getting together outside of the formal group is not recommended.
Parent Support Group

Parent support groups are sometimes available to parents and other family members. These groups typically include an educational component and a supportive environment. Feedback obtained from parents and patients regarding their involvement in a parent support group have consistently indicated the positive impact of the parents’ attendance in the parent support group on both the patient and the family.

The Psychotherapist

Eating disorders have the highest death rate of all mental illnesses. The cause of an eating disorder tends to be due to several factors and very complex. Eating disorders are more about existing emotional and/or behavioral problems and difficulty coping and not all about food or thinness. The food and weight issues have developed as a way to cope. Eating behaviors and related obsessions tend to help the patient to cope with stress and other emotional symptoms. The child or adolescent is using eating behaviors to express and alleviate emotions and possibly to feel more in control when her/his life seems out of control. A person with an eating disorder may not be aware of existing emotional issues that are driving their eating behaviors and may truly believe that it is all about being thin. However, existing personality characteristics and several emotional symptoms are typically underlying the eating issues. Some of these emotional symptoms include feeling inadequate; low self-esteem; anger; resentment; depression; loneliness/social isolation; family issues; anxiety; dependence; and perfectionism. The underlying psychological issues need to be addressed in order for recovery from an eating disorder to happen. Psychological treatment is the most important component of treatment of and recovery from an eating disorder.

The Psychotherapist works to help the patient to gain some insight and clarity into the underlying issues related to his/her eating disorder. Treatment plans are developed for each patient. The psychotherapy process consists of individual sessions with the patient. The therapist strives to: build and maintain rapport, maintain confidentiality, be nonjudgmental, and provide support and encouragement. These are necessary components in the treatment process that will help the patient explore emotions and face negative feelings and thinking patterns that drive the eating disorder. Therapy might explore: past and/or current problems or experiences; family issues; distortions in thinking; how personality/temperament affect life functioning; and building adaptive skills in identifying and coping with emotions. Family therapy sessions are also important and focus on addressing family issues and communication.

Common goals of therapy include addressing the symptoms and functions of the eating disorder:

- Behavior change regarding weight and food
- Body image distortions
- Problematic thinking patterns
- Interactions with others
- Emotional expression and positive coping
Medical Monitoring and Nutritional Support
Patients need to be regularly monitored by a medical professional and a dietitian to promote recovery. Frequency of medical monitoring and nutritional follow-up appointments are determined by necessity based on medical status and medical/nutritional needs.

The Medical Doctor
Eating disorders are serious and life-threatening. Medical monitoring is crucial to prevent or treat acute and chronic medical conditions. Eating disorders can affect all organs of the body. Below is a list of common problems caused by eating disorder behaviors.

Signs and Symptoms - Anorexia:

- Inadequate growth in height
- Poor weight gain or weight loss
- Lack of energy
- Dizziness and fainting
- Low heart rate, low blood pressure, low body temperature
- Cold intolerance (always feeling cold)
- Poor attention and concentration; short-term memory loss
- Brittle nails, dry skin, loss of scalp/body/pubic hair; development of lanugo (fine hair on back, arms, face, neck) as body attempts to keep warm
- Muscle wasting
- Heart problems:
  - Reduction in heart size which leads to slow heartbeat and inadequate oxygen supply to arms and legs which results in cold/blue/splotchy hands and feet
  - Irregular heart beat which could cause chest pain
  - Decrease in muscle mass can result in mitral valve prolapse (valve does not close properly resulting in blood leaking back into the heart)
  - Changes in the heart can lead to fatal arrhythmias
- Digestive system slows down and causes constipation, stomach aches, bloating as food sits in stomach longer
- Delayed puberty (lack of menstrual periods or regression); could lead to infertility
- Bone problems: osteopenia (decreased bone density); osteoporosis (significant bone loss), due to low levels of estrogen and calcium, as well as malnutrition. Low fat intake and malnutrition limits the body’s ability to make estrogen and stops menstrual periods. Bone loss continues until a healthy weight and menstrual cycles are restored. 90 percent of a person’s bone mass is developed by age 20. Oral contraceptives (birth control pills) containing estrogen are not indicated and will not help. When the patient’s body is healthy, it will produce enough estrogen to have a period.
- Blood values: leukopenia (low white blood count), anemia (low iron count)
- Lack of adequate fluids can cause dehydration
- Refeeding Syndrome: results from rapid re-feeding and sudden increase in calories and can cause heart failure, cardiac arrest, and seizures due to low magnesium and phosphate
**Signs and Symptoms: Bulimia:**

- Blood electrolyte imbalances which can lead to heart problems, possibly fatal
- Fluid imbalances – dehydration, swollen hands and feet
- Swollen salivary glands in the face
- Throat and esophageal problems (sore throat, mouth ulcers, reflux)
- Frequent vomiting for a long period of time can result in the development of pre-cancerous lesions
- Eye problems (burst blood vessels, retinal detachment)
- Digestive problems (heart burn; stomach pain; constipation; diarrhea; blood in vomit)
- Dental enamel erosion, development of cavities
- Calluses (irritation) on knuckles from friction of fingers against roof of mouth while trying to vomit
The Dietitian

Dietitians are qualified to provide nutritional services to patients with eating disorders and their families. They possess knowledge regarding a growing body’s nutritional needs. Additionally, they are well-informed and trained with regard to eating disorders. The primary goal of the dietitian is to help patients to return to and/or maintain a healthy weight through teaching healthy eating habits. The dietitian understands the emotional aspects of eating disorders. The dietitian will consider the patient’s ambivalence, fears, and anxieties regarding food and weight issues. The dietitian will work with the patient to develop an individualized meal plan that contains goals that will help her/him to regain healthy eating patterns. The patient determines the pace but is also offered encouragement to challenge her/himself.

Eating disorders do not result from lack of knowledge and/or education about healthy eating. Dietitians recognize that many patients are often well educated about the nutritional content of foods, including the calories, fat, sugar, and carbohydrate contents in food. However, the patient’s understanding of the amount of calories, fat, and carbohydrate that he/she needs may be inaccurate. The patient’s existing emotional needs make it difficult for her/him to be able to consider accurate facts about healthy eating and to admit their current unhealthy eating habits. The patient needs to learn that the body’s healthy functioning requires all nutrients, including fat and carbohydrates. The dietitian aids in developing a healthier perspective on eating.

The dietitian is an advocate for the patient and the family. Our dietitians work with the patient and parent(s) to obtain each one’s perspective on the problem. The patient also works individually with the dietitian to support development of the ability to handle nutritional health responsibly and independently as she/he matures. The patient’s confidentiality is respected at the level appropriate for her/his age. Parents should be actively involved regarding the recommended meal plan so they can assist in the patient’s following of the plan.
**Nutritional Vocabulary:**

**Calorie** – a unit of energy released as the body breaks down food; the more calories in the food, the more energy for your body.

**Ideal body weight (IBW)** – desired healthy weight range determined by age, gender, body frame and growth history. In children and teens healthy weight ranges change with each month of age and as height changes.

**Set point** – the weight the body strives to maintain despite the number of calories taken in; the weight at which you are most healthy; below this weight, the chemical reactions in the body slow down, resulting in reduced muscle tone, body temperature, blood sugar, and the heart works below full capacity.

**Metabolic rate** – rate at which the body uses calories.

**Body mass index (BMI)** – a measurement of weight in relation to height. For children and teens BMI changes according to age and sex. For children, if BMI is high it may point to overweight or obesity. A low BMI points to underweight or malnutrition. However, BMI alone should not be used to make a diagnosis of overweight or underweight status. For example, a child may have a high BMI for age and sex, but this could be due to having more muscle mass rather than be overweight. To determine if excess fat is a problem, a health care provider would need to perform further tests. These tests might include measurements of the skin, evaluations of diet, physical activity, family history and other appropriate health screenings.

**Growth curve/growth chart** – Each patient’s weight, height, and BMI is marked on a growth chart at a certain age. As the child grows and gains weight these points should follow a “curve” to make sure he or she is following a normal and expected pattern of growth.

**The food guide pyramid** – a guideline for healthy diet; includes five food groups with minimum serving requirements from each group: grain, fruit, vegetable, dairy, and protein plus calorie needs from fats and sweets. The Dietary Guidelines give science-based advice on food and physical activity choices for health.
Medications/Psychiatry
No medications have been approved by the Federal Drug Administration (FDA) to treat eating disorders. Medications for anxiety and depression are sometimes prescribed to treat these symptoms. They have also helped some patients in reducing bingeing and purging episodes. Fluoxetine (Prozac) has been approved by the FDA as a medication that can help with reducing binge or purge behaviors. Medication use is usually temporary as it helps the patient with relief of symptoms. Medication becomes no longer needed as a patient learns skills and becomes more able to cope with stress and emotions in a healthy manner. Malnutrition itself can contribute to symptoms of depression and/or anxiety. Therefore, before initiating psychiatric medications, the eating disorder specialists focus on helping the patient gain weight to a normal range for their age and height.
Important Information Regarding Treatment and Recovery

The average duration of treatment for an eating disorder is two years. Recovery is very individualized with patients recovering at different rates. Some recover in less than two years while others require more than two years of treatment. Some patients are in and out of treatment throughout their lives. It is very difficult to determine what recovery will look like for each patient. Some patients recover fully and have no recurrence of the eating disorder while other patients recover but have periods of relapse during times of increased stress. There are also patients who never fully recover but struggle with symptoms at varying levels of severity throughout their lives.

The treatment team will work collaboratively with the patient and parents in deciding when a patient is ready for discharge from treatment. Treatment progress and medical, emotional and behavioral readiness for discharge will be regularly discussed with the patient and family. It is tempting for patients and their families to desire to leave the treatment program when the patient’s medical status has improved; however, it is important that the patient arrive at mental well-being before leaving treatment. Remember, psychotherapy is the most important treatment component in the recovery from an eating disorder.
Information to Promote Understanding That May Support the Eating Disorder Recovery Process

If your child or adolescent has an eating disorder, she/he has a serious psychiatric (mental) illness. Do not pretend that there is not a problem. Never view an eating disorder as just a phase that you do not need to be concerned about. Try to develop awareness of what might be maintaining the eating disorder symptoms and what you might be able to do to change, alleviate or eliminate them. The person suffering from an eating disorder might react with anger, opposition and irritability due to her/his experience of intense fears. The eating disorder is a source of comfort from these fears. Plans to treat the eating disorder can be frightening to the patient. To be supportive, focus on helping to alleviate the fears related to recovering from the eating disorder.

First and foremost, a parent can be supportive by putting effort into being a positive role model. Make every effort to avoid focusing too much on your own weight, body shape, dieting, or overemphasize the importance of appearance. These behaviors may lead to your child also focusing on body weight and shape and lead to or perpetuate unhealthy attitudes about food and eating. Increasing your knowledge of healthy eating and providing healthy balanced meals will improve your ability to educate your child, model healthy eating, and identify unhealthy eating in your child.

Maintain life outside of the eating disorder
Try to maintain as much of a normal life as possible despite the distress being caused by having a child with an eating disorder. Take care of your own emotional and physical health by finding healthy ways to handle your stress. Try to keep family functioning the way it was prior to the eating disorder. Maintain relationships and activities. Find ways to relax and have fun.

Do not blame yourself or your child
Blaming is often used as a way of finding answers about what caused the eating disorder. However, blaming does not provide answers. Blaming leads to anger, resentment and defensiveness and makes it difficult to be supportive. It also affects relationships and makes the current problems worse. Keep in mind that there is often not just one reason for someone to develop an eating disorder.

Tips on how to avoid blame:
- Do not get bogged down with trying to figure out what caused the eating disorder, experts do not even know exactly what causes each individual eating disorder to develop
- Take responsibility for your own worries
- Focus your efforts on healthy problem-solving
- Instead of negative thinking, try to be more positive or neutral
- Make every effort to respect another person’s right to make own choices and mistakes, make changes at own pace, and choose own coping style. Avoid trying to have too much control over these.
- Remember: acceptance is not the same as approval. Accepting another person’s choices does not mean you approve of her/his choices.
**Maintain healthy boundaries**

A boundary includes an individual’s personal (physical and emotional) space.

- Unhealthy boundaries/limits (enmeshment, being too involved) lead to negative emotions (anger, resentment, frustration) and exhaustion
  
- Avoid trying to control what you cannot control
  
  - Focus on what you can do rather than trying to control what someone else does

**Four Steps to Healthy Boundaries:**

1. Evaluate your role
2. Set limits
3. Develop healthy ways to communicate what you need
4. Maintain your boundaries/limits

**Step One: Evaluate your role:**

- Knowing what your role is helps in determining what you can do and what you cannot do
- Avoid doing things that might be detrimental or result in negative outcome:
  
  - Avoid trying to get your child to explain his/her motivations or intentions behind eating disordered behaviors
  
  - Do not try to forcefully stop your child from engaging in unhealthy behaviors
  
  - Avoid over-invading of privacy; it is ok for children to maintain an appropriate level of privacy
  
  - Monitoring of your child’s food consumption and caloric intake can be helpful but should be at the level that has been discussed with the patient and treatment team members

**Step Two: Set Limits:**

- Set limits based on what you actually have control over
  
  - You have control over your own behavior, time, money, what you will pay attention to, what you will talk about and how you handle conversation and conflict
  
  - Be aware of how eating disordered thinking may try to convince you of things
    
    - In conversation or conflict, state your different viewpoint and redirect the conversation
    
    - Avoid arguing with eating disordered thinking because it is irrational. You will not make any progress and will likely end up frustrated and mad

- Do not change normal routines to accommodate the demands of the eating disorder:
  
  - Maintain your usual eating routines; do not make a special meal in addition to the prepared meal because the eating disorder won’t eat the prepared meal (do not short-order cook to please the eating disorder); do not avoid eating out, but rather help your child plan what they might eat when going out; do not alter your diet to accommodate eating disorder diet

- Avoid enabling the eating disorder
  
  - Continue to expect to be treated respectfully; do not “walk on eggshells” for fear of upsetting the person and thus making the eating disorder worse

- Do not place limits or make changes in your schedule because you want to be available to monitor your child with the eating disorder
  
  - Do not give up things that are fulfilling to you and your family; try to avoid the eating disorder controlling family functioning, meals, outings. You need to maintain your own health in order to be supportive of others
Step Three: Develop healthy ways to communicate what you need:
- It is possible to show you are concerned and to be supportive without violating boundaries
- It is o.k. to say you are concerned about what you are observing and to clearly and calmly express your expectations; let your child know you are available to provide support; continue to do things that you and your child enjoy doing together; talk about feelings and thoughts and things that are important to each of you
- Avoid blaming or making demands
- Do not use rejection or guilt to manipulate

Step Four: Maintain your boundaries/limits:
- Maintain your limits and boundaries despite being faced with resistance and anger
- Do not give in to the eating disorder’s desperate attempts to get you to give in to its demands (“If you don’t _____, I won’t eat.”)
Tips on How to Manage Food in the Home

- Avoid getting into power struggles over food – trying to force your child to eat will likely cause conflict and bad feelings and may contribute to lying and secretive behaviors.

- Set limits and offer opinions, but try not to act as the “food police;” avoid nagging or yelling at your child to eat; also avoid constantly asking about how much he/she has eaten. Your child is being educated by the treatment team regarding her/his meal plan and is aware of what he/she needs to do to get better.

- Avoid attempting to help by “guessing” what might be supportive. Ask your child for advice about what you might be able to do that would be helpful to him/her. However, be careful not to follow eating disordered rules (i.e., “How can I help you?”).

- Have family meals together as often as possible. Meals should be a pleasant experience for everyone. Spend time during the meal communicating about each other’s daily activities. Conversations should avoid issues related to the eating disorder, as well as conflict, arguing, discussion of problems.

- Model eating as a healthy and enjoyable part of life. Avoid sending messages that may make a connection between food/eating and being a good or bad person. Avoid discussing foods as “good” “bad” “healthy” “unhealthy” or feeling “guilty” about eating a particular food, such as a dessert.

- Model and encourage healthy eating (three meals a day plus snacks, variety of foods from all food categories, healthy portions, all foods are o.k. to eat in moderation).
Understanding the Level of Motivation for Change

Your child’s level of motivation to recover from the eating disorder will be important to be aware of as you attempt to be supportive in his/her recovery. Their level of motivation will have an impact on the treatment process. Awareness of your child’s current stage of change will be important in how you approach supporting him/her. If you are unsure about what stage your child is in then assume that he/she is in an earlier stage than a later one. Keep in mind that your child may claim she/he is more ready for change than he/she really is in an attempt to please you or others. Encourage discussion about conflicting feelings regarding change and praise your child for any efforts made, even if it seems small. Many individuals move back and forth among the stages of change. Remember that you can be involved without pushing the person for change. Your expectations should be realistic. Avoid having unrealistic expectations regarding progress. Progress can be slow. Be patient with your child.

Two Psychologists/researchers, Prochaska and DiClemente, developed formal Stages of Change which are detailed below:

1. **Precontemplation** - not currently considering change, denial or unwillingness to accept a problem, see no benefits in change
2. **Contemplation** - awareness of problem, ambivalence/fear about change, weighing pros and cons, unprepared for change, not considering change within the next month
3. **Preparation** - Admit problem, not knowing how or what to do to change, openness to learning how to change, planning to act within one month
4. **Action** - actively working on change, readiness and learning, practicing new behavior for three to six months
5. **Maintenance** - continued commitment to new behavior, has taken action with increased ease towards change
6. **Relapse** - resumption of old behaviors

**Stage One: Precontemplation**

In this stage, the individual is not ready to consider the problem. He/she may tend to be defensive and make excuses and minimize the problems brought about by the eating disorder. The eating disorder is a way of coping which is why he/she does not want to change and prefers instead to just ignore the problems it causes.

How to be helpful if your child is in this stage:

- Realize that any efforts to push for change will result in increased defense of the disorder
- Avoid insisting, pushing, confronting, or intervening
- Express what you are concerned about and why in a brief and matter-of-fact manner. For example, “You seem upset or bothered about something. Is there anything wrong? What’s up? Is there anything I can do to help?” Your child may not want to talk about it and that is ok.

**Stage Two: Contemplation**

In this stage, the individual continues to not yet be ready to change. However, there is more awareness and/or acceptance that there might be a problem. The person is experiencing and struggling with conflicting feelings about whether the eating disorder really is a necessity to cope.
He/She may also be starting to worry about the consequences of the disorder. The continued ambivalence results in confusing behaviors.

How to be helpful if your child is in this stage:

- Listen and be supportive of the person’s thinking that is for positive change
- Help the person to think more in depth about the consequences of not changing
- With professional guidance, suggest books, articles, movies about their problem
- Provide ongoing reassurance of your concern and willingness and availability to be supportive and helpful

**Stage Three: Preparation**

In this stage, the person is beginning to accept that the eating disorder problems are more serious than the fears of changing. He/she is not yet ready to take action towards making changes; however, he/she is considering strategies for change and is open to suggestions and information about ways to change.

How to be helpful if your child is in this stage:

- Offer advice but continue to avoid pushing the person to take action
- Provide support without demanding change

**Stage Four: Action**

In this stage, the person has decided on a plan of action and is putting it into action.

How to be helpful if your child is in this stage:

- Be supportive of the action plan
- Avoid continued suggestions or advice
- Demonstrate care by asking how things are going but do not push for discussion

**Stage Five: Maintenance**

In this stage, the person is trying to continue to change and not lose the progress already made.

How to be helpful if your child is in this stage:

- Continue to offer support
- Show concern about how things are going and comment on observed efforts and changes made. When possible, find out what comments may be triggering for your child. For example, saying “you look healthier” or making other comments related to weight and appearance to someone who is struggling to recover from Anorexia can trigger a relapse.

**Stage Six: Relapse**

Relapse is very common and should be expected. Life stress and challenges (such as graduating, going to college, etc.) can sometimes make it difficult for a person to maintain progress and to continue his/her efforts towards making positive changes.

How to be supportive if your child has had a relapse:

- Be encouraging
- Remind them of the progress that has been made
- Encourage them to “do the next right thing” as part of getting back into recovery
- Make sure that the relapse is not viewed as a failure
- Encourage using the relapse as an opportunity for learning
The Impact of Family Style

Family functioning, including communication styles, emotional and behavioral functioning can be passed down through generations. Specific family characteristics have been identified in the literature to have an important role in the development of personal life struggles. Awareness of your own family’s style of functioning is beneficial because this information can aid in your family’s efforts to handle and alleviate problems in healthy ways. Three specific styles of family functioning include:

- Conflict-avoidant family
- High-achieving family
- Chaotic family

Conflict-Avoidant Family

In this style of family functioning, emotional expression tends to be limited and/or very controlled

- Outwardly, family members appear happy
- Disagreements, anger, sadness, etc., tend not to be expressed but are tightly controlled and hidden
- Open expression of emotions is not encouraged but discouraged
- Problems are left unresolved to avoid emotional confrontation
- Feelings of resentment, isolation, unhappiness and anger usually build up

The potential negative impact of this style of family functioning may include:

- Identification of emotions and healthy emotional expression is not learned
- The negative message is often sent that emotional expression is bad and a sign of weakness
- The limited communication can lead to misunderstandings and feeling alone and isolated
- May lead to the negative impression that family member’s feelings are not important or worth discussing
- Individuals may become very sensitive to potentially making others feel uncomfortable by discussing feelings
- Fears of expressing emotions or fears of being rejected may develop
- Poor or inadequate ways of coping may develop (e.g., eating disorders, substance abuse, self-harming behaviors)

High Achieving Family

In this style of family functioning, high expectations for achievement are communicated.

- Parents are often very successful and communicate an expectation of their children to also aim high
- Parents are often very disciplined, exercise personal control, impose high expectations of success; failure is not an option
- Children tend to put a lot of effort into meeting the parents’ expectations and struggle to do so
- Children tend to be very demanding of themselves
- Children tend to develop deep need to please
The potential negative impact of this style of family functioning may include:

- Disordered eating tends to develop as a means of expressing defiance or as a way of making up for perceived lack of self-discipline
- Overwhelmed by high expectations of parents, eating behaviors may develop as a means of obtaining control of something
- Child may begin to feel that achievements are more important than he/she is as a person
- Child struggles with identity development as he/she finds it difficult to figure out who he/she is beyond the accomplishments
- The child becomes unable to tolerate his/her own perceived imperfections
- The child may harbor feelings of anger or resentment towards parents
- Self-hatred may develop due to perceived inability to meet expectations

**Chaotic Family**

In this style of family functioning, communication tends to be inconsistent and family members tend to communicate through arguing

- Parents tend to often disagree and argue
- Parents tend to turn to the child for support
- Stressors, such as illness or death, divorce, substance abuse, may have put strain on family functioning
- Disordered eating may develop as a means of coping with internal chaos and/or trying to be in control of something when life feels out of control

The potential negative impact of this style of family functioning may include:

- The child may begin to isolate him/herself from family and to internalize stress and deny feelings in an effort to avoid more chaos
- The child often begins to act as the parent
- The child may try to cope with the issues by denying awareness of current state of family functioning and to view problematic behaviors as normal; convince him/herself that he/she is not affected by the stress
- Skills in healthy emotional expression are lacking
Recommendations that may Promote Healthy Family Functioning

- Communicate that you care and believe in your child
- Acknowledge the struggles that your child is experiencing
- Be reassuring to your child that even though you want to take control you will respect boundaries and not try to take over
- Let your child know that you are there to help whenever they should need your support
- Keep the lines of communication open. You can do this by asking general questions, “Do you need anything?” “Are you doing o.k.?” “You want to talk?”
- Avoid talking negatively about your own or someone else’s physical appearance or focusing on appearance when judging or describing others
- Display acceptance of your body. Do not criticize your own or anyone else’s body. Embrace people as coming in all shapes and sizes and focus on qualities inside a person as what really matters
- Openly recognize your child’s personality characteristics, skills, and talents rather than just his/her physical appearance
- Keep the lines of communication open with your child: when your child makes comments about his/her body, ask about what may be bothering him/her at that moment
- If your child is involved in sports, be aware of messages coaches may send – some may be unhealthy such as focusing on weight or demanding excessive training or exercise
- Be aware of symptoms of depression, anxiety
- Model healthy eating (balanced meals that include fat, carbohydrates, protein, fruits, vegetables, and dairy products) and exercise behaviors (avoid excessive exercise patterns or modeling of the need to exercise to burn calories)
- Instead of dieting, eat healthy balanced meals yourself unless you have an illness that requires dieting (diabetes, obesity, heart disease). If you need to be on a specific diet for medical reasons, don’t focus on that or on appearance. Try to avoid sharing the details of your specific dietary requirements with your child or adolescent. This could possibly encourage the child or adolescent to mimic your behaviors. Starvation, fasting, restricting or elimination of any entire food group is not healthy and can have serious medical consequences. A healthy diet includes variety, balance, and moderation in meals that combine all five food groups including grains, fruits and vegetables, protein and milk.
- Take care of your body by exercising regularly in moderation. The focus on exercise should be for the purpose of better health, not to burn calories or to change your appearance.
- Model and teach healthy emotional expression and coping with stress
- Avoid trying to control your child’s behavior or ask for details of overeating, purging, restricting, because this could worsen these behaviors and the related stress and guilt
- Encourage communication about feelings when you notice negative behaviors
- Do not allow the eating disorder to control the entire family by demanding the family eat certain foods, not eat out, or not attend social events
- Prepare your child for puberty by providing facts and information and discussing the expected physical and sexual changes/maturation that take place; talking about these as normal, healthy, and natural. Avoid talking about puberty in a negative way.
The Road to Recovery

- Average treatment duration tends to be two to three years
- Each patient’s recovery is different; no patient’s recovery is the same
- Recovery from the eating disorder is mostly the patient’s responsibility; family and friends can be helpful as a source of support but the patient is responsible to do the work towards recovery
- Patients whose families are actively involved in the patient’s treatment have a better chance of recovery
- Early intervention is key; prognosis is better the sooner treatment is started after onset of the disorder
- Adolescents have better prognosis compared to adults who have suffered from the illness for an extended period of time
- Full recovery is not guaranteed, but it is possible
Informative Resources for Patients and Families

National Eating Disorders Association (NEDA): nationaleatingdisorders.org

Theelisaproject.org: The Elisa Project is nonprofit organization created by the family of a woman with anorexia who committed suicide. This is an informational website for professionals and families.

American Dietetic Association (ADA): eatright.org; nutrition resources

Mypyramid.gov: nutritional resources

BodyImageHealth.org; building healthy body image esteem

Eatingdisorderhope.com; information on recovering from eating disordered behavior


Something-Fishy.org; informational website on eating disorders

Gurze Books (gurze.com); books on eating disorders

*Inclusion on this list of resources is in no way an endorsement of these sites. The clinic is not responsible for the informational content of these sites.

References

Helping Your Child Overcome an Eating Disorder: What You can do at Home; Bethany A. Teachman, Ph.D.; Marlene B. Schwartz, Ph.D.; Bonnie S. Gordic, B.A.; Brenda S. Coyle, Ph.D.; 2003; New Harbinger Publications

Just a Little Too Thin: How to Pull Your Child Back From the Brink of an Eating Disorder; Michael Strober, Ph.D.; Meg Schneider, M.A., LMSW; 2006; Da Capo Press

Talking to Eating Disorders: Simple Ways to Support Someone with Anorexia, Bulimia, Binge Eating, or Body Image Issues; Jeanne A. Heaton, Ph.D.; Claudia J. Strauss; New American Library; 2005


Surviving an Eating Disorder: Perspectives and Strategies for Family & Friends – Revised Edition; Michelle Siegel, Judith Brisman and Margot Weinshel; 2009; Gurze books

Conquering Eating Disorders: How Family Communication Heals; Sue Cooper, PhD and Peggy Norton, RD; 2008; Seal Press