



## Questions & Answers for Patients & Families about Eating Disorders

### What is an Eating Disorder (ED)?

Eating disorders are characterized by abnormal thinking and behaviors related to weight and food. Both men and women experience these illnesses. They include Anorexia Nervosa, Bulimia Nervosa, Binge Eating Disorder, and Eating Disorder Not Otherwise Specified (ED, NOS).

Eating disorders have the highest mortality rate of all psychiatric illnesses. All eating disorders have potentially life-threatening consequences.

### How is Anorexia Nervosa diagnosed?

The most important criteria for diagnosis of Anorexia Nervosa are:

- The patient refuses to maintain a minimally normal body weight.
- The patient is intensely afraid of gaining weight.
- The patient has a significantly distorted body image.
- In postpubertal females, menstrual periods have stopped.

There are two types of Anorexia Nervosa: Restricting type and Binge/Purge type.

### How is Bulimia Nervosa diagnosed?

The most important criteria for diagnosis of Bulimia Nervosa are:

- The patient experiences recurrent episodes of binge eating.
- The patient experiences a sense of a lack of control over eating during the episode.
- The patient demonstrates recurrent, inappropriate compensatory behavior to prevent weight gain that occurs at least twice a week for 3 months. For example, the patient may induce vomiting after eating, abuse laxatives, and exercise excessively.
- The patient's self-evaluation is overly influenced by body shape and weight.

### What is Eating Disorder Not Otherwise Specified?

Eating Disorder, NOS is the diagnosis given to a patient who has disabling symptoms of an eating disorder but do not have ALL of the criteria for Anorexia Nervosa or Bulimia.

### Why won't my family member eat now, he/she never had trouble with food before?

Often a different relationship with food becomes strikingly apparent in a person who develops an eating disorder. Eating disorders are illnesses, not choices. Food refusal is not an act of defiance. Meals and snacks are anxiety provoking. Patients usually feel uncomfortable with food that, in their minds, are high in calories or fat or seem just unhealthy. Sometimes, a healthy eating pattern becomes more and more restrictive until just a few food groups are eaten. It is often very frightening for a person with an eating disorder to normalize their eating habits. They may be afraid of rapid weight gain or terrified of becoming fat.

The effects of malnutrition, independent of the eating disorder, increase a person's obsessive thought process around food and can cause odd food related behaviors.

### Why did my family member develop an eating disorder?

Eating disorders are complex medical and psychological problems. Families

do not cause eating disorders. People often choose to go on a diet but no one chooses to develop an eating disorder. There is never one reason, situation or event that causes an eating disorder. There are usually many contributing factors in the development of an eating disorder.

- Biologic contributors: Genes, neurotransmitters, enzymes, hormones and the effects of starvation have all been found to play a part in the development and continuance of eating disorders.
- Psychologic contributors: A person's temperament, world view, and self image can contribute to an increased risk of developing an eating disorder.
- Social contributors: Cultures which value thinness and the effects of media pressures increase the risk of eating disorders.

### How are eating disorders treated?

We know that eating disorders are caused by a combination of biologic, psychologic and social factors. Our treatment must therefore be focused on all three areas as well.

**Biologic treatments:** The effects of malnutrition can exacerbate many symptoms of an eating disorder and mood disorders. Treatment of eating disorders must include nutritional stabilization and nutritional education. Also, medications can be helpful in controlling symptoms of anxiety, insomnia, thought disturbances, agitation and mood problems.

**Psychologic treatments:** Patients are provided individual, family and group psychotherapy.

**Social interventions:** Meal support and social support are necessary to a patient undergoing nutritional stabilization. Media awareness training and building consciousness of conflicting societal expectations are examples of social treatments beneficial to recovering eating disorder patients.

### Who are the members of an eating disorder treatment team?

Generally, eating disorders are best treated with a multidisciplinary approach. Ideally, a treatment team will include a member from each of the following disciplines:

- |                               |                        |
|-------------------------------|------------------------|
| • Primary Care Physician      | • Psychiatrist         |
| • Psychologist/ Social Worker | • Registered Dietician |

### What are some common themes that will be covered in my family member's psychotherapy?

While each patient will have individual needs, some common themes in eating disorder recovery are:

- Making peace with food; restoring healthy eating and exercise habits.
- Getting comfortable with your body.
- Practicing positive thinking. Reducing negative thoughts about self.
- Recognizing and challenging self-defeating behaviors.
- Developing a healthy "voice". Recognizing personal strengths. Practicing assertiveness and conflict resolution skills.
- Discovering how spirituality or a connection to a higher power can support recovery.
- Rediscovering fun. Trying new leisure activities.



The Harold C. Schott Foundation

Eating Disorders Program

at Lindner Center of HOPE



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## **My family member is afraid to eat. How is nutrition restored in an underweight patient?**

It is important to focus on normalizing a person's health status before expecting sustainable cognitive or behavioral change to occur. Once a patient is getting regular, appropriate nutrition, whether by mouth or via nasogastric feeding, they are more likely to respond to the mental health interventions available. Early in treatment, it is very important to focus on and correcting malnutrition, as the patient will benefit most from therapy when they have reached a healthy weight.

The caloric requirements to gain weight once a person is severely malnourished can be overwhelming to the patient who is afraid to gain weight. Two to three times as many calories must be eaten to restore rather than maintain weight. At the LCOH, we offer a combination of meals, snacks and nasogastric feedings to support appropriate weight gain. We often suggest that our patients work to practice eating what will be a maintenance diet, not a weight gain diet.

Nasogastric feeds can be used to provide the needed weight restoration calories and to help re-establish a normal weight. They are not a punishment or a sign of failure.

## **My family member does not want help. He or she does not even think there is a problem. What can I do?**

Eating disorders are illnesses that seem to "tell" the patient that they are not ill. Malnutrition makes these symptoms even worse. When a patient has clearly lost control of their symptoms, we must step in to provide control of the symptoms until they have stabilized. Treatment interventions are always meant to be supportive. In recovery, it is critical that the patient let go of their illness by accepting health. Although firm limits and clear expectations are needed for almost all recovering eating disorder patients, we will never be able to "cure" a patient by trying to wrestle the illness away from them. Supporting the patient in knowing and growing all of the parts of their healthy identity and in learning new skills for self expression can help the patient separate themselves from the illness and come to accept treatment.

## **How can we explain the illness to our family members and friends?**

Many extended family members and friends may want to help with your family member's recovery. Often they are afraid of saying the wrong thing or of giving the wrong advice. It is usually a good idea to talk openly with your family members and friends about the illness. Explain what the illness means to you and your family. Provide education about the illness as you continue to learn about these illnesses. Give your family and friends information about progress and about what is helping and not helping in recovery. Be sure to explain that any comments about food or weight can be unproductive. Any positive comment such as "Oh, you look better" or "oh, you've gained weight thank goodness..." might be viewed negatively by the patient.

## **How can we know when an eating disorder patient needs an inpatient level of care?**

The American Psychiatric Association has developed guidelines with recommendations for utilizing appropriate levels of care for patients with eating disorders. While every patient will need an individual assessment, in general, the indications for inpatient treatment are:

- Rapid, progressive weight loss despite outpatient treatment
- Severe malnutrition: weight loss of more than 25% of ideal body weight for height
- Significant medical comorbidity – e.g. diabetes
- Heart problems: Cardiac failure, arrhythmias, heart rate less than 40 beats per minute, electrocardiogram changes with prolonged QT interval
- Electrolyte disturbance (for example, low calcium or low potassium)
- Low blood sugar in a malnourished patient
- Signs of inadequate brain perfusion, symptomatic low blood pressure or fainting
- Lack of response to outpatient treatment
- Seizures
- Uncontrollable binging/purgung
- Refusal to eat
- Psychiatric emergencies : for example, acute psychosis, severe depression, OCD, substance use, or suicidal risk

## **How will we know when our family is ready for discharge after an inpatient stay?**

Every patient will work closely with a treatment team to establish discharge criteria and complete a discharge plan. In general, patients will not be considered appropriate for discharge until:

- The patient is either tolerating a nutrition plan adequate for ongoing weight gain for a minimum of four days prior to discharge OR the patient has achieved their weight goal and demonstrated the ability to tolerate a maintenance diet prior to discharge
- Vital signs are stable
- If patient is being discharged to family home, the family and patient have tolerated several meals together prior to discharge
- Comprehensive outpatient plan is in place (medical, psychological, school, nutrition, spiritual and exercise plans)
- Patient's weight must be a MINIMUM of 75% of Ideal Body Weight. Note that patients with Anorexia Nervosa will have a significantly better outcome if they remain in a structured therapeutic setting until they reach a normal weight (BMI > 19). Reference: Baran SA, et al. Low discharge weight and outcome in anorexia nervosa. Am J Psychiatry 1995 Jul;152(7):1070-2

## **What if I am interested in research?**

After you call the Research Institute at the Center you will be interviewed over the phone by a research assistant (RA) to assure that you qualify for one of our current research studies. The RA will ask you questions about your eating behaviors, weight and psychiatric history. If it is established that you qualify for a study you will be invited for a visit at the Research Institute where you will undergo a screening process , including a thorough psychiatric assessment, physical exam and some lab work. If it is decided by the research team that you meet inclusion criteria for participation you will further proceed with the study. Your participation in any research study is completely voluntary, you can drop out at any time and you will be reimbursed for your time and travel.

## **Eating Disorder Screening**

For those who suffer with eating disorders, the very process that sustains us can become a source of fear, panic, anxiety and pain. Left untreated, this cycle can race out of control, with potentially deadly consequences.

Below is a self test developed by eating disorders experts that can help people decipher if they may have an eating disorder.

Please answer yes or no to each of the following:

- Do you ever make yourself sick or vomit because you feel uncomfortably full?
- Do you worry you have lost control over how much you eat?
- Have you recently lost 15 pounds or more within a 3-month period?
- Do you believe yourself to be fat when others say you are too thin?
- Would you say that food dominates your life?

If you answered yes to 2 or more of the above questions, we would recommend that you seek professional advice and consider a formal evaluation.

*From Morgan, Reid, and Lacey (1999) The SCOFF questionnaire: Assessment of a new screening tool for eating disorders, Journal of Medical Screening (BMJ), Volume 319, December 4, 1999.*



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