Hopkins BrainWise
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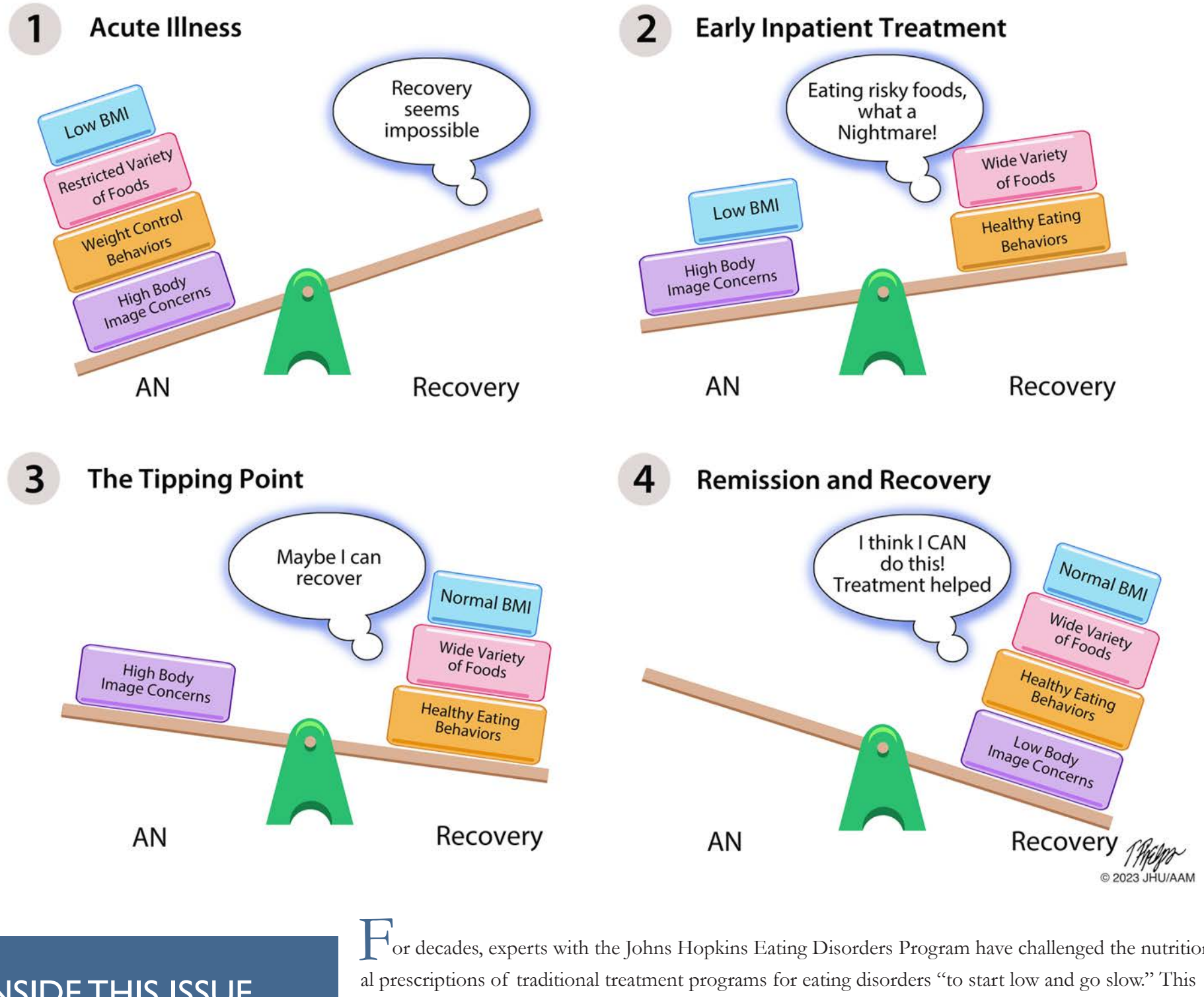
JOHNS HOPKINS MEDICINE
SPECIAL ISSUE

# Unlocking a Healthy Mindset:
## *The Road to Recovery from Anorexia Nervosa*




## INSIDE THIS ISSUE



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For decades, experts with the Johns Hopkins Eating Disorders Program have challenged the nutritional prescriptions of traditional treatment programs for eating disorders "to start low and go slow." This has decreased the time needed to restore weight, normalize eating and weight control behaviors, and master relapse prevention skills needed for successful long-term recovery from anorexia nervosa. The Johns Hopkins team has helped hundreds of patients resume schooling, work and relationships interrupted by illness.

Angela Guarda, M.D., director of the program and the Stephen and Jean Robinson Professor of Eating Disorders, has called for universal reporting of clinical outcomes by eating disorders treatment programs to increase transparency and help patients, families, providers and payors compare treatment approaches. Headed by Colleen Schreyer, Ph.D., director of clinical research for Johns Hopkins' longitudinal eating disorders outcome project, the clinical research team has focused on assessing and publishing the program's treatment outcomes in a series of peer-reviewed articles published in the *International Journal of Eating Disorders* (see page 3 for peer-reviewed papers). The research team's work reports on treatment outcome variables, including the average rate of weight gain, percent of patients who achieved a minimally healthy weight, safety of the meal-based rapid nutritional rehabilitation prescription, relative cost of treatment, and relapse risk. They also examined patients' perceptions of treatment, and whether patients felt they benefitted from the program's rapid weight gain, meal-based, behavioral approach.

In this Q&A, Drs. Guarda and Schreyer explain the rationale for the program's approach to treating anorexia nervosa and discuss its treatment outcomes and research findings.

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**Dr. Guarda, before we delve into The Johns Hopkins Eating Disorders Program's outcomes research findings, could you provide us some background on how patients feel when facing treatment? What is the "anorexic mindset"?**

*Angela Guarda, M.D.*

Anorexia nervosa increases anxiety about gaining weight and eating high-calorie foods — and yet this is necessary for thoughts, mood, and body dissatisfaction to improve in patients with the disorder. Key goals of treatment are weight restoration and eating a variety of foods of differing calorie densities at regular meals. We know the starved state and a restricted food repertoire perpetuate eating disorder thoughts and feelings, and alter brain function, so achieving these goals are crucial first steps in recovery — but ones that often feel overwhelming for patients. The Johns Hopkins Program helps patients overcome anxiety about eating and employs a behavioral, meal-based, rapid-weight restoration approach to (1) minimize time spent in intensive treatment; (2) help patients normalize their eating and weight control behaviors and overcome anxiety about eating; and (3) master skills needed to prevent relapse once back at home. The approach is team-based, collaborative, and it includes group, family, nutritional, and occupational therapies.

**Dr. Guarda, could we say weight restoration and being able to eat a variety of foods is central to having a "non-eating disordered or healthy mindset"?**

In a sense, yes—anorexia nervosa hijacks the healthy brain. Our brains consume 20% of our daily caloric needs; a starved brain simply does not think clearly – and talk therapy is less effective when someone is in a starved state. Furthermore, searching for explanations or a "root cause" — as to why a person developed anorexia — is not enough to get someone well. It's not so much an "aha moment" of insight that leads to change: We need to help patients change their behavior and restore nutritional health for anorectic thoughts and feelings to gradually fade. That's what makes weight restoration and normalized eating crucial treatment priorities. In the absence of headway with those, no amount of therapy alone is likely to help someone get well.

**Dr. Guarda, the Johns Hopkins program's average weight restoration rate is four pounds a week — double that of most programs. Is it safe?**

Yes, back in 2015, we published a study that included 461 consecutive underweight patients and found that the program's meal-based, rapid weight-gain behavioral approach coupled with close medical monitoring was safe and effective and did not result in higher risk of a dangerous complication known as refeeding syndrome. Additionally over 70% of patients left treatment weight restored and at a healthy weight, following a shorter admission and without the need for nasogastric tube feeding. At the time, this approach went against the general belief that restoring weight at a rate greater than 2–3 lbs per week was dangerous and could lead to serious risk. Indeed, partly as a result of this study, the recently updated American Psychiatric Association's Practice Guidelines for the Treatment of Eating Disorders now recommends that residential and inpatient programs should achieve average rates of weight gain of 2–4 lbs per week for anorexia nervosa. Thanks to a faster rate of weight restoration, most patients reach a minimally healthy weight over weeks rather than months. Faster weight gain means less time away from home, work, or school and, in the long run, less costly care.


*Colleen Schreyer, Ph.D.*

**Dr. Schreyer, in the longitudinal study — when you followed up with patients after hospitalization — what were the key predictors of good outcomes?**

Consistent with the importance of restoring weight, we found that weight at program discharge was more important to avoiding relapse six months later than was age, number of past hospitalizations, or how long a patient had been ill with anorexia. Additionally, patients who reported higher confidence in their ability to eat in a healthy balanced pattern at hospital discharge were less likely to have relapsed six months later. And, despite the rapid weight gain and behavioral focus of the program, patients reported being highly satisfied with the treatment they received. About 83% said they would recommend the program to others. As one patient put it: "With anorexia, any rate of weight gain feels too fast — I've lost enough time already because of this illness."

**Dr. Guarda, 83% patient satisfaction with this approach is impressive, given that patients are anxious about weight gain. How is this possible?**

Focusing on rapid nutritional rehabilitation and normalizing eating and weight control behaviors may feel anxiety-provoking at first, but when addressed in the context of a specialized behavioral treatment program that incorporates close medical management, family support, group therapies and a collaborative team-based approach to care, patients support one another, learn to lean into their anxiety, disengage from eating-disordered thinking, and achieve mastery over the disorder. In a sense, recovery from anorexia requires unlocking the healthy brain through nutrition, behavior change and psychotherapy — and mastering the tools and skills needed to maintain healthy function and avoid relapse.

**Dr. Schreyer, how did the pandemic affect patients in the program?**

The COVID pandemic has taken a toll on everyone especially on adolescents — we are seeing a worldwide increase in eating disorders in youth. At Johns Hopkins, we found that adolescents admitted to the program from March 2020 to March 2022 were arriving with more severe eating disorder, depression and anxiety symptoms. Despite this heightened clinical severity, outcomes including weight regain were similar to those of patients admitted before the start of the pandemic. That means we were equally effective in treating these patients, even though they presented as more severely ill.

**Dr. Schreyer, we've been focusing on anorexia, could you walk us through avoidant/restrictive food intake disorder (ARFID)?**

Avoidant/restrictive food intake disorder, or ARFID, is a recently defined eating disorder in which patients restrict their intake due to low interest in food, sensitivity to food odors, tastes or textures, or fear of consequences of eating (e.g., choking, vomiting, or stomach pain). Importantly, patients with ARFID do not endorse marked body image concerns, however their restricted food intake results in a malnourished state and impaired function. The Johns Hopkins weight restoration protocol is effective in treating underweight patients with ARFID. Although weight gain rates were slightly lower for patients with ARFID compared to those with anorexia nervosa, a similar majority of those with ARFID clinically improved and achieved a minimally healthy weight by discharge. ■

PATIENT STORY

# Recasting Body Image and Food Choices

*Excerpt from Hopkins BrainWise Fall 2017 Issue,* "A Seasoned Look at Anorexia Treatment"

When Ashley Bilkie hit puberty, she got taller and lost her baby fat. What wasn't as obvious to her parents was that she also began restricting her food intake, starting a nearly 14-year battle with anorexia nervosa.

Due to some other health issues and the fact that Ashley never appeared severely underweight, "We were not aware she had an eating disorder until she was in her early 20s," says her father, Bob, president and CEO of a Michigan investment firm.

Over the next few years, Ashley moved in and out of four residential programs for eating disorders, never with any lasting benefit. Each time, she told her parents that as soon as she got out she would restrict her eating again and lose weight.

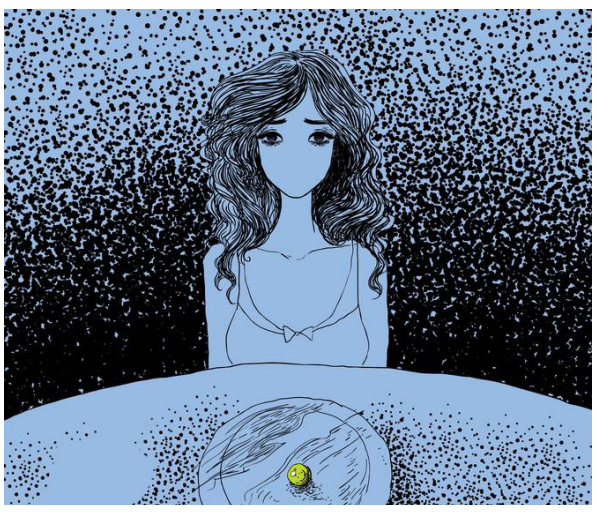
In 2015, when Ashley was 28, Bob met a client whose daughter also suffered from anorexia. The client encouraged him to check out Johns Hopkins' Eating Disorders Program.

Like Ashley, at least two-thirds of patients in the program have failed others, says Angela Guarda, director of the Hopkins Eating Disorders Program. "Treatment must focus on helping patients change their behavior around food," she says. "Once this behavior changes, patients' thoughts and feelings start to improve, which builds their confidence toward achieving recovery."

Unlike other programs that focused on seeking an explanation for Ashley's self-starvation, Guarda and colleagues explained anorexia nervosa to Ashley and her parents as a driven behavioral problem best treated with a behavioral approach. Soon after entering the Hopkins program, Ashley called her parents—she was upset and asked to be released from the program, arguing that it wouldn't help her. "But we knew she really had no other options," says Bob. "This was our only chance to save her life."

With group therapy and the encouragement of other patients who had benefitted from the program, Ashley gradually engaged in treatment. Her anxiety decreased, and she learned to stop dieting. She gradually restored her weight and was encouraged to use her parents as a support to maintain her recovery.

When Bob and his wife, Shari, came to visit Ashley toward the end of her three-month stay, they noticed a big difference when they dined together at the hospital cafeteria and a local restaurant: She had a hearty appetite, says Bob. Before admission, "She would pick at her food or avoid eating altogether," he says. Now she's able to choose, portion and consume a wide range of foods of different calorie densities with much less anxiety, and she can socialize at meals rather than avoid eating with others, adds Guarda.



Ashley is now studying to become a nurse and is engaged to be married. While things turned out well for her, Bob says he frequently shares a valuable lesson with other parents and caregivers of those with eating disorders: "We went along with (previous) therapy teams, assuming they knew what they were doing. I think that's a mistake—you should be questioning everything, every step of the way." ■

## PEER-REVIEWED PAPERS


Redgrave GW, Coughlin JW, Schreyer CC, Martin LM, Leopacher AK, Seide M, Verdi AM, Pletch A, Guarda AS. **Refeeding and weight restoration outcomes in anorexia nervosa: Challenging current guidelines.** Int J Eat Disord. 2015 Nov;48(7):866-73. PMID: 25625572.

Guarda AS, Schreyer CC, Fischer LK, Hansen JL, Coughlin JW, Kaminsky MJ, Attia E, Redgrave GW. **Intensive treatment for adults with anorexia nervosa: The cost of weight restoration.** Int J Eat Disord. 2017 Mar;50(3):302-306. PMID: 28130794.

Makhzoumi SH, Schreyer CC, Hansen JL, Laddaran LA, Redgrave GW, Guarda AS. **Hospital course of underweight youth with ARFID treated with a meal-based behavioral protocol in an inpatient-partial hospitalization program for eating disorders.** Int J Eat Disord. 2019 Apr;52(4):428-434. PMID: 30779365.

Guarda AS, Cooper M, Pletch A, Laddaran L, Redgrave GW, Schreyer CC. **Acceptability and tolerability of a meal-based, rapid refeeding, behavioral weight restoration protocol for anorexia nervosa.** Int J Eat Disord. 2020 Dec;53(12):2032-2037. PMID: 33026118.

Redgrave GW, Schreyer CC, Coughlin JW, Fischer LK, Pletch A, Guarda AS. **Discharge Body Mass Index, Not Illness Chronicity, Predicts 6-Month Weight Outcome in Patients Hospitalized With Anorexia Nervosa.** Front Psychiatry. 2021 Feb 25;12:641861. PMID: 33716836.

Cooper M, Guarda AS, Petterway F, Schreyer C. **Change in normative eating self-efficacy is associated with six-month weight restoration following inpatient treatment for anorexia nervosa.** Eat Behav. 2021 Aug;42:101518. PMID: 33989938.

Schreyer CC, Vanzhula IA, Guarda AS. **Evaluating the impact of COVID-19 on severity at admission and response to inpatient treatment for adult and adolescent patients with eating disorders.** Int J Eat Disord. 2023 Jan;56(1):182-191. PMID: 36394170.


*Download the pdf version of this issue to link to the peer-reviewed papers.*

*Allisyn W. Pletch, RN, MS, PMHNCS-BC*

*Graham Redgrave, M.D.*

# Finding a Treatment Program that Works

*Excerpt from Johns Hopkins Medicine ebook: Eating Disorders – What You Need to Know*

Similar to addiction treatment, it can take multiple attempts at recovery before a person is able to sustain a normal eating pattern indefinitely. For the best chance of recovery, it's important to find a treatment program that not only offers support but also challenges the patient to change their behaviors and eat like a healthy nondieter.

A majority of patients will recover fully from an eating disorder with proper treatment. But a good treatment program shouldn't feel like vacation — the process of recovery is more like mastering a challenging job. Treatment for an eating disorder feels uncomfortable, says Guarda. Feeling ambivalent about recovery at the start of treatment is normal, but most people find their motivation improves as they start to manage their anxiety about eating and master healthier eating behaviors.

It's also important to address issues of body dissatisfaction, but this is not usually effective until someone learns to eat appropriately and is no longer starving, adds Guarda.

There are numerous treatment programs to choose from — everything from hospital settings to residential facilities to outpatient programs — but for a program to be successful, it has to be centered on the behavioral changes that will bring about normal eating. For many patients, outpatient interventions can work. Those who do not show rapid response to outpatient therapy may benefit from a higher level of care. Choosing an intensive treatment program can be challenging.

**A good treatment program should have the following components:**

**Rapid weight restoration:** For anorexia nervosa, the best predictor of recovery is reaching a normal weight. If a person with anorexia leaves a program still underweight, they are more likely to stall or slip backward once at home.

**Behavioral treatment:** This focuses on normalizing eating and weight control behaviors. Increasing evidence suggests that early behavior change is the best predictor of response to treatment for eating disorders in both outpatient and intensive treatment settings.

**Cognitive behavioral therapy:** This therapy helps people with eating disorders learn how to manage and correct or reframe the thoughts and emotions that drive destructive behaviors. It's the most effective type of psychotherapy for battling eating disorders.

**Anxiety management:** Helping individuals overcome meal-based anxiety is critical to eating disorder recovery. Learning to consume a variety of foods in social settings (with friends and family members, at restaurants or public gatherings) helps people with eating disorders transition from intensive treatment back to their everyday lives and avoid relapse.

**Group therapy:** Being part of a program with others who are going through the same struggles can be extremely helpful. Peer support and encouragement help increase motivation and inspire hope in even the most seriously ill patients.

**Family therapy:** Family support is a key ingredient in eating disorder recovery. Family therapy aimed at teaching parenting strategies that help improve a child's eating behavior is absolutely crucial for adolescents with eating disorders, but family involvement in treatment is important for patients of all ages.

**Accountability:** People with eating disorders should work with a clinician to track food intake and weight. This can be done by keeping a food journal and having regular weigh-ins with a mental health professional, dietitian or doctor.

**Relapse prevention:** An intensive treatment program should help people practice the skills they need to maintain normal eating behavior in everyday life and provide follow-up support once the program ends. People most commonly relapse in the first year after intensive treatment, so follow-up visits are critical. ■

## 7 Questions to Ask Before Entering an Intensive Treatment Program for Eating Disorders

For those persons who have lost a significant amount of weight as a result of anorexia nervosa, finding a treatment program focused on rapidly restoring a healthy weight is vital. Slower weight restoration prolongs time in treatment and away from home. Prolonged treatment can also be more expensive and increase the likelihood of leaving treatment prematurely, thereby decreasing the odds of recovery. The risk of falling back into unhealthy eating habits is greater when someone with anorexia nervosa leaves treatment prematurely at a low weight.

*When considering a treatment program, ask these questions:*

**1. Do patients gain weight by eating orally or through a feeding tube?** A meal-based approach is preferable and should be the focus of a behaviorally based treatment program. Sometimes programs use tube feeding to help those who are severely underweight or who refuse to eat by mouth. However, over 95% of patients can be treated with a meal-based behavioral approach alone.

**2. Are patients allowed to choose what they eat?** The program should help participants eat a broad range of foods, including feared foods (typically those high in fat or carbohydrates) and to manage food-based anxiety about eating. Helping people learn to make healthy, balanced food choices is an important goal of treatment.

**3. Do patients practice normal eating in different settings and prepare their own meals?** People with eating disorders often find preparing balanced meals and eating meals cooked by others challenging. Skills such as learning to portion meals, consuming diverse foods, eating family-style and in restaurants are important to prevent relapse.

**4. What do you consider a normal body mass index (BMI)?** Doctors and researchers disagree about the weight that defines remission for anorexia nervosa. Some programs consider reaching a BMI of 18.5 a success. But because that is the minimum BMI for "normal weight" for the population as a whole, it may be too low for most people to maintain without going back to disordered eating. Evidence suggests a BMI of at least 20 is more favorable to recovery.

**5. How much weight can a patient expect to gain per week?** Patients in an intensive treatment program should gain on average 2-4 pounds a week. Rapid weight restoration helps patients move through treatment faster, provides more time to focus on relapse prevention and shortens the total time spent away from home.

**6. What percentage of patients are discharged from the program at a normal weight?** The number of people who attain a normal weight by discharge is a good measurement of a program's success in treating anorexia nervosa.

**7. What if I have bulimia nervosa or binge eating disorder and am not underweight?** For patients who do not need to gain weight, the initial goal is weight maintenance. The focus of treatment is on normalizing eating behavior and food choices. Typically, these patients spend most of their time in treatment in a partial hospitalization program. ■