

DOWN THE RABBIT HOLE

A F.E.A.S.T.
FAMILY GUIDE FOR
COMING TO TERMS WITH
A LOVED ONE'S

EATING DISORDER DIAGNOSIS

F.E.A.S.T. FAMILY GUIDE SERIES
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Although an eating disorder diagnosis may feel like a devastating blow to a patient and their family, it is an opportunity to begin a treatment process that can allow your loved one to restore their mental and physical health and live a full, successful life.

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DOWN THE RABBIT HOLE:

COMING TO TERMS WITH A LOVED ONE'S EATING DISORDER DIAGNOSIS

WE SUSPECT THAT OUR LOVED ONE HAS AN EATING DISORDER AND NEEDS TREATMENT. WHAT DO WE DO NOW?

Eating disorders are serious, life-threatening, brain disorders that often create turmoil within a family even before a diagnosis is made. While receiving an eating disorder diagnosis may offer a moment of relief for families who feel that treatment can finally begin, it can also compound feelings of guilt for not having acted sooner, fear for their loved one's future, and anxiety about facing long term caregiver responsibilities and expensive medical bills.

The experience is usually made worse as families are given conflicting or outdated information, find there is no clear treatment path to take, and receive very little support or guidance to help them make good care decisions. This guide is intended to help you come to terms with the diagnosis and wade through some of the myths and facts that you will encounter when getting started on the road to recovery.

OUR FAMILY SITUATION HAS ALWAYS BEEN LOVING AND STABLE - HOW CAN THIS HAVE HAPPENED?

Families do not cause eating disorders, and patients do not choose to have them. On the contrary, parents and caregivers can be a powerful support for a loved one's recovery from an eating disorder. While you may not be an expert in eating disorders, you are an expert when it comes to your loved one and you have valuable insights, intuitions and parenting skills that are critical to the recovery process.

CAN EATING DISORDERS BE SUCCESSFULLY TREATED?

Yes. With appropriate expert and family assistance, there is always hope for successful recovery.

Treating eating disorders is not easy, and the earlier the intervention, the higher the chance of success. Effective care usually requires a multi-disciplinary approach, specialized caregiving skills, and long-term vigilance. Although an eating disorder diagnosis may feel like a devastating blow to a patient and their family, it is an opportunity to begin a treatment process that can allow your loved one to restore their mental and physical health and live a full, successful life.¹

HOW DO WE KNOW WHAT KIND OF TREATMENT WE NEED?

If you suspect that your loved one has an eating disorder, it is important to seek diagnosis and treatment right away. Evidence shows that early recognition of symptoms and early intervention are correlated with improved treatment outcomes.

The type and level of care that your loved one needs will depend on many factors including: age, physical and behavioral symptoms, medical stability, psychiatric state, and length of illness.

It is important for the patient to receive complete medical and psychological evaluations by providers familiar with eating disorders before a treatment plan can be put in place.

As different providers may recommend different treatment plans, it is essential that caregivers become familiar with the various treatment options, diagnostic criteria, and current clinical guidelines so that they can make informed decisions about the care being offered. Every patient has unique needs and multiple treatment options should be considered.

¹ See APPENDIX A for DSM-5 Diagnostic Categories of Eating Disorders

RELIABLE RESOURCES TO START WITH:

- **APA Practice Guidelines: Treatment of Patients with Eating Disorders**, Third Edition, 2006, American Psychiatric Association, www.psych.org
- **AAP Clinical Report: Identification and Management of Eating Disorders in Children and Adolescents**, 2010, Academy of Pediatrics, www.aap.org
- **AED Critical Points for Early Recognition and Medical Risk Management in the Care of Individuals with Eating Disorders**, 2nd Edition, Academy for Eating Disorders, www.aedweb.org

DOES OUR LOVED ONE NEED FULL-TIME CARE AWAY FROM HOME?

Many patients do not need to be hospitalized; however, in the face of medical instability, lack of progress in outpatient treatment, or an acute psychiatric crisis, a higher level of care may be required.

Needing hospitalization or residential care is not a failure of outpatient care or of a caregiver's effectiveness. These options simply represent different levels of care that provide a higher degree of safety and support for the patient. While hospitalization is designed to ensure medical stability, stop destructive behavior, and begin nutritional rehabilitation, residential treatment provides long-term nutritional and therapeutic care in an environment where medical state can be monitored.

Treating eating disorders requires full time vigilance no matter the care setting.² Although higher levels of care are often necessary and helpful for patients whose medical and/or psychiatric health is declining, Day Treatment and Intensive Outpatient Program (IOP) settings can be effective alternatives to Inpatient (IP) or Residential treatment if available in your community. Any type of treatment should be a collaborative effort involving the patient, family and the providers, with plans and procedures in place for making changes in the level and setting of care as needed.

Planning for your child to come home should begin soon after your child is admitted to a higher level of care. The treatment team should be

² See APPENDIX B for descriptions of common care settings.

working with you (and ideally your outpatient providers) early on to develop a realistic discharge plan for continuity of care at home. Patients with eating disorders become very anxious during transitions between levels of care, and an ill-planned transition can contribute to relapse. Your child will need continued support at home for an extended period of time even after hospitalization and/or residential care. If changes are needed at home to support your child, such as special arrangements with school, a leave of absence from work, or arranging for extended family to help care for siblings, this work should not be delayed.

Higher levels of care are not a replacement for eventual outpatient work. In fact, much of the effectiveness of treatment has to do with work that is done later on an outpatient basis.

WHY IS SO MUCH OF THE ADVICE WE'RE GETTING CONTRADICTIONARY?

One reason why parents hear so much conflicting information is because eating disorder 'experts' come from many different professions, including psychology, psychiatry, nursing, nutrition, medicine, and social work. Even within these professions, no two providers are likely to have the same background, training, experience, and professional affiliations.

In addition, the knowledge base and treatment methods for eating disorders have changed dramatically over time. First, clinical practice is moving toward treatment approaches based on data showing that a specific treatment results in measurable and significant improvements in outcome (evidence-based treatment). Second, recent advances in neuroscience are leading to a better biological understanding of eating disorders, which in turn are leading to new therapies – medical and psychological - that target the specific brain pathways that have gone awry for the patient. Unfortunately, some practitioners do not follow or keep up with this kind of research and some choose not to provide evidence-based treatments. Additionally, there are very few continuing education opportunities that teach about these new findings and ideas.

WE CAN'T AFFORD TO PAY FOR TREATMENT, TRAVEL, OR TO MISS WORK. CAN'T WE JUST DO IT OURSELVES AT HOME?

Very few families expect to face a life-threatening healthcare emergency and most find the resulting financial burden an additional crisis to cope with. The best treatment for your child is not necessarily the most

expensive treatment; but, delaying effective treatment, due to cost, lost income, or proximity, may turn out to be the most expensive option over time.

Evidence shows that early intervention is critical to effective treatment. As with drug and alcohol abuse, it is difficult to stop destructive behaviors and tempting to discontinue treatment once the crisis is past. In addition, it becomes more and more difficult to successfully achieve recovery the longer the patient remains ill and the more times they relapse.

Eating disorders are very dangerous and trying mental illnesses that challenge even seasoned professionals. Mortality rates for eating disorders are as high as 10% and many more patients are ultimately disabled by chronic illness. Just as with a cancer diagnosis, eating disorders need to be addressed quickly and intensely with evidence-based, specialized treatment.

OUR RELIGIOUS COUNSELOR FEELS WE CAN DO THIS WITHOUT PROFESSIONAL HELP

Many people are skeptical about psychiatry and psychology, sometimes due to valid personal experiences and concerns. Certainly, recovering from an eating disorder involves personal tools and resources in addition to professional care. Just as cancer patients can benefit from spiritual counseling while receiving life-saving medical care, patients with eating disorders may benefit from spiritual counseling while also receiving needed evidence-based, scientifically grounded treatments. Eating disorder symptoms are unlikely to respond to religious or spiritual counseling alone. Professional help should be able to work together with spiritual guidance, not against it

OUR DAUGHTER IS ALREADY IN TREATMENT AND LIKES HER THERAPIST HERE IN TOWN.

In general, liking one's treatment provider is a bonus, but is not necessary and does not assure effective treatment or successful outcomes. In fact, with eating disorders it is not uncommon for a patient to feel the most comfortable with treatment that isn't working! Successful treatment requires challenging behaviors that have become rewarding to the patient and this is not usually comfortable or simple. In fact, confronting the illness may initially worsen anxiety and increase

resistance to treatment, and can result in disliking one's treatment provider

OUR SON'S INDIVIDUAL THERAPIST SAYS THAT HE IS MAKING PROGRESS, BUT NOTHING SEEMS TO HAVE CHANGED AT HOME, IN FACT, HE SEEMS TO BE GETTING WORSE.

Progress needs to be evaluated within weeks of beginning any eating disorder treatment. If no improvement is evident, then the treatment plan should be re-evaluated and sensible changes should be implemented.

Since a therapist often has limited contact with a patient, it is important that families be included in these discussions, even for adult patients, so that behaviors outside of appointments can be reported to the therapist. If caregivers are excluded, therapists must rely on patient reports of their progress, and caregivers cannot assess if the provider is delivering effective care.

Unfortunately, patients too often minimize the difficulties they're experiencing in order to avoid the distress of truly confronting the illness or upsetting their families. Recovery is challenging and anxiety-provoking because it requires behavioral, physical and emotional changes at every step of the way in order to create a life without illness.

WHY DOESN'T MY LOVED ONE UNDERSTAND THAT WE ARE TRYING TO HELP?

It is so important for families to know that their loved one is in an altered state even when they are otherwise quite bright and rational. Evidence shows that malnutrition and unhealthy eating patterns affect the brain. The brain is a complex network of systems and one system can be malfunctioning without affecting the others.

People with eating disorders often achieve excellent grades and perform well in jobs even while gravely ill. It is not uncommon for patients to argue forcefully about their reasons for their behaviors, even believing they do not need to eat. They may not be concerned by their physical decline, and may not feel they need to engage in treatment. In this state, they often fail to see the good intentions behind their parents' and providers' efforts to change their behaviors.

Recent research is helping us to understand what brain regions may be responsible for denial and resistance to treatment. This lack of insight is a symptom of the illness called “anosognosia”, and often improves with restored nutrition. This is why it is essential that parents do their own research and make decisions about treatment on the patient’s behalf, as the patient may be unwilling or unable to participate fully in these decisions until a later stage of recovery.

THE THERAPIST SAYS OUR DAUGHTER WILL EAT NORMALLY AGAIN ONCE SHE ‘GAINS INSIGHT’ AND ‘WANTS TO GET BETTER.’ I’M TERRIFIED THAT SHE WILL DIE BEFORE THAT HAPPENS.

Eating disorders are serious mental illnesses that profoundly affect the brain. While we know that full recovery is more than “just” normal eating, food itself is the most important medicine needed to restore a malnourished body and brain to good health.

Unfortunately, taking this medicine is harder than most people can imagine. Just as with chemotherapy for cancer, the treatment for an eating disorder can sometimes feel worse than the actual disease. This is why insight and improved emotional state are not sufficient or reliable motivators for the patient to ‘come on board’ with treatment. True insight and improved emotional state can only occur as the brain receives the food it needs. Do not expect, or wait, for your loved one to ‘want to get better’ before beginning nutritional restoration.

HOW DO WE KNOW IF THE TREATMENT WE ARE GETTING WILL BE EFFECTIVE?

In the past five to ten years a rapid increase in research on eating disorders has changed the field. This research has involved knowledge about genetic vulnerability, how the brain works, personality traits and temperament already present very early in life, and clinical trials that compare how well different treatments work. Much of this research calls into question past assumptions about eating disorders as lifestyle choices, as the result of dysfunctional families, and as chronic conditions that can only be managed but not cured.

New evidence shows that effective treatment for eating disorders is available that can result in improvement of symptoms fairly quickly. In fact, today’s providers should be able to give realistic estimates and time frames for stages of recovery, and recognize family members as

important collaborators in caring for eating disordered patients and effecting good outcomes.

WE KEEP HEARING THE TERM ‘EVIDENCE-BASED.’ WHAT DOES IT MEAN?

Evidence-based means there is valid research to back up the use of a specific treatment. For example, we know from research that antibiotics are an effective treatment for most ulcers, despite strong resistance to that idea before the data was collected. When a medical professional prescribes a certain dose of a medicine to a patient, this decision is generally based on solid research along with clinical judgment.

In the past, with eating disorders, little research existed to establish why certain approaches were used. Most treatment was based on ideas, always changing, about what caused the thoughts and behaviors. Although the current evidence-base cannot explain what “causes” eating disorders, it does show us that certain treatments are more effective than others. Just as a doctor will begin with the most effective medicine known to treat an infection, eating disorder clinicians should be able to recommend and provide “evidence-based” care as a starting point for treatment.

I DON'T WANT TO TELL ANYONE THAT MY CHILD HAS TO GET TREATMENT FOR A MENTAL ILLNESS. I'M AFRAID SHE'LL BE STIGMATIZED AND FEEL BAD ABOUT HERSELF.

Psychiatric illnesses, including eating disorders, still carry stigma. The stigma is based on ideas that are mostly unfounded; for example, that brain problems can't be fixed, that patients don't recover, that they are permanently “broken” or strange, or that they somehow caused their own mental illness.

It is important for parents, children and the general population to know that mental illness is quite common. A new era of thinking about the brain and psychiatric disorders is under way. Just as we can now talk about diseases like breast cancer in public and in common conversation, we should be able to talk about eating disorders very openly. Like breast cancer, eating disorders need not be problems that are only whispered about. Hiding an eating disorder diagnosis reinforces stigma and

outdated ideas and may lead to poor care decisions that can lower the chance of full recovery.

The end of stigma begins with how each of us addresses it. As parents become more open about admitting the problem, and more proactive about finding care for their loved ones and educating others about the disease, the demand for effective, evidence-based care will increase. This kind of advocacy has already helped to de-stigmatize and improve care for patients with autism, Attention Deficit Disorder (ADD), depression, Obsessive Compulsive Disorder (OCD), alcoholism and many other psychiatric disorders.

I BLAME MY EX-WIFE FOR OUR SON'S EATING DISORDER. SHE BLAMES A BULLY AT SCHOOL. THE LOCAL THERAPIST SAYS IT IS ABOUT 'CONTROL.'

The temptation to focus on 'blame' and 'cause' is counterproductive in eating disorder treatment. Researchers and providers do not know enough about these complex diseases to definitively state what caused any given patient to become ill. While family members may have different opinions about what may have contributed to the 'perfect storm' of conditions within which the eating disorder developed, it is important to put these issues aside and instead, to focus on providing quality, effective care as a unified team.

Being ill is terribly difficult, frightening, and disorienting, and patients deserve to have a calm, confident and unified stance family and professionals. Patients are best served if they receive consistent, factual information about the illness and coordinated messages about treatment, and prognosis. When there is a difference of opinion, it should be a priority to sort out any disagreements without the patient present. The value of being on the same page, same line, and the same letter, so to speak, cannot be overstated.

WHAT CAN WE DO AS A FAMILY TO SUPPORT TREATMENT?

Taking care of an ill child is not "normal" parenting, and families often need to learn new skills and techniques to support a loved one with an eating disorder. Below are some of the things that families can do:

- Let your child know that you understand the severity of the situation.
- Validate your child's feelings, but don't pretend to understand them.
- Acknowledge, but do not accommodate your child's fears.

- Set aside all feelings of blame.
- Learn caregiving skills such as motivational interviewing.
- Separate the child from the illness in your mind.
- Make sure all caregivers are “on the same page.”
- Require and support appropriate nutrition at every meal.
- Provide a warm and supportive family environment.
- Work with a clinical team with the most recent training and expertise
- Trust your bravest parental instincts and share these with providers.
- Be calm, confident and assertive as you advocate for your loved one.
- Trust that the symptoms you see are not intended to be a manipulation, but tend to be driven by powerful biological forces.
- Acknowledge the patient’s fears of letting go of the illness.
- Seek support for yourself as a caregiver to prevent burnout and to help you deal with the high stress levels that come with devoted and constant 24/7 caregiving.
- Remember that other children in the home may need support and reassurance that their sibling is getting appropriate treatment.
- Be patient and know that recovery is a long-term process
- Show confidence in your parenting and caregiving roles.

WHERE CAN I GET MORE INFORMATION ABOUT EATING DISORDERS AND HOW TO FIND EFFECTIVE TREATMENT FOR MY LOVED-ONE?

This Family Guide is one of a series of booklets published by F.E.A.S.T. Other titles in the series include:

PUZZLING SYMPTOMS: Eating Disorders and the Brain,
Fall 2012

PORT IN A STORM: How to Choose a Treatment Team for a Loved One with an Eating Disorder in the U.S., January 2014

Digital copies of all of the F.E.A.S.T. Family Guides can be found at:
www.feast-ed.org

APPENDIX A: DSM-5 DIAGNOSTIC CATEGORIES

Eating Disorders are diagnosed in the U.S. according to specific criteria in the Diagnostic and Statistical Manual of Mental Disorders (DSM). The latest version of this manual, published by the American Psychiatric Association (APA), is the DSM-5, which was released in May 2013.³ The DSM-5 categorizes Eating and Feeding Disorders as follows:⁴

- Anorexia Nervosa (AN)
- Bulimia Nervosa (BN)
- Binge Eating Disorder (BED)
- Pica
- Rumination Disorder
- Avoidant/Restrictive Food Intake Disorder (ARFID)
- Other Specified Feeding or Eating Disorder (OSFED)
- Unspecified Feeding or Eating Disorder (UFED).

The OSFED and UFED categories apply to cases where behaviors cause clinically significant distress and/or impairment of functioning, but do not meet the full criteria for any of the other Feeding or Eating Disorders. *These new categories are not an indication of a less severe eating disorder, simply a different constellation of symptoms.*

Health care providers in the U.S. use specific diagnostic codes based on the DSM-5 to bill private health insurance companies for treatment.

APPENDIX B: COMMON LEVELS OF CARE DEFINED

Below are descriptions of the most common types of treatment environments in the U.S. Please note that the terminology used in this guide may have a different meaning in other countries and/or health care systems.

Outpatient (OP): The patient lives at home and attends regularly scheduled (usually 45-50 minute) sessions at a therapist's office. This typically includes one or more sessions per week. The patient may be seen individually, with the family, in a group format with other patients, and/or sometimes in a multi-family group format. The type of therapy prescribed will depend on the age of the patient, the prescribed treatment plan, and the philosophy of the provider. Outpatient treatment does not usually include supervised meals.

³ Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, DSM-5, 2013, American Psychiatric Association, ISBN-13: 978-0890425541

⁴Some changes from the DSM-4 include the addition of BED, the grouping of Feeding Disorders with Eating Disorders, and the replacement of EDNOS (Eating Disorder Not Otherwise Specified) with OSFED and UFED.

Intensive Outpatient Program (IOP): The patient lives at home but spends some of their time at a clinic for therapy sessions and limited meal support. A common IOP schedule would be three hours per day, three days per week, and includes dinner.

Day Treatment Program: The patient lives primarily at home but spends four to twelve hours per day at a hospital or clinic for individual, group and family therapy sessions and meal support. Typically the patient will eat at least two meals and a snack at the program each day. Day treatment programs may or may not include weekend housing and or support.

Partial Hospitalization (PHP): The patient lives at home but spends six to twelve hours per day, five to seven days per week at a hospital or clinic for individual, group, and family therapy sessions, medical oversight, and meal support. Typically the patient will eat at least two meals and a snack at the program each day. Some PHP programs will provide housing and keep a patient overnight for parts of the week.

NOTE: State regulation and licensing will influence whether there are day treatment and/or partial hospitalization programs in your community.

Inpatient (IP): The patient is hospitalized, usually for medical and/or psychiatric stabilization, and may or may not receive therapy. Hospitalization can occur on a voluntary or involuntary basis. Some hospitals have psychiatric beds for involuntarily admitted patients and some do not. Often Inpatient stays take place at a general medical or psychiatric facility which may or may not have a specialized eating disorder unit. Meal support at a general facility usually focuses on medical stabilization (not weight restoration) and may not include regular meal support.

Residential: The patient lives full time at a specialized eating disorder facility where 24/7 care is provided. Residential treatment usually requires a longer-term stay ranging from a few weeks to several months to a year or more. Residential care is usually indicated when outpatient interventions have not been successful at interrupting eating disorder symptoms and when the patient needs a highly controlled environment to restore weight, stop binge eating, purging or other self-destructive behaviors.



**FAMILIES EMPOWERED AND SUPPORTING
TREATMENT OF EATING DISORDERS**

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