

Inpatient Nutrition Recovery for Children

**Child & Adolescent Psychiatry
Adolescent Medicine**



**C.S. MOTT
CHILDREN'S HOSPITAL**
UNIVERSITY OF MICHIGAN HEALTH

Introduction:

Welcome to C.S. Mott Children’s Hospital at the University of Michigan. Your child has been admitted so we can manage their malnutrition and disordered eating. This information guide will help you understand what to expect during your hospital stay. Because every case is unique, there may be elements of this guide that do not apply to your child specifically. The treatment team will talk more with you individually about your child’s diagnosis, treatments, and the most appropriate discharge plan for your personal situation. We value patients and families as a vital part of the team and welcome questions and dialogue throughout your hospital stay.

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Who is caring for my child?

Mott Children's is a teaching hospital, which means that trainees may be a part of your treatment team. This may include:

- Nursing students
- Medical students
- Medical residents (graduated and getting special training)
- Subspecialty medical fellows (graduated and pursuing additional post-residency training)
- Nurse practitioner students

Trainees always work closely with and are under the supervision of:

- Faculty attending physicians (senior level physician)
- Nurse practitioners (nurses with advanced training like physicians)
- Registered dietitian nutritionists (RDNs)
- Registered nurses

We understand that it can be difficult to keep track of all the moving parts in this system, so please don't hesitate to ask providers to re-introduce themselves at any time or to clarify their roles on the team.

We follow a coordinated multidisciplinary care model.

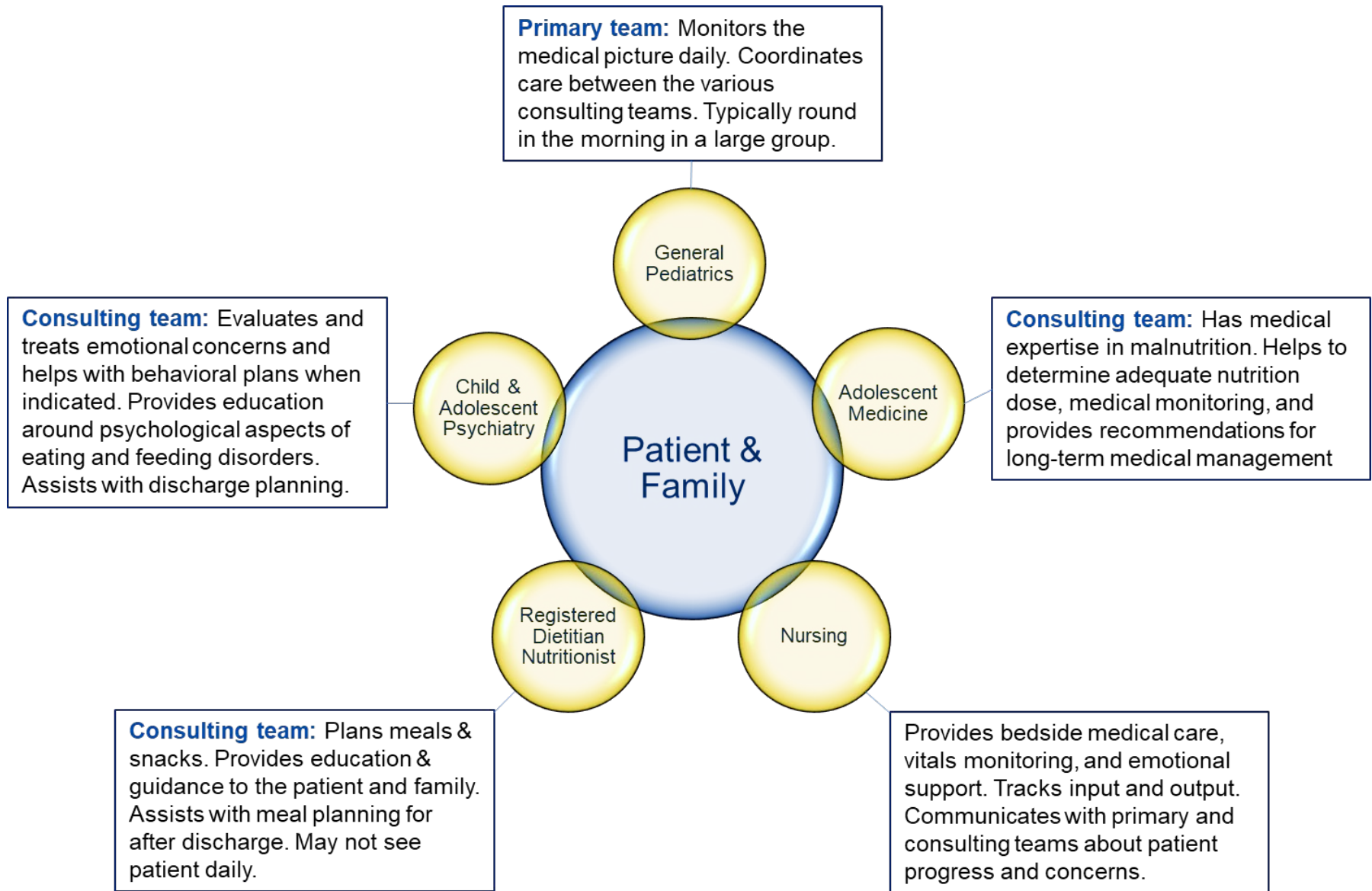
Your daily medical care will be managed by General Pediatrics, whom we call the **Primary Team**. Members of this team are in the hospital 24/7.

The primary team:

- Rounds (visits the room) daily
- Orders labs and medications
- Conducts physical exams
- Monitors vital signs
- Manages any co-existing medical problems that might be pertinent to your child's care (e.g., asthma, seizures, diabetes, etc.)

- Serves as your primary point of contact during your hospital stay

The primary team consults with subspecialty teams who have expertise in specific aspects of care. We refer to these providers as **Consulting Teams**. Three teams are always consulted for **every** patient who is admitted for nutritional recovery: Registered Dietitians, Adolescent Medicine, and Child and Adolescent Psychiatry. If additional consults are needed, the service will be requested by the primary team (for example: gastroenterology, neurology, endocrinology). Consulting services will conduct an evaluation first and provide input on diagnosis and management throughout the stay.



You may also interact with social workers, case managers, and staff from the outpatient side of the Comprehensive Eating Disorders Program (CEDP). We may also offer other important support services, including Child Life, Art Therapy, Music Therapy, Pet Therapy, and Spiritual Care.

As part of the multidisciplinary care model, you can expect to be visited several times a day by the various services involved in your care. Because of other obligations, individual teams may not round at the same time each day. Consulting services may not see your child every day but are closely involved and will have frequent communication with the primary team.

What is happening medically?

Your child’s body has entered a state of **starvation**. Without adequate fuel to provide the energy and nutrients it needs to function, the body turns inward to look for protein, fat, and sugar. The starving body breaks down tissue from vital organs like the heart, brain, intestines, kidneys, liver, and muscles and tries to use those break-down products as energy. This process is called **catabolism**. It prevents these important organs from functioning normally and puts your child at risk for life-threatening health problems. Furthermore, the starving body slows down all its systems to conserve energy. Left untreated, the body will eventually shut down completely. Signs and symptoms of starvation include:

Cardiovascular	Gastrointestinal	Hormones	Brain
<ul style="list-style-type: none"> • Low heart rate • Low blood pressure • Weakened heart muscle • Arrhythmias • Dizziness, fainting 	<ul style="list-style-type: none"> • Bloating • Delayed digestion • Constipation • Reflux • Pancreatitis 	<ul style="list-style-type: none"> • Menstrual changes • Bone density loss • Hypothermia • Thyroid dysfunction • Adrenal dysfunction 	<ul style="list-style-type: none"> • Decreased brain volume • Poor concentration • Slowed speech • Mood changes • Fatigue

Your child was admitted for medical care because the signs and symptoms listed above are severe enough that it would be **dangerous to manage their care outside the hospital**. The goals of this hospital stay are to stabilize your child medically and to create a long-term plan to keep them stable.

What is happening psychologically?

We use the term **eating disorder (ED)** broadly to include several different conditions that have been classified in the “Diagnostic and Statistical Manual of Mental Disorders—5th Edition (DSM-5)”. Eating disorders include:

- Anorexia nervosa
- Atypical anorexia nervosa
- Bulimia nervosa
- Binge eating disorder

Eating disorders have several features in common, including:

- Abnormal or distorted thoughts about food or eating
- Abnormal or distorted perceptions about one’s body or weight
- Problematic behaviors around eating, meals, and weight loss efforts

Your treatment team will talk in depth with you about your child’s specific diagnosis and the anticipated treatment and course for your situation.

Some patients are admitted for nutrition recovery because of a different condition under the DSM-5 heading of **feeding or eating disorder**. This includes:

- Pica
- Rumination Disorder
- Avoidant/Restrictive Food Intake Disorder (ARFID)

If one of these conditions fits your child, the treatment team will talk with you about the diagnosis and how the refeeding protocol might vary to address your child's needs.

Most of the information in this guide focuses on anorexia and bulimia. These are the most common feeding and eating disorders that require inpatient hospital stay for nutrition recovery. The psychological treatments we use to address chronic malnutrition due to disordered eating still apply regardless of the condition. We hope that the information below will help you during your child's nutrition recovery.

Understanding perceptual distortion

One of the most challenging features of eating disorders is that they completely change a person's ability to see themselves accurately. People will often feel, and **wholeheartedly believe**, that they look grotesque or fat, even when their weight is dangerously low. Typically, these misperceptions only apply inward. So, your child might recognize that others around them appear healthy, or that an average weight person is not fat, and yet be unable to view themselves the same way. This is called **perceptual distortion** and it can be very difficult for family and friends to understand or relate to.

Challenging perceptual distortion is an important part of the treatment for eating disorders and it requires subtlety and time. As you've no doubt found, simply telling your child that they are not fat is ineffective. We may be able to begin the work of challenging perceptual distortion with your child here in the hospital, but in many cases, the degree of malnutrition prevents us from making significant gains in this area.

The parts of the brain that are responsible for higher-order thought processes like logic, reason, and emotion regulation do not function well in a

malnourished state. Instead, the brain defaults to **rigid thinking**, which means it is inflexible or stuck in a particular way of thought. This comes with huge instinctual emotional reactions. Attempts to rationalize are often met with extreme anger and fear. This may prompt your child to say or do things that would otherwise be out of character for them.

The distorted thoughts associated with the eating disorder often do not improve until after nutrition is **restored and maintained** for weeks or months. Your child and family will need to engage with a skilled therapist to understand how to best support your child around these thoughts over time. We will help in coordinating an aftercare plan that includes a focus on therapy needs (see the section on discharge, page 34).

Right now, the single best treatment for your child's distorted thoughts and perceptions is to restore their nutrition.

Later in this guide, we suggest specific things that you and other family members can do and say to help with rigid thinking and misperceptions, especially during meals, which tend to be the most difficult and high-stress times. Please refer to the section titled, "**Knowing what to say and do**" on page 29.

Our conceptual model

In thinking about eating disorders, we find it helpful to **externalize** the condition from the person. We sometimes use metaphor to explain this concept: the eating disorder is an **invader or hijacker** taking over your child's brain. This allows us to **reframe** the problematic behaviors that have led to malnutrition: the patient doesn't *choose* to restrict their food, over-exercise, or lie about what they have eaten; the eating disorder *makes* them do these things.

Externalizing the eating disorder puts everyone—the patient, family, and the medical providers—on the same team fighting against the eating disorder. Families have told us that thinking of the situation in this way allows them to aim the **frustration or anger** that they sometimes feel about their child’s behaviors at the eating disorder. In turn, parents can preserve a **sense of empathy** for their child as the victim of the illness.

The person is not the problem. The problem is the problem.¹

Externalizing the eating disorder also allows us to externalize the concepts of **power and control**. Eating disorders often affect people who are high achievers normally. They are used to feeling in control of their choices and are typically very skilled at handling that control. They earn good grades, participate in productive activities, follow the rules, stick to plans, and maintain strict routines. These personal qualities can be very helpful when directed down the right channels (e.g., school performance, sports, artistic endeavors, family responsibilities, etc.). For people who are struggling with eating disorders, however, these qualities become **liabilities**.

The eating disorder **steals control** from your child and sets up its own rules about:

- What to eat
- How much to eat
- How often to exercise
- When to throw up or use laxatives
- What to say or how to behave when someone else challenges them about any of these things.

As a rule-follower, your child complies. Over time, your child effectively becomes a straight-A student in the subject of malnutrition. At the same time, your child continues to have their own goals and drive to achieve all the things they are accustomed to achieving—good grades, extracurricular activities, personal relationships. Your child is caught between **two competing goals and rule sets**: what they want for themselves and what the eating disorder wants for them.

It's hard to focus on schoolwork when your mind is consumed with calorie counting. It's hard to hang out with friends when you're always worried about how you look, or what you'll say if your friends want to go out to eat. It's hard to be honest with your parents when they're constantly asking about how much you've eaten, and you don't want to let them down. In addition, your child is trying to negotiate these things **with a malnourished brain and body**.

The battle for control is absolutely tiring, physically and emotionally.

Externalizing the power and control helps relieve your child of the burden of engaging in this back-and-forth struggle. Imagine a volleyball game, with your child on one side and the eating disorder on the other. The volleyball represents power and control—power over food choices, meal quantities, exercise, purging behaviors, truth-telling, and emotion regulation. The ball pops from side to side, constantly changing hands. The solution here, at least in the short term, is to **remove the ball**.

In the hospital, the treatment team is the referee, removing the “control” ball from the court entirely. The treatment team:

- Chooses the food
- Sets the meal schedule

- Prevents physical overexertion
- Monitors the body's response to treatment

The eating disorder can't steal control if there isn't any control up for grabs.

We'll return to this concept later in this guide when we discuss the dangers of negotiation (page 31). When the time comes to transition home, we will strongly advise that you, the parent, take over as the referee. Your outpatient team will help you create a plan for slowly returning the power and control back to your child.

This externalization model follows the **Family-Based Treatment (FBT)** approach to eating disorder care, which has compelling evidence for success. The Michigan Medicine Comprehensive Eating Disorders Program (CEDP) uses the FBT model in all levels of care, including the partial hospitalization program (PHP), intensive outpatient program (IOP), and outpatient care. Other types of therapy and therapeutic principles can also be helpful in treating eating disorders, including cognitive behavioral therapy, dialectical behavioral therapy, and supportive therapy. The psychiatry team will talk with you more about specific therapeutic models and approaches that could be helpful for your child.

A note of caution about externalization

Some people recoil against the idea that the eating disorder is a hijacker. One concern that patients have shared with us is that separating the condition from who they are as a person (externalizing) feels like it invalidates their experience. Similarly, some people feel that externalizing the disorder means the person is helpless and removes any sense of responsibility for their own recovery.

We have thoughts about each of these concerns. We separate the *cause* and the *experience* and the concepts of *blame* and *responsibility*. We would be happy to share these ideas with you in more depth. If you or your child feel that a different way of viewing the eating disorder would be more helpful, we are happy to discuss that too. If you would like to read more about the conceptual model of externalizing the eating disorder, please see the **Further Reading** section at the end of this guide.

In the end, we all want the same thing for your child: to restore a more typical relationship with food and eating; to emerge free from the emotional toll of negative body image; and, ultimately, to live a happy and healthy life.

The broader emotional picture

An important part of comprehensive eating disorder treatment involves **fully assessing the emotional state**. As we've detailed above, coping with an eating disorder is emotionally draining. The internal conflict for power and control is relentless; living with that conflict day in and day out can lead to feelings of defeat or hopelessness. The malnourished brain also poorly regulates emotion and thinks irrationally, leading to problematic changes in behavior and self-esteem. It is not uncommon for people to develop symptoms of **depression and anxiety** when they have an eating disorder, sometimes to such a degree that they struggle to function.

We also know that specific psychiatric conditions can pre-date the eating disorder and coexist alongside it over time. When a person has more than one condition, they are called **co-morbid**. These include but are not limited to:

- Major depressive disorder
- Generalized anxiety disorder
- Social anxiety disorder
- Obsessive compulsive disorder

- Bipolar disorder
- Post-traumatic stress disorder

It is vital that we identify and treat all **co-morbid conditions** to be effective.

Unfortunately, symptoms of depression and anxiety tend to worsen as the eating disorder strengthens and the malnourished body weakens. People sometimes cope with thoughts of suicide and may even develop specific plans for acting on those thoughts. Anorexia

nervosa has the highest mortality (death) rate of all psychiatric illnesses, estimated at 10 out of 100 (10%), with 1 in 5 of those deaths occurring by suicide.^{3,4}

56 out of 100 (56%) of adults with anorexia and 94 out of 100 (94%) of adults with bulimia also meet criteria for at least one other psychiatric condition. Symptoms often begin in adolescence.²

The child psychiatry consult service will meet with you and your child to conduct a full psychiatric evaluation, including a

comprehensive safety assessment. As part of this process, it will be important for the psychiatry team to spend some time with your child individually. They may also ask to meet with you outside the presence of your child. Any diagnoses made or treatments recommended will always be discussed with you and your child.

What does nutrition recovery involve?

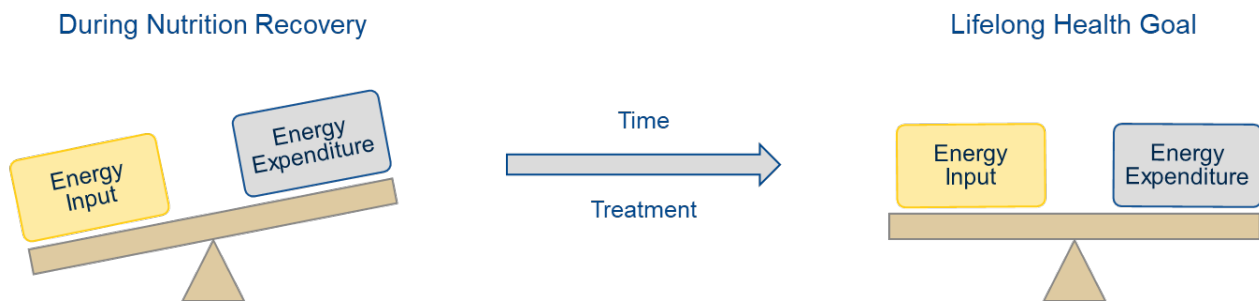
We follow an evidence-based approach to treating malnutrition, implementing a gradual refeeding plan. We start with small amounts of food that your child's body can tolerate and increase the calories incrementally over time. It is important to nourish a starving body slowly, as moving too quickly can lead to a potentially life-threatening complication called **refeeding syndrome**.

Refeeding syndrome

When we replenish nutrition, it can lead to changes in fluid and electrolyte levels in the body. If done too quickly, these fluid and electrolyte shifts can have damaging effects on organ systems in the body, potentially causing dangerous complications like heart failure, respiratory failure, seizures, and muscle breakdown. This is called **refeeding syndrome**.

Refeeding syndrome is rare, and we vigilantly monitor for it with regular blood draws to track **phosphorous, magnesium, and potassium levels** closely. We provide supplementation as needed to maintain appropriate levels of these electrolytes. The danger of refeeding syndrome decreases over time. As discharge approaches, you will be provided with information about calorie needs and meal planning to ensure a safe transition home.

As we provide supervised and measured nutrition, we simultaneously **limit energy expenditure**. This helps to ensure that all the important energy taken in by your child is being used to repair and rebuild the body, without using any unnecessary energy. As the body heals and weight is restored, energy expenditure will be reintroduced gradually. In this way, the process of nutrition recovery involves finding a careful balance between the input and output of energy, with close medical supervision and monitoring.



In the hospital, this symbolic scale will be significantly weighed toward the side of energy input, because our goal is to repair cells and restore weight.

Gradually, even during this hospital stay, your child’s body will send signals indicating that some physical activity is safe to resume. Full return to a more typical input-output balance is likely to take quite some time, however, even weeks to months after discharge, with continued supervision and monitoring from your long-term outpatient team.

The sections below provide more detail regarding nutrition administration and activity limits during inpatient nutrition recovery.

Food selection and schedule

A varied meal plan

Nutrition is the primary treatment for malnourishment and disordered eating. Consuming a **variety of different foods** is important to ensure that your child receives all the macronutrients (like carbohydrates, fats, and proteins) and micronutrients (like vitamins and minerals) it needs to recover. Eating a wide variety of foods is also important from a psychological perspective, as your child has likely been restricting specific foods or categories of foods and needs to **re-learn to eat** them. Similarly, the tongue needs to **get used to diverse**

tastes again and the gut needs to be **re-trained to digest** different elements of nutrition (sugar, starch, fiber, cholesterol) present in diverse foods.

In addition to variety of food, we will often choose foods that have **high caloric density** (foods with lots of calories in a smaller volume). These foods allow us to give your child the calories they need in small amounts without causing too much stomach discomfort (lower-calorie foods would need to be given in larger amounts). Consequently, we may ask your child to eat foods or classes of foods that your family would not typically eat at home. We understand that this will be challenging for your child; we liken this to taking medicine that tastes bad or causes discomfort but is necessary to heal.

For your child, right now **food is medicine.**

If you have questions about the types of foods that are being provided, we will happily discuss this with you, but we ask that this conversation happens **outside the presence of your child.** As we noted earlier, the eating disorder is constantly looking to seize control of the situation; even simple discussions about food choices give the eating disorder the opportunity to negotiate its way back into power.

Menu selection

The **Registered Dietitian Nutritionist (RDN) will select all foods** for your child. If your child needs to eat meals or snacks before the initial evaluation by the RDN (such as the first breakfast after being admitted overnight), the **nurse will choose** the food with input from the parent using a pre-set “refeeding” menu. If your child is admitted after Room Service is closed, we will provide you a pre-set standard boxed meal.

During their initial assessment, the RDN will ask your child to identify 3 “No Foods” that they do not like and will not be required to eat. These 3 foods will be recorded in the chart and cannot be changed during the hospital stay. Foods falling under religious restriction, medical allergy, or preexisting medical comorbid condition (e.g., celiac disease, diabetes, kidney disease, etc.) will also be excluded from the menu and do not count toward the 3 “no foods.”

Acceptable vs unacceptable examples of “no foods”		
Acceptable		Unacceptable
✓	Tomatoes	✗ Bread (too broad)
✓	Bacon	✗ Meat (too broad - see below regarding vegetarianism)

We cannot allow any food from home. All food will be chosen by the RDN, ordered by the nurse, and delivered via Room Service. You are welcome to order guest trays for yourself or to bring in outside food for yourself. We ask that you not bring in diet- or exercise-oriented foods for yourself (e.g., Slim Fast shakes, Weight Watchers meals, Muscle Milk, etc.), as these can be challenging for your child to see in the room.

Vegetarianism and veganism

If your child identifies as vegetarian or vegan, we will ask that you help to clarify the start of this practice relative to the start of eating disordered behaviors. It is not uncommon for people to begin restricting food with single items and then move on to restricting entire classes of food. If the vegetarianism or veganism started as a part of the eating disorder, it will be important for us to gradually reintroduce foods that have been “banned” in that context.

Additionally, because your child needs a high number of calories, it is more difficult for their body to tolerate the amount of food required to reach those calories with a vegetarian or vegan diet. If your child or family has been vegetarian for years, or if the practice is part of religious tradition, we will accommodate as we are able. If you have questions or concerns about this approach, we would be happy to discuss this further.

Meal schedule

Food is administered in **3 meals** and **3 snacks**, following a set schedule:



Patients sometimes say that it feels like they are “always eating.” We divide the food into six meals for several reasons, based on **research and experience**:

1. First, because of the significant level of malnutrition, the amount of food your child needs to consume is quite large, especially relative to what they were eating before admission. Dividing the food into six meals allows us to give your child the calories they need in **manageable amounts** to minimize physical discomfort.
2. Second, the hunger and satiety (fullness) signals are impaired when there is prolonged malnutrition. The **stomach also empties more slowly** than it does in a well-nourished individual. Eating on a set schedule, even if your child does not feel hungry, trains the stomach to empty more quickly and heal. Eventually, the hunger signals will normalize again.
3. Third, eating on a set schedule makes the refeeding process more **predictable and routine**, which may help to lessen the anxiety around food.

4. Fourth, eating every few hours stabilizes the blood sugar, which can prevent uncomfortable shaking, headaches, and irritability.
5. Finally, the act of eating is frightening and anxiety-provoking for people with eating disorders, like a phobia. Eating every few hours provides an exposure exercise for your child to **gradually overcome their fear** in a supportive setting.

Time limits

Your child will have a set amount of time to complete the meal or snack: **30 minutes for meals** and **15 minutes for snacks**. The nurse will “start the clock” when the tray is presented and will provide updates on the time remaining (such as: “you have 5 minutes left.”). The nurse cannot “extend the time” for your child to finish, as it is important to maintain the schedule. Deviations from it can set the pattern for negotiations around rules and protocol, giving the eating disorder an opportunity to seize control.

Completing the meal or snack means that your child has eaten *everything* delivered on the tray, including beverages, toppings, and condiments (such as: mayonnaise, butter, cream cheese, syrup, salad dressing, ketchup etc.). Exceptions to this include: salt, pepper, mustard, parsley garnish, and lemon wedges.

Your child will be encouraged to eat as much as they can during the allotted time. If they are unable to finish the meal in its entirety, they will drink a **liquid supplement** to provide the needed energy that they were unable to consume via food.

The nurse will determine the amount of supplement needed by referencing a formula that takes into account both the amount of

Time Limits	
Meals	30 minutes
Snacks	15 minutes
Supplement	10-15 minutes

food remaining on the tray and the calorie level for the day. The amount given

is not negotiable. Your child will then have 10-15 minutes to finish the supplement (depending on volume).

If it seems like your child's food tray is delayed, use the call button to alert your nurse. We want to stay on schedule without causing distress for your child or interrupting their time during or between meals.

If your child is unable to consume nutrition orally

Finishing food and supplements will likely be the most challenging part of the hospital stay for your child, but it is also the most important part. Taking in 100% of the nutrition provided is what their body needs. If your child is unable to finish the supplement by mouth, then we will provide that important nutrition to their body using a **nasogastric (NG) tube**. This is a small flexible tube that is inserted into the nostril and threaded down the esophagus and into the stomach. The nurse will insert the tube at the bedside, and we will confirm the position of the tube via x-ray. The liquid supplement can then be given through the tube.

It is important to note that use of an NG tube is **not punishment** for being unable to finish the supplement; it is a tool for providing vital nutrition to the body. We tell your child about the conditions for tube use at the time of admission so that they are not unprepared if it is needed later. It is important that the use of a tube **not be presented as a threat**; it is a medical intervention, just like using an IV for a dehydrated patient who cannot drink, or a ventilator tube for a patient who cannot breathe on their own. We will take care to ensure that tube use is not presented with judgement or shame-inducing for your child.

If an NG tube is needed **to help your child with their recovery**, we will leave it in place until they can consistently complete the food and supplements by

mouth. We do this to minimize the distress of placing and removing a tube. Your child will still be able to eat and drink with the tube in place, and they will be given the opportunity to eat food first and drink the supplement orally for each meal and snack.

While the insertion of an NG tube is a strange sensation and can be briefly uncomfortable, it is generally not painful and the process is over quickly. If you or your child feel that tube placement will be distressing, **please let us know about your concerns**. Child Life can be very helpful in providing distractions and support during procedures. The child psychiatry consult service is also happy to talk with you about coping strategies and as-needed medication to help with anxiety during this process.

Activity limits during nutrition recovery

Limits on physical exertion

The body needs to take in more energy than it uses while it is medically stabilizing. Even seemingly insignificant activities like getting out of bed to look out the window require significant energy use. In fact, when a body is in a state of malnourishment or starvation, **the impact of small movements can be profound**:

- The heart must work harder to supply blood to the muscles and brain
- Muscles must divert energy toward motion at the expense of repair
- Blood vessel systems must work harder to sustain an upright position to prevent fainting or falling.

All of these things hinder cellular repair and weight gain.

Your child is working hard to take in nutrition and energy; we limit activity to ensure that all their effort is put toward recovery.

For at least the first few days, your child will be placed on **complete bedrest**. This means that they will be able to get up only to use the bathroom and only with help. Bathing will be by sponge bath only. The medical team will closely monitor vital signs and weight gain (discussed in more detail in the next section) to determine when it is safe to advance physical activity.



We understand that these limits **may be challenging** for your child. Physical activity and exercise have likely been an important part of their life, even before the start of the eating disorder. Beyond that, bedrest can make *anyone* feel a bit stir-crazy. We recommend **keeping the mind and hands as busy as possible** during the hospital stay. We have a robust movie library, internet access, live TV, and Xbox games. Child Life can help with providing other sedentary activities—books, crafts, puzzles, board games, Legos, etc.—and we are happy to involve Music or Art Therapy.

Checking-in on exercise

One common way for the eating disorder to try to regain control of the situation is to push hard for your child to exercise “under the radar.” Patients tell us that they often feel the urge to exercise in bed, and we will sometimes find patients subtly flexing or contracting their biceps, abs, glutes, or thighs. Resisting this drive can be challenging.

We will check in with your child regularly about how they are doing with managing urges to exercise. Nursing and the patient care attendant (more on this below) will also help to monitor for any signs of exercise. You know your child best. If you have concerns that they are struggling with resisting the urge

to exercise, please let us know. We want to be as supportive and helpful as possible.

Limits on emotionally stressful activities

Some patients find it helpful to do schoolwork while they are in the hospital, as it distracts from boredom, provides a productive outlet for their thoughts, and helps to keep them in touch with their regular life. For some patients, however, schoolwork is stressful or takes away from their ability to focus on their recovery, which is their most important obligation in the hospital. The treatment team will talk with you about this, considering the specifics of your child's situation.

Cell phone and internet use can be a useful distraction tool. However, if your child is using a device to track calories, visit pro-eating disorder websites, or engage in self-destructive social media practices, we will need to limit their access. We will talk with you about any concerns that are raised by nursing or other staff so that we can work together to come up with the best plan for protecting your child from destructive influences during their recovery.

Limits on bathroom access

Some patients with eating disorders struggle with purging (self-induced vomiting). To prevent this harmful practice, we restrict access to the bathroom for 1 hour after meals or snacks. The nurse will encourage your child to use the bathroom before eating to minimize discomfort.

Even for patients who have never struggled with purging, we maintain bathroom limits for physical safety. Dizziness is common with malnutrition and during refeeding, and patients undergoing this protocol are at risk for fainting or falls.

During bathroom use for toileting and showers, the door must remain cracked open so that staff can hear any sounds of distress and have easy access to assist your child. During less private activities like teeth brushing and hair styling, the door should remain fully open.

Limits on room temperature

Some patients with eating disorders struggle with the urge to set the thermostat to unreasonably high or low temperatures, thinking that sweating or shivering will burn calories. We want patients and families to be comfortable during their stay and we understand that malnutrition often causes individuals to feel particularly chilly relative to others in the room. If you feel that the room temperature needs to be adjusted, please talk with your nurse. We will be happy to adjust the thermostat within a comfortable range.

Monitoring during nutrition recovery

Vital signs

Your child will be placed on a cardiorespiratory monitor that will remain connected 24 hours a day. This provides us with continuous information about how the heart and lungs are functioning. Your nurse will record your child's heart rate, blood pressure, respiratory rate, and temperature regularly (every few hours initially, even overnight).

Your nurse will help when you need to disconnect or reconnect the monitor.

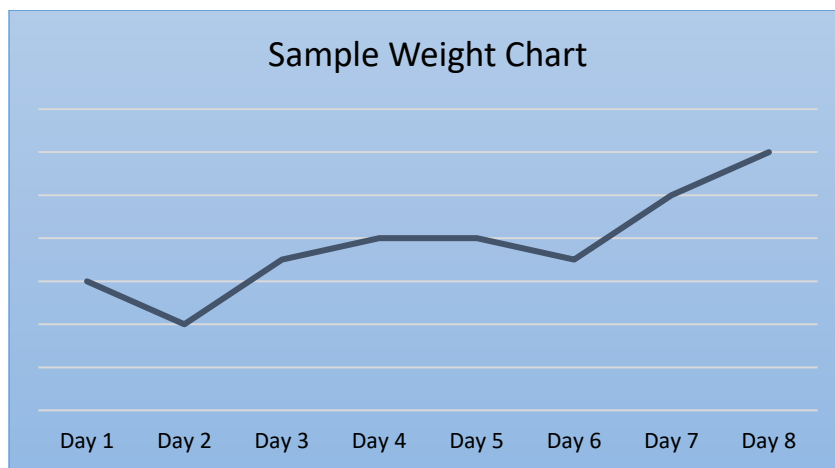
We will also check **orthostatic blood pressures** once daily, which involves taking your child's blood pressure while they are lying down, sitting up, and

standing, with a 2-minute pause between each reading. This gives us helpful information about fluid status and the heart's pump function.

Weight

Your child will be weighed every morning after the first void (urination). To remain consistent, the weight will be taken on the same scale, at the same time, and in the same way each day. Your child will only wear a hospital gown and underwear for the check.

We perform **blinded weight** checks with our patients, which means that your child will not be able to see—and **should not** be told—the number. This frees your child from worrying about the specific number on the scale and helps to prevent backslides in food intake as the weight starts to increase. We will share the weight with you separately during rounds.



Often, the weight drops in the first few days. As the body gets enough calories, weight will begin to rise. There may be days with no weight gain, or even days with weight loss. This occurs as the body uses calories to repair organ systems

and replenish nutrition stores. Watching the weight trend (change over time) can help us to determine the appropriate calorie needs for your child.

Please do not share with your child specific weights or even whether there was a change in weight at all.

It may be helpful in the future for your child to know their weight and process the emotions related to it, but this is something that will occur with the guidance of their therapist and outpatient treatment team.

Labs (blood draws)

Initially, labs will be drawn every morning to monitor electrolytes, glucose, kidney status, and liver function. As your child's condition stabilizes, labs may be spaced out over time. We will share the results with you during rounds and discuss any interventions needed (such as providing oral phosphorous supplementation).

Fluid status

Fluid balance is very important in the process of restoring nutrition and preventing refeeding syndrome. Your child will be given a minimum amount of fluid to drink each day, provided as beverages with meals and snacks, plus some additional water. A **fluid goal** may be instituted (including a **daily maximum**), and there may be times that we have to slow down or restrict your child's fluid intake.

Sometimes, patients who are struggling with eating disorders will overload on water to falsely pad their weight or to create a feeling of fullness without taking in calories. This can lead to dangerous electrolyte problems and can overburden the heart. It may be necessary for us to closely track your child's fluid "ins and outs" or to evaluate the urine to monitor water levels. We will talk

with you about fluid status during rounds and answer any questions you may have about restrictions or monitoring.

Supervision and the Patient Care Attendant

For **at least the first 24-36 hours** of the admission (48-72 hours if admitted over a weekend), a Patient Care Attendant (PCA) will sit in the room for supervision and support. We understand that this can feel like a strange or even intrusive aspect of care, but the PCA is an important part of the team for many reasons:

- The PCA supports your child and family through meals and snacks. In particular, the PCA can help the parent or adult family member watch for and stop any behaviors that may negatively impact your child's recovery (such as hiding food, exercising, attempting to purge, etc.). In providing this extra oversight, the parent is not the only one in the room who is monitoring the child, helping to preserve the child's view of the parent as an ally rather than an authoritarian.
- The PCA's presence allows the parent(s) to leave the bedside periodically, to attend to family or work concerns or to take a break for their own self-care.
- Some patients have an easier time completing meals when a member of the care team is present. The theory is that this person's presence in the room, even if they don't interact with your child, signals to the eating disorder that someone is watching and that any efforts to seize control will be thwarted.
- If there have been any safety concerns regarding self-harming behaviors or active suicidal thoughts, the PCA provides oversight and protection in that area.

It is our preference to use the patient care attendant's services throughout the entire admission. However, once we have had a chance to get to know you and your child and to fully assess the specific concerns or risks in your child's case,

it may be appropriate to discontinue the PCA. To consider this, an adult family member must be present for all meals and snacks and provide continuous supervision and support throughout the entire day. Please **tell your nurse immediately** if you or your child have any concerns about the specific PCA working with you.

Knowing what to say and do

Supporting a child through the treatment of an eating disorder is challenging. Many parents struggle with knowing what to say and how to be helpful, especially during meals and in times of emotional distress. The section of this guide titled “**What is going on psychologically**” is a helpful place to start in order to understand your child’s cognitive and emotional entanglement with the eating disorder.

We also advise that you watch the following short video, available on YouTube (you can find it by searching for the title, “Helping your child eat with trust, not logic: the bungee jump”: <https://youtu.be/2O9nZAWCkLc>).⁶ It may be helpful to watch this video several times.



Fear and compassion

Your child is living in a nearly **constant state of fear**—fear of food, fear of gaining weight, fear of losing control, fear of losing their identity, fear of disappointing you, fear of disappointing the eating disorder, fear of giving in to

the eating disorder. Living in fear means functioning at high-alert at all times, being hypersensitive to anything that might be perceived as a further threat. Every time a meal is presented or exercise is limited, these **internal fear alarms sound**. The eating disorder gets very strong in these moments, elevating the fear of food and gaining weight, and increasing your child's level of distress.

Prior to the hospital stay, your child would calm these fears by restricting, exercising, or purging. These options are unavailable to them now, so you are likely to observe them grasping for control in other ways. This often takes the form of repeated questions or comments about the types or amount of food:

- “This is too much food.”
- “They’re feeding me too often.”
- “It’s too much too soon.”
- “I wouldn’t have eaten that, even before the eating disorder.”
- “This is really unhealthy food and it would be bad for anyone.”
- “No one could eat this much food.”
- “I’m too full, I don’t have room for any more food.”

Often, these comments then precipitate pleas for you as their compassionate parent to intervene on their behalf. This is an incredibly challenging position to be in as a parent. You want to align with your child, but you also know that nutrition is what they need to recover.

It is important to remember at this point that your child is coping with all this under the burden of a malnourished brain. The higher-order functions of logic, reason, and emotion regulation are not available to your child right now. This is why attempts to rationalize with them are ineffective and will likely trigger severe emotional outbursts.

The most helpful responses from you are ones that **validate your child's distress** and then **confidently reinforce the plan**. Vague statements that don't invite further discussion are very useful:

- "I'm so sorry you're feeling this way. This is very hard."
 - **Note:** Try to avoid saying "*I know* this is hard," because you may be met with a response about how you *don't know* what this is like.
- "They're giving you what you need."
- "Let's trust the experts, they know what your body needs."
 - **Note:** Once you've responded with validation and reinforcement, it's probably best to change the subject or transition to a distracting activity. Getting caught in a loop of these exchanges is not productive, and generally only fuels your child's distress.
- "It seems like the eating disorder is really strong right now. Let's focus on _____ (activity)."
 - **Note:** If your child is struggling to continue with the meal, it is most helpful to be direct and brief in encouraging them to keep going.
- "Please keep going."
- "Take another bite of _____."

The dangers of negotiation

As we've discussed, the eating disorder is constantly looking for ways to regain control of the situation. Simple discussions about food choice, food amounts, meal schedules, or activity limits signal to the eating disorder that the refeeding process is flexible, and by extension, interruptible. We caution against engaging in any negotiation. The old adage holds true, "if you give them an inch, they'll take a mile." Negotiating even one time about one small thing strengthens the eating disorder's hold on the situation.

Our staff is trained to pay close attention to efforts at negotiation, and we will help you to identify signs that the eating disorder is working to sabotage your child's recovery.

All this being said, we understand that there may be questions or concerns that arise regarding the protocol and we may even need to change the plan in certain situations. We ask that any discussions about this occur outside the presence of your child, so that we can better understand your questions and talk openly with you about how to proceed, without losing progress with the eating disorder.

The problem with praise

One of the most natural inclinations as a parent is to praise your child for doing the right thing, especially when doing the right thing is hard. In the setting of an eating disorder, however, praise can backfire. Patients have told us that it sometimes makes them feel worse when people tell them that they're doing a good job. This is because the eating disorder is telling them exactly the opposite: "You shouldn't have eaten that. You're being weak."

Feelings of **guilt and remorse are very common** after eating a meal or finishing a supplement, and what your child's malnourished brain hears when they're given praise is that they're doing a great job at giving in. Being praised for something you regret creates complicated emotions.

A simple alternative to praise is to use gratitude instead, padded with validation. For example:

- "That wasn't easy. Thank you for finishing that meal."
- "Thank you for taking the supplement."

Of course, every child is different. If praise would be helpful for your child, we certainly don't want to deny them that encouragement. We suggest that you

talk with your child about this from the beginning. Ask them, “Would it be helpful for you if I tell you that you’re doing a good job? Or is there something else that would be more helpful?”

Taking the cue from your child about these sorts of things is doing the opposite of negotiating with the eating disorder; it’s **empowering your child**. Finding out what would be most helpful for them to stand up to the eating disorder is a great way to align with your child and quiet down the eating disorder.

Eating alongside your child

For most people, it feels strange to eat in front of an audience. Many patients tell us that it is helpful when their family members eat with them, rather than stare at them. This can be a simple and effective way to align with your child. Just as with praise, we suggest that you talk with your child about this from the outset. Find out what their preferences are with respect to sharing mealtime.

Toward the end of the hospital stay, we may suggest that you do eat alongside your child, even if they didn’t want you to before, to practice what mealtime will be like at home. If you have any questions about what would be best in your specific situation, we are happy to share our thoughts.

Take care of yourself, too

This is a challenging situation for everyone. Please take time to care for your own needs while your child is in the hospital. Take a walk, go get coffee, take a shower. If it would be helpful to leave the bedside for a few hours, please do so. One of the benefits of the patient care attendant is that their presence allows you to take a break. Even after the hospital stay, caring for a child with an eating disorder is emotionally taxing and the recovery can be prolonged. Many

parents find that it is helpful to engage in therapy for their own support. We would be happy to help with resources and referrals in this area.

Planning for discharge

The medical team is constantly evaluating your child's physical response to treatment with the goal of getting them home as soon as it is safe to do so. We will begin talking with you about discharge plans and longer-term management recommendations at the start of the admission.

Some patients who are admitted for nutrition recovery already have a strong outpatient team in place and some have not yet established care with providers. If your existing outpatient care team is less familiar with eating disorders (perhaps they have been helping with another aspect of your child's care, like depression or anxiety), we may suggest that you transition to a more eating disorder-oriented provider, at least in the short-term. We will work with you to devise the best plan for your specific situation.

Most patients who are admitted for nutrition recovery are discharged home with an outpatient-based follow up plan. This includes several levels of care and outpatient models to consider. In some cases, however, further treatment in a hospital or residential setting is needed.

Several options for discharge planning are presented here; ultimately, the treatment team will talk with you in depth about the option that best suits your child's specific needs.

Office-based outpatient care

For some patients, a fully outpatient office-based care model works well. This would likely involve:

- Weekly appointments with a therapist
- Regular visits with your pediatrician or adolescent medicine for weight and vitals checks
- Medication management appointments with a psychiatrist (if your child is taking psychotropic medication)
- Office visit(s) with a registered dietitian nutritionist

Partial hospitalization programs (PHPs)

Partial hospitalization programs (PHPs) offer a “step-down” level of care from the hospital. These programs typically involve:

- In-person or virtual contact with specialists during school hours (for example, 7:30 am – 3:00 pm), five days per week
- Continued intensive therapy work
- Supervised meals
- Ongoing weight or vitals monitoring (varies by program)

The typical length of stay varies by program but averages around 2-4 weeks.

The University of Michigan offers outpatient PHP care through the **Comprehensive Eating Disorders Program (CEDP)**, which follows the principles of Family-Based Treatment, or the Maudsley Approach. More information will be provided to you about this program during the hospital stay, including whether the treatment team feels it would benefit your child. Read more here: <https://michmed.org/R3zGW>

We sometimes refer to outside (non-University of Michigan) PHPs as well. We will partner with you to explore all available options if the PHP level of care is appropriate for your child. Unfortunately, there are often wait lists for these programs, sometimes of several weeks long. We will work to develop a reasonable interim plan if you are faced with a wait for PHP.

Intensive Outpatient Programs (IOP)

Many PHPs offer a further “step-down” level of care, called an Intensive Outpatient Program (IOP). These programs are very similar (or sometimes identical) to the PHP except that the program runs fewer days per week.

Inpatient psychiatric care

For some patients, the emotional and behavioral aspects of the eating disorder remain active and problematic even after the body has medically stabilized. In these cases, discharge home and away from the supports of the hospital may be unsafe, or at least unlikely to position your child and family for success at maintaining medical stability. It can thus be helpful to transition the inpatient care from a medical focus to a mental health focus by transferring to an inpatient psychiatric unit.

- On average, an inpatient psychiatric stay lasts several days to one week (occasionally longer).
- In this setting, your child benefits from significantly more emotional and behavioral support, including skilled staff to help your child (and family) through all meals and snacks.
- An inpatient unit offers groups designed to teach and strengthen coping strategies, individual sessions for therapy and processing, and daily meetings with a psychiatrist.
- The inpatient psychiatry team will then work with the family to develop a safe and comprehensive discharge plan for longer-term care.
- If there are co-occurring psychiatric conditions like depression or anxiety, the inpatient psychiatric unit can help to address all concerns together

We have an inpatient psychiatry unit here at Mott Children’s Hospital, for patients 17 and under. If insurance coverage, physical location, or bed availability prevent a hospital stay at Mott, we will look for an appropriate

inpatient unit outside the University of Michigan system. Patients 18 and over will be admitted to an adult psychiatry unit.

If there are significant safety concerns relating to self-harm or suicidal thoughts, inpatient psychiatric admission may be suggested even apart from addressing the eating disorder. The psychiatry consult team will talk more with you and your child about inpatient psychiatric admission, if needed.

Residential eating disorder care

For some patients with eating disorders, longer term treatment in a supportive structured setting can be very helpful. The specific features of residential care vary significantly from facility to facility, including length of stay, which can range from several weeks to many months or even a year. Seeking residential treatment typically means looking out of state. Insurance coverage and out-of-pocket cost can be a barrier to residential care for some patients. If residential care would benefit your child, the treatment team will talk with you further about options and logistics.

Further reading and resources

Books and websites about eating disorders

- **“Help Your Teenager Beat an Eating Disorder,”** Second Edition by James Lock and Daniel Le Grange
 - Where to get it: <https://tinyurl.com/m7rj92w7>
From Guilford Press: “Top experts James Lock and Daniel Le Grange explain what you need to know about eating disorders, which treatments work, and why it is absolutely essential to play an active role in your teen's recovery—even though parents have often been told to take a back seat. Learn how to monitor your teen's eating and exercise, manage

mealtimes, end weight-related power struggles, and partner successfully with health care providers. When families work together to get the most out of treatment and prevent relapse, eating disorders can be beat. This book is your essential roadmap.”

- **“When Your Teen Has an Eating Disorder: Practical Strategies to Help Your Teen Recover from Anorexia, Bulimia, and Binge Eating,”** by Lauren Mulheim
 - Where to get it: Available from online book vendors
 - From the book jacket: “*When Your Teen Has an Eating Disorder* offers a unique family-based treatment (FBT) approach you can use to help your teen recover. You’ll learn how best to support your teen’s nutritional rehabilitation, normalize eating behaviors, and manage meals. You’ll also discover how to help your teen adopt independent and intuitive eating habits, expand food flexibility, and use coping strategies and recovery skills to prevent relapse. With this compassionate guide, you’ll feel empowered to nurture your teen and help them stay on the road to recovery.”

For further reading on externalizing the eating disorder

- “Should You Externalize Your (or Your Loved One’s) Eating Disorder? Who is Ed, anyway? Lauren Muhlheim, PsyD, CED (VeryWell Mind). Access: <https://tinyurl.com/cznztwmy>
- “Externalising the Eating Disorder” (Eating Disorders Queensland) – Access: <https://tinyurl.com/2x664zcc>

The following **websites** provide educational and supportive information on eating disorders. Many also offer guidance on how to locate an eating disorder provider in your local area.

- National Eating Disorder Association (NEDA):
<https://www.nationaleatingdisorders.org/>
- Academy for Eating Disorders: <https://www.aedweb.org/home>
- The National Association of Anorexia Nervosa and Associated Disorders, Inc. (ANAD): <http://www.anad.org/>
- Maudsley Parents: <http://www.maudsleyparents.org/welcome.html>
- Families Empowered and Supporting Treatment of Eating Disorders (F.E.A.S.T): www.feast-ed.org
 - Consider signing up for the free 30-day email support from FEAST
- National Alliance on Mental Illness (NAMI) <https://www.nami.org/>

Crisis support resources

- Suicide Prevention Lifeline - (800) 273-8255
- Michigan Medicine Psychiatric Emergency Services - (734) 936-5900
- If you feel your child is in **psychiatric crisis**, our Psychiatric Emergency Services is available 24/7 for evaluation and support. You can also present to your local emergency room for care or contact your local Community Mental Health for support.

References

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- ² NIMH Eating Disorders Statistics: https://www.nimh.nih.gov/health/statistics/eating-disorders.shtml#part_155062
- ³ Arcelus J., Mitchell A.J., Wales J., et. al.: Mortality rates in patients with anorexia nervosa and other eating disorders. A meta-analysis of 36 studies. Arch Gen Psychiatry 2011; 68: pp. 724-731
- ⁴ Herpertz-Dahlmann B. Adolescent eating disorders: update on definitions, symptomatology, epidemiology, and comorbidity. Child Adolesc Psychiatr Clin N Am. 2015 Jan;24(1):177-96.
- ⁵ NIMH Spotlight on Eating Disorders: <https://www.nimh.nih.gov/about/directors/thomas-insel/blog/2012/spotlight-on-eating-disorders.shtml#i>
- ⁶ Video and free downloadable handout credit to Eva Musby, <https://www.anorexiafamily.com>

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