

GETTING STARTED WITH REFEEDING

A GUIDE TO MOVING FORWARD WHEN YOU'RE NOT SURE WHAT COMES NEXT

by Therese Waterhous PhD, RDN, CEDRD-S

Edited by Judy Krasna

F.E.A.S.T. Executive Director



Getting Started With Refeeding: A Guide To Moving Forward When You're Not Sure What Comes Next Part Of The F.E.A.S.T. Family Guide Series

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ABOUT THIS GUIDE

While widely applicable to refeeding in general, this guide was written with parents in mind who are either waiting for their loved one to start treatment or who have no access to Family Based Treatment.

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Getting Started With Refeeding

A GUIDE TO MOVING FORWARD
WHEN YOU'RE NOT SURE
WHAT COMES NEXT

First Things First

Your child has been diagnosed with an eating disorder, and you may be wondering what this means. What are you supposed to do?

You can take a look at the descriptions of eating disorders found on the F.E.A.S.T. website.

Basically, eating disorders show up as eating that is not "normal." So what is normal?

Normal is eating without excessive concern. It is eating without anxiety, and it is eating enough. Generally speaking, it means *enjoying* the eating process.

Eating disorders look like eating that has become unenjoyable and chaotic. There is usually anxiety over some aspect of eating. It can be fear of weight gain, worry about what is in the food, worry that food is somehow not okay to eat or contaminated, worry about others judging you for what you eat, or not enjoying social eating occasions. Worry and fear are there, which makes eating difficult. [1]

People with eating disorders don't choose this path. It is something that happens to them. They often do not know what is happening and they have little to no insight about what is happening. They can't "just eat" or make scary thoughts go away.

Behaviors seen with eating disorders are:

- **Restriction** restricting food intake to the point that a person is not getting enough to eat
- **Purging** behaviors self-induced vomiting, exercising way too much to get rid of calories, taking diet pills, taking laxatives
- **Binging** eating way more than a person usually eats all at one time to the point of not feeling well; feeling like one can't stop eating.

All of these behaviors can lead to <u>serious medical issues</u>. All of these eating issues make life less than enjoyable for our loved ones, and we want to help them return to a joyful life, to the fullest degree possible.

There are some things that need to be taken care of or looked into before you start to treat your child at home:

- Your child needs a medical evaluation to make sure they are medically stable for outpatient treatment, especially if they have lost a lot of weight. No matter what their weight is today, if they have lost more than 10 pounds in just a few weeks, that is dangerous. Or, if they have not gained the expected amount of weight according to their growth curves, that also represents weight loss.[2] Kids need to gain weight as they grow. If they are trying to grow and not gaining weight, that means they are not eating enough. A doctor needs to check their vital signs and make sure they do not need to go to a hospital to be stabilized. The medical evaluation also needs to assess whether the child is at risk for refeeding syndrome, described here(2). Give this paper to your doctor if they seem to not know about refeeding syndrome when you ask about it...and do ask about it. All of us, even your child's doctor, need reminders!
- You need to trust your instincts and/or get help from a mental health provider or your child's doctor if you feel your child is unsafe, could harm themselves, or present with other dangers. Sometimes people with eating disorders have other mental health issues that get in the way of staying safe. Safety first. Know where in your country you can get help if needed.

Time to Eat

Your child is cleared from any immediate medical or mental health issues. Good! Now you are about to get their eating back to normal. Let's talk about that.

A person who has become scared to eat, or feels out of control with their eating, does not feel good. In many cases their strange eating habits and/or purging habits are helping them to feel OK. Now, you need to change that.

First, understand—and understand at a very deep level—that people who have an eating disorder, especially young people, do not have much insight or understanding of their eating disorder. They usually feel like they don't want to get better. You can learn more about this in <u>F.E.A.S.T.'s</u> <u>30 Day Program</u>.

You might already feel like if you try to change these habits, things will not go well, or your person will get very upset. Yes, they most likely will. Yes, that is a normal part of this refeeding process. So, let's get you ready for that.

Practice **CALM**.



C:

You will need to work to calm yourself and stay calm in the middle of each storm. No matter how nasty and angry your child becomes, no matter how they try to sneak around the rules you set, no matter what, you need to stay calm. If you become angry, resentful, frustrated and show this emotion to your child, it will increase their anxiety. Find any support for yourself that you can. Use any methods you can to keep yourself calm. The support resources at F.E.A.ST. are great for that. If you have a spouse or partner, then figure out ways to give each other a break. Refeeding a child with an eating disorder is a full family affair.

A:

Anticipate the work. Anticipate how life will need to change. Make plans to make those changes, knowing that this is temporary but necessary. Below we will go into detail about how to do feeding and monitoring at home. Then, look at how much time it will take to do the feeding. Make a schedule for yourself and the family. This does make the work easier.

L:

Learn how to work to get rid of the eating disorder behaviors. Learn how the eating disorder will try to manipulate you. Yes, you might feel like you can trust your child but you cannot trust an eating disorder. They are sneaky. (See the How to Stand Up to An Eating Disorder handout.) Learn how to fix and manage meals. Learn how much food is needed. Learn how to outsmart the eating disorder. We will talk about food and nutrition below.

M:

Manage life. Manage the rest of life, including siblings, work, the household and give yourself grace. Don't let the eating disorder take over completely. The eating disorder can make a big mess of family dynamics! Find ways to enjoy things the family has always enjoyed. See your child with an eating disorder for their whole self, not just the self taken by the eating disorder. If you can, get help for things like house chores. Sometimes you may have to let things go; know that this is temporary.

Then, the nitty gritty of feeding.

Refeeding a child at home means you, the adult/s, will decide on what foods to buy and prepare. You do the cooking, make the decisions about food, and then you portion out the food to your child and are with them for all meals and snacks, eating with them, and monitoring to make sure eating disorder behaviors do not sneak in. We will go into more details about these aspects below.

Start to think about what that looks like. The work involved in refeeding a child at home is substantial. As with any illness that threatens your child's life and well-being, you need to find ways to make time to do the work. This might involve taking time off of your work outside the home. That is not always an option for everyone. So, getting the work done might involve getting help from other adult family members or friends. If two parents are not living together, it can mean really planning so the two of you consistently provide enough food and monitor meals. Advanced planning is your best friend, and the best way to be successful.

All adults have to be in lockstep and agree on how to do this work.



Editor's Addition: MAGIC PLATE

Many F.E.A.S.T. families talk about using a "Magic Plate Approach" early in re-feeding. In this strategy, parents and caregivers plan, shop, prepare and then serve up the plate of food at the table "as if by magic" without involving or discussion with the person with the eating disorder. The parents do not discuss or apologize or make a big deal about the contents of the food, they just bring everyone to the table and commence with the eating. This approach can require some practice, as it may have become normal to argue and debate about food, and because it is common to talk about food while eating it. Magic Plate often involves redirecting conversation to other topics now that discussing the menu is no longer accepted. Magic Plate also means plating everyone's food for them, and this can be strange at first for families who have usually told everyone to serve themselves or to have the food on the table for everyone to fill their own plates..

Eat Enough

Eat enough of what, exactly? What do we have to eat to be at our best?

Basic nutrition science is well founded on evidence that tells us we do have requirements for nutrients.

We need water.

We need enough calories to give us energy for growth, development, maintenance of body tissues and functions, and to move. **Calories are king**. Without enough energy or fuel, we won't survive for long. And all those other nutrients won't matter. If you don't get enough fuel on board, everything else goes haywire.

Protein, carbohydrate and fat are called macronutrients because we get them in adequate quantities through food. They are present in food in larger amounts than micronutrients. They also are the nutrients that provide calories. There are requirements for protein that vary with age, stages of growth, and activity. We need enough protein to continue to make all those things protein builds, like skin, hair, hormones, internal organs, and muscles. While there is a requirement for protein, there are no requirements for carbohydrates and fats, except for essential fatty acids needed in very small amounts; carbohydrates and fats are just part of food. Eating foods usually means we are eating something that is a mix of protein, carbohydrate and fat. And, all these macronutrients supply the king.... calories.

We need certain amounts of micronutrients—these are vitamins and minerals that do all kinds of things for our bodies and minds. Usually, if we eat a variety of foods from plants and animals, we get enough micronutrients; but if a person's diet is restricted or off in some way, they might not get enough of these.

A person can get enough nutrients if they are vegetarian. However, if the family is not vegetarian and the child suddenly says they want to be vegetarian or vegan, and this happens as they are becoming sick with an eating disorder, that's a big red flag. Sudden changes in eating habits are a red flag and can precede an eating disorder.

Getting Enough Calories

Getting enough calories is easy if you do not have an eating disorder. You usually just eat when you are hungry and leave it at that. If you are under the influence of an eating disorder, have too many scary ideas about food, have too many untrue thoughts about how food works with your body, or have really scary ideas about how your body ought to look, your food intake will not be okay.

For parents working with their loved one with an eating disorder, first we look at the eating disorder diagnosis. If your child has restricted and lost weight, which is not normal in childhood, we need to have them eat enough to regain lost weight and get back to normal growth and development, which growth curve can help us with.

Eating enough to regain lost weight, or maintain weight, needs to be as simple as possible for family members. This is why we do not recommend overdoing the numbers game.

Start with what your child has been eating. Really—take a close look at their current intake. Also, go back in time a bit and recall how and what they have usually eaten. You have seen this as they have grown. Rely on that historical knowledge to help guide you. If they have a restricting eating disorder and have been eating little, you will have a few days to ramp up the amount of food to accomplish 2 goals:

- 1. Stop any weight loss, and
- 2. start to have them regain lost weight.

The amount of food to do that varies between people. It's not as if we can prescribe an exact number of calories to do the job. Rather, it is best to start to add to what the person has been eating and keep adding food until they stop losing weight (which should take a few days) and then start to gain weight, if they need to gain weight, which should take another few days.

How many calories? Let's not play the numbers game in great detail. It causes both parents—and often, the child—to experience more stress.

And, calorie requirements are not static. Calorie needs are affected by state of mind, activity, gender, outdoor temperature, rate of metabolism and other factors. That said, if you absolutely, really, really need to count calories in order to feel safe and secure in what you are providing, then you, the caregivers, can do that. However, do NOT share these numbers with the child. Their brains already want to be calorie counters and food "overthinkers" so don't help them do that. Keep numbers to yourself and work to try to eyeball amounts and types of food. Eventually you can become very good at doing this without counting calories.

Game Plan:

Start to add more food to what your child has been eating. In a big way, not a tentative way. By the end of the first week, your child ought to be eating 2000-3000 calories if they have been restricting. And that is often just the start; the other thing that has to happen is to have regular meals and snacks. Set a schedule. (Three meals and three snacks is often the plan for weight gain.) And have them at regular intervals, not haphazardly!

So, have two goals at week one:

- Add a bunch of food (we will look at this below) and
- set regular meal and snack times.

Here is another article that gives a meal plan and also a timeline to reach full calories:

Meal Plans to Restore Nutritional Health



Regular Eating

Setting a schedule is very important, both for caregivers and for the child. It eliminates any guessing about what comes next. You know what will be served and at what times, and so does your anxious child. This helps reduce anxiety.

Plan ahead, get the foods you need in order to prepare meals and snacks, set up who will monitor meals and snacks, and rest knowing you have this plan.

NOTE:

On the next pages, we have provided numbers to give you an idea of what a certain number of calories looks like. The only reason we are giving this information is for you to see the amounts of food. It is best to <u>not</u> focus on the numbers, but on the amounts of food. Seeing amounts of food is more normal than counting calories.

It is OK and normal to "eyeball" or ballpark the amounts of food as long as you are not getting lured into providing less than needed.

It is useful to think of the suggested food amounts as the "minimum" amount, which helps us get away from thinking that calories need to be an exact and static amount.

The meals and snacks on the next page amount to about 2000 calories:

What 2,000 Calories Look Like

Breakfast

- 2 slices toast, each with 1 tsp butter toast-160 calories and 6 grams protein. Butter- 90 calories
- 1 Cup whole milk-160 calories and 8 grams protein
- ½ C fruit-canned plums-60 calories
- 2 scrambled eggs eggs-150 calories and 14 Grams protein
- 1 Tablespoon butter to cook eggs in- 135 calories

Snack

- ¼ cup granola or muesli cereal-80 calories, 3 grams protein
- ½ cup whole milk or whole milk yogurt-80 calories, 4 grams protein
- ½ cup berries- 35 calories

Mid Day Meal

- One large tortilla-10 inch across-240 calories, 9 grams protein OR 2 slices bread-160 calories and 6 grams protein
- ½ cup refried beans-125 calories, 7 grams protein OR 3 oz (90 grams) deli meat-135 calories, 21 grams protein
- 1 oz cheese (regular not reduced fat)-100 calories, 7 grams protein
- Add condiments as your family usually uses. Salsa, mustards, mayonnaise, relishes. You can add tomato and/or lettuce to the sandwich or burrito.

Snack

- 1 apple, small-60 calories
- 2 tablespoons nut butter- 190 calories, 8 grams protein

Dinner

- 1 cup cooked rice or pasta-240 calories, 6 to 9 grams protein
- Meat-3 oz (90 grams) chicken, fish, turkey, beef-135 to 225 calories,
 21 grams protein OR 4 oz tofu
- ½ cup cooked vegetables (carrot, broccoli, cauliflower) 25 calories,
 2 grams protein
- 2 tsp butter-90 calories (for vegetables and/or rice & pasta)

You can break up breakfast and lunch in order to make smaller, more frequent meals if your child has gastroparesis.

What 3,000 Calories Look Like

Start with 2,000 calories and add higher-calorie foods. For example:

- Add in 1 Cup whole milk or whole milk yogurt (160 calories)
- Add a third snack of 2 oz. of mixed nuts (340 calories)
- Increase cheese portions to 2 oz. (adds another 100 calories)
- Add in a supplemental drink such as ENU (400 calories in 8 oz.)

You have to add in all of the above for an additional 1000 calories. (See the High Calorie Booster handout for more ideas.)

A lot of kids need even more than 3000 calories a day to replace lost weight. Some, like young men in particular, can need as much as 6000 calories a day.

In these cases, add another high calorie snack and increase portions. For example, a 3-ounce piece of meat is not very big; for young men and boys, this can be easily increased to 6 or more ounces. (See the <u>High Calorie Booster</u> handout.)

TIP

Do not serve low calorie, reduced fat, or "diet" types of food. To bet the most for your dollar and your efforts, serve the highest calorie foods when a child has to gain weight.

Getting Enough Protein

Protein is a key nutrient that has definite and well-studied requirements. The Academy of Medicine and the Academy of Nutrition and Dietetics recommend:

- School-age children need 19-34 grams a day.
- Teens assigned male at birth need up to 52 grams a day.
- Teens assigned female at birth need 46 grams a day.
- Adults assigned male at birth need about 56 grams a day.
- Adults assigned female at birth need about 46 grams a day (71 grams if pregnant or <u>breastfeeding</u>).

Look at the 2000 calorie meal plan above and count how much protein is in it. It has over 90 grams of protein. This tells us that again, if we eat a variety of foods, and have protein at most meals in good portions, that it's pretty easy to get enough. It is OK during recovery from an eating disorder (and really for most people) to have more protein than the basic requirement.

Getting Enough Micros

Let's not think too hard about this. If a person is eating a variety of foods, including fruits, vegetables, different starches, different protein foods then they will generally be getting enough vitamins and minerals. The exception is often calcium—if people can't or won't consume dairy foods (from cows, goats, other mammals), a calcium supplement might be needed, or consumption of enough calcium containing foods from other sources. See the handout on calcium of various foods, which also has needs for children and adolescents.

Certain micronutrients do merit special attention, as they are often low in those who do not eat enough or have enough dietary variety. Vitamin D is often low in the human population due to either lack of exposure to sunlight or low dietary levels, and not many foods are high in Vitamin D. Research supports that low Vitamin D levels negatively affect children's overall mental health.

Maybe it's hard to afford enough food. In this case it becomes necessary for people to access resources in their country to help them get enough food.

Other Food Ideas

Convenience Foods

Yes, of course, use these to make life easier. If you live in a country where the norm is to have all food be fresh, organic, cooked from scratch and IF you think you have time to do that, then do that. However, it is totally fine to use a frozen pizza and add on some cheese, or buy frozen

entrees, or a dish from a local farmers market to serve. Food does not always need to be fancy or perfect...in fact, perfection is tied into eating disorder thinking. The important thing now is to feed enough to your child with an eating disorder and give yourself permission (do you need permission?) to eat in a simple and easy way. If you need permission, look at the messaging you might be giving your child.

Canned and Frozen Produce

Canned and frozen fruits and vegetables are totally okay! See above.

Desserts

Yes; if your family regularly has dessert, then work to continue that and put it in the meal plan. Desserts add calories; and depending on the type of dessert, they can add micronutrients, protein and other good things. If your family rarely had dessert, you do not need to try to have it now. There are many opinions on sweets and how often to have them. It's best to think of getting what you need first, meaning the food that gives you enough protein and micronutrients, and adding in dessert if you want it. Family traditions often are around desserts, like a special cake every Sunday, or weekly outings for ice cream. These are nice times to bond, and bringing these back into regular eating is beneficial; however do not get into big fights with the eating disorder over these occasions at first. Work to have the child eat regular meals with enough foods that provide enough nutrients, and as time goes on, work on the special occasions that involve dessert.

Exercise

Not a food idea, but tied to disordered thinking. For people who are undernourished, for those who need to gain weight, and for those who are medically fragile, exercise is usually stopped, until full physical health and regular eating are restored. It is so much harder to gain weight if a person is exercising a lot, and it is just dangerous to exercise if a person is physically compromised. Exercise purging is common in many with eating disorders, so if exercise is reintroduced, it has to be monitored to make sure it is within reasonable limits. Yes, this is stressful to people with an eating disorder, especially if they have been "exercise purging." The eating disorder will try to hide exercise and

sneak in tiny amounts of exercise. Again, this means more of our time, to closely watch for exercise happening when it is not supposed to be.

Anyone who has been restricting often has two things that make it difficult to eat enough:

- 1. Gastroparesis the gastrointestinal tract has slowed down because of the lack of fuel
- 2. Hypermetabolism the body has slowed down, then ramps up big time once fuel is added. Effectively, this can mean that a whole bunch more calories are needed for refeeding!

Gastroparesis

This is very common in people who have been restricting. It is the slowing down of the stomach and small intestines because of lack of fuel. It is a way the body conserves fuel. Gastroparesis causes discomfort, bloating, early feelings of being full when eating, and pain. The best treatment is to start to eat again, at regular intervals. Sometimes, at the start of refeeding, a low fiber diet is more comfortable to help with gastroparesis. Also, having more frequent small meals can be helpful. (See the Low Fiber Booster handout.)

Hypermetabolism

Very often, if a person has been restricting calories and foods, their metabolism, or rate of energy use, has slowed down, in order to conserve energy to maintain life. That is a very cool thing that our bodies do when we encounter famine or get less food than we need for any reason. Then, when we get enough food, our bodies go into hypermetabolism, or an increased rate of using fuel, in order to replenish anything we have lost. This is another cool thing our bodies do to preserve life. When we see that as we add calories to our child's eating, they seem to need more and more calories in order to not lose weight or to gain weight, we can be pretty sure our child is hypermetabolic. The only thing we need to do then is to keep adding more and more calories in order to keep them gaining weight and not losing weight. So, the game plan is to add, and keep adding calories as needed, as indicated by the scale.

Who weighs?

While weight is not the only marker of health, and sometimes weight restoration is not part of a person's plan to get better, weighing a child who does need to gain weight helps us know if we are on the right track with the food. You might have to weigh your child at home, or they might be able to be weighed at regular intervals at a doctor's office or clinic. If you need to stop weight loss, it can be helpful to weigh your child twice a week, to make sure you are providing enough food to do this job. After that, as your child gains needed weight or maintains their weight, once a week is usually frequent enough. Whether or not your child knows or sees their weight is controversial. Many clinicians feel having a child see their weight helps them learn to cope with this number. Other clinicians see that having a child know their weight is very stressful and often leads to increased resistance. Often, this decision is made with parents and clinicians, and determined on an individual basis.

Other Diagnoses

ARFID (Avoidant/Restrictive Food Intake Disorder)

Some people with ARFID need to gain weight, so follow the guidelines above for restricting eating disorders like anorexia nervosa. Some people with ARFID do not need to gain weight, but rather need to expand their food variety. We'll talk about variety below. There is a type of ARFID that might not be as pathological as people think. People with this type of ARFID do not experience the joy of food and eating that most of us do. Maybe they have some type of neurodivergence. At any rate, often these people are not highly motivated by food, do not enjoy eating, but also do not seem to be scared of weight, or food components. They simply are not big foodies. For them, if you have access to a nutritionist who can do a food analysis, collect several days of their food intake and analyze it. Often, even though they eat little variety, they have a really decent intake of nutrients. So, where is the problem? Some people with this type of ARFID report that being constantly pressured to expand their food choices is really what causes stress. Sometimes we need to adjust expectations about people's food intake, if in fact it provides enough nutrients. Allow people with this type of ARFID to decide if their way of eating is disruptive to their life, or if they need support to be the person they are.

Bulimia Nervosa

Some people with bulimia nervosa need to gain weight, some need to maintain weight. For weight gain, follow the basic guidelines for anorexia nervosa and add in monitoring for purging behaviors. Purging behaviors include compulsive exercise, self-induced vomiting, laxative abuse and use of diet pills. These behaviors need to be watched for and then monitored, especially before and after meals. Caregivers need to watch for behaviors like loading up on water (assists in self-induced vomiting) or running to the bathroom right after a meal. Exercise often needs to be stopped while a person is being treated for an eating disorder. If it resumes, it needs to be non-compulsive.

Binge Eating Disorder (BED)

Some people with BED will need to gain weight and some will not. Some will need to work on maintaining their weight, which we will discuss below. A big aspect of treatment is to end chaotic eating. Frequently people with binge eating skip meals, do not have a regular schedule of eating, or actively restrict eating. Then, hunger returns which can lead to a binge. Having a regular schedule of eating, and eating enough of all nutrients, is very helpful in regulating hunger. There is a genetic mutation that can interfere with normal hunger signals. It is worth mentioning because if a person has this, they deserve to know about it. It is the mutations of the melanocortin 3 and 4 receptors. (3) These are involved in hunger and energy regulation.

Here is an excellent site for information on this subject: https://www.mc4r.org.uk/

Weight Maintenance or What?

Children and adolescents continue to grow and develop until approximately age 20, so their weight will have to increase in order to support growth and development as they age. They do not reach a certain weight and then stop gaining weight. Adults can do that, as hey have stopped growing and developing. It is best to work to find the ood intake that supports them growing along their historical growth curves.

If people have been binging and have had a large uptick in weight, then returning to a less chaotic manner of eating is important, along with staying close to their historic growth curves. Bodies differ in how they work with food, so it is an experiment to find a way to eat that is both satisfying, health promoting, and leads to psychological well-being.

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