

## **Frequently Asked Questions (FAQs) about Eating Disorders and their Treatment**

### **What caused my child's eating disorder?**

- We don't know. No one does. Eating disorders, especially anorexia, are complex illnesses.
- We don't know exactly why they start, but we do know that there is a genetic component to them (just like almost everything else). We think when those teenagers who are at risk for developing an eating disorder do not get enough to eat and lose weight that the weight loss can trigger the start of an eating disorder.
- Sometimes teenagers do not actually lose weight initially. They just do not grow and gain weight the way they are supposed to. When this happens, the lack of weight gain and growth may also start the development of an eating disorder.
- We are sure there are other things that play a role in its beginning or that help to keep it going. But we cannot go back and change the things that may have started it. We focus on the things that keep it going. Not eating enough keeps the eating disorder going, so we work to help your child eat more.

### **We need to focus on coping skills... why aren't we doing that?**

- We are! It just may not seem like it right now.
- While your child is in the hospital, the focus is on regaining physical health and getting them to a place where they can be safe to be at home while continuing to get better. We make sure they get enough food every day while they are here.
- They are learning to eat again and learning that they can eat. The meal plan challenges them with foods they have not had in a long time. This helps to prepare them for when they go home and need to continue to eat all their meals and snacks.
- Coping skills are something that your child would have learned naturally through interactions with you, your family, their friends, coaches. The eating disorder interrupted this process.
- By requiring them to eat all their meals and snacks and by providing consequences for when this does not happen, you are teaching them the building blocks of coping. By doing it over and over again, they learn that they can eat the food, that the world does not end, and that their anxiety will (eventually) be more bearable or even go down.
- When you provide them with meals and support them through this process, you are showing them how you cope. Your teen learns from watching you, too.

### **Doesn't my child need someone to talk to?**

- Maybe, but likely not right now.
- We know that the brains of adolescents who are malnourished are literally smaller than they are supposed to be. The brain stops growing and developing and does not do as good of a job communicating with different parts within the brain.

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- Right now, the brain needs food to “bounce back” and return to the size it is supposed to be. It needs to be able to communicate better and finish the growing and developing it is supposed to be doing. Once the brain is nourished, then it can actually do the work it needs to do in traditional “talk therapy.”
- When your child meets with a therapist, they learn new ways to interact with their thoughts, build on the coping skills they are learning, and begin to view their thinking differently. The brain needs energy and nourishment to do this.

#### **But my child is anxious or depressed....**

- When a child is malnourished, the brain must prioritize what work it can do. It shuts down all non-essential systems (in girls this may mean not getting their period). The brain is working to keep the body alive. The brain basically starts to act like it did back in caveman times and there was no food around. It wants to conserve energy and make sure it keeps the body alive until more food becomes available.
- One thing that is not essential to surviving is some of our emotions. We do not have to feel emotions, like joy, happiness, or fun, to survive.
- Anxiety, on the other hand, is really important to keeping the body alive. The brain needs to watch out for dangerous things in the environment (like lions, tigers, and bears or poisonous berries) – so it keeps anxiety working.
- The thing is, we don’t live in caveman times and the likelihood of running into a lion, tiger, or bear in Philadelphia is pretty low. So other things (like missing school) become very anxiety provoking.
- If your child was anxious before the eating disorder, malnutrition will make that anxiety stronger.
- We also know that a depressed mood is a side effect of not eating enough. Think of those commercials – “you are not yourself when you are hungry.”
- Without a lot of positive emotions, there is nothing to balance out the depressed mood when the brain is tired and not getting enough energy. Once the brain is nourished, it will start to return to normal functioning – including feeling positive emotions again. We know that with nourishment, depression improves and anxiety reduces.
- When it comes to treating anxiety or depression – we need to be able to determine what anxiety/depression is due to being malnourished and what is not due to being malnourished. It is possible that much of the anxiety and depression will go away as your child gets better. If your child is still experiencing anxiety or depression after weight is restored, these emotions can be treated then. The brain needs to be nourished to learn how to manage anxiety or depression.

**Why do we have to monitor all my child's meals?**

- Eating disorders are strong, scary things that will guilt your child into not eating.
- It can be very difficult to manage the thoughts that come with an eating disorder or to cope with the feelings of guilt after eating.
- When you prepare, serve, and monitor all meals; you are making sure that your child eats everything. It also relieves some pressure from your child. They don't have to choose to eat anymore. They **have** to eat, or you won't let them go to school, practice, have their phone.
- When you take the decision to eat away from them, it makes it harder for the eating disorder to make them feel guilty.
- By monitoring meals, you are making sure they can complete the meal. Essentially, you are making sure your child takes their medicine.

**Why can't my child pick a food?**

- We can't be sure at this time in the process that it is your child who is actually doing the picking. It may be the eating disorder.
- Parents take over all decisions around food to ensure that the eating disorder does not get a say in what your child eats.
- While it often seems very reasonable to do what your child asks (for example, "if I have a low-fat strawberry yogurt, I will for sure eat it. The whole milk blueberry yogurt is just gross"), what this does is tell the eating disorder that it can bargain with you. The requests will slowly get more frequent and bigger and bigger.
- What you can do in this situation is remember that your child prefers strawberry yogurt and next time buy whole milk strawberry yogurt for them.
- We also ask that your child eat all the foods they used to eat. If they stopped eating something in the last year or so, we don't know if they stopped eating it because they really don't like it or because the eating disorder stopped them from eating it. By requiring your child to eat these foods, we are making sure that we know your child **can** eat them. Then when the eating disorder is gone, if they choose not to eat those foods, we have more confidence that it is their decision to not eat them.
- Your child also knows that if they are out and the only food available is one they do not like, they can eat that food.

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#### **Why do you talk about the eating disorder like it is a person?**

- Parents and teens with eating disorders regularly say it is like an alien has taken over their child.
- Parents will also tell us that at some point in the recovery process they feel like they have their child back.
- We talk about the eating disorder as a different entity because the eating disorder is not your child. It helps to remember that when your child is refusing to eat, arguing with you, or throwing things, that it is not your child doing this but rather the eating disorder.
- It also helps to remind your child that they are not the eating disorder. Remind them that they have things they love and want to do **and** that they can do those things once the eating disorder is gone. This is really important in helping them to get better.

#### **It feels like I am taking everything away from them, isn't this punishment?**

- It does feel that way for you and your child, we are sure.
- At this point in time, the goal is to save your child's life and make sure they get enough nutrition.
- It is important to remember that you are providing natural consequences for their (or the eating disorder's) behavior. If you don't go to work, you don't get paid. That is not your boss punishing you – that is a natural consequence.
- It is also the eating disorder that is taking things away from your child. If they don't eat, their body doesn't have the energy to do what they want to do (so they cannot do those things). Just like not letting them go to school with a fever is not a punishment, not allowing them to do things when their body is not nourished is not a punishment.
- We can also use consequences to leverage things they want (school, phone, sports) to motivate them to do the really hard thing of eating food.

#### **What about going to school?**

- When your child leaves the hospital, we will likely recommend that you keep your child at home for 1 to 2 weeks. They have been in the hospital. It is likely that their heart is still recovering, and we do not want them to push their bodies too hard in these first few weeks.
- And yes, carrying a backpack, going from class to class, up and down stairs can really exhaust their healing body. Their body will burn energy to do that, and we want their brain to direct all the energy to healing.
- Once your child's medical doctor has cleared your child, they can start back ½ or full days. You will be able to discuss this with your child's therapist to determine the best way to re-integrate your child back into school.

- Do not be surprised if your child is more exhausted than expected after a few days back. Homework and schoolwork may be hard, so they may not be able to do all assignments.
- Our social work team can work with you on getting documentation for a 504 plan for school.

### **What about eating at school?**

- This is something that you will problem solve with your outpatient therapist.
- In general, we recommend that all meals and snacks be monitored. Even in school.
- Each family approaches this differently. It can depend on when your child has lunch at school or school rules about eating in classes. Many families will plan for their child to eat with a teacher, the school nurse, or other staff. Some parents will pick their child up for meals, others go to school and eat with their child there.
- You can work with your therapist to figure out what works best for your family.

### **When can my child return to sports or physical activity?**

- This is a two-part answer. The first thing that we must consider is whether your child is medically stable and if it is safe for your child to be more active.
- Once your child is medically cleared for activity, then the question becomes whether they are ready for activity from a psychological perspective. What does that mean? Well, exercise can be part of an eating disorder. If your child has over exercised or compulsively exercised, we need to make sure that this does not occur once they start being active again. Exercise is a place where the eating disorder can hide.
- When your child is recovered, exercise will be joyful, flexible, and not excessive. You will work with your outpatient therapist to decide when it makes sense for your child to become more active. You will know what to watch for in terms of red flags for disordered exercise.
- And before you ask – sports are a little different. If your child is an athlete, the same process applies. They must be medically and then psychologically cleared. We don't want them going back before their body is ready and getting injured. We also want their sport to bring them joy. Some teens will go back to practice and sit on the sidelines or may be able to do some aspect of their sport once medically cleared (like foot work in soccer). This is something to discuss with your child's outpatient therapist.

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#### **How do we know treatment is working?**

- In outpatient treatment, your therapists will weigh your child every session. This is to track how things are going with eating.
- If weight is going up, we know that they are getting enough energy. If it is going down or staying stable, we know we need to look at the calories in and calories out equation.
- You will work with your therapist to figure out what is working (and do more of it) and where things might not be going that well (and change them so they work better). Weight is one way we know it is working
- We also look at the kind of food your child is eating and what they are doing. Are they eating a wide variety of foods? In different places? On the fly? Are they getting back to school? Hanging out with friends? Going to practice or after school activities? Getting back to work? That is how we know it is going well.

#### **Doesn't my child have to want to get better?**

- No. The eating disorder is strong.
- In one of our favorite books (Decoding Anorexia by Carrie Arnold), the author points out that you do not wait for a drowning person to stop drowning and ask for help – you just jump in and do it.
- We hope that as your child gets better, more of them will come back and they will be more motivated to get back to life. Sometimes this happens clearly, sometimes it does not. But it does not matter. The eating disorder is a terrorist. It is time to get it out of your house.

#### **Why is weight gain so important?**

- It is one way we know that things are getting better.
- Full remission is possible and there is a pattern to how it happens. We look for improvement in the physical domain, behavioral domain, and cognitive/emotional domain.
- We know that improvement can happen in all three areas at once, but that in order to get 100% in one domain, you have to be 100% of the one before it. Your child must be 100% physically recovered in order to get 100% behaviorally recovered. They have to be at 100% behaviorally recovered to get 100% better in the cognitive/emotional area. Once they achieve that – they are in remission!
- Weight gain is a key piece of physical recovery. It is not the only piece, but it is correlated with improvement in brain functioning, re-starting puberty, normalization of hunger and satiety hormones, feeling full, and the body getting back to the business of growing (laying down new bone, growth spurt in the brain). So early and rapid weight gain helps to get all this moving.

- We also know that gaining between 4 and 6 pounds in the first 4 weeks of treatment (or first 4 weeks out of the hospital) is the single best predictor of getting to goal weight. Since weight is part of physical recovery, early weight gain is the best thing to start your child down the path to full remission. We aim for a 2 to 4 pound weight gain every week once you leave the hospital.

### **Won't they have this the rest of their lives?**

- NO! Eating disorders are curable. We need to treat it swiftly and aggressively.
- We focus on re-gaining physical health first and then we tackle the other issues.

### **How do I make my child do this?**

- Here, it is always helpful to remind yourself that you have “made” your child do things in the past. How did you handle things when they were 2 years old? How do you manage when they have a fever and cannot go to school or practice? What do you do when they break house rules? How did you get them to the dentist? You know how to parent; this is just a new and scary situation.
- The other thing to remember is that your child's brain is starving. While they might be a certain age, they are likely not acting that age. Think about the eating disorder as being a toddler having a temper tantrum. How did you manage those moments? It is hard work, but you've got this. Your child's outpatient therapist can help support you and help you problem solve what will work with your family.

### **Why are calorie goals so high?**

- Your team dietitian can answer this question in more detail. Know that the team dietitian calculated what your child needs to gain weight, grow, and get back to psychical health. On average, youth recovering from anorexia need 4,000 calories/day. Some need more – even over 5,000 calories. Sometimes a little less is enough. Again, everyone is different.
- Calories are simply units of energy for your body (like gas for your car). The body needs a certain amount of energy (calories) to function every day. Your brain can burn 500 calories just to do its job! The heart needs to pump, lungs need to breath, kidneys, the liver, all of those organs need to do their jobs every day. That takes calories.
- Once you start moving around, the muscles need calories to do their job. The more you move and the more you do, the more energy you need.
- Your child also needs to gain weight – that takes energy. The body needs to build back muscle and tissue. Once you have more muscle – your body needs more energy to support that muscle.

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- Finally, your child is hypermetabolic and can be that way for a year or longer. What does this mean? It means that your body speeds up the rate that it burns or uses energy. It is a side effect of starting to eat again after being very malnourished. Essentially, your body starts to gobble up energy and try to use it as fast as it possibly can (remember, the brain is working like it is in caveman times). The body becomes inefficient in using energy, so it needs even more.
- The calories your child needs are a combination of the calories the body needs to be lazy and lie around, the calories it needs to move around, the calories it needs to gain weight and repair damage, and the calories it is needs because it is hypermetabolic.
- During your child's stay with us, we will slowly increase calories (by about 400 a day) until they are consuming what they need. The calories may need to increase a bit when you go home because your child will be moving around more.
- You will work with your child's outpatient therapist to increase or decrease calories as needed. The therapist will be able to help with this.

#### **But my child is not hungry or eating hurts their stomach too much. Why can't they eat less?**

- Your child's team dietitian can talk to you about why your child needs the prescribed number of calories. It may be that your child is not hungry or that they get full really fast.
- In the body there are several hormones that help to regulate our eating. Two of them, ghrelin and leptin, become dysregulated when your child is malnourished. Ghrelin is a hunger hormone and leptin is related to satiety (feeling of being full). These do not return to normal for quite a few months. What this means is that your teen cannot accurately assess whether they are actually hungry or full. They need to eat their food no matter what.
- Their stomach can hurt because it is not used to getting enough food and digesting it. It is a muscle that has not worked to its full potential in a long time. Because of this, it can take longer to digest food and can hurt after meals. Your teen's nurse can provide a heating pack to help ease discomfort.

#### **Why does my child need to weigh so much? (My child never weighed this much before, why do they have to weigh that much now? My child was that weight and was unhealthy – why are you making them unhealthy again?)**

- Your child's team dietitian will walk you through why your child has their goal weight (or catch-up weight for those who are younger).
- We work to get your child back on **their** growth curve. Not everyone belongs on the 50<sup>th</sup> percentile. If everyone was on this percentile, it would not be the 50<sup>th</sup> percentile anymore. Each body grows differently, we want your child to get back to doing what their body has done their whole life.

- If your child is older than they have ever been before then they need to weigh more than they ever did. Children grow and gain weight until their late teens or early twenties.
- Normally this weight gain would occur naturally, and you would not really notice it. The eating disorder derailed things. We want them to gain weight so they can finish growing.
- If your child was at a higher weight – that does not mean they were not healthy. Weight is not an indicator of health and some bodies need to be at a higher weight to function properly and be healthy. Your child's team dietitian can give you more information.

**Why are you feeding my child “unhealthy” foods? These foods make my child anxious, and they do not want to eat them.**

- Sometimes, “healthy eating” spirals out of control and becomes an eating disorder. Our program philosophy supports rapid changes to help your child's brain get healthy as quickly as possible. The longer that your child's brain is starved, the more likely it is that their eating disorder may become more severe and/or chronic.
- Nobody likes to feel anxious. Anxiety makes us want to run away from whatever we are afraid of.
- Treatment for anxiety requires facing our fears. In the psychology world, we call it **exposure**. When treating eating disorders, this means exposure to feared foods.
- There are 2 different strategies for exposure:
  - One focused on making small changes over a long period of time.
  - Another that encourages rapid change in a short period of time.
- When it comes to eating disorder treatment, we encourage rapid and intense exposure to help your child overcome anxiety about foods as quickly as possible. This means presenting patients with their fear foods from day one.
- Your child is so strong and capable. We want them to recover as quickly as possible.