

## When Your Child Has an Eating Disorder

For Susan and Gary, getting their daughter into treatment was just the beginning. Here's what happened next—and everything they learned along the way.

By Elizabeth Foy Larsen • Photography by Ackerman + Gruber



If you've ever felt like you woke up one morning to find your child was suddenly taller than you or had curves where before there were none, you'll begin to understand what happened to Ellie's parents. Susan and Gary felt like their 13-year-old daughter had lost almost 20 pounds overnight. In reality she'd been slowly getting slimmer for the past few months. Yes, they had wondered why Ellie didn't want cake on her birthday, but then just assumed the messages they'd passed on about healthy eating were sinking in.

And when she asked for a yoga mat as a birthday present, they thought it was another good sign. But once Ellie ordered a salad with no protein, no croutons and no dressing after an intense hike

on a family vacation, Susan decided to keep an eye on her daughter. Soon after, Susan contacted Ellie's pediatrician to ask what she had weighed at her last checkup. Neither Susan nor Gary could have ever imagined that call would lead to the shock of hearing a doctor at an eating disorders program tell them that Ellie had anorexia nervosa. At that panic-stricken moment, the only question Susan could choke out through her tears was "How did this happen?"

In retrospect, Susan wishes she'd been less concerned about what she and Gary might have done wrong and more focused on making sure Ellie was getting the right treatment—a process so confusing it would overwhelm a professional researcher, much less a family in crisis. While there's a shortage of therapists and pediatricians who have training in treating eating disorders in the U.S., the number of for-profit residential programs has more than tripled since 2006. The surge is thanks in part to the Affordable Care Act's expansion of coverage for mental health disorders, including anorexia, which has the highest fatality rate of any mental illness. What's more, eating disorders are being diagnosed much earlier—the average age of onset for anorexia is now 12 to 13. Which is right when Ellie's life (and weight) began to decline.

### **"I had no control."**

As the summer after seventh grade got under way, Ellie was laying the groundwork for a fresh start to her last year of middle school. She was neither overweight nor underweight when she began replacing sweets with fruits and vegetables. She was, however, curvy, having matured before most of the girls in her grade. "I hated that boys were thinking about my body like that," says Ellie, a dedicated student who wanted to be seen as smart, not sexy.

Ellie eliminated all junk food from her diet and began running up and down the streets of her St. Paul neighborhood, believing that improving her eating and exercise habits would make her look less developed. While a preoccupation with wellness, "clean eating" and "getting fit" are all common early signs of anorexia, her new habits didn't raise any concerns because they sounded healthy. "Our culture has had to focus on fighting obesity, so the overarching message is that everyone should diet and exercise," says Craig Johnson, PhD, the chief science officer and director of the Family Institute for Eating Recovery Center in Denver. He says that a first diet for someone at risk for an eating disorder can be like an alcoholic's first drink. "Dieting and exercising are the two gateway behaviors that trigger anorexia," explains Johnson. "There is no other psychiatric illness that carries the burden of releasing patients into a society that says you should engage in the actions that can cause a relapse."

Soon Ellie's behaviors escalated from doing crunches and drinking smoothies to cutting out all carbs. At dinner she'd sneak her food to the dog. And she couldn't stop running, even in the Minnesota humidity. By the time eighth grade started, she felt like any food she put in her body had to be counterbalanced by physical exercise. "Even though I thought I was completely in control, I had no control," Ellie says.

What Ellie didn't understand was that her reasoning had already been altered by anorexia. Experts, including Walter Kaye, MD, the director of the University of California, San Diego's Eating Disorders Center for Treatment and Research, believe that multiple factors may create a predisposition toward the disease. In Ellie's case, it may have been the social, emotional and hormonal challenges of puberty. They hypothesize that the pathways governing the brain's reward system, which regulates pleasure and positive reinforcement, don't function properly in a person with anorexia. "If you stop drinking water for a few days, your body will bombard you with messages to drink water," explains Kaye. "But for people who have anorexia, the brain doesn't tell them to eat, even if they've had only a few hundred calories a day."

### **"We thought she was in the right place."**

After Susan made that fateful call to Ellie's pediatrician, the first stop was an eating disorders program operated by a respected and accredited center in Minnesota. The staff recommended that Ellie start with outpatient treatment, which the program says is usually the first-line treatment for adolescents with anorexia because research shows they make better progress remaining at home with family. The staff also prescribed weekly appointments with a team made up of a dietitian and a therapist, as well as a psychiatrist and a doctor when needed. But within weeks, Ellie's weight plummeted. Terrified, Gary and Susan scrambled to find other options, eventually contacting the Center for the Treatment of Eating Disorders at Children's Hospitals and Clinics of Minnesota. Ellie was admitted the day after Halloween.

Looking back, Gary and Susan struggle to understand why the first program didn't refer their daughter to a hospital the minute she was diagnosed. They hadn't questioned the advice, figuring the medical pros were the experts. "We wish we would have known more so that we could have acted more aggressively," says Gary. "But we thought she was in the right place."

It's an assumption many parents facing this level of crisis make. What they don't know is that not all centers are created equal when it comes to treating such a complicated and stubborn disease. "Treatment programs are underregulated and vary incredibly across the country," explains James Lock, MD, PhD, director of the Comprehensive Eating Disorders Program at Lucile Packard Children's Hospital Stanford in Mountain View, CA. "They aren't standardized, so you don't know exactly what you are getting into."

Ellie was losing weight rapidly and she was too malnourished to benefit from outpatient psychotherapy. "When you are at this level of crisis, medical stabilization is required," explains Julie Lesser, MD, Ellie's former doctor and the medical director of the Center for the Treatment of Eating Disorders at Children's Minnesota.

The next seven months quickly turned into a vortex of consultations, hospitalizations, conversations with health insurance providers and struggles to find a way to pay for expenses

that weren't covered, including enormous premiums and out-of-network costs. Whenever Ellie's body mass index hit the number the Centers for Disease Control and Prevention considers healthy, insurance would stop covering her hospitalization. She'd return home, lose more weight and then, depending on what insurance allowed, would be readmitted to Children's or to inpatient care at the center that originally prescribed the unsuccessful outpatient treatment. All told, she was in either inpatient care or the hospital seven times and missed half of eighth grade.

While most patients with anorexia don't require as many hospitalizations, Lesser says that because the illness is so difficult to treat, many families seek help at multiple facilities before finding an approach that works. Today, out of all the options treatment centers offer for adolescent anorexia, only family-based therapy is supported with actual data. The lack of research is not likely to improve anytime soon: While research spending on schizophrenia, which impacts 3.4 million people in the U.S., amounts to \$81 per individual, the National Institutes of Health reports spending of just 93 cents per person for eating disorders, which strike 30 million—nearly 4 in 100 teenage girls and an increasing number of boys.

### **“They'd take away my pillow.”**

“Prison” is the best way Ellie can describe life at the inpatient eating disorders center. “If I didn't do what they said, they'd take away my books, my pillow, my bedcovers—even my pencils,” she remembers, unable to hide her frustration. What's worse, she wasn't allowed to have her phone, and visits were on a very restricted schedule. “I'd eat and sit in a room and eat and sit in a room,” she says. The center says all patients have 24/7 access to landlines, but adolescents aren't allowed to have smartphones in order to protect the privacy of other patients, since phones can be used to share photos and videos on social media. They offer daily visiting hours and sometimes take away objects if they believe a patient is at risk for harming herself or that object is preventing her from participating in treatment.

Gary and Susan were also frustrated with the inpatient program at the center and begged their insurance company to allow Ellie to be readmitted to Children's Minnesota. “I couldn't understand how punishing her for being sick was going to help,” says Gary. But because Ellie always lost more weight at home, the couple felt it wasn't safe to discharge her, leaving them at the mercy of their insurance company.

Hospitalization at Children's Minnesota, while still difficult, was better because there were fewer restrictions on visitors and Ellie could keep her phone and stay in touch with her friends. “You don't want to disrupt the life of a child,” says Lesser. The more Ellie was reminded of everything she loved in the world, the better.

The hospital's goal was for Ellie to consume 4,000 calories a day so that her brain would receive enough nutrients to be able to process therapy. But while food was Ellie's medicine, it was also

what she feared most. Under the supervision of the staff, she had to finish every last bite on her plate within 30 minutes, even though her brain was screaming at her not to eat.

While the Children's staff was working to stabilize Ellie's weight and vital signs, Lesser supported Susan and Gary, explaining that they needed to do whatever they could to help Ellie be mentally and physically healthy. She also reminded them that recovery wouldn't be as simple as tempting Ellie with her favorite foods and encouraging her to eat more. Lesser practices family-based therapy (FBT), which is founded on the idea that because a child has to eventually leave the highly controlled world of the hospital and return home, treatment is more effective if parents learn how to get their child to eat. Families consume "practice meals" with a therapist, who teaches them strategies and builds up everyone's confidence so that the dinner table doesn't have to be a battleground. FBT is currently the most effective treatment for anorexia, with up to two-thirds of patients significantly improved after completing treatment.



### **"It never really goes away."**

Gary and Susan learned to trust their gut when it came to what was best for Ellie. So when they noticed her perk up after a relative suggested that she visit him in Spain to practice her Spanish—and she then set a goal of taking him up on the offer—they knew it was an investment they needed to make. They started by hanging a map of the country in Ellie's room at Children's (where they had successfully lobbied insurance to have her readmitted).

The Spain trip came with two conditions, however: First, Ellie had to maintain a healthy weight range for a month. Second, the entire family (including her 12-year-old brother) would travel to San Diego for a one-week multi-family-based therapy program at the University of California, San Diego, where they would receive extensive training, relearn how to eat meals together and get support from other families in their situation.

For Gary and Susan, the week in San Diego was a breakthrough. "I felt supported and could ease up and be more positive," says Susan. It also offered relief to their son, Peter, who was finally able to tell his family how tough Ellie's illness had been on him. At the program he learned that instead of siding with his parents and encouraging Ellie to eat, his role was just to be Ellie's brother. If tensions flared at the dinner table, coaches told him it was okay to get up and leave. While the San Diego program benefited the entire family, Ellie says planning for Spain was a bigger turning point for her. The trip was a perfect reminder of the exciting world waiting for her beyond clinic doors.

Three years after leaving an eating disorders facility, Ellie is busy with debate, acting in school plays and dreaming of a career in foreign affairs or medicine. Even though those terrifying months of being in and out of hospitals are over, the memory of them lingers on. "It never really goes away," she says, referring to the messages that invade her brain and tell her not to eat. "But I know that if I let those thoughts in, I have to go back to that world of IVs, blood draws and hospitalization. It's not worth it. Life has so many more opportunities now that I don't want to miss."

## When Your Kid's in Crisis

Having a child with an eating disorder can be devastating. Here are Susan and Gary's tips for moving everyone toward healing.

**1. Don't take it personally.** Parents do not cause eating disorders. Also remind yourself that raising a teenager is challenging under the best of circumstances. But with anorexia the difficulty can feel like an already hot pot that's boiled over.

**2. Trust your instincts about what will or won't work to improve your child's health.**

"Even if we didn't understand anorexia, we understood our daughter," says Gary.

**3. Take care of yourself.** Go on separate vacations so one parent can rejuvenate while the other cares for the kids. Also consider individual therapy with a professional who has experience with parents of kids with eating disorders.

**4. Manage expectations.** Unlike some physical illnesses that can be cured quickly, anorexia is a complicated ailment of the brain and body. It takes time to see improvement, so prepare to be in this for the long haul.

## Choosing the Right Treatment Center

- Search for a facility that is accredited by the Joint Commission, which evaluates health care facilities. (New standards for eating disorder treatment centers went into effect July 2016.) They should also involve your family in your child's assessment, therapy and treatment plan.
- Make sure the center uses therapies that are evidence-based, such as FBT for anorexia and cognitive behavioral therapy for bulimia. Therapies that focus on underlying causes, family dysfunction or "control issues" instead of behavioral interventions are no longer considered effective.
- Ensure that the location uses medical guidelines to guarantee a patient is medically stable enough for outpatient treatment. If there are any signs of medical instability, including low heart rate, low blood pressure, abnormal labs or rapid weight loss or if your child weighs less than 75% of her expected body weight, contact your child's doctor about hospitalization.
- Ask whether the facility can show that underweight patients gain at least 4 pounds in the first 4 weeks of treatment. If your child doesn't make this level of progress, that's a sign you should seek a second opinion or re-evaluate the treatment plan.

For more tips on how to choose the right treatment center, check out Families Empowered and Supporting Treatment of Eating Disorders at [feast-ed.org](http://feast-ed.org).