

One Spoonful at a Time

By HARRIET BROWN
Published: November 26, 2006

On a sweltering evening in July of last year, I sat at the end of my daughter Kitty's bed, holding a milkshake made from a cup of Häagen-Dazs coffee ice cream and a cup of whole milk. Kitty (the pet name we've used since she was a baby) shivered, wrapped in a thick quilt. "Here's your milkshake," I said, aiming for a tone that was friendly but firm, a tone that would make her reach for the glass and begin drinking. Six-hundred ninety calories — that's what this milkshake represented to me.



Deborah Mesa-Pelly

But to Kitty it was the object of her deepest fear and loathing. "You're trying to make me fat," she said in a high-pitched, distorted voice that made the hairs on the back of my neck stand up. She rocked, clutching her stomach, chanting over and over: "I'm a fat pig. I'm so fat."

That summer, Kitty was 14. She was 4-foot-11 and weighed 71 pounds. I could see the angles and curves of each bone under her skin. Her hair, once shiny, was lank and falling out in clumps. Her breath carried the odor of ketosis, the sour smell of the starving body digesting itself.

I kept my voice neutral. "You need to drink the milkshake," I repeated. She lifted her head, and for a second I saw the 2-year-old Kitty, her mouth quirked in a half-smile, her dark eyes full of humor. It was enough to keep me from shrieking: Just drink the damn milkshake! Enough to keep me sitting on the end of the bed for the next two hours, talking in a low voice, lifting the straw to her lips over and over. The milkshake had long since melted when she swallowed the last of it, curled up in bed and closed her eyes. Her gaunt face stayed tense even in sleep.

Kitty's anorexia was diagnosed a few weeks before, at the end of that June. My husband and I knew something was wrong for several weeks; we just didn't know what. She'd started reading *Gourmet* and planning lavish dinner parties. She called me at work several times a day, needing to know what dinner would be the next night and the next. She exercised for hours each night, doing situps and push-ups in her room. On Mother's Day she worried that she might have obsessive-compulsive disorder, because she couldn't stop thinking about meals and food.

My husband and I told ourselves, She's 14, we can't be overprotective. We said to each other, I wouldn't be that age again for anything. Kitty didn't want to see a therapist; we didn't want to insist. Yet.

She was thin, too thin. She ate fruit and vegetables, turkey and low-fat yogurt — healthful choices. But as she crossed the floor at her eighth-grade graduation, we saw that something had changed; suddenly she looked emaciated. I called the pediatrician the next morning.

The day anorexia was diagnosed, the doctor told Kitty to eat more and told us to find her a therapist. Two weeks later we met with an eating-disorders specialist who talked to Kitty as if she were 3 years old. That's when we panicked; we'd been pinning our hopes on the therapist, but clearly she was not going to save the day. So we tried to get Kitty to eat: we encouraged, we reasoned, we yelled. Kitty cried, said she wasn't hungry, her stomach hurt; she would eat at her friends' houses, at camp, tomorrow.

On a hundred-degree day that July, she spent hours frying chicken and baking carrot cake, then ate almost none of it. I begged her to drink water; she swore she wasn't thirsty. Late that night, she put her hand on her chest. "My heart feels funny," she said. The emergency room doctor admitted her with an abnormal EKG; she was dehydrated, and her resting heart had slowed to 31 beats a minute (normal is 60 to 80). When she didn't eat, they moved her to the I.C.U., where a frazzled doctor ordered a feeding tube. Kitty wept. "I won't be able to taste my food!" she cried.

I wanted to shout, "But you're not eating anything!" The doctor gave her a choice: eat a protein shake and a small bowl of spaghetti in half an hour, or he would order the tube. She did it — and she kept eating, three tiny hospital meals a day, more than she'd eaten in weeks.

That first night in the hospital, we asked Kitty's pediatrician where her other anorexic patients went for treatment. "When they're this sick, they go away," she said, referring to inpatient eating-disorder clinics, where people often stay for two or three months. The nearest was an hour away and cost \$1,000 a day, most of which would not be covered by our HMO. Kitty was terrified at the prospect. "Don't make me leave you," she cried. It would have been easier on one level to send her away to some place that could help her. But we couldn't send her off when she was so frightened.

We visited an adolescent day program at a local psychiatric hospital; it felt like the set of "One Flew Over the Cuckoo's Nest." On every subject except food, Kitty was completely rational; how would rehashing eighth grade in the hospital's "school" help her?

Had the diagnosis been, say, diabetes, we would have been given a list of guidelines and medications — a road map for recovery. We would have looked at research and treatment protocols. Look anorexia up on Amazon, and you'll find hundreds of titles, but we couldn't sort the useful books from the flaky ones. And in terms of treatment, there isn't much systematic scientific research on the disease. No one could tell us exactly how to make our daughter well. All they could say for sure was that the odds weren't good.

Anorexia is one of the deadliest psychiatric diseases; it's estimated that up to 15 percent of anorexics die, from suicide or complications related to starvation. About a third may make some improvement but are

still dominated by their obsession with food. Many become depressed or anxious, and some develop substance-abuse problems, like alcoholism. Almost half never marry. It is thought that if anorexia is not treated early on, during adolescence, it tends to take an average of five to seven years for the person to recover — if it happens at all. I pictured Kitty, starved and weak, at 16 and 18 and 21, and felt sick.

I went home and started researching, hoping to find another option. Among the few studies done on anorexia treatment, I came across one from 1997, a follow-up to an earlier study on adolescents that assessed a method developed in England and was still relatively unknown in the United States: family-based treatment, often called the Maudsley approach. This treatment was created by a team of therapists led by Christopher Dare and Ivan Eisler at the Maudsley Hospital in London, in the mid-1980s, as an alternative to hospitalization. In a hospital setting, nurses sit with anorexic patients at meals, encouraging and calming them; they create a culture in which patients have to eat. The Maudsley approach urges families to essentially take on the nurses' role. Parents become primary caretakers, working with a Maudsley therapist. Their job: Finding ways to insist that their children eat.

The two studies showed that 90 percent of the adolescents recovered or made significant gains; five years later, 90 percent had fully recovered. (Two other studies confirmed these results.) In the world of eating disorders, I was coming to understand, this was a phenomenally high success rate.

The idea that parents should be intimately involved in the refeeding of their children can be quite controversial, a departure from the conventional notion that the dynamic between parent and child causes or contributes to the anorexia. Many therapists advocate a "parentectomy," insisting that parents stay out of the treatment to preserve the child's privacy and autonomy. They say that a child must "choose" to eat in order to truly recover. Maudsley advocates see the family as the best chance a child has for recovery; no one else knows the child as well or has the same investment in the child's well-being. That felt right to us.

Over the last few years, most eating-disorders researchers have begun to think that there is no single cause of anorexia, that maybe it's more like a recipe, where several ingredients — genetics, personality type, hormones, stressful life events — come together in just the wrong way. Maudsley practitioners say that focusing on the cause is secondary, ultimately, because once the physiological process of starvation kicks in, the disease takes on a life of its own, unfolding with predictable symptoms, intensity and long-term consequences. Anorexics become almost uniformly depressed, withdrawn, enraged, anxious, irritable or suicidal, and their thinking about food and eating is distorted, in part because the brain runs on glucose, and when it has been deprived over a long period of time, when it's starved, it goes haywire. It's important to get the patient's weight up, fast, because the less time spent in starvation, the better the outcome. Adult anorexics who have been chronically ill for years have much poorer prognoses than teenagers.

I called **Daniel Le Grange**, an associate professor of psychiatry at the University of Chicago, who directs the eating-disorders program there. Le Grange spent five years training at Maudsley Hospital in England, and he and James Lock, a professor of child and adolescent psychiatry and pediatrics at Stanford, have written Maudsley treatment manuals for physicians and therapists and a book for parents. The two are in the middle of a \$4 million N.I.H.-financed study designed to measure the effectiveness of the Maudsley approach. Le Grange compared anorexia to cancer. "If you leave it, it's going to metastasize," he said. "You need to figure out an aggressive way to eradicate it as quickly as you can. You're not going to hear an oncologist say, 'Oh, it's Stage 0 cancer, let's wait till it becomes Stage 3.' "

I asked Le Grange what he thought about a critique of Maudsley: that it violates the usual boundaries between child and parent, derailing the adolescent work of separation and individuation. "If your child has diabetes and doesn't check her blood sugar often enough, you'd make sure she did," Le Grange reassured me. "What we're trying to achieve is taking anorexia away so the child can go on her way unencumbered by the eating disorder. What could be more respectful of adolescent development?"

There were no local Maudsley therapists, so my husband and I lined up a pediatrician (in whose office Kitty was weighed weekly), a psychiatrist (whom she saw weekly, then twice a month), a therapist (weekly) and a nutritionist (two or three visits). We didn't know if Maudsley would work. We didn't know if it was, objectively speaking, the best choice. But anything was better than watching Kitty disappear, ounce by ounce, obscured by the creature who spoke with her voice and looked out through her eyes. Anything.

On Day 2 of refeeding Kitty, our younger daughter, Lulu (also her nickname), turned 10. We had cake, a dense, rich chocolate cake layered with raspberry filling — one of Kitty's favorites. Of course she refused it. I told her that if she didn't eat the cake, we'd go back to the hospital that night and she would get the tube. I hated saying this, but I hated the prospect of the hospital more. The tube felt like the worst thing that could happen to her, though of course it was not. Five minutes after Kitty was born, I fed her from my own body. Now the idea of forcing a tube down her throat, having a nurse insert a "bolus" every so often, seemed a grotesque perversion of every bit of love and sustenance I'd ever given her.

She sat in front of the cake, crying. She put down the fork, said her throat was closing, said that she was a horrible person, that she couldn't eat it, she just couldn't. We told her it was not a choice to starve. We told her she could do nothing until she ate — no TV, books, showers, phone, sleep. We told her we would sit at the table all night if we had to.

Still, I was astonished when she lifted the first tiny forkful of cake to her mouth. It took 45 minutes to eat the whole piece. After she'd scraped the last bit into her mouth, she lay her head on the table and sobbed, "That was scary, Mommy!"

At age 4, Kitty went for a pony ride and was seated on an enormous quarter horse. When the horse reared, she just held on. Afterward I asked if she'd been scared. "Not really," she said. "Can I go again?"

This was the child who was now terrified by a slice of chocolate cake.

That night, when I checked on her in bed, she mumbled, "Make it go away." I now knew what "it" was. It seemed as if she were possessed by a vicious demon she must appease or suffer the consequences. I pictured its leathery wings and yellow fangs inside her. Each crumb Kitty ate was an act of true bravery, defiance snatched from its curved talons. I've heard women joke, "I could use a little anorexia!" They have no idea.

This demon was described nowhere in the books I was frantically reading. It wasn't until I stumbled on a 1940s study led by Dr. Ancel Keys, a physiologist at the University of Minnesota, that I began to understand. During World War II, Keys recruited 36 physically and psychologically healthy men for a yearlong study on starvation. For the first three months they ate normally, while Keys's researchers recorded information about their personalities, eating patterns and behavior. For the next six months their rations were cut in half; most of the men lost about a quarter of their weight, putting them at about 75 percent of their former weight — about where Kitty was when she was hospitalized. The men spent the final three months being refed.

Keys and his colleagues published their study in 1950 as "The Biology of Human Starvation," and his findings are startlingly relevant to anorexia. Depression and irritability plagued all the volunteers, especially during refeeding. They cut their food into tiny pieces, drew meals out for hours. They became withdrawn and obsessional, antisocial and anxious. One volunteer deliberately chopped off three of his fingers during the recovery period. The demon, I thought.

"Starvation affects the whole organism," Keys wrote. Given what I'd seen of Kitty, that made sense to me. But I wondered why — if starvation triggers the cognitive, emotional and behavioral changes that are so uniform in anorexia — the Minnesota volunteers did not develop the intense fear of eating and gaining weight that characterizes the disease. And what about the millions of people around the world who are starving because they don't have enough food — why don't they develop anorexia?

Once more I turned to Le Grange, who explained that at the core of anorexia is the notion of starvation in the midst of plenty; starvation when food isn't available doesn't usually trigger the same response. As for the Minnesota volunteers, he said, they were males (most anorexics are female), and they were beyond adolescence, outside the developmental window when anorexia tends to strike. More important, the volunteers ate about half their caloric requirements for six months; most anorexics eat far less, over a much longer period of time. "We're talking about a 14-year-old who is profoundly starved for 12 months," he said. "These guys were semistarved for a relatively brief period." It's not just the weight; it's the pattern

of behavioral reinforcement. Each time an anorexic restricts what she's consuming, the anorexic thoughts ("I'm so fat, I'm such a pig") and behaviors (constant exercising, for example) are strengthened. Which is why it takes not just weight gain but the experience of eating meal after meal after meal to truly cure the disease.

Of course this brings up the question: which comes first, physiological starvation or the mental and emotional changes of anorexia? "You or I would earn the Nobel Prize if we figured that out," Le Grange said. "It's a bit of both, probably, and the two impact each other. So if you are constitutionally slender and it's easy for you to diet, and you like ballet, and you live in the United States, and you're 13, and your personality is perfectionist, your chance of developing this illness is very, very high."

Switch gymnastics for ballet, and Le Grange had just described Kitty. I used to hope she'd get a B in school so she'd see that the world didn't come to an end. Clearly, she wasn't going to be O.K. in a week or a month or six months. We were embarking on a long journey, one that would change us all.

A week into refeeding, I'd become an expert in high-calorie cooking. I made macaroni and cheese with butter and whole milk, chicken breasts dredged in egg, rolled in bread crumbs, fried in butter. Carrot cake with cream-cheese icing. Thousand-calorie milkshakes and muffins. When a body is in a state of starvation, it isn't enough to simply eat a normal diet, Dr. Walter H. Kaye, director of the eating-disorders program at the University of California at San Diego, explained to me. The body requires huge numbers of calories to gain weight and maintain it. Every few days we added 300 calories; by Day 9, Kitty was eating 2,100 calories a day. Still, she'd lost another half pound, which panicked me until the pediatrician explained that Kitty's metabolism, slowed by starvation, was now revving high. It's not unusual to lose weight at first, she said; just keep feeding her.

A heating pad helped with the stomachaches and bloating that followed each meal. But nothing helped with the thoughts and feelings. Faced with a plate of food, the demon inside my daughter bargained, cried, lashed out. Her anxiety was so great that there was no reward that could motivate her to eat. Her fear of the tube was what kept her eating in those first few weeks. I wondered what would happen when she'd gained a few pounds and the tube was no longer a possibility.

Meanwhile, the demon sat at our table and spewed venom: "I'm a lazy pig. You're trying to make me fat." And, one night, terrifyingly: "I just want to go to sleep and never wake up."

With that comment, Kitty's younger sister, Lulu, looked up from her plate, her face full of anguish, and bolted from the table. I found her in the basement. "I don't want to go to my sister's funeral!" she cried. "Neither do I," I told her.

Later that night, when Kitty and Lulu were asleep, I stood in the middle of the kitchen and thought of how our lives had shrunk to the confines of these four walls. The counter and sink were piled high with dirty plates, ice cream tubs, glasses and pans. Between shopping, cooking, eating with Kitty, spending time with Lulu and going to work, my husband and I had no time for cleaning, much less anything else. Suddenly I was filled with fury. I grabbed a dish and smashed it on the linoleum, where it broke into half a dozen pieces. I broke another, and another, and another. There were so many things I couldn't fix or make right, so many feelings I couldn't handle. I swept the pieces into a bag and carried them outside. Tomorrow we would eat off paper plates.

Three weeks into refeeding, Kitty was consuming 3,000 calories a day; she'd gained about eight pounds. My husband or I would sit with her while she ate three meals and two snacks each day; we needed to know she was eating, and she needed us to compel her to eat, to get past the demon's grip on her. One of us brought her to work, as we had when she was an infant. In many ways this process felt like reparenting as well as refeeding, taking her back to a time when she was totally dependent on us.

Some parents don't want to or can't go backward like this. Some don't have flexible work schedules and can't be home for every meal and snack. Some are overwhelmed by the relentless and exhausting work of refeeding. For any of these parents, Maudsley may be impossible. It works best when two parents are involved — so they can take turns losing it, offstage — and when those parents agree that their top priority is refeeding. I heard stories from other families about anorexics who slipped meals into the trash when softhearted Dad was in charge, or about weight-conscious mothers who couldn't bring themselves to serve their daughters that much food. When we started refeeding Kitty, my husband had never thought much about nutrition, and the idea took some getting used to. By late August, though, he could tell you how many calories were in a pat of butter, a chicken breast, a glass of milk. And he was often far more patient with Kitty than I.

During that first month, Kitty smiled once or twice, which made us feel hopeful for the first time since the spring. We watched movies together and took walks around the block — the only exercise she was allowed. We had moments that seemed almost normal.

But the night before she was set to start high school, four weeks in, the demon re-emerged. This time it was far worse than anything we'd experienced, maybe because Kitty was stronger now. At the dinner table, she put her matchstick arms around herself and shouted, "I don't want to go to high school and have everyone say, 'Look at Kitty, look how fat she got over the summer!'"

She refused to eat anything. We cajoled and begged and threatened. She wept and flailed and lashed out. I left messages for the psychiatrist, the therapist, the pediatrician. I told her we'd have to go back to the hospital, though I suspected she now weighed too much to be admitted. Finally I reached a psychiatrist on call, who suggested that we give her a tranquilizer and put her to bed. "If she won't eat in the morning,

bring her in," advised the psychiatrist. I was relieved, and also terrified: What if this was the start of a new downward slide?

But the next morning she ate breakfast as usual. After school, she came home with a couple of friends she hadn't seen since spring. As I made milkshakes for all of them, I was surprised to hear Kitty say jokingly, "We know all the ice creams with the most calories!"

One friend said, "We want to know which ones have the least!"

"Yeah," chimed in another, "because my butt is huge!" Another girl said,

"I hate my thighs!" There was a chorus of agreement.

I offered, "You girls are beautiful and healthy and strong." But I felt incredibly sad. Even face to face with the devastating effects of this disease, they were criticizing their bodies.

I've heard the arguments that media depictions of unrealistic female bodies are what drive girls to starve themselves — the Kate Moss syndrome. And it's tempting to see anorexia as a metaphor, a result of a cultural crisis in the zeitgeist. If this were true, though, millions of American girls and women would become anorexic instead of the roughly 1 to 3 percent who do. Clearly there are other factors involved.

My nightly Internet prowling turned up some interesting research by Kaye, the director of the eating-disorders program at the University of California. While Kaye suspects that social and cultural factors contribute to anorexia, he says that recent studies suggest that genetics is the most significant factor for anorexia and bulimia. He has found chromosomal abnormalities in anorexics, as well as irregular levels of the neurotransmitters dopamine and serotonin. The National Institutes of Health is currently spending \$10 million in a five-year study to look at the genetic links of the disease.

I grew up in a household where disordered eating was the norm. My aunt was bulimic; my mother enrolled us both in Weight Watchers when I was 15. She recorded her weight each morning on a chart and went on to become a Weight Watchers lecturer, delivering weekly pep talks to a roomful of people who were engaged in an ongoing war with their own bodies. You had to stay vigilant, lest your appetite betray you and the pounds creep back on. I'd tried to teach my daughters to enjoy good food and to love their bodies, but maybe I hadn't gotten over my dieting-obsessed childhood. Or maybe I'd passed along a genetic predisposition that triggered Kitty's illness. The deeper into refeeding we got, though, the less I worried about causes. We could figure that out later. The important thing was to get Kitty to eat and gain weight.

By October, we'd settled into a pattern. My husband, whose work schedule is flexible, ate lunch with Kitty most days; I covered that meal when he couldn't. Kitty gained another six pounds and, encouragingly,

grew an inch. But she hadn't felt hungry since before the diagnosis. I worried that anorexia had permanently short-circuited her brain-body connection; how would she ever regulate her own eating?

The rough days were predictable only in the sense that they kept coming. One night she sat at the table, hands over her eyes, in front of a plate of salmon and squash. "I'm bad! I'm bad!" she said, sobbing. "I won't eat, I won't!"

Calmly I said, "Food is your medicine and you've got to take it." Long minutes ticked by. Eventually she said: "I want to eat, but I can't. If I eat now I'll be a total failure!" The anorexia talk spilled out of her, on and on and on. I wanted to wrap her in my arms and say, "Of course you don't have to eat, poor baby." But I couldn't give the disease an inch. If I did, the same thing would happen the next day and the next day. We had to sit there until she ate, no matter how long it took.

By the first week of November, Kitty was up to 90 pounds, 10 pounds short of her target weight. More important, her mood improved significantly. But later in the month, she developed an upset stomach, which isn't unusual during refeeding, and began refusing the daily milkshakes. She complained of dizziness, wanted to know what I would be serving her, then argued for something else. She raged at me and at herself. One afternoon she cried so much she "accidentally" threw up her lunch. Back in September she tried to make herself throw up a few times; about half of all anorexics do become bulimic. Luckily, Kitty was never able to do it. I hoped she hadn't learned how.

In December, Kitty gained and lost the same pound over and over. At the end of the month she was still, frustratingly, at 90 pounds, still deeply in the grip of the disease. We boosted her intake to 4,000 calories a day. In mid-January, finally, her weight went up four pounds. It was astonishing, how much food she needed, but not unusual. Anorexics become metabolically inefficient; their temperatures rise, and they tend to burn off calories rather than put on flesh. "That's one reason for the high rate of relapse," Dr. Kaye told me. It's hard to gain enough weight to truly recover, and even harder to maintain it.

As went the fall, so went the spring. The pounds came on, very slowly, and Kitty's spirits continued to lift. More and more, she hung out with boys. "They don't talk about how fat they are," she explained. And they didn't make her feel self-conscious about eating. "Yo, Kitty, you done with your 10,000-calorie milkshake yet?" one boy said one afternoon in March, and she actually giggled.

In April, Kitty grew another two inches, which meant that her target weight went up, too. I felt despair at the thought that it would take longer now for her to gain enough weight, longer for her to get well. I told myself that her health was more complex than a number on the scale, that she was recovering. But I couldn't forget the sunken, unspeakably sad look in her eyes that past summer and fall.

One day in May, she came home from school grinning. "Guess what?" she said. "Sue brought cake to school, and I ate a piece. Aren't you proud of me?" All year she'd avoided parties, potlucks, lunches — any get-together that involved food. The fact that she ate a piece of cake, one of her "scary" foods, meant that she gave up, for a moment, being the anorexic at the back of the room. She became one of the group.

But the next day I made her and Lulu bagels with melted cheese, and Kitty complained, "You know I don't like sesame bagels." "You used to," I said. I knew what was behind this, and I wanted her to say it. I wanted it out in the open.

"They have more calories than plain bagels!" she burst out. But she calmed down quickly. "I know that was an eating-disordered thing to say. I couldn't help it," she said quietly, and ate the bagel.

I felt proud of her ability to name the demon and defy it. I wished we could just yank it out of her, unhook the claws that tormented her body and mind.

On a morning this past June, she called me at work to say the two most beautiful words in the English language: "I'm hungry!"

"I'm so happy!" I blurted out.

"I'm happy, too, Mom," she said.

She reached her target weight a few weeks later, and maintained it through the summer and early fall. Maudsley therapists say that true recovery entails weight restoration and functioning well psychologically and socially. Kitty would continue to see a therapist from time to time, to work on perfectionism and other issues. For now, though, she seemed happy and whole. The phone rang for her; friends trooped through the house. Life seemed normal again.

But one night recently I dreamed I was running through a strange house, looking for my daughter. I found her — though it wasn't really her — and grabbed her by the arm. "You didn't eat dinner last night, did you?" I shouted. "What did you have for breakfast?" Not-Kitty smiled. "A teaspoon of air," she said sweetly. I woke with my heart pounding, full of rage and hatred for Not-Kitty, the demon who lived on air, who wore my daughter's face and spoke with her voice.

The Maudsley approach advocates separating the disease from the sufferer, the anorexia from the adolescent. And this helps, especially on the worst days. But it's also true that the demon is part of our family now, lurking in the shadows. We will never forget it. We don't know if or when it will re-emerge — two months from now, two years, five years. We don't know if we've done the right thing. Is Kitty cured? Will she ever be cured? There are so many questions I can't answer.

That morning, I got out of bed in the gray predawn and went down to the kitchen. I pulled out eggs, milk, butter and raspberry jam and set to work making crepes. It was all I could think of to do.

Harriet Brown is the author of "Mr. Wrong: Real-Life Stories About the Men We Used to LOve," to be published by Ballantine in January. She's currently at work on a book about anorexia.