

Lydia answers:

1. Can you give us some background on your family and let us know when you first realized there was a problem?

My husband and I are in our late 50's. He's a practicing physician, and I've retired. Our 27-year-old son and his wife recently graduated from law school. We have 22-year-old twin daughters E and J, both college students. We live near Chicago, Illinois (USA).

We first realized E was having problems in high school when we received a call from a school counselor who told us she had been discovered cutting herself. The school helped us find a therapist to help her, and we learned that cutting is often associated with eating disorders. At that time E was still at a healthy weight and said she "needed" to keep running on her school's cross country team to relieve stress.

In therapy with her I learned that E was struggling with memories of bullying during her years in elementary school. Her therapist felt that working through painful childhood issues would help her heal and move forward with her life. I couldn't believe my intelligent, beautiful, and talented daughter could be so overwhelmed with feelings of hopelessness.

After several months E announced that she felt much better and stopped therapy. She ran longer and longer distances, gradually losing weight until her freshman year of college.

Then the bottom dropped out.

At Thanksgiving dinner, after she had helped prepare all the usual trimmings - sweet potatoes with marshmallows, pumpkin pie, and other treats - we realized E wasn't eating anything but lettuce. By this point she appeared emaciated.

E had been rooming with her twin sister at college who told us E had been refusing to go to meals in the cafeteria. E insisted on bringing J's meals up to their room, and then she would sneak small amounts of food to eat in the bathroom in their dormitory. J was angry that she was being forced to eat her meals in their room, but scared that if she didn't, E would starve.

We were scared too. Our whole family, including my husband, her sister, her older brother and his wife; sat with her and told her how much we loved her, and that she needed help. We told E we were sure she had an eating disorder, anorexia, and that we would help her find a therapist. My husband and I made it clear that we would not continue to pay for schooling unless she got help. She dragged her feet, but by February E was finally seeing a therapist who specialized in eating disorders near her school and we thought she was getting the help she needed.

We were wrong.

2. How did you decide on treatment/find your Maudsley provider? Aside from Maudsley did you employ other interventions?

We tried everything to help our daughter. When it became clear that individual therapy wasn't enough, we began to work with a family therapist. We tried to keep track of her weight, which was constantly going down, but as she was over 18, we weren't privy to her medical information. By the next summer she was desperately ill.

Her doctor finally had to inform us that she had been trying to persuade E to admit herself for inpatient care for several days without success. We will always be grateful to this doctor, who risked breaking medical confidentiality laws to save our daughter's life.

Our whole family insisted, and finally E agreed to admit herself to a residential care facility in Texas. She had to spend her first 2 months in a wheelchair. She stayed there for nearly 3 months before returning home. She tried living with her brother and his wife for a time, but they could see that she was still deeply anorexic. They felt she needed more help than they could give her (both of them were working full time), and she decided to move home again.

Despite her continuing struggle, she transferred to a college in our community, first living at home and later in an apartment a few blocks from home. She was seeing a therapist, doctor and nutritionist regularly; and we continued in family therapy. But it became obvious she was losing ground. By the following summer she needed to be admitted to residential care again.

Two days after she admitted herself to the program (this time in Arizona), we received a call from their physician that she had been taken to coronary care in a

hospital in Tucson. It's impossible to describe the fear that gripped our hearts at this point. After a week her cardiologist determined that she was stable enough to return to residential care.

Three months later she returned home, still underweight, but expressing a strong determination to "beat" her anorexia. She continued to see a therapist, doctor and a nutritionist fighting valiantly to get well. By the following year she was sinking again. We were losing hope in the treatment methods she had been trying and sought a new way to help her.

Last November, my husband and I read an article by Harriet Brown in the New York Times, "One Spoonful at a Time", where we learned about family-based therapy, and the Maudsley approach. I sent an e-mail to Dr. le Grange, at the University of Chicago, asking if it would be possible to implement Maudsley treatment with a young adult woman. Dr. le Grange responded immediately, and helped arrange an appointment for us with his colleague, Dr. Chen, who specializes in treating adult women sufferers.

3. How did you accomplish re-feeding?

In our first meeting, Dr. Chen listened to E's history, and the story of our family's efforts to help her get well. She frankly explained the grim prognosis for young women with eating disorders. Dr. Chen told E that she still had a chance for complete healing, because her family was determined to help her, but that this kind of help usually vanishes as parents age and siblings "burn out".

Dr. Chen emphasized the importance of separating our daughter from her disease if we were going to be able to succeed. She asked E if she would be willing to turn over all control to us. She explained this meant that E would need to move back home; allow us to prepare and serve all meals and snacks, which she would need to eat; and that all forms of exercise would have to stop.

E wept. She was afraid of the consequences of her disease, but the thought of handing over so much control was overwhelming. We just sat with her, and gave her a chance to work this through. After a little while, she said she was willing to give Maudsley a try and acknowledged that nothing else had worked.

I asked Dr. Chen if there was a menu or calorie plan we needed to use, and to my surprise she said no. She told us that the Maudsley Approach is based on the premise that loving and committed parents are competent to manage these

choices. She reassured us that she would help us fine tune things as we went along, but ultimately we could be trusted to make the best decisions to help our daughter get well.

We drove home and cooked dinner. E struggled to eat a full plate, with meat, vegetables, potatoes, bread and butter, and whole milk...but with patience she ate everything we gave her. A few hours later she had cream of wheat with whole cream and fruit and more milk. Again she was able to hang in, and kept hanging in meal after snack after meal.

We went to the Maudsley Parents website to look for ideas for high calorie meals and snacks and found lots of helpful information. For our daughter, homemade milk shakes and smoothies really helped. We invited her to choose flavors, but the ingredients were up to us. We kept her out of the kitchen during meal and snack preparation, because it was too stressful for her to watch, as she put it... this just "triggered" the voice of the disease.

4. How did you talk to your child about anorexia, eating, recovery, and other related issues while you were refeeding? Do you have any coaching tips on handling your child's anxiety?

We tried to let E bring up these questions. We found that talking about anorexia added to her stress, so when she wanted to talk about the big picture we focused on offering support and encouragement. We stayed away from lectures and teaching, knowing that this would backfire and only make it harder for her to let us stay in control. Most of the time, we allowed family therapy sessions to be the safe space where she could open up about her feelings, so we could work together with Dr. Chen to help her through the tough job of psychological healing.

E worried about the pace of weight gain initially. She needed a lot of reassurance that we understood her fears, but also that we would not back down to the voice of the disease. I came to see that E needed to "borrow our will", to overcome the cruel impulses that are driven by anorexic brain chemistry.

We learned that anxiety during refeeding is real and can't be dismissed. We approached this by being both loving and firm. We had to face anger, frustration, tummy pain, long drawn out meals, and tears. Thankfully as our daughter got closer to goal weight, her emotional turmoil lessened in intensity and frequency. As she neared her target recovery weight, we learned that her disease was fighting back through water loading, so we had to begin routine testing for

specific gravity to protect her against this danger.

5. What practical problems arose and how did you handle them? School, jobs, etc.

E was attending a university in our city when we began Maudsley. We decided that her meal schedule and activity restriction wouldn't work if she continued her schooling. She took time off from school until we felt (and Dr. Chen agreed) it was safe for her to return part time. In our minds, her education had to take a back seat to restoring her health.

We simplified our own lives. We told friends and family that we would be doing family based therapy for E, so social engagements involving meals would not be in the cards for us for the foreseeable future. We stepped away from most of our community involvement other than church, to minimize scheduling conflicts with meals and snacks. My husband informed his partners that he needed a lighter schedule to help our daughter recover.

6. How did parents work together to see Maudsley succeed?

My husband and I switched off responsibility for meal planning and preparation as his work schedule allowed. One of us would be in charge for the whole day, doing all the cooking and tracking E's intake. The other would stay close, offering encouragement. Most important was mutual support, never allowing the anorexia to triangulate our decisions. At times it took both of us to overcome the powerful resistance of her disease.

We tried to avoid conflict in E's presence, because this would only make things harder for her. When we met issues we couldn't resolve without support, we turned to Dr. Chen for her take on things.

We made it a point to spend a few moments alone every evening to talk about the day, and to comfort and encourage each other. I think paying attention to our own relationship was one of the most important things we did during the stressful refeeding process.

7. What was the greatest challenge for you? For your child?

After adjusting to the challenging task of consuming 3500 to 4000 calories daily, I think the biggest hurdle was helping E come to terms with the seriousness of her

osteoporosis and the need to put off exercise until she is able to do this safely. I think this was very hard for her as well.

8. What was the most helpful support for you? For your child?

We all felt tremendous support from Dr. Chen, our Maudsley therapist. She continually offered praise and encouragement to all of us. Her demeanor was both firm and reassuring; and kept us on track. She was especially gifted at helping us with problem solving when we felt we were getting stuck on a question or issue that could divide us.

For my husband and me, the [Around the Dinner Table](#) Forum for Parents of Eating Disordered Children was a real lifeline as well. We found hope in the stories of success, practical "how to" advice (especially recipes), and solace from families around the world who understand the frightening lonely struggle of parents who are working hard to beat this disease.

9. How did you go about re-establishing independent eating? How are things going now?

We worked closely with Dr. Chen to adjust E's caloric intake as she neared her recovery weight goal, to help her transition to a more normal lifestyle.

Once it became clear that E was at a safe weight, we began to return control of meals to her one small step at a time. We started with one snack, then another, and then the third. We monitored her weight, but more importantly her attitude, to see if she could approach control in a healthy way. For us this meant that she could get in enough calories and diversify her choices away from the rigid patterns and prepackaged foods that had been characteristic of her disease.

We waited a week between each snack step to see how she was handling things, before taking the next step.

We began with meals by allowing her to choose her own lunch and then to make it. One of us stayed with her to see how she was approaching this. We considered this a critical step to determine if she could return to college.

Once we felt she could and would make healthy decisions about lunch and snacks, we agreed that she could go back to classes. We continued making breakfast and dinner, and eating those meals with her until she had maintained healthy weight for 6 months.

Today E is living back in her apartment, but we still have family dinners with her usually 6 nights a week. We think she has made a remarkable recovery, but we are still very careful: listening and committed to her continued healing. We love our dinners together, and are overwhelmed with gratitude for the miracle of having her life restored.

10. What advice would you give to families starting out?

- Separate your child from the disease.
- Hug your other children every time you see them.
- Read [Harriet's article](#)...you'll learn this is hard but possible, and you are not alone in this struggle.
- Read [Laura's book](#), *Eating With Your Anorexic*...you'll learn this is hard, but a sense of humor is still possible and you're not alone in the struggle.
- Find a therapist who is committed to family-based treatment and trusts parents to be primary caregivers for their child.
- Don't trust any professional who thinks their protocol trumps your parental instincts.
- Buckle in for a long ride, family therapy takes time, patience, and determination; and most of us had to learn how to do this through trial and error.
- Accept love and support from people you trust, take a vacation from anyone who "means well" but drags your spirit down.
- Listen to your own beating heart--it's okay to feel lonely, sad, or scared, but then it's time to regroup and eat dark chocolate.