



If I knew then what I know now...

Laura Collins

If my daughter developed anorexia NOW, instead of back in 2002 when I knew nothing about eating disorders, boy would I do a great job!

I'd know all about how the illness works, what recovery looks like, all the theories on what causes it, the evidence behind different treatment approaches, the role of nutrition, and the best way for parents to respond. I'd have met lots of families who had been through it, I'd know countless fully recovered survivors of the illness, and I'd be aware of all the great work going on to help patients and families.

But I didn't.

“What to expect when you are expecting” didn't teach me how to recognize or cope with my child's sudden onset of mental illness. I didn't learn anything about eating disorders in school or from my peers. My husband didn't know, my parents couldn't help me, my friends were just as surprised and clueless as I was. Our pediatrician thought our daughter needed “more salt.”

In the fall of my daughter's high school sophomore year, she stopped eating, thinking or acting normally. She became irritable and detached from others. She developed irrational ideas about her body and how others treated her. She rejected food and she rejected help. But not only did I not know anything about eating disorders, I didn't know what I didn't know. I didn't know what to ask for or how to interpret the answers. And as I started to ask questions I did quickly realize that every person I consulted about the changes in our daughter had an equally sure, but completely different answer, as to what we should do.

A succession of therapists and psychiatrists told us that there was little we could do, and that we should not be the “Food Police.”

Our family was fortunate. We were among the first in the U.S. to learn about the Family-Based Maudsley Approach, and were able to assist our daughter to a relatively fast recovery with little physical damage. Because our daughter's recovery was home-based, we were able to avoid the costs and disruptions of inpatient or residential care. Although she was once gravely ill and the illness was on track to kill or disable her, we are very happy to report that she is fully recovered and lives independently and happily.

The approach our family took, the only evidence-based treatment for adolescents as they first become ill, was very different from the one historically offered to eating disorder patients. The Maudsley approach assumes these basic things: that the illness is controlling the patient and not the other way around, that food is medicine to heal the brain condition controlling the patient, and that parents are the best equipped and most skilled way to deliver that medicine. Done under the coaching of trained clinical support, families are brought together as a team to fight the illness and not the patient. Parents lovingly and protectively choose what, when, and how much food as well as monitor and

support between meals to keep the patient safe from bingeing and purging. As recovery progresses, control is handed back to the patient and the family is assisted in re-establishing normal roles.

We sat down with our daughter every day, every meal, and every snack for many months and served her a great deal of wholesome food. It was not low-fat, low carb, or low-calorie. And no, she did not like it. In fact, it was horribly hard for her and for us and she suffered a great deal. But once we understood that the things she feared were the things she needed, we knew we had to save her life and her future. In time, as her brain repaired, we began letting her take responsibility back. It was frightening for her to start making choices again, but we were alongside her and supporting her all the way.

“Didn’t she hate you?” People ask. Yes, at the time she did. But it was her illness that hated us.

“But what about the underlying issues that made her ill?” People ask. There isn’t any evidence that eating disorders are caused by underlying issues. Although our daughter had the expected issues of adolescence and our family is by no means perfect, we know now that this illness is biologically based and genetically transmitted. Her illness was set in motion by eating too little for her growing and active body. She didn’t choose anorexia, and she couldn’t just choose her way out of it. But with brain repair, and re-learning how to eat and cope with the emotions that semi-starvation held at bay, our daughter was able to regain her cognitive ability to fight the eating disorder brain patterns that tortured her. Had we not done what we did my husband and I are quite sure she would have died.

There were no Family-Based Maudsley therapists in our area, so we had to buy the manuals and literature and train ourselves and local clinicians in how to support our family through this harrowing time. We made mistakes, and we fumbled through. I would not wish this experience on anyone: it was the hardest time any of us have ever had.

I will tell you frankly: this approach was shocking and even offensive to many at the time. People told my husband and I that we were too involved, that we’d make her worse, and that we needed to “look inward” for the real cause of our daughter’s eating issues. Even now, many eating disorder clinicians remain skeptical and only a minority seek training to offer Maudsley support. There is no denying that this approach flies in the face of, and challenges the premises of, traditional eating disorder treatment.

“What does your daughter think of what you did now?” You may ask. Our daughter is thankful that we stepped in the way we did and we refused to give in to what her eating disorder demanded. She encourages other families to do the same. She supports my work in spreading the word to other families about this option in treatment.

I’m immensely proud of my daughter. She did not choose her illness, and needed us to step in, but the reality is that she had to take up her own recovery at some point and eventually she was able to do that and has done it spectacularly. She is my hero, and my

husband and I are proud to have supported her – we do not take credit for her recovery, only for making it possible. And we feel passionately that parents need to know that treatment option exists and let them make a reasoned choice for their family. Too many parents are still being told that eating disorders are lifelong, that the patient has to choose recovery, and not told that full nutrition and weight recovery are a necessary tool for recovery.

Our daughter is 21 now, attending college and living in another city. We see each other often and we remain a close family, as we were before anorexia threatened to destroy her and us. We learned a great deal about ourselves, and in some ways the experience strengthened each of us and our family bond. I am not thankful to the illness, but I am grateful for how we all responded.

Since our daughter's recovery, I have devoted myself to public education and encouraging other parents facing this situation. I wrote a book, started a popular online forum, and recently joined with hundreds of other families by creating a nonprofit to support families and caregivers. I believe very deeply that our ill loved ones need us to be assertive partners in the treatment team, and that the legacy of blaming and marginalizing parents has caused untold suffering to the very patients those policies meant to help. I have nothing but optimism that the trend of trusting and empowering families will continue and become the norm.

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