

Testimony of Larry D. Espel

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Words are barely adequate to explain the confusion and dismay my wife and I experienced the first night our family physician arranged for the hospitalization of our fourteen-year old daughter for what we would learn was anorexia. We suddenly found ourselves face to face with the strange idea that our bright, athletic, musically talented daughter was in dire health.

We knew something about the virtually inexplicable wreckage that eating disorders could cause. We had watched several members of a rival girls cross country team go from state champs one year to a group of weaklings who could barely finish races the next year. We had watched a star basketball player in our own school wither before our eyes.

We were certain that we had never suggested to our own daughters that they were too fat. We never encouraged or even allowed diets. We ate meals together. We enjoyed a wide variety of foods and desserts were always part of the deal. We had a solid home with a happy marriage and two daughters. We had enough economic success to be comfortable. Our girls fared well in school. No objective factors could explain how we had a daughter with an eating disorder.

But there we were, at a mental health ward of a hospital, leaving our daughter. She screamed out: "Don't leave me, Daddy." But she needed help at that point that we did not know how to provide.

Over the next few months, we participated in what would be the first of innumerable group and family therapy sessions. We shared our experiences with other families who had their own problems.

We heard about and read dismal mortality statistics for young men and women with eating disorders. We learned that treatment processes could often consume five years or more. Frankly, I was convinced early on that those statistics were irrelevant for us. Eating disorders seemed so illogical to me. I was confident that we could fix our daughter's problems in a few months.

We read books that provided a dizzying array of explanations and recommendations. We read books by therapists, patients, and family members. Some books suggested that parental problems like drinking, divorces, abuse, loss of jobs, or deaths were associated with eating disorders. Others suggested that parents needed to leave the treatment process entirely to professionals. Various therapists had read the same books and espoused many of the same theories. It was hard not to feel guilty about our daughter's situation.

The few months I had anticipated turned into a long series of years. I've lost count of the number of emergency room visits and hospitalizations for our daughter. We also placed our daughter in a couple of residential programs. Before her senior year of high school, we devoted ourselves to an approach known as family-based therapy, in which her mother and I ensured that our daughter ate enough to restore weight, with terrible battles of will. She graduated. We hoped that the problems were past.

She went to a fine college in Pennsylvania but lost a shocking amount of weight in her first semester. She could not return for her second semester. Another couple of hospitalizations followed.

In the first four years of so, I was the eternal optimist. I believed my daughter every time she told me that she was turning the corner and starting recovery. I had my heart broken over and over again when it became obvious that she had deceived her parents and her treatment team. Details don't matter too much, but she found ways to fool doctors, nurses, dieticians, counselors, parents, relatives, and friends. Except that she could not fool her own body, and when its needs were too neglected for too long, it would always finally betray her.

In the second four years or so, I no longer even dared to hope for recovery. Her mother and I never threw her out or pulled our support for her, although we sometimes wondered if we should. Our marriage was sometimes in trouble and I'll never be surprised again if I hear that other couples split after a family tragedy. We continued to participate in therapy sessions and programs, but I was so discouraged that my heart could no longer be in the sessions. Even when we heard about recovery stories from girls and their families, I could no longer believe that such events could become relevant for our family.

Ultimately, I believe that our efforts were of some benefit. Sticking by her, even when there was little apparent reward, helped ensure, at least, that she remained alive. We are grateful to the various hospitals and programs that offered her treatment. Even if she remained reticent and enmeshed in her eating disorder, they averted the ultimate tragedy.

I must emphasize that the role of parents to a daughter with an eating disorder is rarely gratifying. Our daughter frequently expressed her resentment, her loathing, her disdain for anything relating to her parents. She withdrew from her friends. She was unable to complete a number of activities, including sporting events, piano recitals, choir concerts, and academic commitments. She was so withdrawn into her weird world that she seemed unreachable.

Finally, just two years and one month ago, our older daughter was getting married. Our younger daughter was to be the maid of honor. But my wife and I were entirely uncertain that our younger daughter, then 21, could make it to the wedding. That is, we feared she would collapse, require hospitalization, or even die. She announced in the month or so before the wedding that she was finally willing to admit herself to a residential treatment program. But she learned that if she entered the program immediately, she could not get leave to come to the wedding. So, her gamble (and ours) was that she could make it to the wedding and then to the residential program. She did make it to the wedding, and gave a wonderful, moving toast to her sister. We are grateful for that. But we will always wince to see the pictures with our daughter at her perilously thin stage.

Our daughter entered the residential treatment program the Monday after the weekend wedding. Upon arrival, she announced that she would stay only one month. But at least she had gone into this program, this time, on her own volition. As the month end approached, she expressed willingness to stay a while longer.

While she was there, about three months after she had checked herself in, one of her friends died. That friend had also struggled with her eating disorder. She had been in our home. At the very time that our daughter had decided to accept treatment, that friend had not gotten such treatment. Her death underscored the serious stakes of such decisions.

Sometime in the six months that our daughter was in her residential program, things changed. She began to engage more seriously in the recovery process. She restored some of her lost weight. She expressed a readiness to come back to the world and continue recovery on the outside.

The program provided out-patient support for our daughter and it became evident that recovery was, this time, at long last, more than a charade. She made progress on her own, and continued to restore weight. This time, it was plainly her choice and her actions.

In the ensuing months, I could only gradually begin to dare to hope again that our daughter could really sustain her recovery. She reengaged with family, friends, and school.

Now, two years after she entered her treatment program for what I expect will have been the last time, she is here and can speak for herself. She holds promise for the world, and I dare to believe in her future again. Indeed, I am certain that she will contribute to the recovery of many other young victims of the unaccountable and perplexing conditions known as eating disorders.

It is impossible to express completely the jumble of emotions that I thrill to experience now that our daughter is restored to herself, to us and to the world. Words like relief, excitement, pride, joy, love and admiration come to mind. Her mother and I can look forward to our frequent interactions with our daughter without dread. Now, when we have our differences with her, the issues are merely trifles which we can discuss reasonably. We can laugh again. We explore and debate ideas. Our daughters have become friends and confidants again. It is a new world.

I am grateful to the insurance programs that my place of work could provide and those who ensured that my daughter received needed insurance support for her treatment. Without them, my wife and I would have been driven to likely bankruptcy or at least daunting financial hardship.

I am grateful to the numerous treatment programs, dieticians, therapists, doctors and nurses who provided help along the way. My wife and I will be eternally grateful to some key persons who were vitally important to our daughter and us.

Some others of those who endeavored to help us were misguided in their science or their methodology. Some were less effective than others. But none of those who offered help lacked good hearts or good intentions. Sometimes, only hindsight helps to distinguish who was right and who was not quite as right.

Where this experience takes me is to a conviction that the FREED Act is vital. I know that others have presented information about the incidence of eating disorders. The need for help is there. Our experiences have shown that, with the right kind of help at the right times, the seemingly impossible can occur. Those with eating disorders can and do recover. But we need better research about eating disorders because there is so much to learn about their causes and the optimal modes of treatment.

Families whose insurance programs are less favorable or accessible than those that benefited our family need help.

Without help, our daughter could easily be just as lost to the world as the friend of hers who died two years ago. Had our daughter died, the world would have lost not only her, but who knows whether my wife and I could have handled the loss, or whether we could remain productive members of society, in a united marriage. Other family members and close friends would have been similarly challenged.

But with the help for which we will always be grateful, lives can be saved. And these beneficiaries can pay forward the help with the lives that they have regained.