



Aimee Liu's most recent book is "GAINING: The Truth About Life After Eating Disorders." She is also the author of the first anorexia memoir, "SOLITAIRE," as well as three novels and numerous articles and essays on psychological and literary topics.

Her eating disorders resource website is www.gainingthetruth.com.

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Swimming Upstream

Robbie Munn, MA, MSW

It has been a little over a decade since I almost drowned. When my daughter at the young age of not yet 13 developed severe depression and swiftly sought out anorexia and other means of self-harm as antidotes, our family was forced to follow across unknown and unlit waters in pursuit of her. It is difficult enough to cross a calm ocean in a well-equipped and sturdy craft with a full crew. It is foolhardy at best and lethal at worst to try the same in unendingly foul weather in an exposed dug-out with no navigational system. Add the fact that the crew is forced to split up for long periods of time, and the voyage becomes bizarre parallels of dangerous solo journeys that no person would attempt; no one but a parent desperate to save their child.

Even with all my years of graduate and post-graduate training at fine universities and departments of psychiatry, I was sorely ill-prepared for what I would encounter trying to find substantial and appropriate treatment, both outpatient and residential, for our daughter. While the road maps for physical ailments are fairly well laid out in detail and there are distinct crumbs to follow, the road atlases for psychiatric illnesses are, pardon the pun, still all over the map. Eating disorders have only recently been recognized as true psychiatric illnesses rather than "harmless phases that will pass." All these factors contribute to the length of delay in appropriate response from family to professional. These unnecessary delays add to the complexity and severity of the symptoms, once true treatment is finally found.

Through my daughter's long and desperate struggles, I would learn that I already knew what anorexia looked like, smelled like, felt like. I had already almost drowned once as a child and again later as a

young adult. I just didn't know what to call it then. My mother, born in 1910, also had severe anorexia, probably in place by her adolescence from what I have learned of her history. Her "unique" and compromising ways came to be called by other names over time: demanding, selfish, generous toward others and unendingly exacting of family, unbending, difficult, rageful, dangerously unpredictable, obsessive, depressed. These are just a few of the words used to describe her. Her anorexia did not fully bloom until later in her life, after my step-father and older half-sisters had all left home, some fleeing as they did so. My half-sisters, from different marriages, each one to two decades older than I, knew in detail of our mother's bizarre compulsions and fears, knew of her refusal to leave the house except "guarded" by others, knew of her diet of only seven kinds of food religiously prepared exactly the same way day after day, year after year. They also knew of how our increasingly small lives came to be organized around and evaluated by input and output of all things, material and emotional. And yet, because they had moved on to their own families and did not live with her in the same house during those decades, their understanding of the impact of her illnesses differs vastly from mine.

Eating disorders, like most psychiatric illnesses and addictions, do not play well with others. They are arrogant, want to upstage everything in sight, and want to set all the rules. They ignore and implode centuries-old social structures and boundaries that help to keep families intact, on course, and functioning best for all involved. Eating disorders are not unlike substance abuse in that they quickly begin to claim all ambiguous or open space as their own. Like

smoke, eating disorders wind up the stairs into bedrooms, follow you out the door to work or school, slip into the car for previously happy family outings, and change all who try to challenge their right to exist, including siblings, children and other stray souls who happen to get in their way.

Eating disorders have gotten a "hold" on my family: my mother, my daughter, a niece here, a first-cousin there. Me. I flirted with and held hands with anorexia for a decade or three, knowing that I was playing with fire even then but not knowing why. Like most young women in the last quarter of the 20th century, I was never diagnosed, largely because I never told anyone anything. And yet it determined everything. All I was trying to do was outrun my crippling depression and bizarre childhood; I knew as little as my mother that the path I was taking was only making things so much worse and intractable. Even when I studied eating disorders in college and grad school, met them in dorm rooms and even later as a therapist, I failed to recognize my mother in them. Her eating disorder did not then match textbook descriptions. It was not a "clean" case, not linear, more like a broken, messy vacuum, both gobbling and spewing simultaneously. I certainly never recognized myself as having one. Not until my daughter did.

Over the past decade people both within and outside of the field of eating disorders have attributed my determined response to the sudden and critical onset of our daughter's psychological derailment to my professional background and training. Certainly, my training and professional experiences gave me a much-needed framework a long decade ago – a different lifetime ago – by which to try to make fear-drenched decisions, both for my daughter and for her

younger and confused brother. However, it was the memories of what my mother and niece had never been able to have or become that fueled the intensity of my involvement. It was the memories of all I had given up, as well.

In the past decade, the field of eating disorders has done a virtual 180 degree turn in how it views, treats, and educates families and parents. Instead of seeing parents as antagonists responsible for their child's illness, therapists, nutritionists, and most clinicians of any demeanor now view families as potential resources; necessary components of the hope of sustained recovery. Yet, only ten years ago I was still viewed with skepticism, if not derision. My professional degrees and knowledge counted for virtually nothing, as I had never worked in the eating disorders field. The fact that I had once been a county-level supervisor in charge of one of the first Family Counseling Programs created within a Juvenile and Domestic Relations Court system in one of the largest counties in our country counted for naught. I was part of the enemy camp.

In seeking treatment for my daughter in 1996, it was as if I had fallen down a little-known psychiatric rabbit hole, reminiscent of how families of people with bi-polar and schizophrenia had been viewed 20 years earlier. I was incredulous at the backwardness of the overall premises by "those in charge." At times, I could not even get past the receptionists handling the initial phone calls while I was looking for a safe residential treatment center to send my 13-year-old daughter. My questions were resented and went unanswered; some places would not even talk to me until I had completed their financial forms. I literally spoke to over 100 people during those two endless weeks. Later, as the lack of consensus within the best of the eating disorders field became increasingly apparent, I began to read everything I could find and talk to anyone who didn't walk away. And, many did. I could not imagine a comparable scenario were my child to have a strictly physical illness, you know, something "simple" like childhood diabetes. I still can't today.

If I were given the opportunity to help my child find her recovery all over again, there would be years worth of things I would do differently; however, there would be a few critical points I would insist upon. These lessons apply to parents and families

but therapists need to know them, as well. Therapists should be emphasizing these points for their patients and their families.

1. Learn all you can about the illness. This is no different than a parent would do for any other condition their child has. Psychiatric illnesses may seem more difficult to grasp than strictly physical ones, but the material describing them accurately is available for study. Ask for help, ask the questions, read and read and read some more. Get to know your loved one's illness inside and out. It is your single best shot at helping to kick it out of the house.
2. Go find a therapist yourself. You need a knowledgeable, objective guide to help you survive this intact. This illness will change all those close to it, just as having cancer in the house changes that family's dynamics and priorities.
3. At the same time, don't give the eating disorder the upper hand. You do not want the weakest part of the link determining the most important decisions for the family. Just as you would fight a substance abuse from "taking over the family," you need to fight this illness. This is a hard one and requires constant re-balancing. Undeniably, there will be critical times such as when your child is in true danger, either physically from the disorder itself or from the psychological damage upon which it thrives, when a parent needs to respond to the chaos being created. Nevertheless, the illness needs to take a back seat for all involved as quickly and as appropriately as possible. It is not going to want to stay there, however, and that is going to be part of the ongoing dance toward recovery. For all.
4. Pace yourself. This is a marathon, not a sprint. Unfortunately, most families cannot begin to grasp this until they are already exhausted by their efforts. The idea that this may literally continue for several years to come can be overwhelming to digest. It is critical to get this framework on board, however, because it will help to establish realistic goals and expectations for all. It will also help to shore

up constant waves of discouragement and depression when too much is hoped for too quickly.

5. Accept the fact that you and your family will not come out of this "the same." That land no longer exists. This is like going through a fire. There will be mountains to regret and mourn, but there is also vast opportunity to learn about oneself and others in ways that never would have come about in easier times. Look for the hidden gifts, and hold on tight.

When people ask me what I do, I still have to stop and think, "What will I tell them today?" I started this article talking of almost drowning. We, as a family, are very, very fortunate to have each survived this part of our respective and collective journeys, largely intact, if fundamentally different from where we each started. However, families everywhere continue to flail and take on water unnecessarily every day. Too many will begin wading into the water tomorrow with no idea of what they face in their own little dug-out, nor how many years it will take to reach any shore at all. For everyone's sake, these trips all need to be cancelled.



Robbie Munn, MA, MSW was one of the first family members invited to join the Board of the National Eating Disorders Association (NEDA).

Robbie has been active for over ten years on both regional and national levels to help the public better understand and respond to the severe ramifications of eating disorders. She helped to create and co-chair the first conference in the field to include families, individuals, and clinicians.