



AN OPEN LETTER TO PARENTS AND CAREGIVERS OF A LOVED ONE WITH AN EATING DISORDER

Dear Mom, Dad, Caregiver:

While it may seem cliché to talk about how quickly time passes as your child grows up, one minute they are dependent on you for everything and the next, their most pressing need is independence. For those of us who have had a child facing a serious illness, we learn that time can often feel painstakingly slow yet moments later, insanely fast. When we received an aftercare follow-up phone call from the Aftercare Clinician at the ACUTE Center for Eating Disorders and Severe Malnutrition at Denver Health (ACUTE), a year after our daughter had been discharged from their program, it felt like a lifetime had passed since her time there, and yet her recovery process is still very present in our life. That being said, our story, while by no means finished, appears to be destined for a happy ending.

As we talked to Sara Nieder, LCSW, ACUTE After Care Clinician, we expressed our gratitude for the staff and the expanded availability of their life-saving programming, as it wasn't until recently that they expanded their care to include adolescents as young as 15 years old. We also shared that it has been incredibly eye-opening to reflect on how little we understood about eating disorders when this all started; if only we knew then what we know now. Given this moment of reflection, Sara and I discussed what I wish we would have known and the desired insight on what to expect in our recovery journey the day we walked through the doors to admit our daughter to ACUTE.

I write this letter to you, as a caregiver to your loved one, with hopes of providing some insight of our lived-experience and a desire to provide comfort, support and hope as you embark on your own treatment and recovery journey. As my family and I wrote this letter together, it's important to note to you that we became overwhelmed by emotions and were surprised by the challenge of attempting to concisely articulate how the vicious disease of an eating disorder can manifest and present itself in so many ways.

If you haven't already discovered through a frenzied web search of "eating disorder treatments" or lectures ad nauseum from your child's pediatrician, there are a multitude of opinions, philosophies, etc. Before we add to that abundance of information, we want to start this letter by stating that:

There is not a "one size fits all" treatment for eating disorders. Therefore, as parents and caregivers, you must trust your instincts and you must ask questions, even when care providers, family, friends, etc., look at you like you are lost, confused or ignorant. You are your child's best advocate. That said, your child's eating disorder is a master manipulator of your loved one AND to those of us who provide care for them. We now know and believe that you must be sure you are advocating for your child's health and are listening to your instincts and not the eating disorder's. In your gut you will know the difference.

To that end, the information we are sharing is only our experience. Our only “qualification” for giving these opinions is that this is based on our story and our lived experience. Please take the information that helps you feel supported or resonates with your situation and feel free to ignore the rest. Treatment is a very individualized journey, but you don’t have to do it alone.

- **Why this happened doesn’t matter** and trying to “figure it out” is not something to spend any energy on right now. There will be a time and place for that, but it’s not now.
- Similarly, **wondering what you did “wrong” or placing blame** on a friend, coach or some activity, is equally futile. Eating disorders take hold under a “perfect storm” of internal and external “things” and while there are lists on every website of “at-risk indicators,” there is no real way to predict or prevent its inevitability.
- Your child’s brain is operating in “survival mode” because they are malnourished. **Their brain has no capacity for mental healing until they are close to reaching their ideal body weight (IBW)**. Therefore, refeeding and nutrition must be the sole focus, nothing else matters until their brain is nourished enough to begin recovery. We know it might feel like your child is a stranger, but the child you remember is in there, and they will be back, so just keep loving them.
- We were amazed to learn **what the human body does to protect itself when it becomes malnourished** – it is nothing short of miraculous. But that protection means that reintroducing nutrition is an incredibly intricate and delicate task. So, if you start to wonder why “more” isn’t being done to hasten the refeeding process, spend a little time web searching “recovery from/effects of malnutrition” or specifically “Minnesota Starvation Experiment” and you will have a whole new respect for your child’s recovery process.
- Your child’s **eating disorder has become their preferred coping mechanism** for anxiety, stress, depression and/or other challenging emotions. Since these emotions are a reality of life, the ultimate goal is to help them replace their eating disorder thoughts with a healthy coping mechanism, but it won’t happen until their brain is no longer malnourished.
- Nobody wants to sit in shame, fear, pain, but as the eating disorder takes hold, an emotional disconnect occurs and the child becomes committed to their story – **the eating disorder becomes their identity**. If they aren’t their eating disorder, then who are they? Establishing their new “identity” is key component of their long-term recovery.
- **Body dysmorphia** is usually the last piece of the recovery process, and it can take years for the child to see their body accurately. We bring this up now only because we didn’t learn this until much later in our daughter’s recovery and not having the right expectation about this was an unneeded source of frustration.
- We are a family that tends to view **prescription medication** as a last resort, so we were slow to get onboard with the idea that an anti-anxiety medication would help our daughter. We can only say, we wish we would have done it sooner. If your child’s caregiver is recommending it, consider giving it a chance.
- **Ongoing therapy and working with a dietician after discharge is critical** to optimizing the efforts of ACUTE and/or any residential treatment. However, finding professionals experienced in eating disorder treatment that can strike the balance of gaining your child’s trust so they buy into recovery and can meet your family needs geographically, financially, logistically, etc., can be an incredibly taxing challenge. Starting to explore options now can be helpful so you have some sense of what’s available, waitlist times, etc. Look for professionals with one of these credentials – CEDS, CEDRD, CEDRN, CEDCAT earned through the International Association of Eating Disorder Professionals (<http://www.iaedp.com>). There is a Member Directory under the Membership tab. Once you make a choice, give the professionals time to form a relationship with your child but, if at some point your instincts tell you it’s not a good match, don’t be afraid to ask questions or start a new search. In our opinion, **having a dietician with significant eating disorder experience was our best investment** in our daughter’s recovery.



- One of our daughter's greatest anxieties about entering treatment was **missing school** (she was a junior in high school). Do yourself a favor and don't worry about it, there are plenty of ways to get caught up once they are healthy.
- Like your child, **you won't "hear" all the information** given to you. You will hear it when you are ready for it. Take notes, review them as needed and give yourself grace.
- **Find your support system.** This process is physically and mentally taxing. Misinformation and lack of education about eating disorders can lead to feelings of guilt or shame and you may be reluctant to share what is happening to your family (and it does impact the entire family), but find someone or some group you can lean on. As we opened up about our experience, we were surprised to find so many other families dealing with similar issues and those families, along with a renewed commitment to our faith, became the foundation of our support.
- Recovery from an eating disorder is a complicated process. Unlike an alcoholic who learns to avoid and abstain from drinking, a person with an eating disorder can't avoid or abstain from food. Eventually, **they must develop a healthy relationship with the "enemy" and there is absolutely no shortcut.** This further highlights the importance of an experienced dietician and therapist. The recovery process is so much more than to simply "eat".

From our experience, this process isn't a sprint or a marathon. **It is an ultra-marathon on a winding, rocky trail with many hills to climb and descend.** It takes time. Somedays the steps come easy and other days we lose ground or get knocked down. Recovery is not linear. It's not complete when they come home from residential care, and there is no option to "check the boxes" of recovery and make everything go back to "normal." It is messy, emotionally exhausting, and at times, all consuming. Just know that the "bad" days are normal, and it is ok to stop and rest on the side of your journey. You will find the energy to stand back up and move forward.

We want to emphasize, this is a family disease. It affects you, your spouse, and other kids (even if they are no longer living at home). **Your family's care is as essential as your child's.** If the child is doing all the work and the family is not receiving help, only half of the problem has been addressed. Consider family counseling, faith-based support or a local eating disorder support group.

Lastly, this time of your life can feel lonely and isolating, especially if one parent is staying near the treatment center, while the other is home. Do what you can to stay connected and find moments of laughter, love and engagement within the family, even if it's over video chat! If your child is in a program with limited communication, consider some of the ways to stay connected listed under "Resources" below. Thousands of other families have traveled this path, but their children have mastered their recovery and are thriving in their post-eating disorder life. The idea of an ultra-marathon may feel terrifying, but for better or worse, your family is now on the trail, just take it one step at a time, one day at a time and know all the families that came before yours are supporting you in spirit!

Warm Regards,

CJ & Andie

RESOURCES

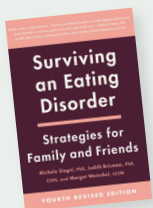
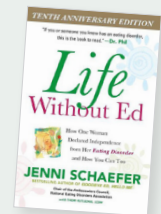
There are thousands of websites, books, and videos out there. As we indicated at the beginning, there is not a “one size fits all” program; the disease is too nuanced in its triggers and execution. We think the important thing is to find the resources that speak to you and that you feel address your child’s particular situation. Below are a few resources that we either found useful or subsequently heard others found useful.

WEBSITES

- » **Sinnergy Wellness**
<https://www.sinnergywellnessgroup.com>
After our daughter came home from residential treatment, we found our incredible ED dietician here.
- » **Ophelia’s Place**
<https://www.opheliasplace.org>
Free resources and support (via phone & virtual groups)
- » **Project HEAL**
<https://www.theprojectheal.org>
Breaking down systemic, healthcare, and financial barriers to eating disorder treatment
- » **Academy for Eating Disorders**
<https://www.aedweb.org/home>
On the “Resources” page there is a lot of information as well as informative videos under “AED Recommended Resources and Services.”
- » **Eating Disorder Hope**
<https://www.eatingdisorderhope.com>
An online community that offers resources, education, support, and inspiration to those struggling with disordered eating behaviors
- » **The Eating Disorder Foundation**
<https://eatingdisorderfoundation.org>
A Denver based support group that may be helpful if you’re staying in Denver during your child’s treatment
- » **The National Alliance for Eating Disorders Awareness**
<https://www.allianceforeatingdisorders.com>
The leading national organization providing eating disorder help, support, and education. They offer a tremendous amount of free and low-cost support groups with specialty groups such as Caregiver Support, Transgender Support, etc.

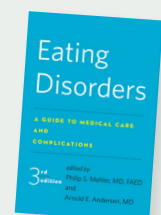
BOOKS

Life Without Ed (Tenth Anniversary Edition): How One Woman Declared Independence from Her Eating Disorder and How You Can Too by Jenni Schaefer. It was written for those battling an eating disorder, by a woman battling an eating disorder. Her stories and explanations of the “logic” she employed while deep in the clutches of “Ed,” are both mind-boggling and comforting in that, it shed a light on how eating disorders are mentally consuming. We realized that our daughter wasn’t making decisions about food to spite us, she was truly being ruled by this ugly disease.



Surviving an Eating Disorder: Strategies for Family and Friends by Michele Siegel, Judith Brisman, Margot Weinshel and Harper Perennial. We picked this book up and set it down at least a dozen times. We weren’t fully ready to take in all the information until we thought we were going to have to send our daughter back to residential treatment. It forced us to take our heads out of the sand, declare our position as the parents, and get back on that trail.

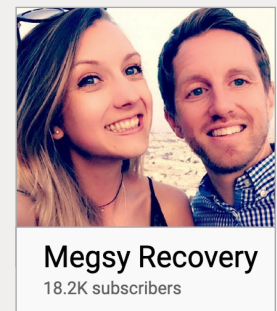
Dr. Philip S. Mehler, the Founder of ACUTE, wrote the book *Eating Disorders: A Guide to Medical Care and Complications*. Our daughter received a copy as a patient. Dr. Mehler notes in his forward that “the intended audience “is clinicians with direct patient care responsibilities,” so if you’re the type of person who likes to understand the science behind a medical condition, this is your book. We can honestly say that Dr. Mehler is clearly committed to ensuring those involved in treating eating disorders are well educated through solid research as evidenced in his book and other supporting research.





> VIDEOS

YouTube had hundreds of (mostly) women vlogging about their eating disorder recovery. We found “**Megsy Recovery**” genuine and helpful in understanding how our daughter’s eating disorder was manipulating her and us. If Megsy’s story doesn’t resonate with you, look for others that more closely align with your child’s situation. A word of caution, there are a disturbing number of ugly vlogs that either support or encourage eating disorders or suggest there is something wrong with you or your child. If the possibility of seeing these will cause you further distress, stick to the websites and books.



> COMMUNICATION

To start, we gave our daughter note cards and stamps. We picked ones that had French Bulldogs on them because she knew that when she was healthy, we were getting a puppy (both our dogs had passed a few months earlier). We also tried to send notes that weren’t focused on her eating disorder or recovery, these are a few things we did:

- » **Tic Tac Toe:** Start a game on a piece of paper with one “X”. When your child receives it, they put an “O” and mail it back, so it goes until it’s complete.
- » **Stories of Strength:** We bought the book *Bad Girls Throughout History* with one-page profiles of significant women. Once a week or so, we would copy one of the pages and on the back, write a note about a woman she knows, that has similar characteristics. Often, she would write back about someone else she thought the person was like.
- » **Bad Art:** We are not an artistically gifted family, so we would draw something, mail it and she would guess what it is and then draw her version of it and mail it back; bad art can be highly entertaining!

**CALL 877-228-8348 TO
SPEAK WITH A MEMBER OF
THE ACUTE ADMISSIONS TEAM.**



ACUTE
**CENTER FOR EATING DISORDERS
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