

Chapter 1

Abandon All Hope



The fear and pain and terror of eating disorders are debilitating and paralyzing. Every part of your mind, your feelings, your outlook and your spirit become compromised. You live in a vacuum where hope and horizon do not exist. Initially, this all comes out of nowhere and hits you like a brick. As you slide down into this morass, you thrash about trying to learn where you are and why this is happening, all while the mortality clock is ticking. And even when you bottom out and learn what's going on, where you are, how bad things have become, and how impossible it is to climb back out, all those oppressive and confining feelings have to be ignored if you have any chance of survival or success. And while it would be sound to assume that I am talking about those who suffer from eating disorders, I am actually talking about the folks who treat the suffering. I'm talking about the parent of a kid who cannot eat because of a raging mental disorder that is trying to kill her. I'm talking about me.

The first time these feelings hit me was in June of 2019. M, my daughter, was just finishing her freshman year of high school, and she was finding success

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across most of her endeavors. Her older brother was a senior at the same school, and even he admitted that she was really fitting in and standing out. She took a zero period, meaning that she was up and out early, and also that she took seven classes in her first year, yet earned a place on the honor roll with a 3.7 grade point average. She was popular and part of a big social group. She was picking up followers on social media. She was asked to homecoming, and then had a few boys from various schools asking her out. Hell, I had other parents, parents of her friends, take me aside and tell me she was a baller.

The previous fall, she tried out for and made the freshman girls' soccer team, which was no small feat considering that the school's varsity girls' soccer team regularly competed for league and state championships. That program was for elite athletes, but we also live in a community full of high-achieving parents, competitive sports programs, and Type A kids. M was a starter the whole season and her speed up front made her stand out as other teams had to mark her. Overlapping with the end of the soccer season, she went straight over to a starting position on the junior varsity girl's lacrosse team. Here again, she played at a very high level, leading the team in ground balls, assists, shots on goal, and was second in goals scored. Her coaches awarded her MVP of the midline at the end of the year and predicted that she would make the varsity team as a sophomore.

Within a week of lacrosse ending, we saw her doctor about a pain in her hip, who referred us to an orthopedic surgeon. After the exam and an MRI, it

turned out that a plate on her left hip bone had still not finished growing, and it was causing a debilitating tissue bruise that made running, and sometimes walking, hurt. So, we went to physical therapy two times a week for the eight weeks leading up to the end of school and the start of summer. And she was no longer allowed to run or exercise.

This is where the train started to go off the rails.

All the ways in which I have described M are the same behaviors of kids with a typical eating disorder (ED) profile. These kids are high achievers in sports, social activities, and academics. They are rule-followers and people-pleasers. They are Type A and hyper-focused. And then all, or some, of these successes come up against a roadblock like an injury, and these innocent children, carrying all this focus and drive, can no longer hold back the mental disorder that has been waiting for an opening to strike.

So, in June 2019, I was sitting on our back patio in the middle of the afternoon, hiding in the shade of an umbrella, and looked up when I heard the back door open. M was walking toward the pool, towel over her shoulder and huge aviator sunglasses covering half her face. It was summer, it was hot, and she had on a bikini. It barely clung to her shriveled shell of a body. At first, I saw M's hip bone sticking out because her suit bottoms were hanging onto them to defy gravity. Then I noticed her shoulder bones were like coat hangers keeping up her suit top. Next, she leaned over to spread out her towel, and her arched backbone stuck out of her pale skin like a dinosaur skeleton. Not long before this, I had happily watched her strong and ath-

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letic body run around the lacrosse field. But this day, I was shocked and nauseous at the sight of her. This was also when the fear set in. I didn't know what of, but I was upside down. And it wasn't just her appearance, it was her deep yet quiet voice, it was the cold and dark look in her eyes. It was her indifference to my inquiries about her weight, and then about her eating, and then about her obsession with weird water concoctions, and then about her getting back into exercising even though she hadn't been cleared by the doctor. She wasn't 'she' anymore, she was pushing back on anything I said and was retreating and running away from our relationship. And suddenly I didn't know her.

Just two months earlier, I was driving carpool for her lacrosse team. She was hugging me after games. We were doing our normal post-game breakdown of her performance, usually with a lot of dark humor, but really evaluating what was good and bad. We were stopping for food or making stuff together in the kitchen at home. We were best friends back then. But not anymore.

For the next month, my fear became a constant state of anxiety as M continued to refuse to eat or acknowledge that there was anything wrong with her. The only idea I came up with was to get her into her pediatrician for a fall sports physical. Maybe the doctor would see the signs and get M some medical help and be the one to stop this madness. Unfortunately, as I will discuss in greater detail later, the pediatrician turned out to not be the person we needed to see. She was like many physicians, who are not trained to recognize or diagnose eating disorders, and this lack

of experience led her to simply refer M to a dietician. Here again, while the dietician gave us fabulous information about food, there was no real treatment for the mental disorder that was infecting M's mind.

Our lost and meandering journey went on through July, all the while I stupidly let her play club lacrosse tournaments in Illinois and Oregon... oh, I paid to travel around the country with her while she was a whisper of her former self. I thought I was forcing her to eat, but I was delusional. She was so far gone, I had no ability to affect her behavior. I had nothing. I was so angry, and while I thought I was angry at her, I was angry at myself. What the fuck was I doing? She was physically melting away in front of my eyes, and she was becoming so bitter and dismissive.

The fear in me went up a level on Saturday, July 27th. The day before, we had somehow gotten in to see a psychologist who worked with eating disorder patients... but we still didn't say "eating disorder." We didn't think it. We didn't know it. The enormity of anorexia was just about to hit us like a sucker punch. Like any surprise trauma life, you don't know you've been sucker punched in the face until you're lying on the ground staring up at the asshole who did it. In this case, the asshole was the demon, was the eating disorder everyone calls "ED," was anorexia trying to kill my daughter.

The psychologist saw M for an hour late on a Friday. After we left, she called the most preeminent eating disorder physician in the area, Dr. Sue Knight, and begged to have M seen the next morning. Ironically, we had an appointment with Dr. Knight for later in

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August, but what the psychologist saw in M was classic anorexia that was becoming medically dangerous.

When we arrived at Dr. Knight's office on that Saturday morning, it was very quiet, and we were the first people there. Right away the nurses took M into the back, where they took a urine sample, and then laid M down to begin taking vitals. Tina and I waited in a separate room, not knowing what to expect or why this would be any different from M's pediatrician appointment.

After a while, Dr. Knight called us in to talk without M. She informed us the situation with M was dire and she needed immediate medical attention. Dr. Knight said M's weight was 88 pounds, down from 120+ in April. Her resting heart rate was 41. (She would go on to have an overnight heart rate in the 30s.) Her orthostasia was on the dangerous end of the spectrum: the change in her heart rate from lying down to standing up was +60. Her blood pressure barely registered.

These vital signs were alarming and Dr. Knight recommended M be admitted to an in-patient treatment center immediately. She then told us about the treatment program at Stanford Hospital that could help M, because it is specifically designed to save the health and lives of people whose vital signs are this poor. The program stops the decline in weight and heart strength, starts the refeeding, monitors the vitals, and gets the kids medically stable. Dr. Knight had already called Stanford and they confirmed that a bed was available. It was now time to talk to M. This was the moment, we were later told by our psychologist, that M was about to slip under the surface of

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quicksand, and we only had one rope left to throw at her.

M came back into the room, sitting between us while Dr. Knight explained her medical situation. She told M that she was vastly underweight, that she was not healthy, that her condition was life-threatening, and that she needed immediate help. M started to cry, but she didn't protest. She knew. She also felt very deeply and secretly the first twinge of relief in months. (M told us much later that she had passed out in our shower the night before this appointment.) She knew something had to break. So, we took her to Stanford Hospital to save her life.

The hospital is about an hour drive from our house, and while I don't remember if or what we talked about, I do remember the music. M had her phone plugged into the car stereo, and was playing all her comfort songs, songs she would blast repeatedly with her friends, or after games. One Direction. Five Seconds of Summer. Soldier Boy. I can remember thinking I could hear her thoughts, feel her emotions as she laid her cheek on the back seat window looking at the side of the road while we drove. Crying.

I think that maybe the difference between fear and scared is a matter of sequence. Fear is when you may not know, you're unsure, it's not defined what's up. Scared is when the shit shows up and you see it. The monster no longer *might* live under your bed or in the closet, it busts the fuck out like Sully and bares its teeth with a roar.

You are scared.

We got to Stanford Hospital, went up to the 4th

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floor, rang the bell and were let into the ward. M was immediately taken to her room to get hooked up to a heart monitor and set up in her bed. Tina and I were at the nurse's station doing intake paperwork, getting some kind of introduction, confirming insurance. Then it hit me. I never knew what path we were on. I never knew I had been walking on railroad tracks in the dark with my earbuds in, unable to hear the approaching train. I just happened to step off the tracks for a minute, and the freight rumbled by...the concussive wave of air blasting me as a warning or a reminder of what we barely avoided. My daughter could have died within a week if we hadn't come to the hospital.

This is scary shit.

A couple of days into this first hospital stay, M was no longer confined to bedrest and was allowed to move around in a wheelchair. I wheeled her around as much of the 4th floor as I could find. In the most relaxed and secluded manner, she told me she was relieved to be in the hospital. She didn't have to make decisions or fight her demon, she just had to obey. She just had to eat. It was a stress relief for her. Hearing and knowing that was cathartic for me, but at the same time kind of retroactively stressful. *She* always knew she wanted relief from the demon, but *we* never knew.

Holy shit, I am scared of this demon.

You have to know that hospitalization is not about treating or curing an eating disorder. This is a MASH unit where they triage the worst, do the hard work to get patients stabilized, and then get these folks healthy enough to go back to real treatment. You are released

from hospitalization once you no longer need hospitalization. Your vitals (weight, resting heart rate, orthostasia, blood pressure) need to be back in the black, not in the red. After a week in the hospital, and after all the consultation from the crew of eating disorder experts on staff, we were then faced with her discharge. Time for next steps. Time to treat her out there in the real world. But how? Does she go away full-time to a residential facility? Does she attend PHP (Partial Hospitalization Program) or IOP (Intensive Outpatient Program)? Do we all use Family-Based Treatment (FBT)... who's your treatment team?

This is next-level scared.

During one of our many sessions with M and the hospital's in-house psychologist, I stupidly got both M and myself really worked up. The psychologist outlined to us in vague terms a description of Family-Based Treatment (FBT), which was one method of living with and feeding M upon release. This included one of us eating every meal with M and supervising her afterward to ensure that no food was hidden or purged. I then made some insensitive, though I thought funny, comment about how M and I would be having lunch at school together for the next year in the parking lot and how fun it would be.

Wrong thing to say.

Fuck, M lost it. She went off on me and started crying. Tina and I had to leave. It took me an hour or so to calm down and realize M's fear, her anxiety, and her acceptance of this new reality. I texted her a soul-bearing note about my insensitivity, my stupidity,

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and my love for her. It took a while, but she finally responded and acknowledged it. Unspoken, we both knew we had a long road to go.

I had just gotten my daughter stabilized in the hospital and now they were sending me home. It was like when she was a newborn and they let me go. And I was, like, WTF? I have to leave and do this on my own? It was the same kind of feeling this time, but way worse. I was terrified of her. Tina and I had committed to treating her at home via FBT. Basically, no institutions, we would do it as a family. She answers to us and not any doctors.

I was scared to run a feeding schedule for a girl I just learned has a mental disorder with the highest mortality rate of any mental disorder. I was scared of the fights she would put up. I was scared that she would run away, and I would have to run after her. I was scared she would hurt herself or hurt us or hurt our animals. I was scared that I would have to put up a bigger fight and hold her accountable and go to war for three hours over a plate of food. I was terrified about battling with my little girl, my best friend from soccer and lacrosse games, the kid whose smile and laugh can bring me to my knees. I would have to suit up and beat back the beast in her, but I would only see her. And it will go on for years, with no guarantee that we would make progress.

I'm fucked.

Then there's the fear of admitting your daughter to a residential facility when your first attempt at FBT fails. Or the fear of her getting a one-day pass to come home from that residential care. Or when she gets out

of residential care and comes home for good. Or when you get her into PHP, and every day that you pick her up.

All of this nauseating terror ramped up around Thanksgiving 2019. M had been out of residential treatment and attending an outpatient (PHP) program for 45 days. But starting in mid-November, both the head therapist and the dietician at PHP had been telling me that M was stalling out, losing weight, that she needed “another level of care.” This diagnosis and recommendation was also coming from Dr. Knight who was monitoring M’s vitals weekly. Coincidentally, Tina had a work trip to Denver in mid-November, where she visited the Eating Recovery Center (ERC), one of the best eating disorder treatment program facilities in the country. This would be a bigger residential program than the one M had already lived in, followed by a step-down PHP program, all the while involving the parents. I live in Northern California, so a lot of travel is looming. Hell, how would we even get M on the initial flight out there? When Tina left ERC, she put M on the waiting list for a room. I was starting to plan on flying to Denver every weekend throughout the holidays and into the New Year. Another missed semester of school would mean M would never have her sophomore year. This made me sad for M, thinking of all the things she would miss out on and the potential effect on her college admissions opportunities.

On the Friday before Thanksgiving, Tina and I went to M’s PHP facility for our weekly family therapy session. We brought up to M that admitting her to ERC Denver was an option to increase her level of

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treatment and get her moving toward recovery. Very soon after that, M stormed out of the room.

Tina and I, as well as the PHP psychologist and dietician, followed M and found her on the floor of the waiting room. She was sitting, crammed between a couch and a side table. Her knees were bent up, her arms were wrapped around them, her head was down, and she was crying. We all found spots on the floor around the furniture and sat down with her. I asked her how we could help and what we could do to make her feel safe or happy. She was shaking and breathing hard, she was having trouble speaking. She whispered that she didn't want to fail, that she wanted to find recovery. She said she knew her weight was going back down, and that she was still hiding and restricting food. She said the voice of the demon in her head was too strong for her and that she was terrified that she would never have the strength to resist or seek recovery. And then, out of nowhere, in the quiet and tense air of that waiting room, she asked for the most mature and unseen option I could have predicted: could we check her back into Stanford Hospital right then? Could she reset, start over, could she please get some un-assailable structure to get her back on track? She said that she didn't want to go back into a residential facility, and she specifically did not want to go to Denver to ERC. She admitted that she was slipping and in trouble. She told us that she was scared.

She spent five more days in the hospital this second time. What made those days worse than the first hospital visit was what Tina suggested we needed to do going forward. Tina had been reading and analyzing

the merits of continued reliance on institutionalized treatments versus Family Based Treatment (FBT). Homeschooling her recovery, so to speak. Battling the beast not only on the home turf, but in the place where M had to eventually come back. This was the first time I ever had shortness of breath and dizziness and a racing heart. I was thinking about managing her anorexia and battling the demon at home, being the only person to bar the door, being the foe to her disorder. This was the fear of not knowing how bad it was going to be and scared because I'd seen some of it before.

When she was discharged from the hospital, we told M that we were pulling her out of PHP and were going to stay home full-time to treat her, along with the help of an FBT therapist. Tina was going to take FMLA (Family Medical Leave Act) from work, and I was going to just punt on wine sales for a while. M shut down all communications with us, and she became very cold and angry. Dark. Evil. That night, the day she got out of the hospital, she ran away. It was dark, it was raining, and we were out of town in a rental house for the long holiday weekend. That was the first time I had cried in years. I grabbed Tina and sobbed. I was panicking, I was imagining the worst scenarios, I was terrified of who or what M was becoming. We called in both the city police and county sheriff. They didn't find her, but M came walking back in the door on her own a couple of hours later. She was wet and cold and shivering, but she had a stone-cold countenance on her face. She said she ran away to make us scared.

The first night we got back from Thanksgiving break, we may have been in our home, but we were

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really in the boxing ring. The battle was about to start. M ate her dinner with very little resistance, but when we enforced the night snack, she started fighting back. She screamed that she would never eat night snack, that she didn't have to obey us, and that she hated everything about us. She told us to fuck off, and then she started trying to lock herself in rooms around the house. We had to stay calm and keep pushing all five of those Ritz crackers, no matter what. And when I went into the kitchen to get more crackers because M had flushed the first batch down the toilet, I heard the front door open and slam shut. It was the first of a few times I had to run after her through the streets of our neighborhood. This time, I caught her a few houses away in the street. In the rain. While I kept my cool, each time it ended with me hugging her hard and bringing her down to a sitting position in the street. Just to calm her down, to stop her from going, but also to show her that I was serious. No, to show the demon that I was serious about this battle and that I would not be dissuaded from pursuing this treatment and getting my daughter re-fed. You want to take my daughter for a joy ride? Fuck you. I'm stronger. And when she turned around and put on a show about being mad and was stomping back toward the house, I was cool with that. The demon knew it lost that round.

Six weeks into our second attempt at FBT, we hit a really bad spot. I'm foggy on which shitstorm it was. I think it was the second time we called the cops on her, but the result was the proclamation that may have changed my life forever. M told Tina and me, in a much longer and profanity-laden speech, that if we

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thought we could control or hurt or change her, then she would do worse to us in return. Because we had taken away so much away from her (freedom and control), she was going to take even more away from us. She was going to hurt herself. She was going to hurt us. She was going to hurt the dogs. She was going to hurt other people. And she was going to disappear. She was going back down the rabbit hole to hell to live skinny forever.