

October 20, 2010  
Essex County Club  
Manchester-by-the-Sea  
For the Harris Center and Dr. Herzog

Thank you for inviting me, and for that very nice introduction, David. In some ways this area feels like a second home. Long ago, my dad taught at Boston College, and we lived in Brockton. 4 siblings and I attended Harvard in Cambridge. My 2 daughters go to college in Massachusetts—one at Harvard, the other at Hampshire. And my college roommate and dear friend, Maura Costin Scalise, lives in Nahant. I have known and admired Dr. Herzog for many, years, for the person he is and the wonderful work he does in the area of eating disorders. You just heard him speak from his 30 year background of involvement with this disease: as a medical professional, Director of the Harris Center, and as a doctor who cares for people who suffer. I am going to add some personal details—how ED's have affected one family, and what an ED feels like.

So this is the story of our family's history, particularly focusing on my daughter and me.

My firstborn child, Nelia, is now 20 and very healthy. When she was 13, and in 8<sup>th</sup> grade, she struggled with anorexia and bulimia. She slipped so far away from me I thought I would lose her, both literally and figuratively.

I was 21 when my ED started, and it raged uncontrolled for more than 10 years. I have dealt with the eating demons, in small ways and large, for 3 decades now.

I don't often speak about my family and EDs. Tangentially, of course—I would mention my family of origin and my kids, but only as a part of *my* story. I wanted to claim the ED as mine and mine alone, so I could protect and shield them. It was somehow more controllable that way. My therapist remembers, as do I, that long ago, when she brought up family dynamics in our sessions, I retreated--fast. I assured her that my family was fine; they were all healthy and happy. Even as the subject of an ABC made-for-TV movie depicting my struggle, I did not truly face my family dynamics. The parents and siblings portrayed in the movie were so different in

appearance and affect from **my** family that it was easy to dismiss them as not really mine. I never talked about the movie in a substantive way with most members of my family. The ED was my problem, and I had to take care of it myself.

I don't often speak about my daughter's ED publicly either, though for different reasons.

A few years ago a Denver columnist wrote about the "culture of silence" surrounding ED's. We are all familiar with that—the stigma, the shame, the isolation—that keeps us from discussing ED's in this society as an illness, worthy of *care* and *concern* and medical *coverage*. ED's are still seen by many as an upper-middle-class white girls' dieting technique—a chosen behavior. The Denver newspaper article reported on a group of girls all at the same high school, all in treatment for their ED's—and---all families were unwilling to come forward to engage in open discussion.

The culture of silence keeps us bound to our illness. Unless we can disperse this unhealthy silence and shame, we will not enable individuals or families to get the help they need. We need more events like this and more places like the Harris Center.

So, hard as it is to dredge up, again, the pain of my own ED, and agony to relive my daughter's, I am here to talk to you about my family's experience with EDs. And I am here to say, first and foremost, that *it is no one's fault*. The blame for my ED does not rest with my parents, or with me. My daughter did not choose to get an ED, and I didn't cause it. Until we get past that idea of blame, we perpetuate the culture of silence and isolation surrounding the disease.

So, let me begin.

I come from a wonderful large Catholic family, comprised of 2 loving parents and 8 children. Now in our 30's to 50's, we still get together at least twice a year out of choice. We not only love, but enjoy each other. There are 19 cousins, some of whom count each other as their very best friends. But growing up, wonderful though it was, the family dynamics were also complicated. We were expected to show a united front to the world, work hard, do our very best, and excel in our endeavors. We were taught that we could achieve anything we wanted if we were willing to work for it. Although my parents were the first of their families to finish high school and then go on to college, they sent all 8 of their children to college—as I mentioned, 5 to Harvard, and 3 to Georgetown.

I was the second child of the family, but in some ways treated as the first, in terms of favor and responsibility. In the great busy mix, I distinguished myself by being perfect. Not just *wanting* to be perfect, but *being* perfect. I remember in 6<sup>th</sup> grade, *needing* to do an athletic skill in softball perfectly, getting angry at myself, and then practicing until I could do it without making a mistake. Later, in 7<sup>th</sup> grade, when the teacher would announce the highest grades on the weekly test, I had to be, not just at the top, but the one scoring 100%. Everything was a competition, and I had to win. I'm not sure of the exact circumstances, but somehow, my dear sister, favorite person in the world, ended up with a bloody nose at the end of our game of jacks. Funny but sad.

I started running in 7<sup>th</sup> grade, after I lost to someone at our annual school track meet. I determined that I would not lose again. So at age 13, I started getting up early before school, and going running. I LOVED to run. At least as much, I loved to win. Winning was something I could *do* on the outside to feel good about me on the inside.

So the “perfect” story, abbreviated: I was a National Merit scholar in high school, the outstanding student-athlete, winner of every individual sports trophy, with a ticket to Harvard University. There, I was on the dean's list all 4 years, won 8 varsity letters, held several school track and field records, was captain of the Ivy League championship soccer team, interviewed Georgia O'Keeffe for my senior thesis, and had lots of friends and lots of fun.

One day at track practice in my senior year, we weighed in. My coach told me I would run faster if I lost some weight. So I did. A month or so later, he remarked that I was running “heavy” and suggested I be vigilant about the weight loss. I can still remember something going “click” in my brain. With every ounce of grit, I determined that he would NEVER say or even *think* that again. And he didn't. But I began a ten year battle with anorexia and bulimia. At first I dieted and lost weight. But when I couldn't restrict any more, and overate, I made myself vomit. It was so weird and disgusting, not to mention painful, that I vowed I would never do it again. But then I couldn't stop. At first it was just a safety net for unwanted calories, but then it became both a net and a blanket for my feelings, and took on a bigger and bigger role in my life.

By my senior year in college, my script for being the perfect little girl was nearing the end. I was scared of what came next—being an adult, being responsible for myself and my choices, possibly failing at something for the first time in my life. The whole sexuality thing was difficult too. I wasn't ready to get married, but there was pressure to be more sexually active

with my long-time boyfriend. I could articulate *none* of this, because, after all, I had a perfect life and I wasn't supposed to feel anything bad. So I just buried it all. I put all my energy into controlling my body—training it to run at a national and world class level, and forcing it to operate through an ever-worsening ED. I functioned on the outside, but my inner life was dominated by food—pushing it away, or alternately, finding, preparing, devouring, and purging it, and then vowing that that was the last time. But the episodes came as often as 5 times a day. The days stretched into months, and the months became years. So that by the end, I'd wasted a third of my life. Sure, during that time I'd gotten a Harvard degree and a law degree. I'd won a national championship in road racing, set an American record, and finished third in the Olympic Trials. I'd married the mayor of Denver and was a fine “first lady.”

But I say “wasted” with reason. Because for that decade, there was nothing I accomplished, experienced or felt that was not overshadowed and permeated by my addiction to food, whether it was personal relationships, athletics, academics or work. I struggled with food every waking minute of the day. Food was my enemy, or at best, my weapon against myself. My health became seriously compromised, with symptoms ranging from headaches, shaking, memory loss, inability to concentrate, digestive and reproductive system problems (including amenorrhea for several years and infertility), coldness, weakness, and pervasive fatigue. While once I had run world class marathons, by the end, sometimes I could barely run around the block.

I missed out on a lot during the decade I lost to my ED, because my obsession with food precluded my experiencing things fully: things like my Harvard graduation day, my running victories, the day I was sworn into the Colorado Bar, and my wedding day. I lost the chance to know if I would have been a good teacher or a good lawyer. My ED could have been the difference between making the Olympic team or not. And I almost missed out on having a family. But I was lucky. I worked hard at trying to recover, and I got a second chance.

My recovery occurred in several stages, and as a cumulative process. Over the years I had tried anything I thought might help—group and individual therapy, 12 step programs, meditation, prayer, and so forth and so on. Frustration and hopelessness only grew when I felt I'd made some progress on underlying issues, yet no corresponding improvement with behavior. I thought I had everything that anyone could possibly want, yet I was still severely bulimic and only getting worse.

Finally, there was for me a transitional moment, which became the catalyst for a life change. When I got pregnant, I was sure I'd be able to eat healthily. But little by little, I began to binge and purge again. I was terrified, but I couldn't stop. Six months into the pregnancy, I thought I was going to lose the baby. At that point, I found I could do for that tiny person what I couldn't do for myself—stop abusing my body. I was given new life—not just my child I didn't yet know, but also my own. I finally felt that I was worth it too, and was able to risk a self-acceptance not dependent on weight and appearance and achievement and control.

My leap of faith had to do with starting from the inside core-- with acknowledging my self-worth as a person, not connected to what I accomplished or how I looked. I had to believe that that was enough, and I had to start trying to express and care for myself in new ways. After 10 years, I didn't know how to eat anymore—I couldn't really even identify hunger and satiety, let alone trust myself to eat normally. It wasn't easy and it wasn't pretty, but little by little I got the hang of it. Over the next 11 years, I not only rediscovered the necessity and joy of eating, but I started to discover my inner self—what I liked and wanted and needed. I was even able to believe I deserved to be comfortable and happy and well-nourished—physically and emotionally.

As I grew healthier, my marriage deteriorated. I wanted and needed more than to be the submissive, consummate-but-never-good-enough caretaker. Deterioration degenerated into divorce. In the middle of my divorce I relapsed. I was guilt-stricken about the failed marriage, and broken-hearted about the pain I was causing my children. I was injured, so did not have available my usual stress relief, exercise. I felt lost and alone and unsure of my future. So I turned, again, to food as a false measure of control over my life circumstances.

This time was different, though. I immediately sought help, worked incredibly hard at recovery, and managed to reach a plateau within a year. I will never again take my recovery for granted. I have now gained additional tools to help me in my journey with food. I have a more acute knowledge of triggers, and a more secure sense of my self. I have now been healthy for 8 full years. A measure of that is having just competed in the Ironman Triathlon in Hawaii in October, where I finished 1st in my age group. That event consists of a 2.4 mile ocean swim, a 112 mile bike through lava fields (temp 104), and 26.2 miles of running. At age 52, I'm finishing up a season of training and performance I could not possibly have done when I was 25. I am now able to see that changes in my body are the result of my athletic training, not a trigger for a return to ED's. And it's OK to be a little soft when I'm not competing. A measure of

emotional health is that I have been with my sweetie, Rob--the love of my life--for over 8 years. I have let him know me and see inside me. And he *still* loves me, even the imperfect parts.

Ever since my kids, especially my girls, were toddlers, I worried about their risk for ED's. If there were one thing I'd wanted to save them from, it was that--the horror of what I'd gone through. Those of you who are parents know that it's one thing to go through a difficult ordeal yourself, but entirely another when it's your child—you would do *anything* to protect your kid. So when my oldest daughter was 3, I asked Dr. Herzog about the potential inheritability of ED's. He told me that while there had not yet been a specific genetic link established (grandmother to mother to daughter), they never saw an ED patient who did not have some kind of compulsive, addictive trait in the family tree. So, for instance, an addictive trait in both sides of *my* family manifested historically as alcoholism in male, blue-collar demographics. But for my gender and culture, that gene manifested as an ED. It was likely, therefore, that I could give the trait to my children. I was extremely concerned, so did everything I could to prevent and be aware of ED tendencies in my children. Neither of my girls has a long and lean body type, so I knew they would not be society's idealized version of the American female body (my girls would be closer to the average American woman--5'4" and 140 lbs--than the average American model--5'11" and 117 lbs).

So I set to work. I figured I'd counter genetics with good parenting. I praised my kids for their abilities and inner qualities, rather than their appearance. I significantly downplayed their clothing and accessories, gave them non-gender-based toys, and pointed out strong rather than pretty female role models. I made food as emotionally neutral as possible, and did not use food as reward or punishment. I read everything on the subject I could find, including the Ellyn Satter approach to food, and the Joe Kelly research on dads and daughters. If anyone could have seen it coming and prevented it, it was I.

And then I missed it.

Almost from the day she exited the womb, my daughter Nelia had her own agenda. One of her first words was "self" which she almost spit at me to tell me she would do it *herself*. She was independent, stubborn, strong-willed, self-reliant, and intelligent. She was off to a good start. But as she grew up, she also became quiet, reluctant to express her feelings, eager to please, and very competitive. And she wanted to do everything just right. There seemed to be

less joy in achieving academic and athletic success, as opposed to the realization that she would be letting people down if she *didn't* do those things. She could push herself to concentrate on an assignment, or keep running on the soccer field, despite pain or distractions. She wanted to be my helper, and she took everything in stride. She quietly accepted that her sister, who had sensory processing disorder, claimed center stage with her frequent meltdowns, and needed all my attention. She was 10 when her father and I separated and divorced. Only later did I learn how utterly taken aback and very hurt she was. Nelia never complained, and never acted out. She was my perfect little girl. She was more like me than I wanted her to be.

When she was 13, in 8<sup>th</sup> grade, I knew she was stressed. She had gone through puberty, and her first boyfriend wanted sexual activity beyond her comfort zone. She had to make some decisions about where she would go to school next. Her father was restricting the diets of all three of the kids at his house. The tension between us parents was very difficult for her, as was the going back and forth between two households with two very different parenting styles. She wanted desperately to please both parents, and that seemed impossible. So she turned her sense of failure and confusion and dislocation on herself. She began to use food to manage her environment and find comfort from the storm. She did the best she could to survive and take care of herself.

When we left town for her 8<sup>th</sup> grade winter break, Nelia heaved a sigh of relief—to be escaping from some of the stress. But it all started again when we returned in January. I knew she was losing some weight, but not dangerously, I thought. While I appreciated feedback from a teacher at school, it seemed to me that Nelia was within the acceptable boundaries of experimenting with food choices and quantities. Her affect seemed perhaps a little down but not withdrawn, and she was still very active in school activities and sports. I was worried and alert, but not overly distressed. She assured me that she was fine.

But then, one afternoon I received a call from a teacher she and I had both come to trust and love. The teacher said that Nel had told her she needed help. She had been restricting food throughout the day, eating only dinner. And now she had started purging that one meal.

I thought my brain was going to explode. I felt a knife carving into my heart. Pieces of the puzzle suddenly came together. It was winter, so she was wearing baggy clothing; she took long showers, so the sound of water covered the sounds of purging; there was the telltale trash in the bathroom baskets, the surreptitious trips to the kitchen looking at food; the fatigue, fainting

spells, and coldness; the pushing back from the table, suddenly too full to continue with dinner. It all made sense now. Sickening sense. I was devastated---- that, not only had some of my worst fears been realized, but I had contributed to it, failed to prevent it, and incredibly enough, failed to see it happening right before my eyes.

We talked. We went to the doctor. She begged to be allowed to try to get herself back on a healthy diet without treatment. Her dad and I agreed. But then things got worse, much worse. So she started treatment at Denver Children's Hospital, which lasted 3 months. Most of it was full day treatment—7am to 6pm. But for a period of time, she was in 24 hr. care. I walked into the ED unit one evening to see my daughter hooked up to a nasal-gastro feeding device—a tube running through her nose and down into her stomach carrying liquid food--because she was unable to consume her required calories for the day. She had reached a wall, where food had assumed the qualities of some monster that she could not take inside her, despite her intellectual awareness of reality. This child I had birthed, nurtured, cared for, and breast-fed for a year—had slipped away. She couldn't hug me, and could barely talk to me. I couldn't touch her, clothe her, or rescue her, and I certainly couldn't feed her.

One morning I saw that Nelia's face and legs were raw. The scabs lasted for days. She had awakened in the middle of the night and rather than expressing her feelings with food, she had used her fingernails to scratch her face, legs, and stomach till they bled. Her anger turned inward was so familiar.

During this time, I felt my own ED baying at the door. I wanted to push away this horrible pain. I saw my own daughter going through all the food rituals and behaviors that were once mine, and I wanted them back. I grieved, I ached, and I hated myself for giving her this disease. She had saved my life and I could not save her.

I did not relapse, and Nelia did get better. Part of my terror at Nel's ED was because my experience had been such a marathon—10 years, no vacations, no days off, just year after year of frustration and self-loathing and illness. I had no experience of someone, like Nelia, who had the self awareness to ask for help, then got good treatment and recovered.

No one can do it for you—no doctor, treatment program, drug, or therapy. At some innermost place, each person has to be ready to take the risk of recovery and be ready to do the hard work required. I watched Nelia's day to day progress, and worked with her on family issues. I still get goose-bumps of respect and admiration when I think of her courage and

determination, and her willingness to be open to a new way of thinking about and taking care of herself.

Nelia got better. When she was in 9<sup>th</sup> grade, and confident in her recovery, she wanted to help other middle school girls learn about and avoid EDs. She did a beautiful, articulate interview with a Denver TV station. She encouraged me to contact the Denver journalist who wrote on the “culture of silence,” and the journalist wrote an article about us. Before either of these was released, however, someone called the TV station and the newspaper and successfully killed the stories. That person didn’t want Nelia to be “branded as a young woman with an ED.” That person was her father. So there we were again, right in the middle of that cocoon of silence, which perpetuates the stigma and prevents the healing.

I continue to believe that only by facing this illness will we overcome it. Through the work of the Harris Center, we **will** make progress. Nelia once said that she felt she disappointed me—I had worked so hard to prevent ED’s, and then she got one. I think that what I gave her was the permission to talk about it and to ask for help. There was still a vestige of belief that if only I had done something differently and better, I wouldn’t have had an ED. But when I look at my beautiful Nelia, I know beyond certainty that she did not ask for this disease. She faced it, she fought it, and she recovered. I am unspeakably proud of her, and I couldn’t feel more tenderness and love for her. I am not so naïve as to think it will never rear its head again, in her life or in mine. But we have tools, and knowledge, and experience of a better life. We have survived.

I’d like to close with a quote from a wonderful Denver writer, Susan Zimmerman. She says,

“Our stories shape us. They give us our songs and our silence. When they are full of joy, they allow us to soar. When they are full of pain, they allow us to journey into the darkness of our souls where we meet ourselves, sometimes for the first time. They destroy us and allow us to rebuild. We must share our stories. They are our gifts.”

I thank you for listening to my story this evening.

Ellen Hart