



Lisa's Story

Even at an early age, Lisa loved the arts---music, visual art, and dance, so attending an arts' magnet school was a natural for her. She began playing the flute in second grade band and learned to read music easily. Drawing and crafts were a favorite of Lisa's in school and at home. One of her ornaments made in art class was selected to hang on a tree at the White House when she was in fifth grade. She took dance classes at a nearby dance studio---jazz, modern, lyrical and ballet were her favorites. By high school she was in the studio's jazz and ballet companies which also involved traveling for competitions. They even won a competition which resulted in her company getting to dance on stage in Tomorrowland at Disneyworld. She played on the school golf team and got to play in the girls' state golf tournament when the number two player on the team had to withdraw due to a back injury. Academically, she was a strong student, always in the top ten percent of her class. Lisa had high expectations of herself...striving for all A's through diligent study and hard work.

Lisa attended Hope College, a small liberal arts college located in Holland, Michigan. Again, she devoted much of her time to the academics and made the dean's list every semester. During her junior year, she did a semester of internship working for the chamber of commerce for Chicago's Magic Mile. She fell in love with life in the big city. During her senior year, she was selected as a Baker Scholar, which is an elite group of business majors who met with local and national business leaders who shared their wisdom and insights with these college students. Baker Scholars culminated with a trip to New York City to meet with alumnae who were working in the New York area.

Shortly after graduation, Lisa worked for a large consulting firm located in Washington D.C. in their marketing division. The company shares current trends and best practices with the Fortune 500 companies. She was promoted fairly quickly and began delivering "content" to the marketing directors of major corporations. It was an intense and stressful job and she worked many nights and weekends.

One would think that she was leading a charmed life. However her life outside of work began to unravel. Having been exposed to many new foods and ethnic culinary dishes, she began to change her eating habits from those that she knew growing up in a mid-sized town in the Midwest. She liked many of the new foods: sushi, shushimi, calamari, octopus, fish roe and more. She also became determined to eat healthy in order to be in good physical shape. She began to eliminate foods that she felt were not good for her---sweets and breads to begin with. Then it moved to any of the foods that had "white" in them---potatoes, breads, rice etc. She began to lose weight and it became noticeable to friends and co-workers that she was no longer looking healthy or well.

Her concerned boss helped to arrange a transfer to their Chicago office where she could continue to do her same job, with the hope that being closer to family and a return to the Midwest might help. When her weight got down below 70 pounds she was admitted to Rush Hospital's eating disorder program. She was there for four weeks, plus another 3 weeks as an out-patient and she did return to a healthy 105 pounds. She also began seeing a therapist and a nutritionist following her dismissal from the program. Unfortunately, the therapist moved away from the Chicago area and Lisa never found another therapist that she liked. After about two years she began losing weight again, and often she was not following the nutritionist's plan. The weight began to drop again. The nutritionist recommended a nationally recognized program in Denver, Colorado called the Eating Recovery Center.

Arrangements were made, and Lisa entered their program. She spent her days doing group therapy, individual therapy and various other programming that they offered. Patient's phones were restricted to two hours in the evenings. She called us every night, most of the time complaining about how she needed to get out of there and get back to work. Or she talked of foods that she had to eat and how uncomfortable she was when doing so. We wanted to come out to visit her, but she would not have it. She pleaded with us to allow her to keep her dignity and not have us see her in that environment. She remained in their program for three months, once again returning to a healthy weight. She returned to work and things seemed to be back on track. She continued to see the nutritionist, but not a therapist...

While at the Eating Recovery Center, Lisa's diagnosis was "eating disorder, not otherwise specified". It is sometimes associated with anorexia as both diseases manifest themselves with being very thin and underweight. It is common for anorexic people to feel or see themselves as being fat when they really are not overweight. This was not the case for Lisa. She knew that she was too thin and was embarrassed when having to give a presentation at work. She would wear bulky clothes so that the clients would listen to her and not be distracted by her thinness. Lisa had a great fear of foods that she felt were unhealthy. Red meat and fats would "clog the arteries and lead to a heart attack". Too many sweets would cause diabetes. Too much alcohol would cause liver problems. Nothing with white flour...in fact no white foods at all. She did not want any foods that may be mixed with other ingredients---casseroles, sauces, low-calorie desserts because a person couldn't quantify or identify what was included in them. She yearned for M & M's, but was afraid that if she ate just one, she might not be able to stop. Family and the professionals could not convince her otherwise. Early on, social gatherings that included food became very stressful for her and she avoided them whenever possible.

We joined a support group for family and friends of those with eating disorders in our hometown of Ft. Wayne. It was led by three therapists and two nutritionists on a rotating basis. It was helpful initially, but eventually we could see that our situation was vastly different than most in the group. Most of the families had high school students who were still living at home and very dependent on the parents for everything, including meals. There were only two of us in the group who had daughters who were living away from home and very independent. Monitoring how they were doing and what they were eating was very problematic. It often alarmed parents if we talked about some of the physical problems that go along with extremely low body weight.

Almost two years to the day from when she first went to the eating disorder clinic, we got a phone call from a friend of Lisa's in Chicago. She relayed to us that Lisa was getting so thin and so weak that she could hardly walk down the center aisle of church without holding on to the pews! We called one of the therapists from our support group and the three of us did an intervention with Lisa. The therapist told all three of us that with such a low body weight index the brain is affected, making it hard to think clearly and rationally. The heart can stop at any moment. And one's bones often become so brittle that sometimes just stepping off of a curb can break a bone! That convinced us that again she needed to go back into treatment. Very reluctantly, she agreed to do that.

There was a difference this time around though. She was so low in weight and so weak that she could not immediately enter their program. She had to go to the Denver Acute Hospital to be stabilized. She wore a heart monitor 24/7 and had vitals taken at regular intervals throughout the day. It was a week before she was pronounced stable enough to go into the eating disorder program. Again, she stayed with their program for about three months in which we talked nightly and listened to her ruminate about the loss of freedom, missing work and how unhappy she was to be there. Again, she would not let us come out to visit. She signed herself out when she thought that she had had enough...

About a year later, we received a call from Lisa on a Friday night. We were stunned when she said that she was back in Denver and had signed herself in. She recognized that she had gotten so weak that she could hardly step up on the bus to get to work. She was under 70 pounds of weight at that point. And she so desperately wanted to conquer this eating disorder! She remained in Denver Acute Hospital for **two** weeks this time around before they could get her stabilized. But this time around she showed determination to succeed in their program. We rarely heard complaints and more often, we heard about her milestone successes. She stayed for four months and transferred to a Chicago out-patient program that works with Denver Acute and the Eating Recovery Center.

After several months went by, Lisa felt that the out-patient program was not helping her. She was not learning anything new or that she hadn't heard before. She was gaining no new insights into her own personal struggles. We encouraged her to then do something...anything...to change the cycle that she was in of work, treatment center, work, treatment center, work, treatment center. She decided to leave the big city and work someplace that was more consistent with what she experienced when growing up. She took a job in Holland, Michigan where she had attended college and my sister and her family live. Lisa had accumulated enough money from her job in the big cities that she was able to make a sizeable down payment on a condo and to buy a 2016 new car!

She lived with my sister Barb and her family for about a month until her condo was ready for occupancy. Barb tried everything to make meals that Lisa would eat and like. Fish or chicken, roasted vegetables, salads and sweet potatoes. Soon however, Lisa began leaving more and more on her plate. She began finding reasons that she couldn't be there to eat dinner with the family. She had to work late, get to the license bureau to get her Michigan license or go to the library for some books to read. She would eat her own dinner long after the family had scattered for the evening. After experiencing this, Barb said that she could now see firsthand how hard it is to get someone with an eating disorder to eat and what a struggle it is for someone with an eating disorder.

On her own and in her condo, Lisa loved decorating it, shopping for furnishings and accessorizing! She loved being able to drive right into her garage and enter the house, avoiding the bad weather. Lisa loved the thrill of a bargain when finding something at a garage sale. We visited her on several weekends and Laura went up for a "sister weekend". She even had friends stay with her during Hope's homecoming. Her new workplace encouraged a good work/balance and she participated in a team softball tournament. She delighted in the company's version of Amazing Race around the town. And she described her weekends as "guilty pleasures" as she had the time to herself to do the things that she wanted to do. She went to an art studio for their Saturday morning art time. She went to the beach to watch the sunset. She had pedicures and manicures. She joined a group of women from her condo addition who were single or widowed who met once a month to go out for dinner or events. She found a therapist that she liked as well as a nutritionist and doctor. She loved her new job and the people she worked with. She even had a really successful big presentation at her job for about 300 dealers who came for a work showcase. Life seemed like it was turning around!

About five months after she began her life in Holland, we got a phone call at 7:00 in the morning from my sister and her husband. They said that Lisa seemed to have lost a lot of weight in a very short period of time and that she wasn't looking so good. Within a couple of hours, we were on our way up to Holland. Lisa was not happy that we were up there for that reason, but we felt our time together was well spent. It was obvious to us that she was eating very little at her meals. However, she also said that

most recently it had become *physically* painful to eat. She was cutting her meal intakes in half to avoid that pain! From her time at the eating disorder center, she knew of a medication that is supposed to help with digestion. Since it was a Saturday, she agreed to call her doctor on Monday to ask about that medication. When talking further on Saturday night, I remember this so distinctly...she was on her brand new red couch, crying. She cried out, "I hate this disease and what it has done to my life!"

On Sunday morning, she was expecting us to leave and go home. We were reluctant to do so and Steve, Lisa and I all gathered at my sister's house. After a heart-wrenching conversation, we decided that we would go to the emergency room and let the professionals decide if she was in good enough shape for us to go home. After an EKG and blood tests, the doctor reassured us that she was stable. She was happy and we left to go back home. We knew that she had appointments with her nutritionist, doctor and therapist in the week and a half before she would be home for Thanksgiving. Once again, we felt that things were under control...

Lisa took Wednesday afternoon off from work in order to make the three hour drive home during the daylight hours. We had emailed her explicit directions for the drive home as it had been seven years since her college years when she made the trip. However, early in that Wednesday afternoon, I got a panicky call from her. In tears, she kept saying "I can't find Delano Street! I can't find Delano Street!" When asked to give me some landmarks so that I could figure out how to get her to Delano Street, I soon realized that she was in the entirely wrong town. She was in the town before she needed to get to Delano Street. Once I told her that, she was relieved and said that she would be fine. But I sure had a sense of dread. She wasn't even at the tricky part of the drive yet! When I told my husband of her distress, we were afraid to call her back since she would be to the interstate soon, but we wanted to know if she had found the Delano Street turnoff that would get her to the interstate. Fortunately, she stopped to call us to tell us that she was about to get on that heavily-traveled highway.

It was such a relief to finally have her pull in our driveway late that afternoon! She seemed fine and wanted to go furniture shopping to look for pieces for her new condo. After shopping and dinner, we had the usual kids versus parents euchre game. On this rare occasion, the kids won! On Thanksgiving Day, our oldest daughter takes the reins of the kitchen and the rest of us are there to help her. Lisa begged off that morning, saying that she was tired and wanted to take a short nap. She slept for two hours that morning. We all thought that the driving trip had worn her out. The early afternoon meal was delicious and filled with foods that Lisa would like such as turkey breast, roasted green beans and fresh fruit. Her nutritionist had challenged her to eat the stuffing and pumpkin pie. She did eat them and marveled at how good they tasted as she hadn't eaten those two items in years!

Friday was filled with more fun family activities. We girls all got pedicures. We all played euchre. We went out to our favorite Japanese restaurant for dinner. We came home and watched Laura and Lisa's high school alma mater win the state football tournament in a nail-biting, overtime game. Everyone went to bed shortly after the game ended.

We awakened the next morning to Laura's cries of "She's not responding! She's not responding!" Steve and I rushed into the bedroom while Laura called 911. We were told to lie her down on the hard surface of the floor to facilitate her breathing. It seemed an eternity before the first responders got here, but Lisa was hanging on. She was in respiratory failure and her heart was very weak. When we got to the hospital, the chaplain met us at the door and led us to a small room...

But Lisa's story doesn't end here. Lisa's older sister, Laura, posted the following entry on Lisa's Facebook page:

Dear friends of Lisa,

It is with pain and sorrow that I write this news on her Facebook page. My baby sister passed away unexpectedly on Saturday, the 28th at the home of our parents. We were visiting for the holiday. As you may know, although she didn't post much to social media, Lisa kept up on all of our news and loved deeply. I will try and post more information as I can, but right now there is nothing to report beyond a funeral service perhaps next weekend.

*God bless,
Laura*

Our family was overwhelmed with the responses that were sent back on Lisa's page and to Laura on her FB page. High school and college friends sent pictures and postings. Co-workers sent pictures and postings as well. We even heard from several friends from the eating disorder clinic. Many of the friends and co-workers posted notes that Lisa had sent to them, telling of how Lisa's notes were always uplifting, thoughtful and humorous. One of them described Lisa's notes as "the kind that you save for years" and she included a picture of a note from Lisa that was dated 2010! We knew that she had sent us nice notes through the years, but we had no idea that she was doing that for all of her friends and colleagues. A friend of the family was able to use many of those pictures and combined them with family pictures of Lisa through the years to make a beautiful tribute to Lisa's life on a CD.

When the funeral plans were announced, we learned that 15 of Lisa's college friends were flying in from all over the country (none of them lived in our hometown). One of Lisa's eating disorder friends who was on vacation in Iceland cut short her vacation to come for the funeral. Her elementary school band teacher asked us if she could play the flute at Lisa's funeral. Her boss from Chicago started a Gofundme.com page to contribute to the charities that the family selected. For the sense of encouraging or supportive or humorous notes and emails that she frequently sent to all who knew her, friends and co-workers sent us copies of notes and emails that they received from her:

From Lisa to her recent boss:

"Cool. I can't wait to absorb all of your knowledge. Yoda you be, I'll be young Jedi"

From Lisa to a Hope College friend, sent last year:

"You never cease to amaze me in all that you do. I mean how do you mother and wife and manage to take such amazing pictures and create lovely dolls/crafts? You are a wonder woman!"

From Lisa to her eating disorder clinic roommate:

"Enjoy! Know that I'm in your corner, cheering you on to chase your dreams and your purpose"

From Lisa to a co-worker who was bemoaning that she didn't have a single flower on her desk on Valentine's Day:

"Here's a flour to make sure that you will always have at least one flour on your desk every day!" sent along with a baggie of flour tied up with a pretty, gingham bow.

As her best friend Stephanie said, “she fought hard against her eating disorder....really really hard.” But as with so many other illnesses or addictions, it is hard to get a handle on the mental aspect. It doesn’t work to just say, “you need to eat more,” just as you can’t tell someone who is bipolar to “stop being bipolar,” or someone who is suffering from depression to “just get over it.” Lisa often said, “I just want to be normal. I want to enjoy myself at social gatherings”. She was a woman of strong faith, attending church wherever she lived. She was so much more than just her eating disorder. She exemplified caring and true love.

When a young person who has so much promise and potential dies, it seems so tragic. We mourn the untimely loss of our beautiful daughter, sister, niece and friend. She is irreplaceable in our lives and in our hearts. Lisa spent most of her time thinking of others and how she could help them---with their jobs, with their eating disorders, with their studies and with their life in general. She touched and inspired so many lives. That is her legacy and it will live on.