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CHAPTER 3: IT'S A LOVE HATE RELATIONSHIP

Erika

I was born with a congenital heart defect called Tetralogy of Fallot. I had bypass surgery when I was two years old and open heart surgery to correct the defect when I was five. I was one of the first babies to survive both surgeries at the medical facility where I was being treated. Because of this, the physicians at the time did not know what my future would hold. They couldn't promise I'd see the age of ten, let alone have a family one day.

After my initial surgeries, I followed up with my cardiologist annually and had no restrictions on my activities. I played some sports and was very involved in extra-curricular activities at school. I never really thought about my heart condition. I did my best to make sure it wasn't an issue, but sometimes there were reminders. I'll never forget my sophomore year biology class. For some reason we were talking about open heart surgery and I mentioned that I had one when I was five. The teacher looked at me strangely and barely acknowledged my statement. Later that day at home, my teacher called our house. He let my mother know what I said. He honestly thought I made it up. I remember my mother spending some time explaining my diagnosis and what had happened to me when I was younger. The next day when I went to school, the teacher took me aside and apologized. He felt guilty that he thought I would make up such a story. He said that just looking at me, he would have never guessed what I had gone through as a child. I told him it's not something I talk about and I want to do my best to be as "normal" as I can. I appreciated the fact that he didn't make a big deal out of it and he respected my privacy afterwards.

When I was about twenty years old, my life changed drastically. I worked at a local TV studio and was getting ready for a live production when I suddenly became very lightheaded and dizzy. My heart was beating so fast it felt like it was going to literally pop right out of my chest. I was doing everything in my power not to pass out; I am not one who likes to cause a scene. Once the sensation went away I called my parents and told them what happened. They suggested I go to the ER. At the ER, they did an EKG and lab work and could not find anything wrong. Looking back on my experience, I wonder if the ER staff thought I was crazy or looking for attention. I was so adamant that they were wrong and they just shrugged their shoulders and said, sorry we can't find anything.

A few weeks later I followed up with my cardiologist. When I told her what had happened, she said it was possibly an anxiety attack or maybe it was all in my head. I was so offended by what she said. Anxiety attack?! In my head?! Are you kidding?! In that moment of frustration, I looked at her and said I was done. I asked her to refer me to another physician. I knew what happened that night was real and I needed answers. I needed someone to believe me.

Thankfully she referred me to an electrophysiologist, a cardiologist who specializes in arrhythmias. After meeting with him, he suggested I should have an electrophysiology study to find out whether I had an arrhythmia. The symptoms I described were similar to one, but he wasn't sure what kind. The day of the study I was very nervous since I didn't know what to expect. Aside from my yearly follow-up with the cardiologist, I had not had any major testing previously.

A few minutes into the study, they were able to induce an arrhythmia. I was feeling dizzy, lightheaded and my heart was pounding like it was going to pop out of my chest. I recall the doctor asking me if these symptoms were similar to the ones I had that day in the studio. I told him yes. I recall him being very calm and stroking my hair and telling me I was going to take a little nap and that we would talk again very shortly. Then everything went dark. Later, when I woke up I could hear my doctor talking to my parents. I heard words like dead, lucky lady and the statement, she really shouldn't be here. She should be dead.

That day we learned that I have ventricular tachycardia, a.k.a. sudden death syndrome. My heart was beating over 300 beats per minute in the lab and they had to defibrillate me three times to return it to normal sinus rhythm. Once the doctor realized I was awake, he came over and told me how lucky I was and the fact that I survived the first episode without any medical intervention was nothing short of a miracle.

I stayed in the hospital for about 4 weeks. They tried every drug possible to try to suppress the arrhythmia. I was in and out of the EP lab so often I lost count. At one point a cardiac surgeon came in to my room with a flip chart with fancy pictures and introduced me to the implantable cardioverter defibrillator (ICD). When he explained what an ICD was and what it would do, I told him pack up his stuff and get the heck out of my room. There was no way that device was going inside of me! I was stunned they would even think that was an option. I was still hoping there was a drug out there that would help me.

At one point my doctor was out of options and suggested I meet with a colleague in Philadelphia. I was transferred by air ambulance and once there I had yet another EP study. They were unable to induce the arrhythmia, which you would think was good news. The bad news is the drug that finally worked is not the kind of drug a young person should be on for the rest of their life. The side effects are brutal, such as organ failure and blue skin discoloration which is irreversible.

Once I came home from Philadelphia I met with my cardiologist again. He gave me yet another option. He spoke to two different physicians groups, one in London, Ontario and another in Texas. Both groups felt confident they could help me and were very eager to take me on as their patient. I chose London, Ontario because it was closer to home. My mother was coming with me and I wanted my dad to be able to travel back and forth on the weekends to visit. With all the issues I was having, they were still busy at home raising my brothers and sisters. We needed to be close by.

Once we arrived in London, I was greeted by some of the best doctors in the field of electrophysiology. I loved the fact they had a plan and that the guessing game was over. The plan was to do an ablation. They would induce the arrhythmia and try to ablate the scar tissue. It was determined that the arrhythmias were a result of scar tissue build up from the surgery that I had had when I was five years old. They explained to us that the ablation procedure had been successful in many patients and there was a good chance it might work for me. We were thrilled.

They did four ablations and none of them were deemed successful. They wanted to make one more attempt, but with the understanding that this time if they didn't feel confident the ablation was 100% successful they would implant an ICD. I remember saying, "an ICD"? What is that? Then I remembered the doctor who came to visit me with his fancy flip chart. I panicked. I thought this could not be my only option. All the research out there and my only option was a box with a bunch of wires that would zap my heart. No way! There is no way that is going inside of me. I cried and screamed until I was exhausted.

As a joke (partially) I asked my mother if Dr. Kevorgian would come to Canada with one of his contraptions. In that moment, I wanted to die. I can honestly tell you today that I wanted to die more than anything. I was done being pricked and prodded. I just wanted to escape my new found reality.

As I reflect back, I feel so guilty about my behavior toward my mother that day. She had been at my side the entire time supporting me emotionally and suddenly she became a verbal punching bag for me. I know it wasn't fair. I wish my dad was there to hold her hand and let her know that everything would be OK. Instead, she did her best to be strong. I know she broke down when she left my room that night. I can't imagine her alone and crying. I am sure she felt helpless as well. My mother has always been a positive person no matter what comes our way. She would always tell me that God never gives people things they can't handle. At first, I resented that statement. I wondered why God would do this to me. What had I ever done to him? I don't think anyone deserves what I have gone through in the last few months. I wouldn't wish it on anyone.

After my temper tantrum, the doctors sat down and explained I did not have a choice. If the last ablation did not work they would have to implant the ICD. They would not let me go home without it. What was I to do? I wasn't going to live in a hospital for the rest of my life and besides my insurance probably would not allow it either.

The next day I had my final ablation and this time they did it as an open heart procedure. When I woke up from the procedure, I remember reaching down to the left side of my abdomen praying that nothing would be there. I was disappointed to feel the tape and the packing that covered my incision. I knew that the ICD was implanted. I remember falling back asleep and tears falling down my face. I just wanted everything to go away. When I finally awoke it was explained to me that they ablated 99% of the scar tissue but 99% was not good enough for them. They felt they had no choice but to implant the device. For some reason, I felt someone owed me an apology for what they just did to my life. I sat there waiting for someone to say it but they never did. We just sat and looked at each other. It was a very awkward moment. At one point they went as far as to tell me that I probably would never need it. It was more of a back-up than anything else. That statement gave me hope. I desperately clung to their words.

I know doctors cannot predict the future but they were wrong. In the twenty plus years that I have had an ICD, it has saved my life nine times. Nine times! Can you believe it? It hurts like hell, but it has given me a gift, the gift of life. There aren't enough words in the dictionary to express my gratitude. Never in a million years did I ever think I would say that.

The first time the ICD fired it was horrible. I became paralyzed with fear and would not walk out to the car so my parents could take me to the ER. I felt that if I walked it would raise my heart rate and it would start firing again. I have never felt such fear like I did that day. After the initial shock, I barely left my house for three months. I was always afraid it was going to fire. I would sit in a chair and count my pulse all day long. I wanted to be ready if it was going to happen again. I did not want to be caught off guard. When I did leave the house, I always had to have a plan. If I was in restaurant, I had to sit by the door. If the ICD was going to fire, I needed to get out, and get out fast. One time my friends talked me into going to a movie and instead of sitting and enjoying the movie, I sat in the bathroom worried that my heart would do something funny and the ICD would fire. My parents would take me for car rides and I would lie in the back seat and just take naps. I would think, if I am sleeping, it won't fire. My heart is at rest so it won't beat fast enough for anything to happen. Once I attempted to venture out to a video store by myself and had

an anxiety attack. My dad had to come and pick me up. I was admitted to the hospital so many times for anxiety, it's almost embarrassing. At one point, it was suggested I meet with a therapist. I was willing to give it a try. I was exhausted both mentally and physically, and I was finally admitting I needed help.

My therapist was the best. In the beginning, I would meet with her twice a week. She was very tolerant of my behavior and was a very good listener. She would give me small goals to reach each week. I remember one goal was to simply go to the movies and try to stay in my seat as long as I could. She taught me breathing techniques that I could use any time I felt anxious. She was wonderful. At one point she suggested I attend a support group meeting. I laughed and said, "No way am I going to sit around with a bunch of people that could be my grandparents. What could we possibly have in common?" After weeks of her asking me to attend a meeting, I did. I did it for my therapist, not necessarily for myself. I really needed her off my back.

When I arrived, I noticed I was the youngest person in the room and wasn't a bit surprised. Everyone was so kind and they were doing their best to engage me in conversation, but I just couldn't do it. I wasn't ready. I felt like I had this wall around me and I needed to protect myself. As I sat and listened to everyone speak that day, I was in awe over how much we all had in common. It really didn't matter how old we were. We all suffered from some type of anxiety due to the ICD. The difference between me and the group is that yes, they had anxiety, but they learned to cope. They learned that life must still go on. This meeting really changed my perspective. I remember the ride home that evening. I cried all the way home. I wasn't crying because I was sad. I was crying because I didn't feel alone. I had people that I could relate to and it gave me hope. I started to see the light at the end of the tunnel. I just needed a little more time.

I continued to attend the meetings and eventually I shared. I was no longer the scared girl in the corner who wouldn't speak. It was a great outlet for me and I learned so much about myself. It was so nice to express my fears and have others understand. As I sat and listened to others, I realized how much energy I wasted worrying about something that more than likely wasn't going to happen. It also made me realize how much I missed out on, and how unhealthy it was for me to continue living like that. I was mentally and physically exhausted. It was time for me to move on. I knew it wasn't going to happen overnight and I had to be patient, but I needed it to happen. I needed to enjoy life and be thankful.

I have had my ICD replaced numerous times over the years. The first time it was replaced I ended up with an infection. A few weeks after I was discharged, I spiked a fever and noticed a blister on my incision site. I went back to my cardiologist's office to discuss my symptoms and find out what to do next. My cardiologist was on vacation so one of his colleagues was following my care. Without doing any tests the doctor decided it was a "female issue" and that I should just go home. He blatantly ignored my symptoms and wanted to send me on my way. When I called my mom to give her an update she was appalled. She called another colleague in the office and begged for them to do an ultrasound. He agreed it was appropriate and would do it the next day. The ultrasound was done and they found the pocket where the ICD sits was infected. The infection was so severe that I was sent back to London, Ontario that afternoon. They said later that if I had waited another day or two the infection would of spread to my blood stream and I could have died.

They removed the ICD and I was put on I.V. antibiotics for four weeks. Since I was no longer protected against ventricular tachycardia, the doctors didn't want to risk it and they admitted

me for the duration of the treatment. At this point, I was depressed. It seemed like every time I went two steps forward I went back four. Nothing was really going my way.

After I was discharged, everything seemed to be going well. Then one day the blister reappeared. Without even talking to the doctor I knew the infection had returned. I was so tired of the ICD and the problems it was causing that I just wanted it out. When I met with the cardiologist it was determined that the electrical leads that connect the ICD to my heart were infected too. I refused to go back to London and demanded that something be done locally. The doctors agreed to treat me and remove my ICD. I was tired of dealing with the issues and really needed a reprieve. The doctors removed the leads and the ICD with the understanding it would be for a short period of time. When it was time to put the ICD back, I refused. Emotionally, I wasn't ready. I wanted things done on my own time.

As time went on I started to date again. My relationships never really lasted because who wants to date a girl with a heart issue who has both emotional and physical scars? Then one day, I finally met the man I was destined to marry, Bryan. I wouldn't say it was love at first sight. At the time I was still leery about relationships and didn't want to commit to someone knowing it may not last. The first time we met I told him I had Tetralogy of Fallot and that I also had sudden death syndrome. I explained that I'd need an ICD implanted eventually and how much of an emotional mess it has made me over the years. I also told him about my scars and that they were not a pretty sight. To me it was like a little test. If he really likes me, he won't care and he will ask me out. If he doesn't ask me out, then it wasn't meant to be and I nipped that in the bud. Well, he asked me out and almost 3 years later we married.

Prior to that, though, about six months after the ICD had been removed, and not long into my relationship with Bryan, I was driving in my car on my way to play softball when I became lightheaded. I was dizzy and my heart was beating rapidly. I was so scared; I thought I was going to die. I didn't have my ICD which meant I didn't have a back-up. It took that one moment for me to decide I needed my ICD. I called my doctor and set up a surgery date for the next week.

I learned that Bryan was the one when my mother tried to give him an out during the ICD placement. Part of the workup to getting the new ICD included another visit to the EP lab for more tests. Bryan came along with my mother so she wouldn't have to sit alone. They wanted to put in an arterial line for the study. I refused to have the line inserted. Arterial lines are very painful and in the past they always inserted them after they gave me the anesthesia. This time they refused to do it that way. They finally gave in and gave me two different medications: one to calm my nerves and one to make me forget about the procedure, yet I was still awake. I don't remember anything, but I understand I was not a very good patient. Let's put it this way, my mother didn't know I could swear like a sailor. At this point my mom looked at Bryan and said, "We understand if you want to walk away. We know this may be tough to handle." Bryan's response was, "You can't help who you fall in love with and I am here for the long haul." My mother loves to tell that story, and she knew at that moment that he was the one for me.

Before Bryan and I married we agreed to meet with a high-risk OBGYN to talk about the possibility of having children. I was always told that I probably should not have children. It would put too much stress on my heart, and there was a really good chance that my children would be born with the same heart defect as well. After meeting with my OBGYN and consulting with my cardiologist, they both agreed it would be safe to try. About a year and a half into our marriage, our son Ethan Matthew was born. It was a tough pregnancy due to a partial placenta abruption which

put me on bed rest for almost five months, but everything worked out well. Ethan was born almost 6 weeks early and weighed 4 pounds 4 ounces. He was a very healthy boy. Four years later, almost to the day, our daughter Sophie Catherine was born.

My pregnancy that time was much different. I was able to work until the day she was born. Five weeks before Sophie was due I noticed a tremendous weight gain in a short period of time and called my doctor. As soon as I made that call, I knew that day would be her birthday. When I arrived at the hospital it was determined that I was in early stages of congestive heart failure. Almost 5 hours after I made the call to the office, Sophie was born via a C-section. She too was a healthy baby weighing in at 5 pounds 4 ounces. I was very fortunate because the congestive heart failure resolved itself on its own.

Since my marriage and the birth of my children, my anxiety is almost nonexistent. I still have my moments but they are not as often or as bad as they were years ago. I have learned to live and, most importantly, love and enjoy my life. I have a great marriage, career and am very involved with my kids' activities. When I share my cardiac story with others, they can't believe everything I have gone through. I look like a normal wife and mom with a full-time job who is doing her best to raise her kids and take care of the family. I love to hear that, because normalcy is what I strive for. I just want to be normal. I know that without this ICD, I would have never had the opportunity to live this wonderful life I lead. I am grateful for my mother and father who never let me give up. I am thankful for my brothers and sisters, who I am sure felt neglected at times, yet they were so patient and loving. I am thankful for my wonderful extended family and friends. I don't know where I would be today without them. Last but not least, I am thankful for Bryan for loving me. We have been through some rough times but he has never wavered. He is always by my side and that is what makes it easy for me to get through the tough times.

Over the years I have been diagnosed with atrial tachycardia, atrial fibrillation, pulmonary hypertension and congestive heart failure. I have had my ICD replaced numerous times and battled a few more surgical infections. I had my pulmonary valve replaced a year and half after my son was born. Then a few years later diagnosed with endocarditis.

To the average person this may seem like a lot for one person to handle. But when I look back at my experiences, I think about the statement my mother would repeat over and over – God gives us what we can handle. As much as I resented that statement, I have grown to appreciate it. What God gives us does make us stronger. Because of this strength, I consider myself a survivor and will always be ready for what he will give me next.