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CHAPTER 9: MY RHYTHM OF LIFE

Lisa

“Hmmm...” That’s never a comforting sound from a physician. But, that was exactly what my primary care doctor said as she looked over the ECG tape from the test she had just administered.

I had gone in for a yearly physical with a new doctor whom I hadn’t been to before. After listening to my heart, she asked if I was a long-distance runner or if I had ever been told I had a murmur. When I answered no to both, she thought it would be a good idea to have an ECG, which I never had before. After looking at the tape, she told me she wanted me to see a cardiologist right away and made an appointment for me.

At only 21 years old, I was trying not to worry but was actually freaking out inside. I had a normal childhood, played sports and never had any kind of medical problem other than chicken pox and the flu. A cardiologist? Right away? I figured there was no way this was a good thing.

After seeing the cardiologist and having stress tests, echocardiograms and other tests, the cardiologist informed me that I had third-degree, or complete, congenital heart block. In layman’s terms, the top and bottom chambers of my heart had no electrical conduction to cause them to beat with each other and instead were beating independently. Although I never had symptoms, it was something I was born with. I was stunned. How could no one have ever diagnosed this? How could I never have known? What did it mean? Was I going to die? Quite frankly, I was terrified.

The doctor explained that it was a very rare condition that was often fatal in newborns. At the time, (the late 1980s) he said he couldn’t explain why some people, myself included, didn’t have severe symptoms and had hearts that compensated for the electrical malfunction. He suggested the best course of action was to have yearly checks wearing a 24-hour monitor and alert him immediately if I developed any symptoms like lightheadedness, inability to exert myself or passing out. He then explained that at some point in my life I would probably become symptomatic and need a pacemaker.

What? Aren’t pacemakers for old people? And would I have to give away my microwave? That was pretty much all I knew about pacemakers. After my initial shock and fear, I did what he said and just went on with my life, rarely thinking about this strange disorder I had.

Fast forward almost 20 years. I still hadn’t developed any symptoms. In fact, I had gotten somewhat lax in being timely with yearly checks. I had moved, switched doctors and nothing changed. Doctors still couldn’t understand why I worked given my condition. No matter the doctor, I was always the only patient they had with my disorder.

Then one day my mom asked me when I had last seen a cardiologist. I realized it had been more than a year. I also realized that strangely enough, I had never searched the Internet on my

condition. When I did, I found a recent academic paper about my condition exactly. Reading the words, “In many asymptomatic cases, the first symptom is sudden cardiac death,” was not exactly the comfort I was looking for. In fact, all the worries I had from that first diagnosis came rushing back at full speed. I contacted the researcher and surprisingly, he wrote back immediately and urged me to see an electrophysiologist and suggested the University of Michigan Health System would be an excellent place to go.

I was pretty scared but once I met my doctor, Eric Good, I immediately relaxed. First of all, he was very knowledgeable about my condition and had treated many other patients with the same thing. It felt so much better to know there were others such as me who had been successfully treated by this doctor. He recommended a pacemaker to create the electrical pulses that my heart could not do properly on its own. Given that I was really not interested in exploring the sudden cardiac death “symptom,” I scheduled the surgery.

I realized then how important it was to have a doctor whom I trusted completely and who listened intently to my concerns and wishes. He explained everything in terms I could understand, assured me that my worries about how the device would look were normal and OK and that he would do his best to hide my device. Most of all, he made me feel like a partner and not just a patient.

I had my pacemaker implanted a week after I turned 40. Getting a pacemaker for your 40th birthday isn't the best way to celebrate, but I realized I was lucky to be able to celebrate at all given the chances I had taken with my heart for all those years. In the back of my mind, I had always known this was a possibility, so emotionally I managed pretty well. My doctor kept his word and did an outstanding job of making the device hardly noticeable. I recovered quickly and started to adjust to living with a device.

Things seemed to be going well when I had a checkup five months later. I visited the office and Laura, a wonderful device clinic nurse, ran through the tests. Though she didn't say, “Hmmm,” while looking at the report, I could tell something wasn't right. She left and later came back with a doctor whom I didn't know. Dr. Good wasn't in the office that day but there was a concern with my results. It seemed that the pacemaker had actually recorded an additional problem with my heart while I was sleeping – an episode of ventricular tachycardia – that was very dangerous and could result in sudden cardiac death. I was told it was something that couldn't be controlled with the pacer alone and that I would need to either have cardiac ablation or have my pacer replaced with an Implantable Cardioversion Defibrillator.

I was completely thrown for a loop. In my mind, I had finally gotten my pacer and taken care of my problem. How could I possibly have another problem that put me at high risk? Wasn't one enough? It was all extremely overwhelming and I was terrified that the V-tach would happen again before they had a chance to try ablation. It didn't help that my doctor wasn't there to deliver the news, but it did help to have Laura there. I remember her asking if I needed her to drive me home — probably forgetting that I live an hour from the hospital. I made it home by myself that day, amid a snow storm and a lot of crying.

Dr. Good contacted me within a few days and arranged for me to be fitted with a Life Vest, an external defibrillator that is worn strapped to the body at all times. Needless to say, it was quite

the fashion statement when worn with lovely holiday dresses that season. Then again, it was there to save my life and made the wait before my procedure much less stressful.

I went in to the hospital about six months after receiving my pacemaker so that my doctor could try cardiac ablation to take care of the area that was causing my V-tach. I knew going in that if he wasn't successful with it, my pacer would have to be replaced with an ICD. I was terrified of the very idea of having an ICD and had convinced myself I wouldn't need it. I knew that they were bigger, had a shorter battery life, and — oh yeah — could administer a huge shock to my body that had been compared to being kicked by a horse. In my head, I knew that I would get what I needed to keep me safe but my emotions kept telling me that I didn't want any of this. I simply wanted to go back to a time when I thought I was “normal” and not a “heart patient.”

I woke up from surgery and immediately put my hand to the left side of my chest. Yep...there was the same bulky bandaging I had had just six months earlier. I knew then that the ablation hadn't worked and I was now the new recipient of something I didn't want — an ICD. Because the drugged haze I was in, I don't remember much more from the recovery room but I was told later (by the psychologist consult that showed up at my bedside) that I was pretty angry and yelling about how I didn't want an ICD. Awesome. Not only did I have to get an ICD but I embarrassed myself by yelling so much they assumed I needed a psychologist.

Since I had just been through the same recovery six months earlier, I knew exactly what to expect and prepared accordingly. I remembered a strapless bra, I took my meds before the pain started, I wore clothes that were easy to get into and I had prepared things at home so I wouldn't have any reaching to do. The one thing I wasn't prepared for was my emotional state. This time my emotions were so different, but I couldn't really figure out why. I couldn't stop crying. I couldn't stop thinking about the device in my chest. And then I got angry with myself for crying and not being strong enough to soldier on like nothing had happened. I didn't understand why I managed with the pacemaker so well and this was bothering me so much.

Again, Dr. Good had been absolutely wonderful. My incision was minimal and he managed to hide my device so that there was no discernible lump that I had been worried about. He visited my room the day after my surgery and said all the right things. Physically, everything was wonderful and recovery was relatively easy. (Well, except for that maize and blue University of Michigan sling they sent me home with to East Lansing. This lifelong Spartan had a lot of explaining to do. It's my heart, not football, so yes, I went to U-M).

And yet still, something wasn't right with me. I tried talking with family and friends. They tried to be supportive and understanding, but still no one really understood what I was going through. Thinking they were being helpful, some told me I was lucky and that I should just get on with my life. In my head I knew that was true, but I really didn't feel all that lucky at the time.

To this day I still can't really put my finger on why I was so sad and worried for months after my surgery. I know now that there was nothing to blame, nothing I did wrong. Emotional rollercoasters are a very normal part of any health challenge, and every patient has the right to feel however he or she feels and work through those emotions in whatever way he or she needs to. No one is the same, and no one deals with anything exactly the same. And no one should ever tell someone, “Just forget about it.” When you're the patient, doing so is much easier said than done.

Dr. Good was extremely compassionate and understanding. He knew that my whole self, not just my heart, needed care and suggested I go to a counselor.

Through my employee assistance program at Michigan State University, I was able to see a wonderful counselor. He let me talk. He let me cry. He told me my feelings were valid. He gave me coping skills. He helped me work out why I was so angry and sad. He gave me ways to talk with family and friends to express what I needed from them. He made me feel like I was entirely normal. And, most importantly, on the day of my last session, he told me he was proud of me. That was the day I realized I was proud of myself and that I had been given a great chance at a wonderful life.

I've had my ICD for five years now, and I've never been shocked. I'm still paced almost 100% of the time. Do I still have moments or days when I worry? Absolutely. Who wouldn't in my situation? But, it's just a new part of what makes me, me. I'm not shy about it. I use my situation to educate people. I used to hide my scar. Now I wear it proudly. I've participated in conferences to meet others with ICDs and have met some amazing women who have become great friends. I've spoken at employee training sessions at the UMHS. I've joined a patient family-centered care advisory council to help improve patient experiences even more.

I enjoy my family and friends. I work hard. I play hard. I don't let my condition or my device slow me down.

I remember when I was asking Dr. Good about the limitations I might have with my ICD. After talking about standard things like MRIs, magnets, etc., he told me something I try to remember every day. "I put your ICD in you so you could live. So go do that. Live."