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CHAPTER 4: ME, MY WIFE, AND HER ICD

Bryan

My wife Erika has asked me upon occasion throughout the years if I regret anything about our life together. Asked in jest it still provokes reflection and calls for an answer. Marrying her wasn't as much a choice as it was finally finding my other half and grabbing on. Trite as it sounds, I can't imagine my life without her in it- nor do I want to. She was the only person that could have given me the family and memories I have now.

I think it helped that she started off being very frank about her heart condition. We weren't long into our first conversation when she brought up rather sobering concepts including sudden-death syndrome, Tetralogy of Fallot, open-heart surgery, ventricular tachycardia, arrhythmia, life-threatening infections and six-week hospital stays. She told me about the trials her parents and siblings went through as she endured myriad medical tests and treatments including repairs, ablations and placement of an implantable cardioverter defibrillator (ICD), disrupting their lives for weeks or months.

She told me how, after getting shocked by the I.C.D. for the first time, she never wanted to leave the house. When she did go out, anxiety would overpower her reason and she'd constantly worry, "What if it goes off, what if. What if?" to the point of obsession, always having an exit plan. Once she went to the movies and worried so much that she went and hid in the restroom for the rest of the time. Erika underwent rounds of therapy in trying to cope with her new reality, developing the tools to live life despite the anxiety and depression.

When asked to describe what would have been the perfect woman for me at the time of our introduction, none of this would have been on my list, I assure you. How often do you hear the phrase "sudden-death syndrome" when you first meet someone and wind up getting married and starting a family?

Though she was between ICDs when we met, it wasn't long before I had my first exposure to Erika, the patient. I didn't know what to do but just be there despite a healthy discomfiture at being in a hospital and the awkwardness of being the new boyfriend while her folks- especially her mom- looked after her, talked to the doctors and nurses, and made care decisions. I saw dynamics and heard medical terminology that left me reeling and feeling helpless. It ultimately was an epiphany though for Erika, for her folks and for me.

Erika knew that we had a chance after that first surgery that I'd been a part of: I saw her at what she considered to be her worst and I stayed. She told me later that's when she knew I was the one. Her mom graciously offered me an out during that surgery, telling me that no one would blame me if it was too much or if I couldn't deal with it. While she was looking out for me on one level, of course it was all for Erika's sake. Anyone that sought a serious relationship with her

daughter would be taking on all the hardship and worry that comes with a complex congenital heart condition and ultimately would be the one at Erika's bedside.

For my part, I can only write here what I told my mother-in-law then. You can't help who you fall in love with. Erika knew after the surgery that I was the one, but I knew before that. I saw what we would be up against. I realized I had much to learn and it would be a long time until I was the one holding her hand first, making care decisions with her, and understanding her situation and its ramifications. But I loved her, warts and all.

My folks asked me about it too, and of course I thought about it--who wouldn't? Love can be a force to motivate and bind, but you have to be pragmatic. If I wanted a family, could she? If we did, what were the chances the children could have the same problems? How long can she work? What does insurance cover? Will I get shocked if I'm near her? What would that be like? Can I handle seeing her as a patient? What would I do if the worst happened? These were my thoughts and my folks urged me to look at all of the angles, for my own good. They really liked her but they worried about their son as any parent would.

My dad told me much later that my response taught them something, though I didn't realize it at the time. I told them the same thing I told Erika's mom- you can't help who you fall in love with. I took it one step further with them, however, addressing the mortality considerations: Yes, she could be gone tomorrow but so could I, anyone could. It's said, that tomorrow is promised to no one and I agree. You can't live life worrying about it - that's not living. You have to take the risks with the rewards. I saw myself with Erika and that was a huge reward.

Along the way, I decided to discern whether I could share in Erika's Catholic faith. I had never really gone to church and while I had some Christian beliefs, religion was pretty much a complete mystery to me. I went through an R.C.I.A. (Rite of Christian Initiation for Adults) program and ultimately joined the Church to the delight of Erika and her family. Erika wanted a big Catholic wedding (not that we had a choice on the big part because she has a huge family and a million friends).

Most important to me though, was that this new faith taught me that we don't need to bear the challenges of life alone--particularly the ones that faced us with Erika's situation. I learned that faith and prayer can help immeasurably and I'm forever thankful for that. I also recall a lesson that a nice couple shared with us as we went through pre-marriage counseling: Your marriage is a hope chest, to be filled with the good things you share. You only put things in it that make you stronger and closer as a couple. Nothing else goes in, you set that stuff aside. For me, that meant setting the anxiety aside and embracing life with Erika, for however long we're allowed to.

There was still the matter of starting a family. God, after all, wants us to be fruitful and multiply! We both wanted children, at least one. We consulted with a wonderful doctor who specialized in obstetrics for high-risk cardiac patients like Erika. He assured us he saw no reason we couldn't try, counseling us not to wait long, though. Soon after that discussion we married, bought a house, and learned we were having a baby. I still remember the day we told our folks, only 6 weeks in. We wanted to be up front with her pregnancy in case health concerns arose. It's a good thing we did but the day we announced it, it was a good day.

The bottom almost dropped from beneath us a couple months in. Erika was diagnosed with a partial placenta abruption. The doctor ordered significant bed-rest for something

like six months. That shook me up, I worried both for our baby and Erika. I wondered if we'd made a mistake, if we shouldn't be doing this (my faith said trust in God). We worried about whether the baby would have a heart problem. Erika stayed home, able to do some work remotely and things stabilized. We went to many, many appointments and enjoyed many more ultrasounds than the usual anxious parents do. The baby was growing, moving, living. We decided against learning the sex since we wanted to have a nice surprise at the end, given the tension and anxiety we were going through.

The doctor kept telling us, we have to get to 27 weeks and then if the baby has to be born, it will have a good chance. We made it 33 weeks and Erika went into labor, 5 weeks early. The doctors tried to stop it but the labor continued. I worried so much, I barely slept. They didn't really want to do a C-section due to Erika's situation but she wasn't dilating much. After two and a half days of labor, the baby started to show signs of distress. The baby had to be delivered surgically.

Ethan Matthew was born, a tiny thing of 4 pounds, 4 ounces, with a headful of red hair. He cried a good healthy cry and his heart was good. His daddy's eyes overflowed with proud tears. I remember it seemed like thirty people were in the room; the whole floor wanted to know what we were having since it was rare not to know ahead of time. Once he came out, it seemed like half the people left. They weren't there just to find out if it was a he or she, were they?

Ethan's umbilical cord was as thin as a pencil and he'd have to spend a week in the N.I.C.U., but he would be fine. Much later, our doctor confessed he wasn't sure we were going to get a baby out of this. But here he was, a true miracle, and I'd never felt such euphoria. You did it, Erika, you did it. He's here and he's healthy. And, thank God, so was my wife. She just wanted to know if his heart was good, and it was. Thank God.

We were going to stop with Ethan, the whole situation scared us both. I find we consider Erika's situation when making certain decisions. Having kids was a huge concern. Deciding where to live was another. Prior to getting a house, we explored moving to Chicago. We would have been virtually alone, far from her doctors and family who made up an important support system for both of us. We both come from close-knit families and we decided it was best to stay close, especially since we wanted kids.

I learned about Erika's coping mechanisms as we went. We met others with ICDs and I learned how people with them avoid the particular situations that they were in when their defibrillator went off. For example, Erika told me about one fellow whose ICD went off when he took a shower in the morning, so he started showering at night. Based on what Erika's gone through, I can't blame them. Her biggest fear was always, "What if it goes off?" It's not just the pain. It's a complex weave of emotions, embarrassment, worry, fear, sadness, anger, and helplessness. Don't underestimate the pain though. I hear it's like getting kicked in the chest by a horse. ICDs save lives, but those with them definitely have a love-hate relationship with them. I personally love it, 110%. It keeps my wife at my side, where she belongs.

The closest I've been when Erika's ICD went off was in the middle of the night. We were sleeping and I swear I sensed it was coming just before it did, I don't know how. But I saw this brilliant flash of light prior to opening my eyes. What I think happened though was that the shock set off the static in the blankets, resulting in this relatively bright flash. I felt a bit of a static shock. She was OK but we found out that her ICD was giving unnecessary therapies- yet another trip to the E.R.

There have been many visits to the hospital. I think we can usually count on one visit a year, often for different things. Getting the ICD back in, problems with drug interactions, arrhythmias that weren't stopping, infections, and new ICDs. The scariest visit by far was when Erika needed a pulmonary valve implanted to help fend off further enlargement of her heart (left untreated, a very bad thing). That was the first open-heart surgery she'd had since I was with her and I was terrified. I relied heavily on both my family and hers to get us through. My clearest memory is when the doctor came in after a very, very long and anxious wait- to tell us that the surgery was a success and Erika was on her way to recovery. I remember collapsing shortly after, into a warm and much needed hug from my family.

Erika needs a support system, that's obvious, but spouses also need help. No one should bear this alone. A huge team of physicians, technicians, pharmacists and nurses look after Erika's well-being medically. She and I now make all of her care decisions. I know more about cardiology than I'd ever imagine wanting to know. I'm a hospital pro, now. Bring a book, wear layers (hospitals can be cold) and comfortable shoes. You wait, a lot. Seriously, hospitals are about the waiting and waiting and waiting some more.

One must come to terms with the fact that our medical professionals can't fix everything. They don't know everything. It's OK to question anything and everything. As Erika-the-patient's spouse I have to be her advocate, a detective, a bouncer, a listener, a complainer, an arguer, a liaison, a sounding board, and an inquisitor. It's OK to cry, to pray, to be angry and frustrated. It's okay to say nothing to your loved ones, just hold their hands, and just be there. Most importantly, when the crisis is over and you're back home, it's OK to slip back into a "normal" life, be a "normal" couple, and let the memory of the last incident fade.

Life went on for us after the valve surgery. We started camping, Erika had her gall bladder removed, and we had a surprise pregnancy. Yes, despite our intentions, we found out we were pregnant again. It went much better and this time we found out what we were having a little girl--daddy's girl who I call my little Jumping Bean because she had hiccups in the womb and would jump around during ultrasounds. We had the same worries about whether she'd have heart problems, and of course I worried about my wife. But Erika worked the whole time and was mostly fine until showing signs of congestive heart failure toward the 34th week. Our doctor said, "God made this decision easy." Sophie Catherine entered the world on a snowy Wednesday, another preemie but outweighing her brother by a pound (5 pounds, 4 ounces).

We're a typical family, but I thought early on that the kids need not be shielded from Erika's condition. They knew from an early age that she goes to the doctor often and has an "ouchie" heart that needs looking after. I wanted it all as just part of our lives, and so far it has worked well with the help of wonderful parents and families on both sides. They've been a huge part of our lives and we've leaned on them heavily.

We try to keep things "normal." Erika has said many times that she just wants to be 'normal'. To me, our lives are normal. I know what she means, and she's certainly entitled to her woe-is-me days. When she gets a shock (which is fortunately- knock on wood- a rare occurrence), she handles it pretty well now. But there is an inevitable delay and then she gets a bit morose and weepy a day or two after. When her heart goes willy-nilly (and not just because I enter the room), I can always tell because she kind of freezes, sits forward, raises her arm a bit like she's going to make a muscle, and clenches that fist. Sometimes she counts her pulse- counting beats is a big part of

getting through an event. And I have to talk to her, about anything, which is tough because I'm not much of a small-talker. That drives Erika nuts. See, we're just another average married couple!

I'm still not always sure how to act or what to say when something's happening. Erika has atrial fibrillation now. While it's not as bad as ventricular tachycardia, it is still scary because clots can form and clots are bad--potentially scary-bad. So when an event happens, sometimes it can last hours and we have to weigh going to the ER. I catch myself thinking about her condition when making travel plans, too. For instance, I'd love to go to Yellowstone with the family and go hiking out there, but is that wise given what could happen? How fast could we get to a hospital? Is there a good one nearby?

Mostly though, we just take things as they come. For me, as a spouse, things are pretty normal. I don't think about her condition daily, like she does. She has to, it's always there. She suffers little runs of arrhythmias, moments of light-headedness, little reminders of mortality, and of how fragile this all is. But we don't let it dictate life to us. We live the best we can, we have fun, we raise our children and we enjoy our family and friends. We live in the present, with a cautious eye on the future. We live.

Do I have any regrets? I have more wishes than regrets. I wish Erika didn't have a congenital heart condition. I wish I always knew the right thing to say or do. I wish Erika didn't need the ICD, didn't have the worry, and didn't have to go through those surgeries. But this is all a part of her, a part of her life and therefore it's all part of my life, a part of me. It's made her the person she is: a loving mom, a successful professional, a dedicated advocate, and a strong survivor. Most importantly to me, it's made her the wife and companion I was meant to have and will always cherish, whatever may come. I'll never regret it.