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CHAPTER 6: LIVE YOUR DREAMS...ONE BEAT AT A TIME

Terri

Becoming part of the YOUNG ICD CONNECTION is a lot more exciting than receiving a very different invitation, to become part of AARP. I was invited to join that club because I just turned 55. Some people say that I do not look my age, but I will let you be the judge by my picture in this publication. (Please be kind!)

I have known my whole life that I have a complex congenital heart condition and have recently learned that I am one of the oldest surviving persons with that condition in Michigan. Whether you have recently learned of your heart condition, have known your entire life, or have a loved one or friend with heart abnormalities, we are all, in some way, connected. The reason for this connection is my friend and yours, the implantable cardioverter-defibrillator (ICD). I received my little ICD friend almost 3 years ago and will tell you about it in the next few pages.

Many of you have never met a heart patient older than yourself, so let me introduce myself – my name is Terri and I am living proof that you can live with an uncorrected congenital heart problem and still enjoy a good life. My heart condition consists of a ventricular septal defect (VSD), Pulmonary Stenosis (narrowing in the Pulmonary Artery), and L-transposition of the Great Arteries (LTGA). My diagnosis at birth was that I was a “blue baby” due to my lack of oxygen. I can only imagine the horror my parents felt when they learned that their baby, in the doctor’s words, “probably would not live to adolescence”.

Back in 1956, when I was born, survival with such conditions was virtually unheard of because surgical intervention was rarely considered, due to the medical knowledge and technology of the times. Thank God for Drs. Alfred Blaylock and Vivian Thomas, who pioneered the first open heart surgery on a “blue baby” at John’s Hopkins Hospital. (Their collaboration was wonderfully portrayed in the movie *Something the Lord Made*.) The techniques they developed were later taught to other surgeons, including my heart surgeon, Dr. Herbert Sloan at University of Michigan Hospital. In 1960, Dr. Sloan performed that surgery on my heart, allowing me to be less cyanotic (blue) by opening up arteries and allowing additional oxygen into my system. Back then, the odds were not good, but by the grace of God, and the steady hands of my surgeons, plus the continuous support and compassion of my caregivers and family, I defied those odds. That surgery, at four years of age, gave me another chance at life. The other defects are still present. Sometimes I smile and think of my heart as driving on a highway in England; it seems backwards--“quite so,” as they say over there - but it works! 😊

Going through life with congenital heart disease is challenging, limiting and is not an easy feat; but with hard work and a daily commitment to, as well as encouragement from my parents to stay as active and positive as possible, I turned my limitations into my own personal adventure—one that comes with challenges, as all adventures do. It is difficult to sum up 55 years of life into a few pages, but I will try by giving a few good examples.

When I was in elementary school, I was teased a lot-- especially by the boys. (Maybe they just liked me-- you know how boys are at that age!) Sometimes they were relentless in teasing me about my inability to take part in gym class, participate in outside activities in the cold, or even walk to school in the winter months. So, I tried to turn that situation around by telling them if they did not leave me alone, I would "give them my heart condition." As you can imagine, this was not a good idea, because now they were afraid of me. I felt like an outcast but I also chuckled at the thought that the boys would actually think I could do that. Boys!

No small child should need to know words like cyanosis, PVCs, and arrhythmias. We shouldn't hide from the truth, and my mother taught me the meaning of these words to help me understand why I could not do all the things the other kids could do. I began to connect these words to how I was feeling. For example, connecting the word cyanosis with being blue in color went along with the feeling of fatigue. Feeling blue. Understanding is a wonderful thing.

Camping, hiking, and skiing were activities that were off limits to me. My brother and sister were able to participate, but it was merely a dream for me. So, I used that time to read, which ultimately allowed me to get through school with high grades. I completed my Business degree at 19 and earned a degree in Veterinary Medicine at 45, the field in which I am currently employed. I am also completing classes to combine those two degrees into a bachelor's degree in Business Health. I believe you are never too old for education, as it is a lifelong pursuit.

As a child and teenager, I had problems riding a bicycle, especially on gravel. It was hard for me and very strenuous. So I learned how to ride a motorcycle. What a wonderful feeling that was, and still is, as I ride a 750cc Honda Shadow. I ride mostly with my younger brother, as he is my protector, and we have great times in the sun. The wind in your hair and the feeling of freedom is unlike any other. (Bugs in your face are not fun, however, so wear a helmet with a shield!)

The inability to participate in sports such as volleyball, basketball and track did not slow me down. I learned the fine art of cheerleading. Of course, it was different back then but cheerleading nonetheless. At first I became an alternate cheerleader, but the next year I was accepted on the team. Even now, I am one of the biggest cheerleaders of all! I cheer for my grandbabies (yes, my grandbabies – all five of them) sporting events as well as the Detroit Lions--for whom, by the way, I have waited 55+ years to become contenders. Go Lions and go grandbabies!

When I was first married, I was advised by my cardiologists that it would be risky to have a child. I am not saying that you should not listen to your doctor on this one, as all cases are different. In my case, when I became pregnant, the doctors quickly concluded that my baby and I would only have a 50% chance of survival. I decided that I would take the 50% chance and have the baby. I had a bouncing baby girl of 4 lbs 10 oz. and 19 inches long on a mild October evening. For me, it worked out wonderful. I was and am a "mommy," with immeasurable responsibilities and pride! My daughter Rebecca is healthy, happy and 33 years old at this writing. (I am certain she would try to tell you she is only in her 20s, but don't let her fool you!) I was able to raise my daughter just like any other mother. I worked outside the home, as so many of us do, but still had time and energy to help Rebecca with her homework. I taught her so many things in life and encouraged her to be the best she could be. I'll admit I lived vicariously through her at times, as I watched her extra-curricular activities in her cheerleading and pompon days. (She teases me in a good-natured way about my days as a cheerleading "alternate.") I always tried to keep her grounded and focused on school and family. At one point, we attended college together; and both received licensure in

Veterinary Technology. In truth, my best friend was born that day in October. How many people can say this?

Running was never an option for me. So I learned to ride a horse in my preteen years. This was always a dream of mine and my cardiologist was in agreement with this decision—with one condition. If I ever fell off, he said I must sell the horse. Now anyone will tell you that learning to ride a horse has its ups and downs. I had a few small “downs” which I failed to mention to my cardiologist. (“My bad” as the kids of today would probably say.) In my 30s, I began learning English riding and jumping. I began with 10-15 minute lessons and worked my way up to 1-2 hour lessons, 4 days per week. I joined the MHJA (Michigan Hunter Jumper Association) and began jumping fences in competition along with my daughter. I can only tell you that it was one of the most rewarding experiences of my life. Not only did I stay in perfect shape, but won Michigan’s 1992 Championship in Primary Adult Jumping. (The same year, my daughter Rebecca won Reserve Champion in the state. I guess the apple doesn’t fall far from the tree!) It is a thrill I will never forget, jumping 2-3 foot fences felt like I was flying through the air! Even with a severe complex congenital heart problem, I won the Championship against all the healthy hearts. I think I took the lifelong practice of learning my limitations and dealing with them to a new level. And so can you!

On the subject of being a grandmother, I can only say it is the greatest! I have four grandsons and one granddaughter, they all call me Nana and I love them all so dearly that I cannot even begin to tell you. Maybe I cannot keep up physically with “normal hearted” grandmas, but it doesn’t matter! They love me just the same. I am always there for them and try to keep up as best as I can. This year alone, I have been involved in their soccer, football, special person’s day, and even volunteered at their schools on occasion. Plus, I take them swimming, skiing (yes, I am learning to downhill ski on the bunny hill), golfing and to the fair. I must look a sight “trotting” down the sidelines screaming cheers of joy when one of my babies gets a goal, scores a touchdown, or putts the ball into the cup. Being a grandma is truly the BEST! It keeps you young and I would not miss one day with my babies!

April 3, 2009

Sitting in a café eating dinner after a long Friday at work was a good way to wind down. The work week had been a long one, filled with emergency cases, radiographs, cranky dogs and cats, plus a technician who was not feeling well. Dinner came and went and I felt much too full for dessert... when all of a sudden – lights out!

As I opened my eyes a bit dazed and confused, I looked around the room and realized I was lying in a hospital bed. The next thing I recognized were some I.V. lines, an oxygen tube in my nose, and a feeding tube. I was not prepared to hear the beeping of the cardiac and blood pressure monitors that continued to blare in my ear. As I took in the room more clearly, I saw pictures of my daughter, son-in-law, me with my five grandchildren, my husband, and my dog. There were many questions pulsing through my brain: Why was I here? What happened? What day is it? What time is it? I saw a familiar face--that of my sister. I tried to cry out to speak but to my astonishment, had no voice but only a whisper. So I whispered, “I feel as though I just woke up from the dead.” Her reply in a soft and gentle tone was, “Well, you kind of did.” My sister explained that I had experienced a v-fib cardiac arrest and that I had been in the hospital for three and a half weeks. I simply could not hear anymore except to be sure my grandchildren had been taken care of by the Easter Bunny, which apparently I had missed. I realized my muscles had atrophied and I was so lethargic that is

seemed impossible to get up, move, or do anything. Exhaustion took over from the news and weakness – so I went back to sleep in hopes of waking up after a terrible nightmare!

Looking back at that event, similar to what many of us have experienced, I have come to realize that in that restaurant was Michelle, an angel. Because of her medical training she was able to instruct my husband in artificial respiration, and perform CPR until the EMS unit arrived. The miracle of her being in the restaurant is the primary reason that I survived v-fib cardiac arrest, which claims 95% of its victims. When the EMS technicians arrived, they administered 2 shocks of the defibrillator and had me transported via U of M helicopter (Survival Flight) to the University of Michigan Hospital. They say that I received a \$10,000 chopper ride, but was unconscious and unable to look out the window. I do believe them, as I received “wings” from the Survival Flight crew. (I think maybe U of M should offer patients who “missed out” on the experience of looking out the window, a free ride on their amazing helicopter. Seriously, what a thrill that would be! :)) All jokes aside, the extremely talented Survival Flight crew is incredible. They flew in the wind and bad weather to come to my rescue. I will always be in awe of their dedication and talent. As for Michelle, she is an angel, my guardian angel, and we are friends to this day. You see, there are wonderful people that will help you when there is a crisis situation and then continue in your life as your friend.

Upon arrival at U of M, I was quickly placed on the inner cool system (cooling of the blood) and a respirator as the wonderful doctors and staff used their skills and talents to revive me. Looking on with great care was my awesome Dr. Gregory Ensing, who kept my family informed of my progress and has always been there for me. I am certain it was a truly trying time for my family and friends. I always tell them that, “I wish I could have been there to help;” I guess I was! After 1 month, I was on my way home with an external defibrillator (a vest worn around the outside of the body), working to get strong for my upcoming heart surgery. Three months later, I had that surgery. Dr. Edward Bove and Dr. David Bradley were brilliant as they worked to insert a shunt (to help my original problem, pulmonary stenosis) and placed your friend and mine – the ICD. I have named my ICD – it is “Sparky.”

Don’t be afraid of your ICD. It is your friend and an insurance policy that we get to carry around inside our bodies. We are lucky to be able to say that! Having the device for almost 3 years--even though I have not been shocked by the ICD (and pray I never am)-- doesn’t necessarily come without incidents. I had recently purchased a “Smart Phone” from Verizon. It does everything: internet, movies, texting, and of course, phone calls. A few days after the purchase, I began hearing a chiming noise that seemed to follow me. This went on for 4 days until finally I decided to take the phone back to the store, figuring that something must have gone wrong with the battery. For a Smart Phone, you’re pretty stupid, I kept thinking! Ironically, the same day I intended to return my phone, I received a call from the University of Michigan Hospital explaining that my defibrillator wires were having a problem! I thought, “What?! Are they kidding me?” As it turns out, I needed a thoracotomy to fix my fractured wiring! Ouch--a painful problem, but nothing I could not handle. Long story short – it was NOT my Smart Phone at all; it was my even smarter defibrillator trying to signal me that there was a problem. How amazing is that? In my life I’ve time-traveled from the “Dark Ages” of medicine, in which ether was a common anesthetic and we communicated using rotary dial telephones; to the era of today’s modern technology in medicine, with sevoflurane as an anesthetic, and texting on Smart Phones!! Think of the possibilities for your future!

I also had an incident in a courthouse. I was there to support a friend during a traffic violation, and the officers would not frisk me, even though I had the appropriate paperwork. They

insisted on using the magnetic scanner, which I refused. It was a bit of hassle but finally after a little complaining, I was allowed into the courthouse. Now the airport was a different matter – it was simply a BREEZE! I went through a scanner that uses radio waves and was in, out, and waiting for the rest of my family, less waiting for me! So, you see, there are some perks to being part of this “club” we belong to. ☺

Living with a defibrillator can sometimes be frightening and I will admit there have been times I’ve caught myself thinking, “Why me?” or that this just isn’t fair. But then I stop and realize that life isn’t always fair and I should count my blessings and continue living. That is the key – continue living. The ICD in my body is a life-saving device to help protect me against another cardiac arrest. I think of it as my friend, even though I am sometimes frightened. Most defibrillators are placed in the shoulder but “Sparky” is located in my abdomen. This is not the most flattering place for a woman to have a lump. But, I now can say that I have a good reason why I don’t look as good in a bikini as I used to! ☺ Who knows, one day these ICDs may only be the size of a dime and then the lump in my abdomen may become fashionable. I could have a happy face painted on it, making it look like a tattoo or new piece of jewelry. More possibilities!

As positive as I sound, fear does exist. I am frightened daily concerning a shock from “Sparky” or that something else may go wrong. But I do not spend precious time worrying about what might be. I have already been there--to the point in life where things go very wrong--and I need and want to stay positive about where I am heading. So, I have been very active my entire life. I have always kept myself in good shape by working out, walking, riding horses, motorcycles, golfing, swimming, bowling, snorkeling, swimming with dolphins, and even parasailing. (Really I was not trying to give my cardiologist a heart attack.) But, you name it and I would try it--within reason. Since my cardiac arrest and implantation of my ICD, I have needed to make modifications to tone down my activities. I still stay as active as possible, however, as I feel the importance of staying strong. I do count on my family and friends to support me. I must say I am extremely fortunate to have such wonderful medical care. My faith is strong and also has helped me through rough patches in my life, and to this day, I draw from the strength of faith and family to work, play and live.

People with “unique” hearts like ours are truly stronger than most. We are stronger emotionally, can be stronger physically, have a zest for life, and have more compassion and loving in our hearts because we understand what it is like to have physical limitations. I have been told by many that I am truly one of the strongest people they know, even among people with perfectly healthy hearts. I think this is true. We try harder, compensate for our physical limitations, and appreciate life more than the average bear! (I would much rather be a *unique* bear, than an *average* bear – wouldn’t you?)

So, in closing, please be strong, live life to its fullest, stay positive, stay confident, and trust in your own strength. Moms and dads of heart patients: Allow your children to grow, encourage them to push themselves and stay as active as they can, and explain their limitations and conditions. Be patient with them. It will come back to you two-fold! Not only did I make it to adolescence, but I am living positively through adulthood. Children and teens: Push yourselves as much as you can (don’t hurt yourself, of course), for as time goes on, you will be able to understand and realize your limitations. And young adults: By now, you know your limitations! There is much to be said for the “human spirit and will to live.” Please don’t be afraid to live your life! Embrace all the moments you possibly can from life; it is wonderful to be here. If I can do it without much correction of my

heart, so can you! You have many more advantages and tons more technological assistance. I hope you can take some inspiration from my life to apply to your life.

I am honored to have the chance to reach out and I hope to touch at least one person. Giving you hope and encouragement, gives me hope and encouragement. Please never hesitate to reach out to me as I will be available to speak to you. I am proud to be a part of your life and am proud that you are reading about a small part of my life.

Let me leave you with this thought: In one of his songs, John Lennon wrote, "*Life is what happens to you while you are busy making other plans.*" This is so true! So make your plans and don't be surprised if life happens somewhere in the middle! ☺