

Michael

Pump Me Up!

Just because it isn't perfect, doesn't mean it isn't awesome. - M.R. Mathias

Our lives are one entire story made up of individual smaller stories, a book with many chapters. Some of these stories may be thought to be 'interruptions' in the story of a life but in reality, they are part of that story. This is one of those stories in my life.

Let me begin my story in December of 1982. I was 37 at the time. My father had passed away about a decade earlier at age 65. He unexpectedly collapsed at home just before going to work and died of a heart attack within twelve hours of being transported to the hospital by the EMS. My mother would, within a couple of years, pass away at age 59. She too unexpectedly collapsed at home after attending a wedding reception and died in the hospital of a heart attack, like my father, some twelve hours later. Neither my father nor mother had any history of heart disease as both of their parents lived well into their eighties. Unfortunately, both of my parents were smokers, neither exercised and my mother was overweight, which may have contributed to their subsequent demise.

In December of 1982, I was in good health, having given up smoking seven years earlier, gone on a diet losing thirty pounds, and began an exercise program, jogging fifteen to twenty miles per week. I changed my eating habits to a lower fat diet and my blood cholesterol was at normal levels. I was looking forward to our annual ski trip with friends to Jackson Hole, Wyoming. Life was good and having changed my lifestyle, I presumed that any genetic predisposition to heart disease that I might have inherited would not significantly affect me.

I chose December of 1982 to begin this story as that was the month that a man named Barney Clark, age 61, made international news as the first patient to

undergo surgery and receive a total mechanical heart. He had progressive heart failure and was not considered a candidate for a heart transplant because of concomitant health issues. I followed his medical course closely. As the first person to undergo this procedure he reportedly told his physicians he did not expect to live more than a few days, but in fact lived almost four months, 112 days. His quality of life, however, had much to be desired. His mentation was less than it had been before surgery with multiple episodes of loss of consciousness. His blood pressure often fell to low levels and he was plagued by multiple infections and blood clotting problems, which lead to several strokes. He became a hero for allowing himself to be the first person to have this procedure. I too considered him a hero and admired what he had done for the sake of scientific and medical progress, but did not consider the surgical procedure a success. His life may have been prolonged by several months but his quality of life seemed not improved; in fact, it deteriorated. It occurred to me the procedure could more accurately be described as prolonging his dying rather than increasing his longevity. I even believe it was reported that on at least one occasion he was asking to be allowed to die.

I found it quite incomprehensible the ordeal Mr. Clark underwent. I had never really known another person with heart failure as severe as his and found it difficult to identify with his condition and situation. I did think of him as a hero and a rather brave man, but having followed his ordeal, thought to myself that under no circumstances would I allow any mechanical device to be placed into my body, or that it would ever become necessary.

I was healthy and feeling good. I was skiing in Jackson Hole, Wyoming and watching the Michael Jackson music video *Thriller*, a song he released about the same time as Mr. Clark had his artificial heart pump inserted. Little did I know that this music video might be the seed giving birth to the hit TV series *The Walking Dead* decades later. Little did I know that this remembrance of Barney Clark would haunt me in coming years when I too would develop severe heart failure and physicians recommend I have a mechanical device surgically implanted to assist my failing heart pump and circulate blood throughout my body.

Fast forward to the spring of 1998. Life was still “good.” I was planning my next ski trip to Jackson Hole and had just returned from a two-week rafting trip along the Colorado River, through the entire Grand Canyon. The day before the start of the rafting trip with my wife and good friends, I jogged around the entire city of Flagstaff, Arizona. This would be the last time I would be able to really jog for a period of almost thirteen years. On the rafting trip we went on multiple long hikes and at the age of 53 I was looking forward to many more years of continued physical activity, skiing, camping and vacationing with my wife, two adult children and friends. This was not to be and my life was about to change.

After coming back to Michigan from this spectacular rafting trip, I developed a chronic cough with weakness that progressively became worse over the next few months. I was not able to jog more than a block or two without exhaustion and shortness of breath. I thought this might be due to a viral infection that would improve with rest and a tincture of time. When it did not improve, but worsened with a progressive loss of energy, persistent cough, weakness and difficulty climbing up one flight of stairs or even standing for any length of time without getting short of breath, I thought I might have pneumonia and should have a check-up. A chest x-ray was performed that revealed fluid on my lungs with an enlarged heart. I had congestive heart failure. I had the same disease as Barney Clark and I was devastated; how could this happen to me? Just a few months earlier I was active and feeling well, but now I could hardly breathe and talk at the same time. Life was no longer “good” and I was immediately admitted to the hospital Intensive Care Unit after a follow-up echocardiogram indicated advanced heart failure.

After I was hospitalized, a heart catheterization was performed the next day and drugs were given to help my heart pump better and control the excess fluid on my lungs. A diagnosis of congestive cardiomyopathy was confirmed and I was transferred to another hospital for consideration of a heart transplant. My mind was in a haze of what seemed like a surreal experience. While being worked up for a heart transplant, I was given water pills to keep fluid out of my lungs, and other drugs to aid my failing heart. I began to feel much better and improved to the extent that I was no longer considered ill enough to be a transplant candidate. I was, however, informed by the heart doctors that my heart disease

was not curable, would progressively get worse with time, and I would likely be in need of a transplant within five years. I was subsequently discharged from the hospital, and with medication, able to do most normal activities without much shortness of breath, with increased energy and less weakness. I felt better than I had in months. I could no longer jog, however, or participate in any strenuous activity as I had in the past.

After discharge, I continued to feel even better with less shortness of breath and decided, after a period of time, that maybe the doctors were wrong and that I could have had a virus that affected my heart and with time would go away and so would my heart failure. This was wishful thinking, irrational, and a state of denial. With this denial or what I called optimism guiding my actions, I decided I was healed well enough to begin jogging again and maybe even able to ski in a year or so.

So, one morning I went outside to jog only to almost collapse after about 50 yards. Reality came crashing down on my optimism. A selfish anger then emerged from this change in my perception of reality. "This shouldn't have happened to me, what did I do to deserve this? After all, I quit smoking, lost weight, and exercised." I didn't deserve to have this happen but then, who was I to decide what I did or did not deserve and who was I to be angry at all? Despair and depression followed as I realized the doctors were right and I was wrong. For the first time, I was forced to face the fact that my disease was progressive and I was not going to get better, but even still I was hanging on to some sense of false optimism or denial. This was apparent when it was recommended that I have surgery to implant an ICD (Implantable Cardioverter Defibrillator) along with a pacemaker. I was told this device would give my heart an electrical shock if it began to beat with a rhythm that could stop my heart from pumping. I refused, still having an aversion to any mechanical type of device being placed in my body, and somehow thinking that this was not a necessary procedure for me at that time. I did not feel that sick but it's easy to deny a reality that you don't want.

I did reasonably well with medications and their adjustments until 2004 when I developed an emergent irregular heart rhythm and had two cardiac arrests in

the Emergency Room of Beaumont Hospital. With this reality check, I consented to the placement of an ICD and pacemaker.

I had survived this near death experience very much aware that I'd lost consciousness two times. The experience affected me deeply. I remembered that we all die, even me, and a new sense of living and my own mortality now took center stage. Death comes to us all, something I knew but forgot and was now reminded of. This fresh knowledge of my own mortality gave me a newfound appreciation of my own existence apart from the rest of the physical world, in time and space, a gift not of my own choosing but of grace. I began to truly appreciate life and its many blessings, with the physical quality of life now being of secondary concern. I no longer dwelled on the physical functionality I was losing, but instead became thankful of what functionality still remained. I began to accept the reality of my incurable chronic heart failure as simply part of the life I was living. With this came a sense of contentment that took hold of my consciousness and changed my attitude toward living. I was now at peace with full acceptance of whatever the future might bring and began to experience a joy that had been missing even before I became ill.

Expectedly my condition continued to deteriorate and subsequently my physician daughter-in-law convinced me to come to Ann Arbor for evaluation. Under the care of the heart doctors at the University of Michigan I did as well as could be expected, but in early 2008 I was hospitalized again, with severe congestive heart failure. Subsequently, a different type of pacemaker (bi-ventricular pacemaker) was inserted to pace both my left and right ventricles to further aid my heart's pumping ability. I was then placed on the heart transplant list shortly thereafter.

Near the end of 2008, I had all but lost my ability to speak because my heart had become so enlarged that it was pressing on a nerve that goes to the vocal chords (voice box). I could only talk in a whisper. I no longer answered the phone or participated in conversations since my voice was almost inaudible. I could still talk in a whisper and considered this a blessing, conscious of individuals that are never able to speak and some never able to hear spoken words their entire lives. These individuals, born with such severe disabilities, never seemed to complain. I could hear, see and talk in a whisper. How could

I complain? This was just part of living with my disease. There was no sadness as I had begun to realize happiness and contentment do not depend on extrinsic events and stuff one has, but comes from within, from a change of 'heart' and attitude. Death was no longer to be feared as an end to this journey. I was not due for more from this life than that which I had.

In 2009, my condition had deteriorated further, to the point where I was hospitalized, placed on intravenous drugs to assist my failing heart while waiting for a heart transplant. A heart pump LVAD (left ventricular assist device) had been recommended prior to this hospitalization but the remembrance of Barney Clark's life with a mechanical heart still haunted my thoughts and made me shy away from this option. Over twenty years had passed and there had been many improvements in the technology of implantable mechanical devices to assist failing hearts, but in spite of this I held on to this image of Mr. Clark. My perceived experience of what he went through still affected my feelings and thoughts about mechanical devices in the treatment of heart failure. My physicians assured me of the efficacy of the much newer technology, and a short time later when drugs were no longer working and no heart was available for transplant I agreed to have a mechanical pump surgically placed inside me. This was to be a bridge to buy me more time until a transplant became available. My kidneys were failing now and the only hope for any longevity was to have this procedure performed.

I was taken to surgery and a pump (LVAD) was inserted in my chest and upper abdomen to assist my failing heart. This pump worked well, and unlike my fears related to the memories of Mr. Clark, the quality of my life did improve, rather remarkably. After discharge from the hospital and over the next thirteen months, while remaining on the transplant list, my kidneys returned to normal functioning, my lungs remained free of fluid, I could breathe more easily, and had more energy than I had had in the two preceding years. I was actually walking at a slow pace, distances up to three miles, and my voice had returned as my heart size decreased, relieving the pressure on the nerve to my vocal cord. I could talk again! I was grateful and considered each day a blessing. I remained stable for the next twelve months. Living with the pump had become a new and rewarding experience in my journey with heart failure as the physical quality

of my life had improved considerably. The memory of that first mechanical heart and Mr. Clark's 112 days faded along with my fear.

I was actually quite fascinated by this, new for me, technology. I could hear the humming of the pump when I turned my head in a certain direction and I had lost my pulse as the pump moved blood in a continuous, not pulsatile manner as the normal heart does. And with the increased energy and strength I kind of fantasized myself as one of those *Marvel* superheroes or a kind of *Robocop*. I would recharge the batteries to my pump each night, plugging them and myself into an electrical socket to keep the pump working, readying myself for the next day of action.

Going along with me on this new path in life, this journey with heart failure was my co-pilot wife. Her support along with our son, daughter, other family members and friends were acts of pure charity in the Biblical sense. My daughter stayed with me for days after surgery, during which I was severely physically and mentally impaired; my wife was with me every day and many nights; my brother slept on a gurney in the hospital hallway while I was in surgery; my son and his great optimism and my daughter-in-law who had directed me to the doctors at Ann Arbor; and all who kept my family and friends updated about my condition. My son-in-law composed a song about me and my LVAD on an album. And finally the nurses, surgeons and heart doctors, social workers, along with the med techs, nurse-aids, and all the paramedical personal; I cannot say enough about their care. They actually gave me back a better functioning life with my new LVAD friend, "Mr. Pump." Without this heart pump, I would not be here years later as a functional human being. There was much to be thankful for.

Nearing the end of this piece, I must say a few more words about my wife of over 45 years. First of all, I can't imagine what road my life's path would have followed if I had not met and married her, but it certainly would not have been a yellow brick road. She was my guiding light, always steering me in the correct direction with each fork in the road. It was much more difficult and stressful for her as my co-pilot, nurse and caretaker while on this journey. She had to learn the sound of the different alarms from the heart pump indicating certain problems and what to do in each case. She had to learn how to change the

dressing where the driveline (a “wire” connected to the pump inside me, through which batteries supplied the power for the pump) came out through the skin on the left side of my abdomen. To do this, she would put on a sterile gown, gloves, and mask, clean the area around the driveline and re-bandage the site. This took time and effort. She was my chauffeur as I was not allowed to drive and she was virtually at my side nonstop for the thirteen months while I was supported and kept alive by “Mr. Pump.” When I was very sick in the hospital, she was the one worrying and anxious, much more than me. But this always seems to be the case with a loving spouse. I simply cannot imagine the world without her. I simply would not be the person I am. The LVAD added to and extended that world.

I was now doing well at one year after having my LVAD placed and seeing the doctors only at three-month intervals. I had gained much of my energy and muscle strength back; I was feeling well and fairly functional, though far from how I had been before developing congestive heart failure. After I had turned sixty-five years old and was nearing my sixty-sixth birthday, I felt content to live out what remaining time I had left here on earth with this pump, gratified, satisfied and happy. I thought when I turned sixty-five that my chances of getting a heart transplant were fading. And that was OK by me. I was doing well and others were surely more sick and in need than me. I was now comfortable and had gained a new appreciation of life that I never ever had before I developed heart failure. This I cannot understate. Before I became ill with heart disease, life was doing things, like skiing, having stuff, amusement, working and having fun. Life was about me.

After the experience of losing my health, my voice and my physical ability, the implanting of my LVAD helped me regain much of this and I came to realize - while we’re here on earth, it’s relations with family and friends that are really the important things that matter, not stuff, amusements, travel, etc. The joy this has given me with the increased affinity, love and kinship with family and friends seems a gift that I would never have realized had I not become ill with heart disease. Sometimes we have to lose something to gain something.

After thirteen months with my “Mr. Pump,” with no infections or complications and actually having gone an entire year without being in the

hospital, I often thought of how fortunate I was to be alive and functional. Then at 1:30 am, on December 14th of 2010, I received a phone call indicating that a donor heart had been matched to me. I received a heart transplant later that day.

Joey is my donor's name and I am aware of his heart pumping every hour of every day. I know his life's history from his gracious loving parents. We communicate and meet with them on a regular basis. One can never heal completely from the sudden unexpected loss of one's own child but may have some consolation realizing how much his heart has benefited me, and they seem to sense Joey is with us each time we get together. Joey's mom always takes time to listen to his heart, placing her head on my chest for a short period of time, hearing the sounds of his heart speaking to her while I sense her sorrow and at the same time, my joy and privilege of having received this gift of life. I will honor his heart and memory until the day "we" die and hopefully meet in heaven.

When I first became ill with heart failure, my future was a blur and I had no idea what to expect in terms of longevity. I had read somewhere that having heart failure was similar to having an incurable cancer. Thus, at that time, I had no expectations that I would see my son or daughter marry and have my grandchildren. But years later I was able to walk my daughter down the aisle a few months after transplantation and now have had four grandsons from my son and his wife and two granddaughters from my daughter and her husband. The experience of grandchildren is one like no other; it truly gives meaning to life, experiencing three generations of family with over a 70-year age differential.

This morning, before concluding this narrative of memories, Joey and I took my dog on a 4.4-mile jog in the cool morning. It is during these early morning times that I can pray and thank God for my existence and the consciousness of that existence and beyond. I go early in the morning, often before sunrise when there are few sounds of traffic or other people about. I hear only the sound of my feet hitting the pavement, the jingle of my dog's collar, and feel the beating of a heart I share from another. I am alive for another day. I am blessed. I give thanks. I have a changed heart.