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LIVING LIFE TO THE FULL: My Ironman Journey

By Ellen Charnley

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LIVING LIFE TO THE FULL



My Ironman Journey

Ellen Charnley

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CHAPTER ONE

ICU

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I open my eyes, and the sense of relief is overwhelming, just to wake up and know that my heart did, after all, “restart.” This had preyed on my mind ever since I had been told that during open-heart surgery, my heart would be stopped and my body would continue to survive via a heart-lung machine.

Once the novelty of the relief wears off, next comes the pain—not from my chest but rather my throat and back. I feel a tube in my throat. I can’t swallow. I am desperately thirsty. The tube is connected to a machine that helps me to breathe. Nurses swarm around me as I awaken, reassuring me constantly that everything is normal and that the surgery has gone well. They tell me that I have to be patient (now I know where the word comes from) and gradually start to breathe more on my own. Eventually, when I can prove I am doing so unassisted, they will remove the tube.

I move my head and start to register where I am. The intensive care unit, the Cleveland Clinic, March 26, 2010. I am in a bed that is separated from other patient beds by only a curtain. The room seems large, but I have no real perception. There is lots of activity happening, nurses attending to patients, but I can see very little, as my vision is limited to the space immediately in front of my bed, where I see a specialized nurses’ station positioned with a nurse sitting there, just a few feet away from me.

Don arrives shortly after I awake; he's been waiting patiently for six hours. The Cleveland Clinic has a system for open-heart surgery patients and their families; it's tried and tested day after day, year after year for thousands of patients. The Cleveland Clinic is a reassuring place—well, as reassuring as any cardiac surgical hospital can be.

I subsequently learn from Don that once the surgery was completed, my surgeon had left the operating room and greeted Don in the family waiting area. He had told Don that the surgery was a success. At this time, he had also informed Don that my condition had been far worse than they had originally thought and that the previously counted four holes in my heart were now “numerous” and too many to count. The medical term to describe the wall of my defective heart was “Swiss cheese.” Surgery had most definitely been the only option. He used descriptive phrases such as “wet tissue paper” to describe the weakened wall structure. He also explained that the right side of my heart was three times the size of the left. Given this, he told Don that it was questionable how much longer my heart would have been able to keep functioning, regardless of whether I continued to push my body competitively training and racing triathlon. After the procedure had been carried out and the holes repaired, the surgeon claimed, the right side of the heart had immediately begun to reduce in size.

Every designated family member carries a pager so they can be quickly contacted during the hours after surgery. Two hours after meeting my surgeon, Don was paged in the “family waiting” area and was able to come to my bedside. That's how long it took to close me up and go through the finishing touches of the surgery. By approximately 8:00 p.m., seven hours after I had said good-bye and he had wished me good luck, he began his new role of coach as he helped me through the next few hours of misery.

The sense of fear is quite overwhelming, and time moves very slowly. The nurses gather around my bed and begin asking me to perform some simple tasks. “Ellen, can you wiggle your toes for me?” I oblige. “Ellen, now squeeze my hand.” Again, I oblige. Don and the nurses begin to ask me questions that require simple “yes” or “no” gestures, as I am unable to speak because of the tube restriction. “Ellen, are you in pain?” I nod. The nurses increase my pain medication, a quick process, as the morphine-related drug is administered directly into the IV in my neck, the central line. I feel a little relief instantly.

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I start to feel the need to ask questions, so the communication method soon progresses and I begin to spell out the first letter of each word on my hand, at the suggestion of the nurse. I write on her palm. This continues slowly. I point to the tube in my mouth and motion that I want the nurse to remove it. She shakes her head and tells me we have a little while longer to wait. I am becoming more stressed; I hear my monitors start to beep as my heart rate falls. I motion with my hand that I want to write my questions with a pen and paper. I cannot lift my head or really move my arms to a great extent, so my writing skills are very limited. Don and the nurses do extremely well to interpret my words, although to I, lying flat on my back and heavily sedated, I feel my writing skills are near perfection. I've since seen these scribbles and now feel that Don and I can challenge anyone at Pictionary and win hands down. The specifics of these "conversations" are at best a blur now, but I know that they revolved around me continually asking how much longer I had to wait before they would remove the tube.

Don places the ear bud from my iPod into my right ear and sets the music to some soft tune in an attempt to calm my fear momentarily. At the time my music of choice was from the singer-song writer David Gray, whom we had, coincidentally, seen live only a week before in Cleveland. David Gray's album *Draw the Line* helped me through those first few days and will forever bring back those memories.

I hold Don's hand and do not let go. Finally, the moment has arrived; a nurse explains that they are going to remove the tube. What a great achievement. I'm very excited. I later learned that a patient begins to assess his or her progress by monitoring how many tubes, monitors, IVs, and pipes are still inserted and how many are being removed during each day in hospital. When all of these are removed, there is a hope that the patient can be discharged. The removal of the breathing tube for me now is step one on the road to recovery. Two nurses crowd close to me; one monitors, the other explains that they will pull the inner tube first by simply pulling it from deep down in my stomach. I am asked to relax. It hurts down into my back and throat as they pull. This inner tube is performing some role in my stomach. Next, they slowly tug at the outer tube. As they pull gently, I am asked to cough. I also begin to gag, but within seconds, the tube is out and I am asked to state my name and birth date and where I am. "Ellen Charnley, March 6,

1969, Cleveland Clinic.” They ask why I am here. “I had heart surgery to fix some holes.” The sound of my voice is weak and a few notches higher than normal, as if I’ve inhaled some helium from a party balloon, but that soon wears off. The pain is less now.

I am now able to speak. I ask Don about his meeting with my surgeon. My blood pressure and heart rate are very low. I ask the nurses about this; they are not concerned and again reassure me. I am sleepy but am scared to sleep. What if I don’t awaken again? More drugs are given to me to numb the pain, which is centered on the right side of my chest and back. I am desperately thirsty. The nurse brings a plastic cup full of ice chips. I cannot reach the cup holder, so the nurse gently lifts my head and places a spoon of ice chips into my mouth. She tells me I cannot have more than one spoon this time around, my stomach needs to wake up from the surgery, too, and that will take time. The ice melts quickly in my mouth, and the water drips down my throat, a heavenly moment amidst the chaos running through my brain and body. The nurse places the cup of ice purposely out of my reach and tells me she will let me have more in a short while. I want to gulp a full glass of water or, better still, orange juice. I haven’t drunk a drop for close to 20 hours. The saline that has been pumped into my body during this time has hydrated my body but has done nothing for my thirst.

Around midnight, Don prepares to leave for the hotel room and some much-needed sleep. I let go of his hand and make him promise he will be back when I wake in a few hours. The nurses tell him they will call him around 8 a.m. after the morning rounds are over. While back in his hotel room, before he goes to bed, he dutifully e-mails our friends and family with an update on my condition. I begin my first night in the ICU—the intensive care unit. I am a triathlete; I am healthy and very fit. It is hard to comprehend that I am currently incapacitated and in the ICU.



I had watched the “What to Expect” video the day before surgery, and frankly, this scared me, seeing a patient lying in her bed in the ICU, hooked up to numerous monitors and the breathing tube. This was a tough day for me mentally,

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anticipating, fearing, and trying hard to stay focused on positives rather than the what-ifs. For most people, open-heart surgery isn't on their bucket list, and I would certainly recommend avoiding it if you have the option. As a consequence, few people know much about it and what to expect. For example, until the day before my surgery, I didn't know that to operate on my heart, they would stop it beating first. To do this, they would use the heart-lung machine, clamp the aorta, and use medication to stop my heart from beating. This is a pretty frightening thing to learn the day before surgery.

The more I learned, the more I feared. I started to believe that I still had a choice, that somehow, my heart would miraculously function just fine for another 40 or 50 years and I would still complete my Ironman triathlon dream. I came close to backing out; it was open-heart surgery, after all, and it just wasn't on my agenda at age 41.

I think the reality hit during the meeting with my surgeon the day before. He simply told me the facts—compassionately, but still, they were the facts. He said I no longer had a choice and the procedure was not “elective” but urgent and that without the surgery, my heart would undoubtedly fail. Tears began to roll down my face as the fear started to creep in. These words hit home and helped me mentally get to where I needed to be. At that moment I started to move from denial, where I had been for the past three days, to acceptance. But with acceptance came overwhelming fear.



It is now past midnight, and I am scared to see him go but so high from the medication, I don't fight his departure too much, and I understand he needs to rest and most likely to leave the ICU just for a few hours. I am breathing on my own. The nurses' shift changes over, and my new caregiver takes her position at the end of my bed. David Gray is still

quietly singing in my ear. The right side of my chest and back hurt from the pain.

There are no glass sliding doors in this ICU. It is not like I had imagined from watching TV hospital dramas. There are no quarantined sections, just a ward full of beds, nurses, patients, and complicated equipment. The sounds consist of monitors beeping, alarms ringing, and occasional Code Blue announcements over the loudspeaker. ICU is not a quiet place. The nurses are giving the patients instructions, particularly on what not to do. I hear a patient groaning two beds down from mine. The nurses are telling him to stop biting the breathing tube. I suspect he is in pain and doesn't realize he is biting the tube. The nurses keep at him to stop and don't remove the tube; they talk to each other as if he cannot hear them. His name is Daniel.

ICU nurses are nurses at the top of their field. They are well respected and have trained and worked hard to get to this position. I cannot imagine doing their job, having patients' lives in my hands day in day out.

The night ticks on, lots going on, I drift in and out of a sleepy haze. The noises wake me. New nurses arrive; one of them is responsible for making me breathe into a breathing tube. I have to breathe hard enough to get the line above the blue marker. I try hard and achieve this on the first attempt. I am pleased; one more step to recovery. After the breathing, he asks me to cough hard, but when I cough, it hurts, and my chest feels ready to explode. I cough up thick mucus as my lungs begin to clear; I am told this is normal and what they want me to continue to do. A different nurse constantly monitors and charts my vital signs; she is with me every minute, and I am reassured. A central venous pressure line has been inserted in my left arm and connects to their vital-sign monitor so my blood pressure and heartbeat are constantly monitored. This is why this area is called the intensive care unit. The care you receive is simply full-on 100-percent intensive.

Two or three times during the night, I panic as I doze; my heart rate and blood pressure drop again and my alarms ring. My anxiety and fear rise, which makes things worse, and my pain increases. As I am an avid triathlete, my blood pressure and resting heart rate are typically below

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the average Joe's. My history and athletic achievements are known to the nurses, so they are not concerned with the alarms ringing. I am still concerned, though, as I know that the readings are now below what is normal for even me. I am scared to sleep, and I tell my nurse, Courtney, this. She reassures me that everything is normal and they are watching me; she holds my hand and strokes my forehead and tells me to sleep. I am cold, so she brings me another blanket. The temperature in the hospital is purposely kept cold, especially in the ICU.

The heart takes a beating during surgery and takes a short while to get its groove back, so during most heart surgeries, thin wires are placed into the heart and threaded out through the skin in the chest. If necessary, these wires are then connected to a machine, which can regulate the heart rate and give it a helping hand. The nurses attach my wires to this device, and this increases my heart rate to an acceptable level. This eases my anxiety, and I fall asleep. Every time I wake, my nurse reassures me that everything is normal and I am doing great. The nurses all spend a large proportion of their time with me performing this function. On more than one occasion, tears start to fall down my face; I am still scared. I had open-heart surgery; what if something goes wrong?

At this time, I don't understand all the different pain, and the days that follow will all add to my pain education and help reduce my fear. I am on some serious medication in the ICU, all of it fed through my central IV line, which is located in my neck. I don't feel the needles in my neck but do feel the cool liquids flushing into my body. I also have another IV in my right arm, and one in my hand, although I'm not sure what these are used for.

Saline is the doctors' favorite liquid. The first IV that someone receives before surgery contains nothing but saline, and it is given in the pre-op room before the patient heads into the OR. That was when I first experienced the "saline sensation." Almost immediately, the taste of the saline ended up in my mouth. I learn to tolerate this taste, as I am to experience it numerous times each day for the next week. With this sensation comes weight gain and a bloating throughout the entire body. I was 130 lbs the morning before the surgery. Six days later, after having eaten very little, vomited three times, and experienced an afternoon

of diarrhea, I was 137 lbs. What kind of justice is that! Water retention is a hazard of surgery, as the body is pumped full of salt.



Five months earlier, I had completed in two-thirds of a full Ironman triathlon on one of the tenth most difficult courses in the world as ranked by *Triathlete* magazine: the Silverman Triathlon, Las Vegas, Nevada, 2009. I swam 2.4 miles and rode 112 miles through a steep, hilly terrain in the desert, the last 35 miles of which I did with sight from only one of my eyes. This made depth perception a little challenging. I had been suffering from temporary blurred vision during my long training rides and had somewhat put this to the back of my mind until after the race, simply putting it down to the dry Vegas air or an issue with my contact lens.

A knee injury had plagued me all year and had sidelined my running training from April 2009 through the rest of the year, so swimming and biking had become my focus. By focusing on these two disciplines, I had been able to really push myself and achieve results that were pretty damn good for me. I had hired a coach who pushed me to my limits on the swim, bringing back many childhood memories along the way. The two highlights of that summer were coming in second overall in the aquabike division at the Vineman Half Ironman distance and then completing the Silverman with a 59-minute, 2.4-mile swim. It was a season of personal bests. I had trained, raced, and achieved these results with multiple holes in my heart that were unknown to me at the time.

Following the Silverman race, I had scheduled knee surgery to have my left knee scoped after nine months of deliberation, physical therapy, and cortisone shots. I had the surgery in November 2009, the plan being that I would then have the winter, or “off-season,” to recover before I would begin training for Ironman Arizona, which would be in November 2010. Completing a full Ironman has long been my dream:

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swimming 2.4 miles, biking 112 miles, and running a full 26.2-mile marathon, continuously. In November 2009, I successfully registered online for the race, a full year in advance and just two weeks after my knee surgery. Ironman racing has become so popular in recent years that a race can sell out online within minutes of it becoming available. I paid my \$550 entrance fee and was excited about the year ahead and the journey to realizing my dream.



I awake during the night, Courtney gives me another delicious spoonful of ice chips, and in return I have to promise another round of breathing exercises. One more breath into my breathing device would make it 10 in a row that I had breathed hard enough to raise the blue marker above the required line. One more step to recovery. One more step to my Ironman goal.

At 8:00 a.m. on March 27, 2010, one day post surgery, I notice the clock on the wall above the foot of my bed. The phone rings, and my nurse answers; it is Don checking in. He tells her he will come over to the ICU around 9:30 a.m. I don't remember sleeping, but I must have, as I can't account for the past few hours of the early morning. More monitoring and more medication. I am now able to reach the ice chips myself. What freedom. My mouth thinks it's won the lottery, but I am cautioned by my morning nurse not to overdo it.

Don arrives at 9:30 a.m. and sits with me and takes hold of my hand. I had never realized the value of human touch during times of stress until this moment. I tell him about my pain and my night. He seems simply happy or relieved, I'm not sure which, but calm; as usual, he shows no concern, which is what I need to see.

My next visitor is my surgeon. It is a Saturday and not normally a day he would be working in the hospital, but he is on his way to the airport for a well-deserved vacation. He stops by my bed to see me. He repeats the conversation that he had with Don the previous day, telling me that the operation was a success and that my road to recovery will be quick.

He also confirms that the surgery was most definitely the only viable option for treatment. I tell him I have pain in the right side of my chest, and he explains this is most likely from the chest tube that was inserted during surgery and is planned for removal today before I leave the ICU. The chest tube is a drainage pipe that comes out of an incision in the skin on the chest and drains all the unnecessary posttraumatic fluids that the body accumulates, thus preventing infections by draining. Thankfully, I can't see the tube or the contents of the drainage pack.

Don offers to fetch me a fruit popsicle from the ICU kitchen. He brings me a grape-flavored one, and it tastes heavenly. Time ticks on, and finally, I hear discussions about me leaving the ICU today. It is 2:00 p.m. If all continues to go well, I am to be transferred to a step-down ward later this afternoon. I am one step closer to recovery, but my feelings are not of relief but apprehension. The nursing attention in the step-down ward will be less intensive, and that fills me with more fear. Each step-down ward has one nurse to five or six patients.

I've never been admitted to a hospital before, excluding the outpatient knee surgery the previous November, and hospitals have always frightened me. I remember that during my childhood, our family always seemed to be overly concerned about illness, to the extent that during my teenage years, I was at times arguably a borderline hypochondriac. That was before I met Don during the first year at university, age 18. Don's view on illness is the complete opposite; he always denies having a cold, believes illness can be controlled by the mind to a large degree, and never, ever looks on the pessimistic side of things. I have never encountered anyone more positive. What better person to partner with me for the rest of my life and teach me the value of positive thinking and its power over healing? Now in the ICU as I deal with pain I have never experienced before, Don helps me visualize my "happy place" and focus on my positive thinking.

My happy place is part of the virtual imagery session we went through in the pre-op process. I was asked to imagine a place where I would feel safe and happy and could heal with my family and friends around me. For me, this place was simple to find. The image has always been the same, but until the pre-op imagery session, I had never realized or visualized where it was. Perhaps this place is heaven; I'm happy thinking

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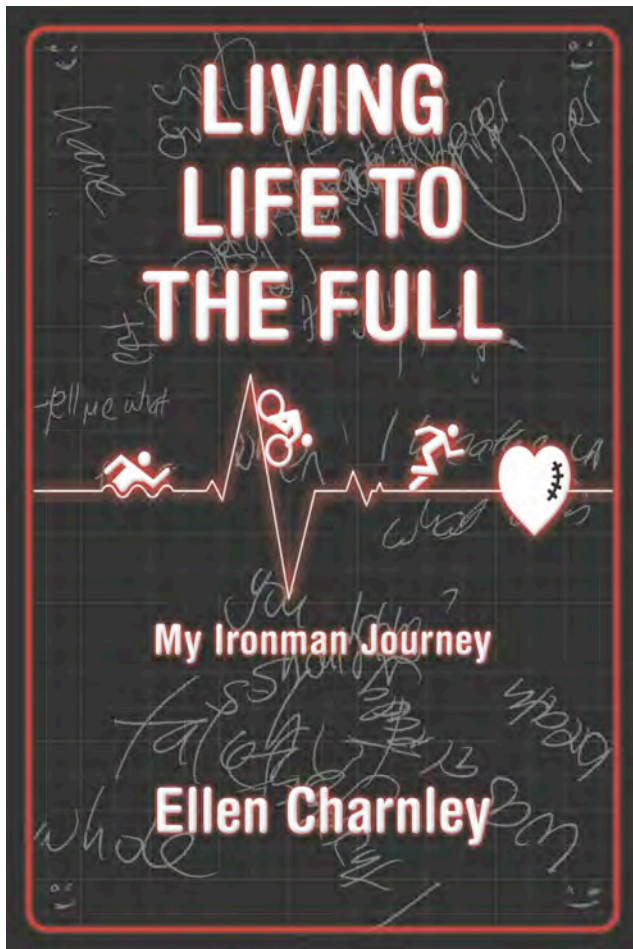


Miller Family Pavilion Heart Center, Cleveland Clinic

that. My heaven is a large oak tree on the top of an English hilltop in the countryside, always with the sun shining and many rabbits playing at the foot of the tree, their home. Don helps me focus on my happy place when the pain and discomfort grow.

I am still in pain, particularly in my right side, where the chest tube is. My current nurse tells me it's time to remove the tube. I thank God. Another nurse assists her during the process. They begin first by giving me more medication, and I instantly feel drowsy. They lift my right arm and unbutton my hospital gown, exposing most of the right side of my body. They gently peel away at the bandages that are stuck to my skin. They then firmly pull the tube out from the incision in my chest. I feel the tugging sensation, but the pain is masked by the medication. They leave the wound open without bandaging it again; it already has two or three stitches to hold the incision together. While my gown is open, the nurse inspects my main scar. This is underneath my right breast. I am not able to see it myself, but she tells me it is healing nicely. Don takes a look and seems surprised and impressed with the neatness and skill of the doctors and nurses who closed me up.

A few more hours pass. Transportation arrives as I am about to begin my journey to the step-down ward and be discharged from the ICU, just 24 hours after my arrival. I am assisted into a wheelchair; my head spins, my legs have no strength, and I rely heavily on the nurses to support me. They tell me to use the strength in my quads and take the weight if I can. I am a long way from walking, let alone running. I am wheeled to my step-down ward, J5-3, room 4.



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