



Peter H.

Chapter 9

My Toughest Marathon

by Peter H.

This is a story that I never imagined would be mine to tell. I have been a health conscious athlete and vegetarian since high school. I have spent most of my 68 years trying to do the best things I can to stay in shape because being active has always been so important to me. I started running in junior high, competed in high school (including setting school records in the mile and other distances), and I was an eight-time All American distance runner in college. I never stopped competing throughout my Navy service (I am a Vietnam-era vet). Throughout my adult life, I have run countless track and road races including forty marathons. No one could have been more surprised than I was to hear that I had cancer.

Like others I have spoken with, my diagnosis came after I complained about difficulty swallowing, particularly when eating bagels or bread. Drinking anything carbonated also really started to bother me. I waited to see my doctor and even delayed in talking about it with my wife, Robin, for almost a year. Once I mentioned my problem, she convinced me to see the doctor. At first it seemed I might have some kind of hiatal hernia or a stiffening esophagus but a swallow test and follow-up endoscopy in June of last year clearly gave the sobering news. I had a Stage III tumor in my lower esophagus and it was spreading into my stomach. On the one hand, I was shocked and on the other, by this point I was prepared for the worst.

I began a five-week treatment of chemotherapy and radiation in early August 2014. I continued to run and rode my bike to radiation treatment every day. While I was able to continue the cycling all the way until my last day of this treatment, about halfway through the doctors suggested I shift to walking rather than daily running as I was tiring myself out more than I was helping.

I do think that my general fitness level helped me get through the treatments with reduced side effects. At the same time it was clear to

me quite early on that the chemo and radiation were having an effect on my tumor. Within a couple of weeks of starting this treatment, my swallowing improved and I could eat more easily than I had in some time. However, by the later stages of the treatment my esophagus was feeling the impact of the radiation and it became harder for me to swallow again.

Over time I realized that the anti-nausea drugs and painkillers that were offered were helpful to me and I needed to take advantage of them in spite of my life-long aversion to taking drugs. Before cancer I was not on any regular medications, which I have been told was unusual for someone my age. Throughout the treatment, the oncology and radiological oncology doctors and other health care providers were supportive and reassuring. They have difficult, demanding jobs but made me feel that they had time for my questions and concerns and that they cared about my outcome. I will be forever grateful for that.

The five weeks of chemo and radiation were extremely difficult, often because I only learned the hard way from experience what I needed to do to get through it. I alternated between constipation and diarrhea that I found difficult to keep in balance. That led me to be dehydrated so severely that I was hospitalized for a few days mid-treatment. My taste for food changed constantly and I would only be able to eat some things for a short period of time before they made me so nauseated that I could no longer eat them.

Throughout this process, one of my concerns was potential weight loss. At 6 feet tall I have weighed 150 pounds since high school, leaving me little room to spare for any loss. My first visit to the esophageal cancer support group in September was very helpful at answering questions but hearing how much weight most patients had lost during their treatment and post-surgery really concerned me. I knew I would have to work really hard to keep my weight up.

In the weeks after chemo and radiation leading up to my surgery, I started to feel better and was able to eat more normally. I was able to take a trip up to northern Wisconsin to our family place for some fishing and to relax before preparing for surgery.

My surgery took place on October 29, 2014. My surgeon, Dr. Carrott, had my full trust as a dedicated and skilled expert. He performed a nine-hour surgery successfully removing the lower portion of my esophagus and my entire stomach with only four laparoscopic incisions and a partial thoracotomy under my arm. I was hospitalized for eleven days following the operation. My wife stayed constantly by my side and slept in my room with me every night. We were very glad that we had made arrangements to board our dog for two weeks so that she had no other outside commitments. She also took a month off of work which helped to reduce her stress and allowed her to focus on helping me recover. Many of my friends and family also offered amazing support to me.

I was out of bed and up walking the day after my surgery. I did have a few complications that were things we understood might happen from the patient education we received in advance. My intestines were slow to revive after the long surgery and use of narcotic painkillers immediately after the surgery. Therefore, I had to stay in the hospital a few extra days until I was able to eat properly. I started on a liquid and then “soft mushy” diet while in-patient. My initial post-op swallow test indicated that things looked good in terms of reconnection and after that I was sent home with a J tube for supplemental feeding. On my first day home I was able to walk to the corner coffee shop and back and thought I was on my way to a smooth recovery.

Within a few days, however, I noticed some difficulty swallowing again. I was experiencing restriction in my esophagus as other patients had described to me at the support group. An additional swallow test confirmed that there was some stricture and also some indication of a small leak. A stint was inserted to allow this to heal. I was required to stay on a liquid diet for the three additional weeks that the stint was in place and my weight continued to fall. Without solid food I also did not feel that I was gaining strength in spite of high caloric intake through the J tube.

Eventually I was re-hospitalized just before the Christmas holiday for an infection in my chest that was related to the stint and required a five-day in-patient stay on antibiotics. At the lowest point my weight

dropped to near 130 pounds. Dr. Carrott, the physician assistants, and nurses on 4-C worked very hard to help me pull through this infection. Once this was cleared up I was able to eat a wider range of foods and my weight started to climb. I also felt much better on solid food and was able to increase my walking every day.

On January 9, 2015 my J tube was removed and I was cleared to begin jogging and doing some light exercise along with eating a regular diet. After that I started to feel the best I had felt since before my diagnosis. I am now an additional eight weeks out past that point. I no longer am seeing Dr. Carrott on a regular basis. My next visit to the oncologist is in April. I am doing the best I can to live in the present and not worry about what the future might mean for my health. My wife is retiring from her position at the University at the end of April and we plan to spend much of the summer in northern Wisconsin, if possible.

The care I received at the University of Michigan was exceptional. The staff was attentive and professional. Not only did my surgeon, Dr. Carrott make me feel personally cared for, but the other members of the team were also supportive. Dr. Orringer came to visit me in my hospital room every day to check on me and spent time at my bedside encouraging me. The nurses were so committed to my recovery and very understanding about how difficult and frustrating it is to be in such a vulnerable state.

I know that my life will never be exactly as it was before cancer. I will have to be very careful about my diet for the rest of my life. I sleep with my head elevated on a wedge pillow at night. I am working hard to regain the strength that I had before my illness. Because of the somewhat unusual complete removal of my stomach, I will require a monthly B-12 shot.

And I will remain thankful for every day that has been given to me by this miraculous medical procedure.