Tim’s fun medical journey

In June 2020, a few months after COVID shut the world down, I discovered a small sore spot on my upper right gum. I thought I might have just bruised the gum on a hard sharp food, like a tortilla chip. When it persisted for a week, I went to see my dentist. “It’s just a simple infection. Don’t worry, it’s not cancer. Hahaha. Take these antibiotics and come see me again in three weeks.” Three weeks later, he looked in my mouth. After a pregnant pause, he slowly said, “Oh my, you need to see a more senior dentist.” The next day, I saw a different dentist who did a biopsy of my gum and sent it off to a lab. Because the lab was swamped by COVID testing, it took three weeks to get an answer. Cancer.

Why me? Oral cancer normally befalls people who either smoke a lot, take recreational drugs, or drink a lot. I have never smoked anything in my life, not even pot in college in the 70’s. I’ve never taken a recreational drug, and my drinking consists of, at most, one margarita or glass of wine every couple months. So, I apparently fall into the fourth category: unlucky.

After a flurry of tests and scans, I had surgery in August 2020 to remove the rapidly growing tumor, more than half my upper teeth, the underlying jaw bone, my palate and 60 lymph nodes from my neck. I was fitted with a custom obturator, basically super dentures to replace what had been excised. In October, after a short surgical procedure to install a Mediport in my upper right chest to simplify daily IV injections, I began chemo and radiation treatments, five days a week. Those treatments ran until just before Christmas. I was fortunate that the chemo never made me sick or fatigued. I didn't lose all my hair, although it thinned noticeably.

The radiation was naturally focused on my mouth and throat, being careful to avoid my eyes and ears. Radiating the mouth and throat often causes burns and sores on the tongue and throat, so the chemo is normally combined with some medication to mediate that side-effect. I agreed to be part of a clinical trial of a new anti-burn medication that was intended to reduce the sores even more. Towards the end of the three months of radiation treatments, I learned the clinical trial gave the new and hopefully improved medication to two-thirds of the patients, and nothing to the other third. Nothing...not just the old medicine. It became obvious that I was in the one-third and by the time I rang the bell, I could barely get any food down it was so painful. I essentially starved myself for about three weeks until I could again consume juices and puddings.

By early February 2021, I had recovered from the radiation treatments. I was walking, talking, driving, and eating anything I wanted. A CT scan showed the cancer was indeed gone. Woohoo! I had totally beaten cancer in just six months!

In early March, the area around my Mediport became reddened and slightly sore to the touch. An infection was suspected. A quick surgical procedure a few days later removed the Mediport and the cavity left behind was thoroughly irrigated with an antibiotic. Apparently, the irrigation wasn’t sufficient. Later in the month, within 48 hours, I went from being perfectly fine, to all my joints aching so much I had to use a walker around the house, and I became so mentally disoriented, I wasn’t even sure what room I was in. My wife Lois is an RN with 30+ years’ experience in the ICU and ER. My rapid decline and symptoms so concerned her that, on the morning of March 27th, she called our local fire department to take me to the Baylor Plano hospital. My mental state was such that I only vaguely remember someone rudely yanking me out of bed, putting me on a stretcher, and rolling across our lawn towards an ambulance.

At the hospital, they determined that my entire body was septic with Pseudomonas. Googling reveals, "*Pseudomonas is a type of bacteria (germ) that is found commonly in the environment, like in soil and in water…Pseudomonas bacteria are generally harmless. When they do cause an infection, it is usually mild in people who are otherwise healthy. However,* ***Pseudomonas infections can be severe in people with a weakened immune system****.*" (Their emphasis.) One very common side effect of chemo is a temporary weakening of the immune system. The doctors had to try several different high-potency antibiotics to find one that would knock out this strain. Before they got the sepsis under control, the bacteria had damaged my lungs, kidneys, and two valves in my heart. Open heart surgery was required. Lois was so concerned about my ability to survive that surgery that, the day before the surgery, she called my entire family from around the country together in my room just to say, "Hi" . . . or maybe "Goodbye." Unlike Lois who has insider experience with the fallibility of doctors, I wasn't the least bit worried. I had complete trust in the surgeon and hospital. Also, the sepsis still had my brain working at half speed.

Ha! I surprised her by coming through the surgery without any problems.

But four days later, in the middle of the night, my heart arrested. It wasn't an obvious flatline, but rather PEA (pulseless electrical activity). The EKG monitor was still blipping, but my heart wasn't really pumping blood. By luck, a nurse happened to be in my room at that moment doing something else. He found me nonresponsive, found no pulse, correctly diagnosed it as PEA, and called a code. Obviously, they were able to resuscitate me. Over the years, Lois has dealt with many PEA patients in the hospital. Every one of them either died, or came away with brain damage due to lack of oxygen. Lois was understandably very scared at what she would find when she got a call from the hospital in the middle of the night.

Ha! Surprised her again! Still alive. No brain damage.

It's often noted that the brain will blot out memories of traumatic events. I have no memories at all of having arrested or being revived. I only know about it because Lois told me a month later.

After reviving me, the doctors inserted a trach tube in my throat and hooked me up to a ventilator. It took three months for my lungs to heal from the sepsis and get strong enough to disconnect the vent. Due to the kidney damage, I was on dialysis for two months until they recovered enough.

After two months flat on my back in Baylor Plano, I transferred to the ICU unit in an LTAC (Long Term Acute Care) facility. I lay flat on my back for another two months until I could kick the ventilator and dialysis. Without those encumbrances, I was deemed medically stable enough to move to a rehab facility. There I was on my back 22-23 hours a day. Each day, one or two Physical Therapists tried to get me to sit up on the edge of the bed without falling over. As many as four therapists at once tried to get me to stand on my own two feet. Total bust. But the therapists did work hard to strengthen my muscles and taught us how I could transfer from the bed to a wheelchair and back using a rope and a slider transfer device.

On September 27, 2021, I moved back home from the rehab center, exactly six months after leaving. Most of our living room furniture was moved out and a hospital bed was brought in. When you stepped in our front door, you were stepping into my hospital room. Privacy was nonexistent. Mortifying.

After six months of lying on my back, all the muscles in my body were atrophied and flaccid. Therapists will tell you that if you spend X time in bed, it will take two to four times X to fully recover, so I was looking at one to two years of rehab. I'm now at 2.5 years and counting. When I first got home, I couldn't use my phone or iPad because they were simply too heavy for me to lift. I couldn't roll over in bed. I could barely lift a foot two inches off the bed. Twice-a-week PT sessions at home started with simple exercises possible in bed, like pointing toes towards the foot or head of the bed or making snow angels. It's amazing how many small steps it takes to regain full mobility. Sitting up on the edge of the bed with someone helping. Sitting up unassisted. Sliding from bed to wheelchair with help. Sliding from bed unassisted. Standing up from the edge of the bed with two large men helping. At New Years 2022, I stood up for the first time unassisted. My physical therapist didn't touch me, but was inches away, ready to catch me if I started to topple. It took several seconds for me to straighten up, but when I was finally upright, I turned to the PT guy and said, "I don't need your stinkin' help." He cracked up! Lois laughed as she videoed that momentous event and sent it to our extended family. Next comes a walker with four rubber feet, then a walker with four wheels. Next comes a cane with four large feet. Then a single-point cane. Finally, you get to walking unassisted like a normal human. I am currently midway between the final two stages. I use a cane when leaving the house, but walk around unassisted most of the time at home. Before the surgery, I was playing pickleball eight hours a week. I won't consider myself fully back to normal until I can play pickleball again

During my entire hospital stay and first 9 months at home, I received all my nutrition via a feeding tube straight into my stomach. As with every other muscle in my body that atrophied, so did the swallowing muscles in my throat. The radiation had shrunk my esophagus to half its normal size, and one of my vocal cords is paralyzed open, obstructing the flow of food. Since last summer, I've been working with a swallow therapist on relearning the simple act of eating and drinking, working up through a progression of more and more difficult food categories. I am now getting 100% of my nutrition by mouth. In early January 2023, after nearly two years, the trach tube was finally removed from my throat. A glorious moment when I had the honor of pulling it out myself! Normally a trach hole will heal itself after two or three weeks. Because I had the trach for two years, it stubbornly refused to heal, so in June 2023, my cancer doctor surgically repaired the hole.

Five years ago, my weight was as high as 400-405. The night before the August 2020 surgery, I was down to *only* 375. A year ago, my weight was 185, exactly half. Losing all that fat is fantastic! Losing a ton of muscle mass with it, not so much. After two plus years of rehab, I'm still working on rebuilding my muscles and regaining my original balance.

I've had at least a half dozen medical professionals call me a *miracle*. But I don't see anything miraculous. Okay, maybe surviving the open-heart surgery and PEA arrest were fairly low probability outcomes, but I just see it as being fortunate enough to have superb doctors and medical care, and my determination to not settle for a lower quality of life. I’m not going to give up. I am going to keep pushing myself until I’m back at least as good as I was before the cancer.

I’m thankful that I came through all this with my brain 100% intact. But most of all, I am thankful for my wife. If not for Lois and her decisiveness in getting me whisked off to the hospital, I might not have survived the initial infection. Lois came to my hospital room every single day for six months where she rigorously supervised my care and adamantly requested proper care for me in all the facilities I was in. Back home, she took care of all my nursing needs until I was able to do them for myself. I’m a lucky man!