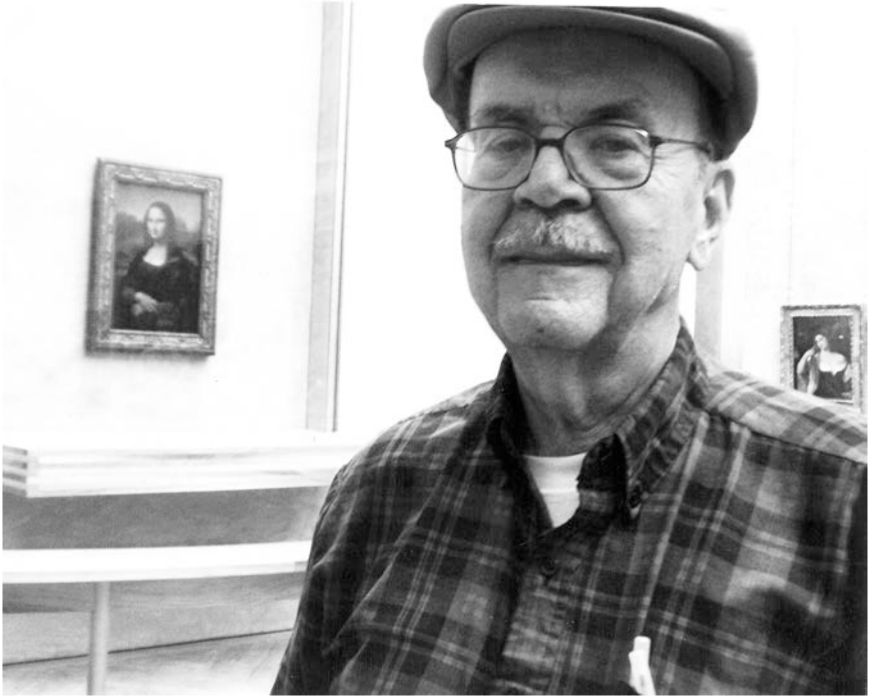

Ken S.

Chapter 7

Each New Day Is A Blessing

by Ken S.

Ten years ago (2005) I was diagnosed with Stage III esophageal cancer and given twelve months to live. Two years earlier (2003) after thirty-six years as an archivist at the University of Michigan, I retired to the area near Cincinnati, Ohio, where most of my family lived and where my mother resided in assisted living. Upon receiving my cancer diagnosis, at the urging of friends, I returned to Ann Arbor for my surgery and follow-up treatment by Dr. Orringer, without whom I never would have made it.

Although I never married, I had strong kinship and friendship ties which proved of great help in battling cancer. In 1937 I was born to a working class family in Mt. Healthy, Ohio (then a small town, now a suburb of Cincinnati). My father was a truck driver and factory worker. My mother was the matriarch of her family as her mother had been before her. During the midst of the Depression, my maternal grandfather lingered with colon cancer for five years, and my mother, being the oldest able-bodied of his children, sacrificed her dream of an education, lied about her age, and went to work to support the family. So while I was an only child, I had cousins who were like brothers and sisters to me.

Like other members of my family, I also developed strong friendships. My maternal grandmother, an Irish-American cleaning lady, had what we called 'the gift of gab.' She was friendly and sociable (as was my dad); traits she transmitted to her children. And she taught me an important lesson early, saying, "What goes around comes around" (i.e., the way you treat others is the way you will be treated). It certainly benefited her for she endured many hard times, and it certainly benefited me.

My swallowing problems developed a year before I was diagnosed with esophageal cancer. At my annual physical on September 1, 2004, I first told my then internist about it. When he learned that I never had heartburn, he attributed it to the normal aging process and concentrated on my growing problem with high blood pressure. On a follow-up visit nearly four months later, I told him about continuing swallowing difficulty. If it continued, he said, I should try artificial saliva, available at any pharmacy. At the time, I weighed 195 lbs., about 20 more than I should.

By my next visit (March 24, 2005) he had retired and was succeeded by a young, newly minted D.O., who specialized in gerontology. When she learned my swallowing trouble was increasing, she sent me for X-rays and a barium swallow test, which showed a narrowing of the esophagus but no tumor. So she referred me to the gastroenterologist who had been giving my family colonoscopies for years. He asked me several questions including whether I'd ever had heartburn (I hadn't). Describing my problem as 'minor' and 'easily corrected,' he scheduled me for a dilation. It showed the stricture was narrower than anticipated and I had an 'ulcer' for which he prescribed medication.

On May 24th (two days after my mom was hospitalized with congestive heart failure), I had my second EGD. My blood pressure jumped during the procedure, which my gastroenterologist reported to my internist. He found my stricture remained 'narrow' and my 'ulcer' hadn't completely healed. So he recommended drinking lots of fluids with meals, and chewing my food more thoroughly. He asked me to call him in two weeks to report how I was doing. He also took some biopsies from inside the esophagus, which proved to be negative. When my swallowing problems continued, he scheduled me for a third EGD on July 5th.

In the meantime, I had my annual check-up with my dermatologist. He removed two suspicious spots on my nose, which a biopsy showed to be carcinomas. So he referred me to a specialist for more surgery (which eventually, after my esophageal diagnosis, made me feel like I was a cancer farm). Afterwards, cosmetic surgery was suggested, but I rejected it - saying I wasn't a Hollywood actor, and I'd lived for years with baldness, so I could live with a couple holes in my nose.

When I saw my internist again on June 15th I told her about my concern with my mom's health and a couple episodes of light-headedness. My vital signs were still pretty good: 168 lbs., 132/84 B.P., and 68 pulse. But she ordered an EKG, carotid artery and heart monitor tests and referred me to a cardiologist.

While I waited, I had my third EGD on July 5th. My gastroenterologist took more biopsies from inside the esophagus, which again proved negative, and ordered a CT scan, which showed a "thickening of the esophageal wall." Because of the latter, he scheduled me for an endoscopic ultrasound with his senior colleague on July 28th. He told my family that he suspected esophageal cancer, which, he explained, meant I had a life expectancy of about twelve months.

In the afternoon, my cousin and his wife took me to the hospital for my esophageal ultrasound, for which I was anesthetized. Five days later, on August 2nd, I received the results. My gastroenterologist told me I had esophageal cancer and needed to act, "As quickly as possible." He referred me to an oncologist who squeezed me into his schedule on August 2nd - the last day before he left on vacation. That evening, I told my mom I had cancer.

The day before my oncologist appointment, I saw my internist for the last time before my treatments started. She handed me two notes to give to the oncologist. One concerned my weight loss (from 195 at the end of January to 155 today). The other said simply, "Mr. S. is an excellent patient and one of my favorite people - please let me know if I can be of assistance."

The following day, I met my oncologist. He commented that my BP reading (128/80) was excellent under the circumstances. And he told me he wanted to treat my cancer aggressively with five to six weeks each of radiation and chemotherapy (including a machine which would deliver chemo 24/7) followed by an esophagectomy. The next day, a feeding tube was installed, followed a few days later by a PET scan, and a port installation.

On August 15th my radiation and chemo treatments began. They were preceded by a meeting with both my radiologist and oncologist. My oncologist began by saying the PET scan showed that the cancer hadn't reached the lymph nodes behind the heart. So there was 'a chance' but 'no guarantee'.

I was still convinced I was going to die. After all, the gastroenterologist told my family I had twelve months to live, and my own research indicated that the five-year survival rate for esophageal cancer was about seven percent, and mine had been discovered late. I was only determined to outlive my mother because I knew how devastating the loss of her only child would be to her. As we left, the radiologist told my cousin, "If attitude can cure, this man will be cured."

As I was waiting for my first infusion, I saw a list of cancer support groups. There was none for esophageal cancer (probably because there were so few survivors), which further confirmed my belief that I was going to die. Within a couple days, radiation sealed my esophagus, so for the next three months, I was totally dependent on a feeding tube for all my nourishment.

At the end of the second week, mouth sores forced the suspension of my chemotherapy. It was resumed two times at reduced dosages, but eventually had to be stopped because of the sores. Despite them, I continued to visit my mom every day in nursing at the Christian Home. I concealed the sores with a mask, telling her it was needed to protect me from infection. The radiation continued, but the fact that I only received about 2/3 of the recommended chemo treatment further convinced me that I wasn't going to make it.

Given my belief, I began contacting as many friends as possible to say goodbye. I wanted to tell them how much I appreciated their friendship and how glad I was that they were part of my life. And I worked on tying up any loose ends which might be left in my life.

A few days after the first chemo suspension, a friend called from Ann Arbor to urge me to come there for my surgery under a Dr. Orringer, whom she claimed was "the best in the country." Other friends soon called, offering places to stay for my family and me during my treatment. I told all of them that I appreciated their thoughtfulness, but I knew I was going to die and preferred to spend my remaining days close to home with my family. But the friend who initially suggested Dr. Orringer didn't give up.

She called my cousin's wife, a retired nurse, whom she knew advised me on medical matters. My Ann Arbor friend converted her by explaining the Orringer procedure. Then my relative convinced me by describing how not opening up the rib cage would make the surgery so much easier on me. So I agreed go to the U-M if Dr. Orringer would accept me as a patient.

When I first broached the possibility of having my surgery done in Michigan, my oncologist was resistant. "We have good surgeons in Cincinnati, too," he asserted. But after I mentioned Dr. Orringer's name, his attitude changed. "Oh, yes!" he said. "We give him our difficult cases. I will write him a letter. He doesn’t like FAXs."

On October 11th, the day after finishing my treatments in Cincinnati (and executing my estate planning documents), my cousin drove me to Michigan to meet Dr. Orringer for the first time. I noticed he had small hands but a powerful handshake. If anyone can reach under my rib cage and do the surgery, I thought, he could. He proceeded to tell us what he was going to do (making me a drawing, which I still have), why he was doing it, and what I could do to increase the chances of success, including walking three miles a day and using a breath-strengthening device. As we left, I asked him how many of these surgeries he'd done. He responded, "Over two thousand."

Six days after I returned from Ann Arbor on October 17th, my oncologist gave me an encouraging report from my last PET scan. "Now," he said, "all you need is a skilled surgeon." On my way home, I stopped at the Christian Home to tell my mom - adding that I'd see her again after lunch. Before I could return, the Home called to say she'd died of congestive heart failure. A burden was lifted from me. At least she died after receiving some good news, and she didn't have to worry about me - and me about her - while I was gone to Ann Arbor.

After Dr. Orringer reviewed my reports from Cincinnati, he asked that I see a cardiologist and have an echocardiogram. I asked my oncologist why, if I were cleared for surgery in Cincinnati, Dr. Orringer needed more information. He responded: "Dr. Orringer is very thorough."

Meanwhile, I was following Dr. Orringer's instructions religiously. This time, with my mom gone, I was just doing it for myself, but I had reason for optimism. Having survived a bout of childhood tuberculosis (in the pre-antibiotic era), I knew I didn't have the best lungs. But I was determined to do everything I could to ensure a good outcome. At my funeral I didn't want anyone to say I hadn't done my best – or that I had been a 'quitter.' And, I had my dad's example to follow. As a child, he'd survived lobar pneumonia, being hit by a car when he was five (almost being knocked into a saloon - he always said that if he'd gone through the swinging doors, his temperance parents would have disowned him), and later convulsions when his adult teeth proved too big for his mouth. So I walked at least three miles a day every day, rain or shine, except for the day I left for Ann Arbor when mid-way on my trek across my square mile home town, I saw my family gathered on my lawn to wish me goodbye.

While I'd endured serious illness as a child, I'd never had major surgery. So I asked my cousin's wife, the nurse, to accompany me and my cousin (whose daughter was named for my mom) to Ann Arbor. Unfortunately, shortly before we were scheduled to leave, her son, who was a diabetic, suffered a stroke, but a Michigan friend, who had been a nurse at University Hospital, took her place to answer any questions we might have and deal with the medical establishment for us.

On November 7, Dr. Orringer performed the esophagectomy - my first major surgery. Immediately afterwards, I returned to my room and was amazed that I had virtually no pain - only soreness. It seemingly took me all night to turn from one side to the other. Dr. Orringer visited me at least once a day during every day I was in the hospital. Not only was he a great surgeon, he also had a great bedside manner. He seemed to know intuitively exactly what I needed – be it a pat on the back or a kick in the butt.

He kept me walking and using the breath-strengthening device. He also started me on his famous 'dog food diet' (soft and mushy) as my new digestive system began its adjustment. On November 13th he gave me a good pathology report and the next day I passed the barium swallow test to go home. But Dr. Orringer wanted me to stay in the Ann Arbor area for a week until he was sure the sutures would hold - saying they would then have 'a lifetime guarantee'. So I moved in with local friends, who were empty nesters.

The following weekend, when members of my family came for the Ohio State football game, they drove me back to my hometown where I spent the next three and a half weeks with family. I continued the exercises which Dr. Orringer recommended and as I trudged in the snow up the high hill outside their house, I used to imagine myself as a concentration camp survivor on an end-of-war death march. I kept saying to myself, "I'm going to make it; I'm going to make it." And I did.

During my stay with my family, I struggled with my weight as well as my energy level. My weight dropped from 157.2 on November 17th to 148.8 on December 5th, the lowest it had been since I was a kid. Despite the great care of my family (they were excellent cooks), I had real trouble adjusting to the loss of 80% of my esophagus and the top part of the stomach. Still, on November 27th my oncologist gave me a good report in my first post-op visit. Eleven days later on December 8th my cousin drove me to Ann Arbor for my second post-op with Dr. Orringer. He removed the feeding tube; from now on I was totally dependent on my swallowing mechanism and he dismissed me to the care of my physicians in Cincinnati.

Inclement weather delayed my return to my own home. On December 15th another snowstorm hit. That evening, the two-and-a-half year old granddaughter of my cousin (the one who always drove me to Ann Arbor for my appointments with Dr. Orringer), was critically injured in an accident. We didn't know whether she'd survive or if she did, whether she'd be permanently impaired.

Fortunately, she eventually fully recovered. It helped put my own problems in perspective. Suddenly they didn't seem very significant. I was a 67-year-old man most of whose life had passed and who knew what was happening to him while she was just a child whose life was just starting. Needless to say, the family spent a mighty grim Christmas.

The next day on December 16th I returned home for the first time since I left for my surgery in Ann Arbor over a month ago. On the way, my cousins took me to see my internist for the initial visit since my cancer diagnosis. She found I was anemic and recommended I see a nutritionist, which I scheduled for January 9th. While I was glad to be home, I was discouraged, despite the good reports from my oncologist and Dr. Orringer. It was all I could do to accomplish simple tasks such as making meals and doing laundry, and there was much I wanted to do.

A considerable backlog had accumulated during my treatments. I had some 90 holiday cards to write, mainly to distant friends, and I wanted to include a personalized message on each of them, as I had in the past. Also, I had my mom's estate to settle. While I started on both, I accomplished little on either, seeing my attorney on December 29th but not completing the task until over a year later.

On January 9th I saw both my nutritionist and my oncologist. The nutritionist came first, and as I sat in her full waiting room, I noticed her overweight patients casting admiring glances at me as if I were some sort of ‘success’ story, while I thought I looked like death warmed over. She gave me some good recommendations, which I cleared with my oncologist, whom I saw next. I told him that I was discouraged with my progress; the difficulty in gaining weight and my low energy level. He assured me that I was doing fine. My blood tests were good, and I'd even gained a little weight. He emphasized that I had one of the most complicated surgeries possible, and it would take me three to six months before I started to feel like my old self again.

As I ate better, I felt better and gained weight, but my swallowing problems returned and, I feared, so had the cancer. On January 21st after a particularly traumatic time with food stuck in my reconstructed esophagus, I called Dr. Orringer's office. Being Saturday, it was closed, and I was referred to the Thoracic Surgery resident on duty. He told me the problem was common after esophagectomy and Dr. Orringer could easily correct it, doing it in his office without anesthetic. So on Monday I made an appointment and on January 26th I drove by myself to Ann Arbor.

To my amazement he did the dilation with only a numbing spray by inserting a few tubes of increasing size down my throat. He explained that scar tissue from the surgery was causing the problem, and the procedure might need to be done again later, raising the possibility of having me do it myself. This was something which was apparently unknown in Cincinnati, as was his dilation procedure.

Shortly after my return home, food again started to get stuck. So I called Dr. Orringer's office, but on learning that my gastroenterologist could do it using the tubes which Dr. Orringer recommended, I opted to have it done closer to home. On February 21st my gastroenterologist performed the second dilation but he did it after I was completely anesthetized (which happened on every one done in Cincinnati). When I awoke, he reported that I had scar tissue, and it would probably need to be done several more times, scheduling the next dilation for March 28th. Five days before that appointment I ended up in the emergency room and was hooked up with intravenous feeding to prevent dehydration. The following Monday a hospital gastroenterologist (I had to tell him not to use the balloon method, which he later said would have been easier) performed the procedure, again under a total anesthetic. On awakening, I was told that the esophagus was badly irritated but showed no signs of cancer and that I'd probably need to have the procedure done every three weeks for a year. A little over a week later on April 4th I needed it done again.

The day before the procedure on the 4th, I saw my oncologist. He urged me to contact Dr. Orringer about having future ones done in Ann Arbor. I was in the process of making the arrangements when I contracted a bad case of shingles. The physician assistant to my oncologist commented that I'd certainly had ‘a lot of setbacks’ on my road to recovery. So I had to have my 5th and 6th dilations on April 25th and May 25th done in Cincinnati, again, under a complete anesthetic. At my next appointment with my oncologist, he gave me a good report on my CT scan and noting my shingles had healed he urged me to contact Dr. Orringer, which I did.

On June 6th my cousin's wife (the nurse) and I traveled to Ann Arbor so I could be dilated for the seventh time this year (but only the second time by Dr. Orringer). This time he didn't even use the numbing anesthetic saying he learned from the first that my gag reflex was limited. After inserting the first two tubes, he let her do the third. She described it as easier than putting a feeding tube down a patient's nose into the stomach. He told us that if I had further difficulty we should return for instruction on how we could do it ourselves.

Two months later on August 17th, after I'd had some further difficulties, we drove back to Ann Arbor so Dr. Orringer could instruct us on using the French-Maloney dilator tube. After showing us how and letting us do it, he recommended we start by performing it every day for a week and then every other day, then every third day, etc. until the scar tissue became elasticized.

Within two weeks my nurse friend and relative taught me how to do the dilation myself so I no longer needed to stop at their home before breakfast. On one of my next visits to my oncologist I brought the French Maloney dilator tube with me, so he could show his staff, who had never seen one before.

My progress was easy afterwards. I ate better and gained weight, but never as much as before contracting cancer. I leveled off at 175 lbs.; 20 lbs. less than before it hit, which seemed ideal for my 5" 10½" frame. When my weight fell below 195 my blood pressure problem gradually disappeared until I no longer needed medication. The intervals between my self-dilations increased from days to weeks to months to years. My last was done approximately two years ago as a precaution in preparation for a foreign trip. The acid reflux attacks that plagued me early in my recovery gradually decreased in number and intensity, so they are no longer much of a problem.

Two years after my surgery the port for delivering chemo was removed, and the intervals between my oncology appointments grew from six weeks to three months to six months, to a year. Finally, on April 6, 2011, my oncologist dismissed me as a patient, saying he never wanted to see me again, which was a compliment.

In the 10 years since my cancer diagnosis, I have led an active life. I have traveled widely in the U.S., Europe, and Latin America. I have remained active in my community: church, local historical society, and city commission. I have also been able to be present at joyous occasions such as christenings, graduations, weddings, and high school and college reunions and at sad ones such as funerals which are an important part of life - my mother's side, being Irish, always has the best funerals because they are 'Celebrations of Life'. And I continue to visit Ann Arbor every fall to see friends and attend major U of M home football games. Life has been good. (I only wish our football team had been better.)

Ironically, cancer treatments have improved both my life expectancy and my quality of life. In many respects, I'm in better shape now than I was before. At my six-month check-up last week with my internist, I registered a weight of 175 lbs., blood pressure of 124/80, and pulse of 64 (at 77 plus years of age). I also take only one prescription medication for glaucoma. Things that once concerned me no longer do. Each new day is a blessing. Thinking I was going to die, I told my family and friends how glad I was that they were part of my life, and I learned who my real friends were. My dad used to say, "You won't know who your friends are until you need a friend". I also tied up the loose ends of my life. So, if I step off the curb tomorrow and get hit by a bus I will be at peace with the world. All of this would have been impossible without the support of family and friends and the excellent medical care I received, especially from Dr. Orringer.