



# My Gift in Disguise

Beyond my cure, the greatest gift has been the opportunity to experience a new side of life and to be able to share it with others.

*Robert H. Miller*

I am young until I am not. One day I look in the mirror and realize I am growing older-my body and face no longer emanate grace and youthfulness. My life is progressing well, and I'm thankful for every minute of it. But as my life evolves, I am learning the importance of hope. I am hoping that my wife, Colleen, and I will continue to enjoy good health and our family, our Lake Michigan house, and a glass of wine together as we grow older. Life is definitely not standing still, and memories surround us everywhere we look. Silence reigns in our home where our children once were. Yet we fully understand how lucky we are to have raised five successful kids who, in turn, have presented us with five delightful grandchildren, all of whom we adore. But life takes an entirely new turn

when, in 2016, I confront two devastating almost back-to-back medical issues that knock me to my knees. For the first time fragility and mortality appear in my field of vision. My travels to faraway places for my photo-journalism career have given me priceless insights into and a better understanding of human lives drastically different from my own. Seeing



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other people's lives through my camera lens has been like receiving a personal gift from a total stranger. In the remotest parts of the world I have learned how fragility and mortality are intermingled. Extreme poverty coupled with illness is sad and hard

to see. For example, one person is diagnosed with leprosy roughly every four minutes in India. On one of my trips there I saw a man with his arms and legs covered with leprosy sores walking near the spice market in Old Delhi. His disease was clearly evident, and everyone near him on the street was avoiding him. My friend who lives outside Delhi told me: "This man is an untouchable in our culture . . . he most likely has no home, no money, and no chance of survival if left untreated." All he could look forward to was insolation, loneliness, and eventually death.

While I was on assignment in the tiny village of Sefhare, Botswana, located in southern Africa, I saw visual evidence of how AIDS has affected this village of 5,300 people and many other villages in Africa. In 2014, in one week the local cemetery dug fifty gravesites. That week forty people died from AIDS, and the ten extra gravesites were needed to stay on top of the unfolding tragedy. Entire families in Sefhare were destroyed, their children orphaned. The local orphanage was beyond its capacity with



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children who had lost both parents to this disease. Little did I realize that my awareness of the problems of those in the wider world would mentally prepare me for what was to come. It helped me to move beyond feeling sorry for myself and to learn to seek the positives in a

dire personal situation. It also gave me the strength and mental willingness to stop asking myself over and over again: "Why has this happened to me?"

Today I ask myself: "Why not me?" As a human I now realize that I am as susceptible to all the same diseases and issues as everyone else on this planet. I have learned that it is how I choose to look at problems and, most importantly, how I accept the difficulties that are placed before me.

Many of us will face our mortality when we least expect it. For me, it began in 2016 when I was traveling in India with my youngest son, Patrick. I developed a severe intestinal infection brought on by a water-borne bacteria. I thought it would resolve itself with the proper medication as most intestinal infections do. A month later, safely back



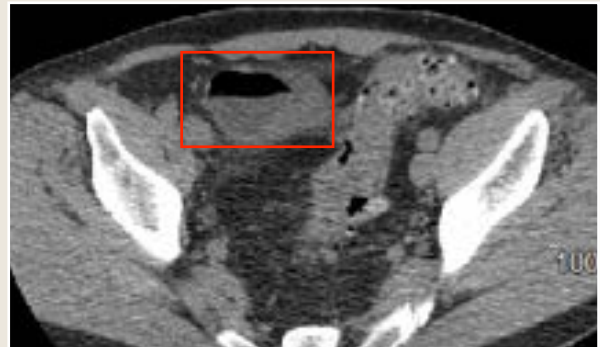
*In the heart of Old Delhi, one of the locals took a picture of me with my youngest son, Patrick, and my good friends Shrey and Priyam.*

home in Michigan and under expert medical care, my condition was not improving. My disease had become resistant to antibiotics and had now moved into my bladder. Like it or not, I was fighting a real enemy, and each day it was getting worse. A severe, unnatural intermingling of my colon and bladder functions added further complications. My fight with this enemy would last for two-and-a half years until I won my battle with the help of a specialized medical team, using every medical treatment available to them. After three major surgeries, two of them using the da Vinci robot, and five other procedures to correct my multifaceted problem, I became overly familiar with the operating room, CT scans, antibiotics, IV's, and the dreaded bladder catheter. Once the colon and bladder side of the equation was repaired, it took a PICC line and some of the most potent antibiotics in existence to rid me once and for all of this menacing infection.

I came to understand that my health had been wholly in the control of



*Drug resistant eColi ESBL bacteria.*



*CT scan showing gas in bladder indicating compromise between colon and bladder.*

one small thing with an odd first name and an even stranger surname, eColi ESBL, a tiny and elusive enemy, highly resistant to change. If left unchecked or untreated, it will wreak havoc on your insides and your emotional well-being.

This health challenge was beyond overwhelming. But it resulted in a new attitude forged from my past global experiences. It is incredibly hard to stay

positive when you are faced with a major health challenge. I focused on my goal of a complete cure so I could continue to live.

Keeping a daily journal helped me greatly as did my photography skills. The story of my troubles was a natural. I was living it each day, and it put me on the road to a positive space, providing the clarity and knowledge to help me see where I had been and how I was improving. It offered a way to define and cope with a situation that had an end result I could not see. Out of journaling came the words and feelings to craft my personal statement below. It now serves as a cornerstone for me in facing other life-challenging situations.

*What does it take to win a challenge? If you run your kite before the wind, you can't take off. You have to turn into it. Face it. The challenge you push against is the very force that lifts you.*

I did succeed in overcoming that medical challenge. But as often happens in life, when one crisis ends another begins. Too quickly I was forced to start thinking again about my mortality. I had been given only a four-month break.

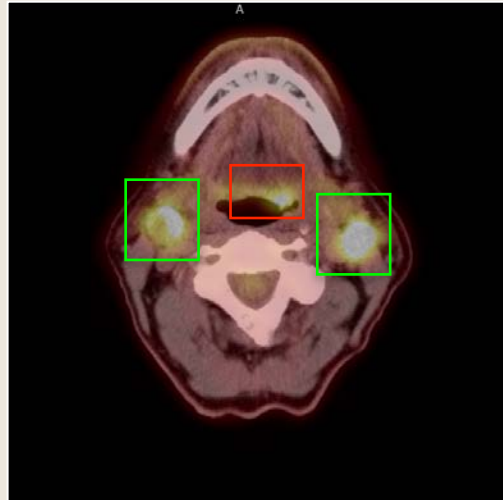
**On October 26, 2018, at 9:36 a.m., I received an entirely unexpected and highly personal gift.**

A little larger than an American dime, this gift's most interesting aspects included an irregular shape, an uneven texture, and a random color pattern. Typically a gift of this size is presented in a small box wrapped in shiny paper and encircled with a pretty bow. This was not to be the case. The gift was accidentally discovered by my dentist and then confirmed by numerous doctors after they analyzed multiple imaging tests and examined two neck biopsies. The process of locating the site where my stage four squamous cell head and neck cancer\* originated reminded me of a childhood fortune hunt. Only now the hunt focused on me and my misfortune.

Once the tumor was precisely located, I knew it was big trouble. I was scared. But I made the choice to remain positive and move forward. Hard

though it was, I committed myself to this approach, despite the uncertainty I faced. As I sought a better understanding of my cancer, I began to perceive some of the interesting benefits it might offer. I looked hard, stretching my imagination and abandoning my comfort zone. I knew I must forgo what I had previously thought to be true, and soon I developed a new perspective. I began to realize that my gift might have good, if hidden, aspects. Either way, good or bad, cancer was going to unquestionably change my life forever. I began to focus on the positives—after all, the right attitude goes a long way.

*PET Scan shows cancerous sites in neck and base of the tongue. Primary site highlighted in red with neck lymph nodes in green.*



And so it began. I rejected the bad, the scary, and the unknown, focusing my efforts on one positive thing after another. Yes, the negatives were all there staring me in the face day after day, but I refused to dwell on them or allow them to control my life. After that fateful decision, I instantly began to sense a new level of love and appreciation from my family and friends. Slowly my feelings recalibrated from the negative spot I had found myself in after the diagnosis. Suddenly I understood with a new intensity how precious life is and that each moment truly counts. I also discovered within myself a new level of compassion, understanding, and acceptance toward others and, most important, toward myself. It also changed the ways in which I view life's challenges. My faith has been enhanced, and this gift has given me a keen, focused approach to my daily activities. I only wish I had attained this level of personal introspection long ago.

Another cool piece of all this is that I learned many things I never knew before. My vocabulary grew, with many new words, most of them complex

and scientific. It is astonishing to me that I am now confident participating in conversations about science, technology, and medicine. My friends are astounded.

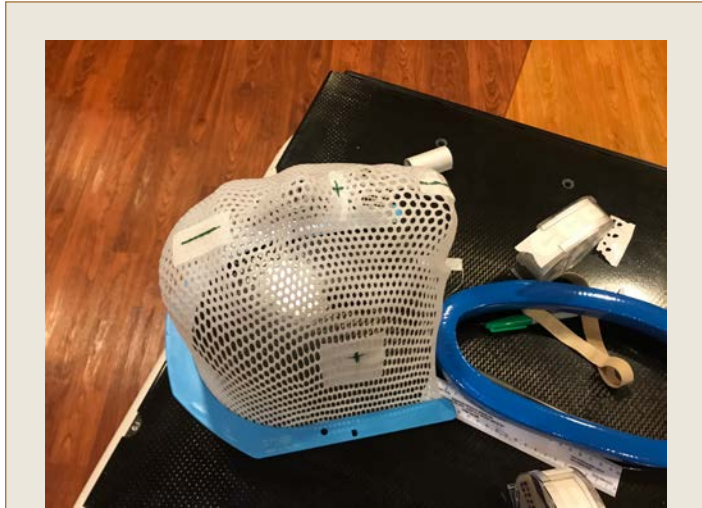
And get this: I gained exclusive access to a special place that is so visually stimulating to me and high-tech that I marveled at the design each



*Time exposure while undergoing radiation treatment.*

time I entered that room. My eyes would catch the beautiful interior ambient lighting that paints the room with warm color, and my ears enjoyed the soft background music, all tailored to my liking. The gracious and highly trained hosts tasked to guide me through my radiation treatments thoughtfully led me to my special place, where they encouraged me to relax and put myself in a deep restorative position similar to a yoga pose. I was encouraged thirty-seven times to lie down for that special savasana

session. My eyes caught the beauty of the cherry blossoms always in full bloom above my head and the green laser beams, pointing to straight-line markers on the walls and ceilings that indicated the exact location where I was supposed to lie still. Best of all, I experienced this luxury five days every week over seven weeks.



*The mask of reality. This mask was used to position my head precisely for treatment.*

Should you also be lucky enough to have this experience, you will improve your winter look with a custom suntan tailored just for you. Did I mention I was also fitted with a custom white mask with blue trim on the bottom to make sure my suntan occurred in the exact spot every time? Looking ahead, I can see the value of using this mask for the scariest Halloween costume ever.

I also qualified for several free therapeutic massages from a massage expert, when I needed them most. Another benefit: I had access to an excellent nutritionist, and I learned how to make nutrient-packed 2,000-calorie smoothies; I was encouraged to drink them as often as possible. Soon I began to love these smoothies, bringing creativity to their composition and drinking them exclusively. I became a bit of a snob, imbibing San Pellegrino nonstop—I always had a bottle in my hand. How perfect is that?

*This gift kept right on giving. Every day challenged, inspired, motivated, and humbled me. Able to express my emotions, I learned that crying privately was not a bad thing.*

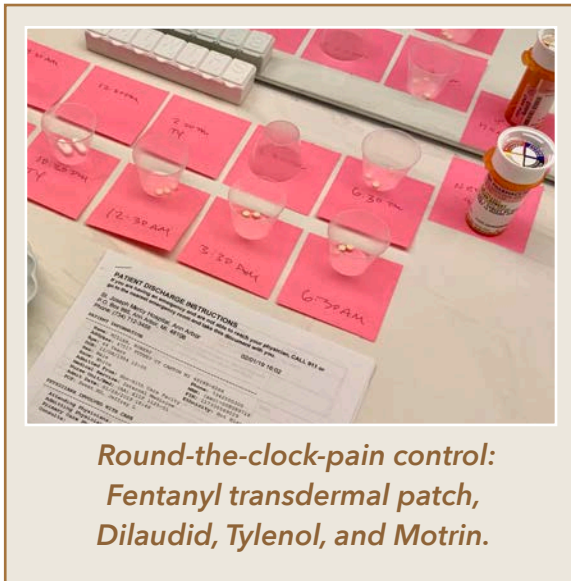
Another hidden gem: Without really trying, I finally shed those few pounds I had always wanted to get rid of. I didn't need to do anything at all



except show up at this beautiful place where the staff always greeted me with: "Hello Mr. Miller! You look great, how are you today?" Best of all, I was encouraged to take naps every day and relax as much as possible. How quickly I understood the focus was all on me!

This gift kept right on giving. Every day challenged, inspired, motivated, and humbled me. Able to express my emotions, I learned that crying privately was not a bad thing. I was blessed to have the support, love, and caring of my wife, Colleen, and our five children and five grandchildren. Everyone rallied around me. My life took on new meaning and purpose, and I quickly learned how to use that new iPad Pro that came from work with the nifty calendar application I downloaded. Now I could schedule my seemingly endless medical appointments effortlessly.

Naturally I experienced some challenging days. Truthfully, my treatment was beyond brutal—almost tortuous—but it was worth the pain. The backstory of being a cancer patient has allowed me to grow personally. Cancer has altered my life in ways unexpected and positive.



How could I go wrong with a highly trained and motivated support team whose only concern was for me and my well-being. Dedicated to taking care of my every need 24/7, one member of the team was always only a phone call away. After years of traveling the world for my work, I can say the attention I was now counting on was superior to any hotel concierge service.

Have I mentioned the drugs? Only if needed for the pain, but expertly dosed and monitored to ensure my days and nights remained as pleasant and pain free as possible. The goal was comfort and pain control in the endless pursuit of happiness.

To ensure my comfort over seven weeks of treatment, my doctor ordered a port placed in my chest so that chemotherapy drugs could go directly into a large vein. Conscious sedation while the port was being placed left me without a care in the world. No more stings and pain from IV's and blood draws! With a small dab of lidocaine cream placed on the skin directly above my port to mitigate any pain, they administered my chemo and collected blood effortlessly. A port has real value, and now it has become a part of me.

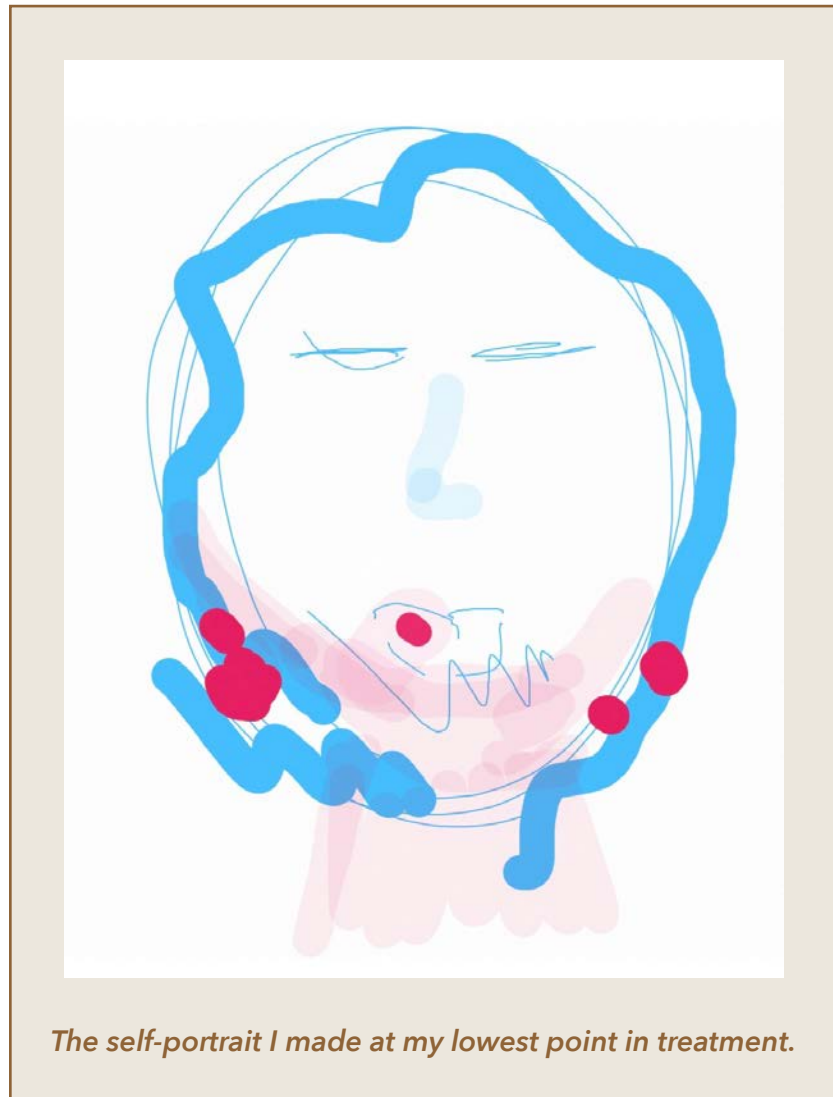
For me, chemotherapy and its side effects became the true life test, shaking me to my core. Thankfully, steroids and anti-nausea drugs lessened the effects. Chemo pushed me into a world of confusion and fog. My sense of time seemed out of sync. I developed a love-hate relationship with my chemotherapy. I define the love part as being able to fall sleep at a moment's notice, knowing that conserving my energy would help fight off disease. The hate side of my relationship to chemo was the way in which it made my body feel electrified and jumpy, causing frequent waves of nausea to come over me like a tide during a storm. I also lost all taste for food—it was horrible, now something to avoid.

What was it like to lose my sense of taste? It was humbling but interesting as well. I quickly understood how much we take our sense of taste for granted. I am thankful for the experience because it has taught me to appreciate the simple pleasure of eating and tasting food. It also pulled me closer to the many people living in extreme poverty I have photographed around the world. Sometimes they have no food, other times they are faced with eating whatever they can find in order to continue to exist. I have food and plenty of it, but to me it is tasteless, repulsive, and sticky, with no purpose in my mouth. In contrast, poor people either have nothing to eat or have no choice but to ingest bugs and other nasty

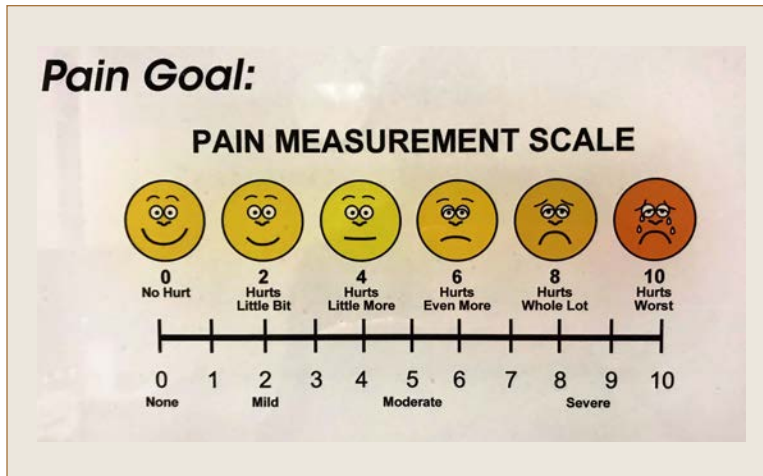
***Each breath and swallow felt like a thousand shards of glass were being pushed further into my throat.***

stuff. I am glad to have had this experience, because now I understand what “yuck” really means when it comes to taste and weight loss.

The upside of this my medical team explained is that it will improve over time, perhaps taking a year or more. So far I have recovered 30 percent of my ability to taste, but it varies daily. Swallowing was a totally different



animal. Six weeks into my radiation, with seven more treatments to go, I hit the wall. My pain level rose to a ten, and I could not swallow anything. Dealing with this amount of pain was impossible. I crouched on the floor, eyes closed, my body rocking back and forth, while desperately trying to sip water and Ensure to stave off dehydration. Each breath and swallow felt like a thousand shards of glass were being pushed further into my throat. I



spent three days under palliative care with IV's for hydration and adjustments to my medications. Gone was the morphine that had ceased to work. I now had a fentanyl transdermal

patch to get my pain under control. This was supplemented with dilaudid transmitted through my IV's every four hours. When I was released from the hospital my pain level was now at eight and under better control. I came home with the fentanyl patch, the dilaudid, and I was taking Tylenol and Motrin around the clock.

Four days after being discharged by palliative care I slipped and fell on ice while at my office, lacerating my kidney. I started passing blood in my urine and soon I was back at the hospital for a CT scan and further tests. I was hospitalized for another three days while my kidney stabilized. Thankfully I was soon released and back home. This new health scare gave me another insight into how fragile life can seem when your health is precarious. I am fortunate to have seen the ravine from the top of the cliff but even more fortunate not to have fallen off.

I hope you now understand the positives and negatives of receiving the gift of stage four squamous cell HPV head and neck cancer. The treatment from my amazing medical team worked, and today I'm cancer free and my prospects are bright.

Cancer is now a permanent part of me and my legacy and knowing this I plan to remain in control of my cancer—I am determined that it will never control me.

Beyond my cure, the greatest gift has been the opportunity to experience a new side of life and to be able to share it with others.

As for fragility and mortality, I know they are always going to be there, but I am moving away from both, at least for now. It's not my time. But I'm grateful to have been forced to confront what is inevitable in life, because it has given me the focus and drive to achieve more. I will strive to enjoy all the best things in my life until I draw my last breath.

What I hope to impart is that the next time you are surprised by an unexpected and challenging event consider that it may be a gift in disguise.

## STATS ON HEAD AND NECK CANCER

\* *Head and neck cancer accounts for about 4 percent of all cancers in the United States. In 2019, an estimated 65,500 people (48,000 men and 17,500 women) will develop head and neck cancer. While younger people can develop the disease, most people are older than fifty when they are diagnosed. More than 90 percent of the tumors are squamous carcinomas. Cancer of the head and neck can arise in several places, is often preventable by a HPV vaccine, and if diagnosed early is usually curable.*



### *About the author:*

*Robert Miller is an accomplished photojournalist and author. His three award-winning books include his latest, Veterans Voices, published by National Geographic Books. He and his wife, Colleen, live in Canton, Michigan. They have five adult children and five grandchildren.*

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