

## chapter 1

# My Diagnosis

I first began to face the reality of my impending death in April 2013. I had just recovered from a hip replacement two months earlier when I developed a cold and a nagging cough. I didn't feel too bad. After the surgery I was walking on my own again and excited to not have any pain. I didn't want "a little cold" to slow me down, so I never gave it a second thought. When Gary became sick with cancer, I went to work full-time; plus I had to be there for the three children. I learned to just keep going when I did not feel well. I became good at ignoring sickness or not recognizing when I was ill, but this resiliency did not serve me well when it came to the persistent cough.

At my first appointment with my primary physician in April, he told me the cough was due to allergies. I was looking forward to an upcoming trip to attend a conference in Florida, so even though I was not feeling well I went ahead and flew there. While at the conference, I felt progressively worse. I barely had enough energy and breath to walk to the airport gate for my return home.

The next day I returned to the doctor, who now told me I had a problem with my heart. Following that visit, I was admitted to the coronary intensive care unit (CICU), and a tube was inserted into my pericardium. I was hooked to suction for forty-eight hours. The pericardium is the sac around the heart, and mine was full of fluid. This was squeezing on my heart, causing a condition called cardiac tamponade. Almost a pint of fluid was removed. After four days, I was transferred to the medical floor of the hospital. Two days later they discharged me with a diagnosis of pneumonia and switched me from IV to oral antibiotics.

In spite of knowing that information, I continued to be in a state of denial. I knew that tamponade was associated with cancer—if the fluid is bloody, it is a strong indication of cancer. But I somehow blocked out that possibility. I look back now and believe that, unconsciously, I was growing more and

more fearful. As an oncology nurse I used to wonder how people could be in denial and ignore blatant signs of cancer. Now I know. Looking back, I cannot imagine how I did not question it because every sign spelled cancer. I do wonder how the doctors could have missed it too. Perhaps denial was the only way for me to have time to absorb the truth of my physical condition.

During that time, cancer was briefly mentioned by medical personnel and then ruled out. Now that I look back, I am truly disgusted that I did not advocate for myself and request a pulmonary referral. I just didn't feel bad enough to think I could have cancer—in hindsight it couldn't have been clearer. I stayed on those oral antibiotics for more than a week and went to my physician again. This time she told me it looked like I had tuberculosis. She then called a few days later to say I did not have it. That was no surprise. I knew I did not have TB. I felt angry, impatient, and more realistic. At this point, I asked to see a lung specialist.

A week later I saw Dr. Hicklin. He put me on a third antibiotic and asked me to come back in two weeks or so, which really concerned me. I thought, *Two weeks? Why so long when I keep getting worse?* At the end of a week, I called for an earlier appointment because I was coughing almost continually

and getting more short of breath. It had now been *more than two months* since I started trying to get relief from my persistent cough.

At the appointment, Dr. Hicklin performed a thoracentesis to check for fluid around the lungs. A long needle was inserted between two of my ribs and about a quart of fluid was taken from around the lung, and I could breathe better after that. Then the fluid was sent to the lab for pathology testing. That afternoon I went to the hospital for a bronchoscopy, in which a biopsy was taken of a mass that was found in my lung. Dr. Hicklin assured me he would call the next day with the results of the bronchoscopy.

The next day about noon, even though he was out of town in Chicago, Dr. Hicklin called to say, "I am sorry to tell you that you have lung cancer—adenocarcinoma of the lung. I am going to call Dr. Buroker right away."

I felt comforted by that because of my long relationship with Dr. Buroker. He called me within twenty minutes after Dr. Hicklin notified him and asked me to come to his office at 4:00 p.m. that same day.

My mind swirled for the three hours prior to going to see Dr. Buroker. *I surely can be cured—after all, I have worked in oncology, hospice, and palliative care*

*for thirty-five years. It makes no sense for me to have cancer—especially terminal cancer. I felt numb and unable to get one thought straight. I asked myself, What is going on? I thought of the people I cared for all those years and had given chemotherapy. They were so sick. I remembered that the ones with lung cancer often died. My memories of caring for those people made me feel scared and vulnerable. Then my mind would dismiss those thoughts and go to, This is just a small thing. It won't amount to much.*

When I went for my visit, Dr. Buroker gave me a big hug. I felt bad for him. I could tell it was hard for him to get the news about my condition. I knew he would be concerned for me, and I didn't want him to have to go through that. At the same time, I wanted him to be my oncologist. I trusted him completely. He explained the pathology report and added that we would need to get more tests to know what we were dealing with. He would order blood tests, a brain scan, and a PET scan to make sure it hadn't gone to the liver, bones, or brain. Dr. Buroker gave me hope, saying that there was currently a pill out that did not have side effects. With this pill, there was a 60 percent chance I could live five years.

My reaction at that possibility surprised me. I thought, *Gee, five years isn't very long.* A blood test would indicate the results, and I didn't ask him

what the prognosis was if I didn't qualify for the pill and had to go on chemotherapy because I was afraid of the answer. He was so kind and assured me, "We are going to do everything to whip this, Juice."

The new pill seemed to be amazing and hopeful. Yet why did five years seem so short? Was I just being greedy? I thought, *Dear God, my only hope is five years. That doesn't seem like nearly enough time. I feel helpless. My granddaughters Margaret and Anabel will still be in high school. The other grandchildren will still be young too.*

I received all my appointments for the scans and tests. Then I left. Again, it kind of felt as if I were watching all this happen to someone else. It just couldn't be me. I love and trust God so much. I don't fear dying, but I thought I would live a much longer life.

## chapter 2

# Telling My Children

*I must tell my children.* The thought of letting them know brought immediate heartache and added to my difficulty of accepting the diagnosis. They, of course, knew I was having some health issues because of my hospital stay two months earlier. I will never forget the day I had to call and tell them about my cancer.

First I spoke with Mike because he lives near me in Des Moines. I always think of him as a gentle giant because he physically appears strong and yet has such a soft heart. Mike had been extremely distraught when I was in the CICU. I felt the news of my cancer would be even more difficult for him. Mike and I have a close relationship. For the last

fifteen years he's lived in Des Moines, and we have become used to helping one another. When Mike's dad, my husband Gary, died, Mike lived a great distance away in Atlanta, Georgia. Nevertheless, he came back to visit me every four to six weeks during the first year after Gary's death. It broke my heart to have to call this dear son of mine. When I phoned and told him about the diagnosis, I could tell he was immediately shocked and brokenhearted.

I tried to lessen his hurt by assuring him that I was seeing Dr. Buroker that afternoon and would call as soon as I was finished. Mike could hardly talk, but he tried to be brave and asked, "Do you want me to go with you?" "No," I said, "I won't really find out much, except be scheduled for tests." I knew he wanted and needed to be with me so I suggested, "I'd love for you to go with me when I get the results of the tests."

When her children are sad or unhappy, it breaks a mother's heart. I have always believed we are only as happy as our saddest child. I desperately wanted to protect all my children from a broken heart, but I was helpless to do so. They each went through such deep sorrow when their dad died nineteen years ago. I didn't want them to have to go through that sorrow again.



I kept wondering how Mike would share the news with his sons, fourteen-year-old Griffin and twelve-year-old Garrett. I have a loving relationship with these grandsons. They came to the hospital several months earlier to see me when I was having tests. At that time, Garrett crawled onto the bed beside me and sobbed. Griffin looked desolate and scared. All the tubes and beeps of the CICU must have been frightening. I tried to assure my grandsons that the doctors were going to help me get well soon.

When I called my only daughter, Julie, in Kansas City, Missouri, to tell her about my diagnosis, she responded much like Mike did—instantly upset but attempting to be brave. Julie and I have always had a close relationship, so much so that when her college roommate moved home, Julie wanted me to come and stay with her in the dorm for a few days. We have always been able to talk easily with each other about almost everything. We call each other every day. Julie is married with three children and works as a nurse in pediatrics. She drove to Des Moines and stayed with me while I was in the CICU and gave me a lot of nurturing. I could tell she was just as scared as Mike. I sensed her worry all along, but I didn't think I was sick enough for my situation to be so serious. After I gave Julie the bad news

she immediately wanted to come from Kansas City, three hours away. I responded, "Please, don't come yet. We won't know anything for a while."

Julie's three children are sixteen, fourteen, and eleven. I knew they would also be distraught because I am as closely bonded to them as I am to Garrett and Griffin. When Julie's children came to visit me in the CICU, they were sad and concerned. They had never seen me that sick before, and it was frightening for them.

After talking to Julie, I called Joe, who lives in Lynchburg, Virginia. He has always been the one who doesn't show much feeling; he has been the one to be concerned about everyone else—a trait of being the oldest child. Joe is an ENT surgeon. He didn't voice as much emotional response as my other two children because of his years of masking his feelings with patients. Instead, he sounded professional, asking questions. Joe had previously spoken with my other physicians when I was in the hospital, so he might not have been quite as shocked as my other two children were. He probably sensed the severity of my symptoms.

I knew Joe was obviously worried when he suggested, "I'll travel to Iowa to be with you." But I also asked him to wait until we had more information. Again, as a mother, I wanted to protect my children.