

Kath Brown

December 2018

MY STORY

IT'S BEEN ALMOST SIX YEARS SINCE I ENTERED THE WORLD OF AN
ICU – A UNIVERSE I NEVER WANTED TO EXPLORE.



Memories of sitting next to the bed of my husband, Dave, come back rather easily. For anyone who has found themselves in a similar situation, it is likely the journey to get there was a story in itself.

For me, it started about seven months before. Dave was beginning the regimen to cure Hepatitis C with a chemotherapy cocktail that included Interferon. There were many days filled with nausea, shots in the belly, sores, loss of appetite, deafness in one ear and extreme emotional disorders. The latter was the most unnerving. Anger, crying and apathy had never been a part of our marriage. But these lurked about continually, showing up without warning and overshadowing everything. It was tiring, and for me, discouraging. Throughout these months the man I knew grew thinner and yet more insistent. His commitment to following through with the “cure” reflected his personality: he wasn’t a quitter. At times I wished he were.

The day before he ended up at the hospital, he had invited his physician friends to our home to hook him up to a saline IV. His climbing our stairs had become crawling on hands and knees to the second floor. This hydration was intended to strengthen him until his next doctor’s appointment. It, ironically, led him to downtown Cleveland Clinic main campus. When I got the call to inform me he would be admitted to the ICU, I was actually not surprised. And I was, for sure, relieved. For a brief few hours I could breathe and not wonder whether I would find my love on the floor motionless.

The sense of calm didn't last long. As I drove forty-five minutes on the road that would become a well-worn path, many thoughts passed through my head. I realized I would have two worlds to balance. One was at home with a puppy left behind. My two grown children, a son-in-law and two grand boys all flashed before me. I sensed obligations approaching that formerly were shared. I faced uncertainty, and it squeezed me so tightly I could barely swallow.

Entering the parking lot of a huge health complex reminded me of all those in beds, the many technicians, labs, nurses, physicians and, like me, partners waiting or scurrying to uncover answers that offered hope. As I walked the hallways, the smells, the sounds and the numbered rooms told me this was not my comfort zone. The report given me was terse. I felt responsibility slam down on my shoulders. I began the calls to our family.

It was right they should come so far so fast. But it emphasized what I really wanted to deny. There would be no quick fix. My introduction to the confusion of this new life came quickly. Dave's phone had been stolen, and I couldn't find his billfold. The everyday equipment of normalcy was crumbling. Right from the start, the tug of maintaining home and focusing on the patient stretched out before me became real and exhausting. That was before my daily routine consisted of hours at the foot of a bed listening to beeps, alarms, heavy breathing, whispered orders, staring at nothing and then trying to see the something that Dave said was there, but wasn't. Every morning I wondered if I could go another day. My prayers were intense. All I had ever found in my walk as a follower of Jesus, I leaned into. My children supported me, sometimes told me hard things and tried their best to comfort me. My daughter was a pediatrician, so her medical explanations were very frank. There came a time when the knowledge she had was so agonizing, she backed off reading the hundreds of test results. Every organ in her dad's system eventually broke down. Scientifically, the cause was not completely understood. On one occasion she told me flat out: he is not going to make it. Our son, an attorney, kept watch on the protocol. He slept at night next to his Pops, eyeing his position and all the machinery that surrounded him. He made note of changes. This allowed me to go home at night and sleep.

One of the primary ICU doctors had given me good advice when I was concerned about my role in this drama. He said this would be a marathon. I needed to pace myself. It became apparent that ours was an extremely unusual situation. Dave was technically the boss of that physician and also the staff that cared for Dave. Not only did they clinically connect with him, they had personal relationships with him. My desire was to make sure I reflected in every way the values of our family and our faith. Unfamiliar, completely, with medicine, I never wanted to get in the way of these wonderful people who worked so hard and did their best. This awkward place often baffled me, frightened me and yet it was the only place I should be. But sometimes I would have given anything to escape. The insight I was given by those who surrounded me was proved right. It would be a long race that required stamina.

Unlike some patients, my husband was poked and prodded by interns, residents and his contemporaries. Discussions were endless among them; they were looking at perplexing, mysterious problems. Dave would come in and out of his mind. One lunch, my daughter and son wondered with me if he had lost brain function. This was a critical aspect of how we would proceed. Being mentally right was a high priority for the man we knew. Sometimes, what I came to know as ICU delirium, would cloud our assessment. But thrown in the mix were very coherent observations. He would tell us to do what a particular doctor prescribed. His sense of humor even peeked through, making us aware of a visiting “nut”, as he described her, who had hovered over his bed. He could be so very tender in his conversation with me, speaking of his love and his heavenly glimpses. He recollected he had a dog he wanted to walk, the foods he wanted to taste and how the institute needed to hire a certain physician applicant. The ups and downs of his thinking kept us speculating.

The two hardest days were when the visit to the “family room” confronted us. My daughter enlightened me with the fact that this room was reserved for bad news. Knowing that never blunted the pain, and listening to all scan results and possible outcomes was overwhelming. At the first gathering there, the facts were followed by prayer, deciding on a plan and figuring out who would implement the next steps. I understood the moral onus. Ultimately it fell on me. Not knowing what would ensue, we delegated our son to go to the bed and awaken Dave. He asked him, after a brief explanation of the graveness of his condition,

what he would like us to do. I remember looking at this once fit man. Now he was down about fifty pounds, hooked up to lines and his ruddy complexion had turned gray. But he stirred, pulled his head up and answered, "Do the next thing." So we did.

He had an interlude of awakening after that. It was, what I believed to be, a gift for me to say good-bye. One of his kind nurses shaved him and suggested I lay next to him. So I did. I thought I would never be able to do that again.

Days droned on in a setting of grim sickness. And yet, those days were a testimony of clinging to something. For me, as a Christian, I had to come to peace with the possibility everything could change. I might be a widow. I may have to move. The rock of a man I leaned on could be gone. I left the room I had come to know in every detail, took the elevator down and stepped out on a stone path that led to a park bench. It was a beautiful, sunny day. Were there days still like that? Was someone somewhere having a normal day of shopping, lunching and laughing? For an instant, I was overwhelmed by a verse in Isaiah I had memorized. "I am the Potter and you are the clay." I was somehow refreshed by that. I knew again that no matter what, God had me and had my Dave. I stood up and took that pebbled walkway. I came to a Y. I muttered to myself: "I don't know which way you will take me. I just know either one belongs to You." I had settled in my heart I could do this.

The next "family room" encounter was a little different. It was a meeting with a physician friend whose family had become close over the years. We met to talk about a really hard thing. Should we put Dave on a ventilator? The time had come to decide that. The best part was this professional before me knew us, knew our family and absolutely knew Dave. They had played basketball together, joked and shared meals. I got the risks that were outlined. But, there were three things I was convicted of at the moment. First, the decision was mine alone. When I said "I do" I took that on. Second, my thinking could not be clouded by fear, one-way or the other. I would undergird this process with trust in the Lord. Third, the man I was married to was a fighter. He was decisive and strong. At the end of that conference, I distinguished the right thing and I did not hesitate. We would try the ventilator—as Dave had said before—do the next thing.

Twice I left Dave's side during that month. Once was when he awoke and ordered both my son and me to "get lost." It was said in a manner I would not have argued with, and I sensed the giving he was offering. We both took it. I went to Target and strolled the aisles. I bought nothing. I just wanted to know the world was still going. I marched back the next day with renewed energy. The second time I left that room was after they began artificial ventilation on Dave. He struggled to breath, and he told me everyone was trying to kill him. I tried to convince him that we were all there to protect him, but in his wild nightmares he was adamant. I had gone home every night and pounded out emails to request prayer, and this development required even more focus. With this conviction, my trying to be strong collapsed. Tears came. I just couldn't do this. My son came to console me, as he did so many times. He gave me the permission I wanted so desperately—to leave for a while. I felt like a coward, but I pulled the curtain back and sped away from that rhythmic in and out groan of a machine that kept my soul-mate alive. A restroom can be a refuge for a broken heart.

But sometimes broken hearts mend. During the night, I got a phone call. Never good. Except this one brought the voice of my son telling me Pops had awakened! He seemed lucid and was using an alphabet board to tell his nurse to remove the breathing tube. He typed out: I've never felt more alive! And he was asking for me. I have never gotten dressed quicker, driven faster nor parked my car more crooked. Arriving to see my one-and-only sitting and seemingly responding to a particular drug that I actually had objected to, was just the moment I had dared to envision.

As I left at the end of that day, our ICU attending motioned me over. His typical look was reserved and calm. That night he was edgy. He whispered in a gasp that he was going to get fired! I was unsure what he meant. He told me that Dave had ordered him to take out his breathing tube, and he felt it wasn't the right time yet. Without a pause, I assured him that after forty years of marriage, I had ways of making sure that never happened. I knew somehow this would be resolved. It was. Not long after that, my hubby was breathing on his own.

There were so many fears a non-medical onlooker, like me, had. Looking at a line that should be yellow with urine but is clear and empty

was horrible. Overhearing that a heart rate so fast can't be sustained was harrowing. Seeing a skeleton supine for days on end forecasted death. But, budding out of despair came inches of hope and a trajectory of rehabilitation. That also took months, and not without a side-glance of skepticism by me! But strength to fight grew into a powerful conviction to overcome. Overcome . . . that was a word and a song our family clung to.

That recovery victory would have been enough for us. But there was more. Dave's suffering produced the realization that he had become a man with the mind of a physician and the heart of a patient. He took early retirement from a familiar job to start a company. Curadux was launched from our story. We were so blessed to have many "care guides" in our unique circumstance. I had access to more opinions and insights than I could possibly absorb. My children, son-in-law and grandchildren were able to be with me, to counsel and encourage. But, for many, an experience of near death, imminent death or serious illness is overwhelming. Having a physician giving wise and experienced input, assurance or information can be critical. Explanations of the notes taken in conference or of medications utilized or outcome possibilities can be invaluable. Being able to get video conferencing with relatives far away and a doctor there to assist in the conversation is a benefit that is therapeutic in itself. It continues to be a marvelous privilege to share how our wholeness can bring healing to others. I never would have imagined Curadux. It is offering back for the miracle we were given.