I REFUSED TO DIE

CHAPTER I

It was early June 2005, and I was lying flat on my back in the Transplant Intensive Care Unit, unable to move a single muscle, to talk, to swallow, to nod my head or even to blink my eyes. I didn‘t know Pope John Paul II had died and Pope Benedict XVI had been selected to replace him. I didn‘t know Tiger Woods had won another Masters. I didn’t know Hunter Thompson had blown his brains out. I didn’t know vice president Dick Cheney, speaking for the Bush administration, had declared the Iraq insurgency was in its “last throes. “ I didn‘t know a world even existed outside room 2941 in Baptist Memorial Hospital Memphis.

To put it mildly, the heart transplant I received on April 3, 2005, did not go smoothly.

I eventually learned I went into a coma in early April and didn’t come out of it for two months. I also learned later I spent a significant portion of those two months on life support, hooked up to a ventilator to breathe for me after my lungs collapsed and a dialysis machine to remove the waste from my body after my kidneys failed.

My family, particularly my wife of three years, had to make the agonizingly difficult decision whether to withdraw life support and allow me to die, as many of the doctors were recommending, or to go against my stated wishes and allow me to be kept alive by artificial means. Fortunately for me, they chose this time to let me live. They made the decision only after two different scans showed my brain still was active and I was not brain dead.

In the diary kept by my wife during the period, Deborah (not her real name) recalled being awakened before dawn on April 6, 2005, by a telephone call from one of the ICU nurses.

“Do I honor my husband’s Living Will, which called for no preservation of life by artificial means, or do I give him a chance and allow the doctors and nurses to do everything they can

to sustain his life?" was how Deborah framed the question put to her at that time.

It was a query Deborah would face many times before the long ordeal was over. It also was a quandary causing me once I regained consciousness to renounce my Living Will and vow never to have another one. From then on, I relied on a Medical Power of Attorney appointing someone to make those decisions for me when they came up if I were unable to make them for myself. After all, if the doctors had followed my Living Will, I would be dead.

In addition to the ventilator and dialysis, I received sustenance through a feeding tube. My medications had to be crushed, liquefied and given to me through the tube. I received literally dozens of blood transfusions. My endocrine system was shot. All the major organs in my body failed or tried to fail. I had been clinically dead on two different occasions -- once for six minutes and again for three and one-half minutes. I only know those things, of course, because the doctors and nurses told me later. I have absolutely no idea how I managed to escape those clinical death experiences without significant brain damage. I believe it was by God's grace. I don't know what the doctors think.

"At least I still have my mind – or at least some of it," I told myself to keep going through the worst of the conditions when I became aware of them.

I never had any of the near-death experiences I have read of others having. I never saw any bright lights or any dead friends or relatives beckoning me to the other side. I never saw myself looking down on my own body lying lifeless below me. I never heard anything said to me during the time I was in a coma. I simply went to sleep in April and woke up two months later in June. It was as if I had just been asleep for the night. It took a long time listening to others for me to realize I had been in such a long coma. I was terrified and I had no way to communicate the terror to anyone. All I could do was listen to what others were saying to me. I

couldn't even nod my head to indicate I heard them. To be cut off from all communication with another human being is in itself a frightening proposition.

The most startling discovery was that sometime during the two month coma, I became 100 percent paralyzed. I heard enough and understood enough to quickly realize no one knew exactly what had happened to me. The ten specialists treating me were puzzled and divided. It seemed as if the ten doctors had ten different ideas. The neurologist called it "undifferentiated polyneuropathy." In layman's terms, he meant many nerves were messed up in ways he couldn't explain.

My transplant surgeon was convinced, and remains so today, the paralysis was caused by Guilliam-Barre' Syndrome (GBS), a rare and severe form of polyneuropathy characterized by its rapid onset and by the fact near 100 percent recovery almost always is possible, although in severe cases the recovery can take years. I, too, am convinced GBS was the culprit and remains responsible for many if not most of my ongoing physical problems, particularly the extreme fatigue I still experience more than four years after the transplant, and the numbness and tingling in my feet and hands. These are classic GBS symptoms.

The GBS Foundation says the disease strikes only about 2 people out of every 100,000. There are no definitive tests for GBS, but one of its characteristics is the paralysis goes from the feet to the head, then reverses itself by going from the head to the feet. Because I was in a coma at the onset of the paralysis, no one knows exactly in what order it occurred. It is certain, however, I recovered first in the head, then in the upper body, then in the trunk, and finally in the legs and feet.

"Certainly every indication is you had GBS," one of my physical therapists said as she watched the order of my recovery.

In addition to the physical problems I faced as I came out of the coma, I also was confronted by the fact I was undeniably bat-shit crazy. I experienced horrible, terrifying hallucinations. At the time, I had an older sister who was dying with Alzheimer's disease. I was comforted by my assumption she didn't know she didn't know what was going on around her. My experience made me question tha assumption. I was fully aware I was crazy; I just was unable to do anything about it.

"I certainly hope Gradine doesn't have to go through this, too," I thought many times during this period.

One night I was so certain bugs were crawling all over me the nurses had to ask my wife to return to the hospital and help calm me down. I knew on some level the bugs weren't real, but still Deborah spent the entire night pretending to wipe the bugs off me and giving me some degree of comfort. A clock on the wall tried to attack me repeatedly during this terrifying time.

"Am I completely nuts?" I kept asking myself. "Will my sanity ever return?"

At some point during the coma, I was placed in some sort of a special bed which turned me every two hours in an effort to prevent me from getting bedsores. It didn't work, by the way. I had terribly painful pressure sores on my buttocks from lying for so many hours on my back both during the coma and after I was awake, but unable to move on my own. In my hallucinations, the special bed looked to me like a big birdcage suspended from the ceiling, with me locked inside.

I also hallucinated the "fact" one of my very favorite nurses sexually assaulted me. I kept the disturbing bit of misinformation to myself. I also thought other caregivers, including other nurses as well as my wife, tried to harm me. I fired a number of nurses during this period, but they wouldn't stay fired. They just kept coming back to take care of me.

Not all the hallucinations were bad. Some, in fact, were quite enjoyable. I thought one night I saw one of the male nurses and one of the female ones fornicating in the corner of my room. They seemed to be having fun. I enjoyed being a voyeur. I kept that titillating tidbit to myself, too.

I learned later distrust of caregivers is the most common hallucination of those suffering from what I now know to be ICU Psychosis, a recognized medical condition experienced by a vast majority of patients who spend significant time in intensive care and on ventilators. I spent almost six months in the ICU, counting the time I spent there from Jan. 19 until April 3 while the medical professionals kept me alive until they could find me a heart. I was on a ventilator for almost two months. I had every right to be nuts.

A professor of philosophy at the University of Toronto, Cheryl J. Misak, PhD., wrote a first-person account of her stay in an intensive care unit and on life support in which she reported hallucinations almost identical to my own. (*American Journal of Respiratory and Critical Care Medicine*, Vol. 170, pp. 357-359, 2004)

"Dying is easy, "Dr. Misak said. "It is the coming back that is unimaginably difficult."

She described her near-death experiences exactly as I found mine, "peaceful and pleasant," but said coming back from the precipice was much more difficult.

"I would have to be horribly unlucky, I thought, to come back from near-death a second time. "

Welcome to my horribly unlucky world.