Chapter 1

Home from Alaska

August, 1991

Dean

It was a late summer evening on the top deck of an ocean liner cruising south off the coast of Vancouver Island. The sea still reflected the multi-hued twilight sky in the west, and distant dark pine forested hills slid by in the east. For a moment, it was easy to feel at peace, that the future was predictable and promising.

Peace had not been a common feeling for the previous six months. My wife, Mary, perhaps hearing the ringing bell of mortality when she turned forty-one, had gotten a new internist for a full physical and promptly completed her second mammogram. Her doctor called me the next day to tell me the test had shown a small tumor that had not been present the year before.

"Do you want to tell her, or should I?" she asked.

I thought about it for an entirely too short a period of time. Mary was busy, she hated going to doctor's offices. I knew exactly what was wrong and would arrange the next referrals, and as a neurosurgeon I was accustomed to giving bad news.

"I'll take care of it," I said.

The next several weeks were filled with a radiology-guided biopsy, a long discussion of

alternative treatment plans, a bilateral mastectomy, and the beginning of a six-month course of chemotherapy.

And a whole new family dynamic. Mary fought depression while I fought back, encouraging her by chirping things like, “It has a very good prognosis.” Our children sensed our fear and reacted with a cautious uncertainty. Every day I would come home from work, and Mary would search my eyes and body language for secrets before asking if someone had talked about her case that day, if someone had given me bad news, if I was withholding something vital from her. “No,” I would chirp, and she would not believe me.

We scheduled a trip to Seattle to reunite with Mary’s brothers and sister along with their families. Since the death of her mother eighteen months before, they were all making a conscious effort to keep in close contact from all corners of the country. A cruise to the Alaskan Inside Passage seemed like a good add-on after the family reunion, a chance to heal before returning to “real life.”

Adam was losing at ping-pong. “I’m seeing two balls,” he said. “I don’t know which one to hit.”

Oh, no, I thought, *brain tumor*. I had seen dozens of patients whose initial symptom was double vision. But immediately I quieted my alarm. Kids get double vision for many other reasons, I told myself. I’m on edge because we are just recovering from Mary’s diagnosis. And I’m not his doctor; I’m his father.

It’s probably nothing, I told myself.

A week later his pediatrician examined him. He said, “It’s probably nothing, but I’d like him to see an ophthalmologist.”

A few days later the ophthalmologist called. “It’s probably nothing,” he said, “but I’d like

him to see a neuro-ophthalmologist."

At this point, I scheduled an MRI scan for my own son on the afternoon of the same day as his eye exam a week later. I no longer believed it was nothing. But I did not want to tell anyone until after the tests were done and I could be absolutely certain. We didn't need unnecessary worry, and I could conceal my fears and "stuff it down."

Medicine has a tradition of what psychologists call dissociation. I call it "stuffing it down." For two decades I had learned that when you're the one involved in direct patient care, everything else gets stuffed down. You're hungry or tired or sick? Your mother and father are coming to visit? You just had a fight with your wife? Your kid has a fever? Nobody cares; stuff it down.

Examples go way back in medicine, and in neurosurgery in particular. Dr. Harvey Cushing, widely considered the father of neurosurgery, received the news of his son's death in a car accident. He took fifteen minutes of solitude then went directly to the operating room to perform the previously scheduled operation.

The ability to "stuff it down" is important. No one wants a surgeon–or a policeman, a fireman or an EMT–dealing with their own emotions when they are dealing with your needs. But detachment has its own consequences, its own scars. If you hide your emotional responses long enough, you might have trouble finding them again. You might be that cold, distant father figure that children in doctors' families so often complain about. But this time, I had good reason.

At noon the following Thursday, the neuro-ophthalmologist called to tell me that Adam had Perinaud's Syndrome, an eye condition that nearly always points to a tumor in the pineal region of the brain. At three-thirty Mary and Adam came to my office and we walked together to

the MRI center in another part of the building. They were laughing; the vacation had worked its miracle. Mary's eyes did not search me for secrets, and I hid my fears. We would all know soon enough.

Then, just as Adam's scan was about to begin, my junior partner called from the operation room. His patient had suffered a rare and life-threatening complication in the middle of an operation, and he asked me to come and help. No other neurosurgeons were nearby. It was me or nobody. I left Adam and Mary blithely ignorant of the pending disastrous results of the MRI and went to the operating room. I stuffed it down again for three more hours while I dealt with the emergency, and Adam and Mary finished the scan and went to my parents' home for a family dinner.

After the crisis abated, I left the OR, changed into street clothes and took a deep breath, knowing that no matter how difficult the last three hours had been, the next three were likely to be worse. Much as I steeled myself, my heart hurt and my legs felt like lead.

I walked across the hall to radiology, the look on the faces of my colleagues telling me the results were as bad as I had expected.

The images hung behind them in a dark room–crisp, clean images in black and white showing the tumor as a white cauliflower in the midst of a gray brain. Two words bubbled to the surface of my mind: *evil incarnate*. Evil had become flesh and dwelt among us.

Clinical jargon quickly took over my thoughts: *Large pineal area tumor in an adolescent male presenting with visual signs typical for a tumor in this area. Most likely diagnosis: germinoma*. My mind flips forward to surgical approaches for a tumor like this, the advantages and disadvantages of each, the myriad of complications.

Then I stop. I can no longer stuff it down. I am sickened by the violence that is surgery. I

am afraid. This time the tumor, this incarnate evil, is in my son’s brain.