

Chapter 7

... To Nightmare

"Great men, great nations, have not been boasters and buffoons, but perceivers of the terror of life, and have manned themselves to face it." —Ralph Waldo Emerson

Protected from the cold winter, we spent a cozy, quiet evening at home. Bambi sat in her chair in the living room next to the window reading the paper, I prepared lunches for the next day, while Amber was in her "jammies" playing with the poodles. Off the dogs went with Amber close behind. She'd chase them, catch them, cuddle them, then set them free and start all over again. Her giggling and romping was music to my ears. Though I knew she wasn't, I could pretend she was normal. I was good at pretending by now, *real good*.

The fireplace was unremarkable: Brick, with a raised hearth about knee-high and very sharp edges. We spent many evenings in front of it, enjoying the fire, absorbing its warmth. This was not one of those nights.

I called from the kitchen, "Amber, be careful. Don't run near the fireplace." Involved in her game, she didn't hear me and she didn't see the pile of newspapers on the floor in front of the fireplace. A second later, it happened. I turned the corner, to warn her again. Instead I saw—in slow motion as if to remember every detail—Amber trip on the papers and fall *full force* on The Lump. I heard it crack on the edge of the hearth. She fell to the floor in a heap.

In one movement, I rushed to her side, took her in my arms, and felt the depths of my despair rise to the surface. She was crying. I tried to soothe her. Inside my head, I screamed at God,

"WHY??? Why Amber??? Why me???" My feeble attempts to calm her were working. She stopped crying and I forced myself to look at The Lump. It was bleeding. I pressed it with a cold cloth and rushed her to the Emergency Room at Yale-New Haven Hospital.

They examined her and she seemed to be okay. The bleeding had stopped and she had no other symptoms. They gave me the name of the Chief Pediatric Resident, Tom Dewitt. We went home.

In the morning, I called for an appointment. He examined The Lump. By now, it was the size of a lemon. A small bruise formed where she had fallen on it. He looked bewildered as he pushed and probed it with his fingers. "Hmmm..." He couldn't explain it either. "It's not a tumor... it's hard and bony... it's immobile... it's benign. If it was soft and mobile, then we'd worry." He tested her for tuberculosis, gave me the name of the Chief of Pediatric Surgery, Dr. Touloukian, then asked me to collect all of the test results and x-rays that were taken over the last six months and drop them off at his office. I drove up to St. Mary's and then to Yale. For months, I'd meticulously collected every bit of information that would give me any answers... any shred of hope. I reluctantly handed them to Dewitt, never to be seen again.

The earliest appointment I could get with Touloukian was two weeks away. In the meantime, I watched her forearm for a reaction to the TB test. "At least TB is *curable*," I lamented. Three days later, there was still no reaction. "Thank God."

At 2:30 pm on March 20th, we walked into Touloukian's Examining Room. He was a kind man in his forties with a very gentle bedside manner. He did his best to put us at ease, chatting with Amber as he lifted her onto the table. Her back to him, she busied herself with a book. She faced me, so I had to be careful how I reacted as I studied his face for clues. "Now... let's see what we have here," he said matter-of-factly. He gently pulled her hair aside exposing The Lump. It was HUGE by now.

THE LOOK. *THAT* LOOK. I will never forget the look on his face as he confronted it. And I saw it before: At Rich's office and on Jeff's face when he compared her x-rays. It was the same look... the same gasping terror as I felt that night in August when I first discovered it. "*CANCER!!!*" I swear I could read his mind. It

was cancer. My suspicions were confirmed. At that moment, I wanted to die. I wanted to die and take Amber with me. I wanted to leave this world for the one beyond where there was no pain, no suffering, and no cancer.

He tried to cover his fear with rationality and professionalism, but he knew I saw "the look" and there was no turning back. Our eyes met. I knew he was a human first and a doctor second. I could feel him pulling away, distancing himself from what he knew to be true. He got down to business but with an urgency. "I want to take a look at this right away. I'll make arrangements to have her admitted Sunday afternoon. We'll operate Monday morning."

Amber, sweet Amber. She was absorbed in her book and reading the words out loud, then louder as he said those words. "Does she know?" I wondered. Quickly—almost frantically—she kept reading. She didn't look up but stayed glued to her book as if she could block out the world that spun around her.

My racing thoughts began to swirl. I felt dizzy, whirling, like we were being sucked down a drain and into a vacuum. "Here we go! Hold on!" I had no control over the spinning world around me... around her... around us. It was happening. I could only exist and allow myself to be swept along. I was an object, not a person. I had no feelings, no needs, no life as I felt Amber's slipping away.

Again I heard God's voice. Peaceful and soothing, He said, "I'm here. You are not alone, but in Me. This *must* happen. It is meant to be. Her death will come soon and I will help you through it." Every part of my being wanted to deny this. My motherly instinct to protect my child was replaced with a hesitant, knowing, acceptance. I looked at Amber differently now—almost reverently — as though she truly *was* a messenger from God... an angel sent to me. Her life, and now her impending death, had meaning and a purpose not yet revealed.

No matter the destiny or outcome, I was put on this path to save her life first, if I could. Whatever it might take, I was willing to try... to sacrifice... to beg if I had to. *I wanted my daughter to live!* I *needed* her to live a full and happy life. I longed for My Dream to

come true and to share it with Amber, Gary, and Todd. This family and the bond that we formed could not be abandoned.

I explained it all to Gary. He knew the truth now, but still refused to say it out loud. We didn't talk about reality. We continued to know but pretend that everything was okay. Still, our actions betrayed this. He helped me pack her suitcase for the hospital.

It was a Sunday afternoon like any Sunday afternoon. Spring was in the air. After a long and dreary winter, the world had renewed its hope. We stopped at the local hamburger stand for some lunch, hoping to delay the inevitable. Neither one of us had much of an appetite, but the kids were ravenous. We fed most of our food to the pigeons as we watched Amber and Todd playing on the picnic tables. This was the last glimpse of our fairy tale life together and we knew it without words. We said volumes with our eyes. He reached for my hand and squeezed it. We were in this together.

Somehow, word by word, step by step, we got through Admissions. Our private room on the third floor was in the "Experimental Wing" of Yale-New Haven Hospital. Small, but bright and cheerful, we set about making it home for the next several days. My cot was placed next to Amber's bed. We put the toys she brought on the table, some drawings on the walls, and her stuffed animals in bed. It was late afternoon. We got acquainted with the staff then set out to explore our new world—the playroom, other patient's rooms, the laundry room, the halls. Since it was Sunday, things were pretty quiet. Amber was the only patient on the floor.

Later in the afternoon some students came by to examine Amber. At that point, my daughter became a "patient," not a person... not a human being with an illness. They talked about her as though she wasn't even there. Probing, squeezing, studying The Lump all the while forgetting who was attached to it. I heard various expressions of perplexity and clinical analyses exchanged between them as they discussed the ramifications of surgery. Then they left, barely acknowledging Amber, a little girl who was facing cancer, and a mother who was at her side.

That night, another series of x-rays were taken. We wheeled her on a stretcher down to the basement where the x-ray department was located. The technicians were taken aback by the enormity of The Lump. It was now the size of a tennis ball. I shifted uneasily from one foot to the other as I watched them prep her. I laughed and joked. I made it a game so that she could live through it... so that WE could live through it. I acted like this happened every day. Yes, I *acted* to keep her from sensing my underlying panic. I knew how to act by now.

While Amber was in the x-ray room, I asked Dewitt, "Are you *sure* this isn't cancer? I mean, it's so *big!*" In two weeks, it had doubled in size. "No, Mrs. Calistro, it's not cancer; it can't possibly be cancer." "Can't possibly be cancer... it can't *possibly* be cancer." Those words went round and round in my mind as I waited for her to come out of that room. I wanted to, but couldn't, believe him.

Back in our room, Amber and I read a book about kids and hospitals that the staff had given us. "Mom, are they gonna take my Bump off? Will it hurt? Are you gonna be with me?" I answered her questions as casually as I could. "Yes, they are going to take it off tomorrow morning, Amber. It'll hurt a little bit but the doctor will give you some medicine to make you feel better. I'll be here the whole time. I'll never leave you, Amber, *never.*" After our discussion we went on to more important things like coloring and playing with her Barbie doll.

Gary came by to see us and find out what we needed... what he could do. He picked up the pieces of my life—paying my bills, cleaning our clothes, making sure our loose ends were secure. Knowing he was at my side and Amber's, was the "rock" I leaned on for strength and courage. Nothing obligated him to be here, but his love for me *and* for Amber, compelled him to stay. He was the one person I could count on... the one person who cared.

Michael visited for an hour or so. He hadn't been involved much and I didn't have the inclination or energy to find out why. I needed to focus on Amber. I asked him to bring his camera, since I didn't have one, so I could take a "before" photo of The Lump. Although I wanted to document this, I didn't know why. The reasons were about to unfold.