

Chapter 14

Crossing the Threshold

"The call of death is the call of love. Death can be sweet if we answer in the affirmative, if we accept it as one of the great eternal forms of life and transformation." —Hermann Hesse

Being human was still difficult for me, but Amber inspired me to try... to allow myself this luxury. She continued to teach me about life, love, and happiness. With a full heart, I followed her example and did my best to learn and integrate the lessons she was teaching me through her life and now her death.

- **Life:** No matter *how* much time we have on this earth, we should do all we can to set aside the bad, glorify the good, and express our appreciation to our fellow human beings as often as we can. We have the power to change another life... to lift someone up, with only a few words, a smile, or a touch.

- **Love:** It is not limited to what we can see, feel, and hear. The temporal world and everything in it will be replaced. The only true love comes from one soul to another. Once it is shared, it will never be broken, not even by death.

- **Happiness:** It does not come without knowing the depths of despair, suffering, and trauma. For it is only *after* we know these things, that we can fully open to the joy and contentment that is given to us by God... by the higher power.

From the time she was conceived, I knew Amber. It was a knowing that could not be explained with words or that anyone could understand or accept or believe. They really didn't need to for it to be so. We were... we ARE intertwined, connected, indivisible. It was remarkable to realize this. I knew I needed to be steadfast in my role as "scribe." I focused on recording the rest of our life together. The closer I came to seeing the end, the more

fanatical I was about documenting. Every waking moment was captured on film or tape. Hundreds of hours of voice... of photos... of movie footage... of her drawings. I wasn't sure what I would do with them, but I knew I would need them someday. I filled one cassette case with 50 tapes and asked Gary to pick up another at the store. I was on a mission and I needed supplies.

Her physical decline was heartbreaking to watch... to stand by helplessly... to accept her fate. She was wasting away, but like a concentration camp survivor, she clung to the finest shreds of life. The instinct to survive, though it was waning, could not be taken from her. Her eyes had lost their sparkle; they were simply sunken orbs. Her legs could no longer hold her body; we carried her everywhere. Her body was shrinking before my eyes as quickly as the tumor was growing. "*How can she still be alive???*" Her spirit was the only force sustaining her; it *definitely wasn't* her body.

I spent my time tending to her, talking with her, reading to her, stroking her. The rest of the time I stayed busy doing chores around the house and preparing for her death. We talked about it freely now. "Amber, what do you think Heaven's like?" "Oh... I think it's a BIG white house, *real pretty*, with lots of rooms and you can have anything you want—cookies, candy, ice cream. And DO anything you want." "When you get there, will you save me a place?" "Sure, Mom, I'll save Gary and Todd a place, too."

October 17, 10:15 pm

Amber got "zapped" today at St. Raphael's Hospital. Radiation is now used to ease her pain, not cure her. Dr. Knowlton, her radiologist, is more than willing to work with us as a team and not an adversary. He is a good man FIRST and a good doctor SECOND. That's the way it should be.

As I left Amber and the Treatment Room behind, I stepped into a gathering of people: Nurses, doctors, technicians, hospital workers, and a priest. I don't know how they knew she was in the hospital, but regardless, they came to pay tribute. Our eyes met. Without words, they told me they shared my pain. I felt that human acknowledgment of

crossing paths down the road of life, if only for a few moments. We stood in silence, bound together by the little girl we watched on closed circuit TV. "Amber is bringing us together," I thought.

Earlier this evening, she woke up from her nap crying and sobbing out of control. "Mom, I had a dream about two swans. They said, 'We will devour the Good Guys!!!' There were butterflies all lined up, and they had faces. The ducks were eating at them!!!" I don't know how to interpret her dreams, but I'm sure they express how she's feeling deep inside. I wish I could reach inside and fill her with joy once again. One more time, just a little spark of joy.

She told me that her head and eyes were hurting. "Mom, it feels like there's water sloshing around in my head... like there's a wheel in my ear." I took a flashlight and looked inside her ear. The hole was gone; the tumor had taken over; it was solid and white like cottage cheese. I wondered at this THING... this inanimate OBJECT. "How can it be killing my little girl??? It looks so harmless... so benign." My hatred for cancer had to be hidden... had to be buried for now.

I am looking over to the lump of blankets that is Amber, asleep on the couch. "Is she..." I hold my breath, waiting to see if the lump will rise and fall. "Yes... she's alive." Then I let my breath go.

As I watched her, day after day, laying on the sofa, watching TV, playing with her dolls, drawing, or playing "doctor," I'd think, "Any day now... I wonder if today will be the day." I just couldn't believe it was humanly possible to live in a body like that. The tumor was nearly the size of her head *outside!* There was just as much growing *inside her skull!* No longer eating, her strength and fortitude and fierce determination to live replaced all sustenance. She was on her way to Heaven and food was not needed to get there.

To the outside world, what was happening inside the walls of our home was surreal. We would have occasional visitors: Gary's parents—Gramma and Grampa Stiewing, the Murray's, Jan, Nancy and Sarah, Linda Bouvier, Harry and Diane, our neighbors when we lived aboard Sea Wing. My family was

nonexistent. They "couldn't handle it," as my mother told me over the phone months before. Many people couldn't handle it. If I believed I had a choice, *I couldn't handle it either*. But I was Amber's mother. Caring for her was something I needed to do... *I wanted to do to show her my love... my undying devotion then and now.*

It took a tremendous amount of courage and selflessness to come into this "house of death." People seemed to be paying their last respects, to do what they could to encourage and support her, and to honor Amber while she was still alive to see them. She lived for these visits; she longed to be loved and embraced. Although she was leaving people; she needed to know that people were not leaving her. It was a lesson in dying that Bernie pointed out so poignantly. "We are losing *her*, but she is leaving *all of us*."

Michael lived a block and a half away, but we saw him only once since we had returned from the Bahamas. For her sake, I would quietly, secretly call him. "Amber needs you *now*." I didn't want her to overhear; I didn't want her to face his rejection ever again. He came by on his way to work to drop off some books for her. He didn't stay long. She was sleeping upstairs and missed his visit. When she woke up, I made some sort of excuse for him—I lied through my teeth—to save her from suffering his indifference and insensitivity anymore. But I couldn't spend time immersed in the past. My focus had to be in the future, however little remained on this earth. My anger for him was replaced by compassion and empathy for Amber. *She needed me to be happy and whole*. And I was—at all costs, even the cost of being honest with myself.

Amber's death was hers to orchestrate, not mine. I listened to my heart and relinquished control. "Where would you like to die, Amber, at home or in the hospital?" "HOME, for sure. I don't wanna go to the hospital, Mom, okay?" "What do you want to wear to Heaven?" "Ummm... I'll pick it out, Mom. Will you take me upstairs so I can pick it out?" I carried her upstairs and sat her on her bed while she pointed, commanded, and listed her outfit. "I wanna wear my school clothes. *Those* brown pants and... oh, yeah... *that* shirt! And my school shoes. I want to wear my school shoes," she said as though she was REALLY picking out an outfit to wear to school, not Heaven. I set everything aside, along with

her black, patent leather shoes, and tenderly placed it on her dresser. No doubt she'd be wearing them soon.

We buried ourselves in the house; rarely went outside anymore. Gary made occasional trips to the grocery store, the post office, or the pharmacy. He was our link... our ambassador. It was too difficult to travel with Amber and too painful to deal with the public. They'd stare, sometimes with their mouth wide open; other times a look of shock would spread across their face and they'd quickly turn away. Children would point and be frightened and cling to their parents as if to say, "Mommy, can that happen to *me*?" I'd look at people hurrying here and there—normal, happy mothers and fathers with their normal, happy, *healthy* children. All of those *other* children. I could feel the simmering rage bubbling under my skin, though I didn't recognize it at the time. I felt uncomfortable, that's all... just a little uncomfortable.

I could keep her out of pain, try to entertain and distract her during her waking hours, and ease her through the transition from life to death. The one thing I could *not* do was stop the tumor from growing, rotting, and smelling. Like a sickening, toxic cloud that surrounded her, the *smell* could not be ignored; could not be washed away. I could close my eyes and make the sight of it disappear, but I couldn't stop breathing the odor that emanated from it. It would stay with me long after her body was gone.

One day after Amber's bath, I wrapped her in a towel and held her in my arms; her head rested on my shoulder. I gave myself up to my mothering instincts and wallowed in my feelings of love for her. I hoped that this moment would linger. "God, it feels *so* wonderful to hold her... it reminds me of when she was a baby and I'd feel her little naked body, wrapped in a towel... her body so warm... she smelled so sweet..." The tumor was nearly touching my face. "My God, it *stinks!* From a sweet-smelling babe, to *this!* How did this happen? And *WHY???*" I would ask this question again and again, each time expecting an answer from God. My thoughts were interrupted.

"Hey, Mom, what's that smell? Did you fart or somethin'?" Knowing the truth, I lied. "Yup, I farted." "Mommy... *pee-yew!*" I glared at the tumor, now next to my face. My mind was screaming, "*I hate you... Oh God, how I hate you!!!!*" My urge was

to hit it and smash it and beat it to death. I held myself back. I buried my primal urge to protect my daughter from harm... to kill anyone or anything that threatened to kill her. "I know I'll kill *Amber*, not the *cancer*." Clinging to her cancer-ridden body, I still didn't want to let her go. I didn't want to let her die but knew I had no choice now. Though she was in my arms, she was now in God's hands. Soon, I would let her go completely.

People were hungry for more news about Amber; they were naturally curious and concerned; they truly cared. The stories that were published in the newspapers throughout her journey, though poignant and touching, were only one dimensional. When Channel 3 called to ask for an interview, I didn't hesitate to say yes. My journey with Amber was so unbelievable and she was so incredibly brave and wise, I wanted to share it, not hide away in the house like so many millions of people with cancer were doing. To shed light on the issue—even camera lights—was to keep Amber's *spirit* alive, open the eyes of the world to cancer, and give them a reason to find a cure. That was my hope. That was my motivation.

She was the perfect example of what cancer is and what it can do. Only months before, a budding child model, beautiful inside and out. Now, a beautiful child, dying from cancer, a cancer you could SEE. God spoke to me again. "Amber is My messenger. You are My scribe. When the time to bring her message to the world is right, you will know." I had no doubt her life and death had purpose and meaning. It was pointless for anyone else to go through this Hell; Amber was sent from Heaven to make sure they didn't. *This* was the reason she was put here on earth—to literally show the world how much we need to stop cancer from killing so many. The only way this can happen is to stop the fighting, the politics, and the competition... to come together... to prevent, treat, and cure cancer. Who was I to stand in her way... in God's way? I swallowed my pride, shame, anger, and embarrassment. I let the reporters come in.

Channel 3, "Eyewitness News"

- **Announcer:** *A sad report, really. A heartbreaking story tonight out of Milford, where a mother and child are struggling against cancer. A struggle that no longer has any chance of being won. Doctors say the little girl is dying. Channel 3's Pam Cross, reports the four year old child understands that.*
- **Pam:** *This is not a story for everyone. It's a strong report about death... about cancer and dying. It's about a four year old girl's dying, and her mother's indignation with the medical community. (Camera scans Amber's modeling portfolio.) This is Amber Calistro a year ago. Her mother began a portfolio, hoping she would be a successful child model. That summer, Patti Calistro found a small lump behind Amber's right ear. Right away she thought, "Cancer." But the doctors disagreed.*
- **Me:** *Generally they would say to me, "Lots of kids get lots of lumps and bumps... don't worry about it." I wanted to believe them and sometimes, I did; for periods of days, I would. But a nagging doubt led me to want to see what was inside.*
- **Pam:** *It was over six months before doctors diagnosed rhabdomyosarcoma—a very rare form of cancer. Patti Calistro says if they'd known sooner, they might've had a better chance of arresting the disease. Amber was operated on once in Connecticut. Later, she received Lawrence Burton's controversial blood therapy in the Bahamas.*
- **Me:** *She started experiencing pain at the beginning of September; but until that time, she had no side effects; no pain. We were snorkeling... playing. Amber was going to school and dance lessons in the Bahamas. We admitted her to St. Raphael's and under the direction of Bernie Siegel, who was willing to work WITH us, we had a lot of tests run. At that time, the surgeons brought me their opinions, and I decided it would do her more harm than good to have surgery.*
- **Pam:** *Patti Calistro, who is a single mother and an artist, has been busy collecting Amber's last words. She wants to spearhead an independent movement to investigate the state of cancer research and*