

## Chapter 15

# *Life Lesson / Life Task*

*"The block of granite which was an obstacle in the pathway of the weak, became a steppingstone in the pathway of the strong." —Thomas Carlyle*

Gary and I left the hospital. I felt light, calm, unfettered, and grateful. Amber was out of pain and with God. Her body, which held her captive and tortured her to the end, was just a shell. She felt no more pain, only glory. She was now on the other end of the rainbow. She was finally with God.

I felt His glory, too. I had come through the experience of Amber with a purpose to my life, a new set of values, and a better understanding of the meaning of life and death. Most of all, I saw myself as human: strong and vulnerable, good and bad, joyful and desperately sad. I knew I would always have these feelings and would always need God to see me through them. But now I had Amber, too. Not the baby I grew or the little girl who never grew up, but the angel I always knew she would be.

I began the slow process of learning how to live again. The hopeful part of me—my future—died that day with Amber. Just as a baby learns to breathe, eat, talk, crawl, walk, and function in society, I had to learn again, too. God became my teacher, parent, and friend. Throughout Amber's journey, I wanted to give up countless times. He had the strength to carry me through the unbearable times—the loneliness, depression, anger, rage, and exhaustion.

Returning home without her, I knew I'd need a plan. I started at the beginning. I returned to her Rainbow Room to pack up her belongings, but couldn't. I wanted to freeze time... to go back to the time before it happened. So, for three days, I avoided

touching or moving anything out of place. I just wanted to live in her world as she left it. I didn't want to make "it" come true.

"You're ready," God said, with a calm and confident reassurance. I was finally ready to say it. "Amber is dead." I took my first step on my way to reliving, I opened the door to her room.

**November 1, 10 pm**

*I am sitting on my bed in my room. I haven't gotten used to Amber's room being "my room" yet. I can still feel her presence here, though I know she is dead. My mothering instincts have not died and I wait to hear her voice calling me... needing me. "Mom... Mommy?" Like an echo in my mind, I can still hear her voice.*

*As I opened her closet door, I felt the first shock wave of her absence. Her clothes were hanging as usual. Her toys lay neatly on the floor, just as she left them, waiting for her return. A small pile of dirty clothes lay in the corner ready to be cleaned. This was part of the life Amber left behind. I sank to the floor—the burden was so great—and closed the door behind me. I shut out the world that took my baby from me.*

*It was pitch black. My eyes were useless, so my nose took over. I reached over to her pile of dirty clothes. Breathing deeply, I took in the odor of Amber. It was my only physical link to her now. Her dresses, pants, underwear, mittens, and dirty socks, replaced her warm touch, her smile, her giggles, that impish look in her eyes, and the sound of her calling my name.*

*I cried, but my eyes were not wet. My heart ached and so did my body. I wanted to linger in this sensory world. I wanted there to be more. "What did she leave me to find?" I opened the door and went down to the Laundry Room to search through the dirty clothes for something... for anything that would reconnect me. I found her little red change purse in the pocket of her jacket. Inside was a partially eaten Peppermint Pattie, a white marble, a bubble gum comic, and \$9. I laughed. "Oh, how she loved to collect things." My memories... I still had my memories. "No one can ever take them away."*

A few days after she died, we heard a knock at the door. We could see the shadow of a man through the curtain. Gary answered it. As he turned to me, I could read his mind. A man in a black suit stood in the opening. He spoke. "Good evening. Is Mrs. Calistro here?" Gary invited him in. "I'm from the Evergreen Cemetery Association..." His words drifted off as I looked at the box in his hands. It was small, shiny, and brass-colored. A large white label covered the front. "I'm here to give you..." I finished his sentence for him. "Amber's ashes."

I asked Gary to get a plate from the kitchen and took the box from his hands. "Thank you... thank you *very* much." The number "12788" was stamped on the lid. I pried it open and looked inside. A small envelope read "Cremation Certificate." The words "Amber Marie Calistro" and "Cremation No. 12,788" were typed on the front. Inside was the certificate dated "November 3, 1980." I read it, carefully folded it, and returned it to the envelope.

As I peered inside the container, I could see a clear plastic bag filled with cream-colored ashes and bone fragments. I poured them onto the plate. The man stood there silently, almost reverently, as I carefully sifted through Amber's ashes. I was looking for her—*any part of her*—that would confirm she was alive at one time, if not now. Nearly lost in this act, I looked up to thank the man as Gary was walking him to the door. I returned to my world.

Touching her again filled me with the love that only a mother... a woman who grew this child could know. I savored the feel of her powdered bones on the tips of my fingers as I gently set aside pieces that I would keep. "A few multicolored brown pieces... almost like small pebbles. A white one... must be her tooth. A coral-colored one... not sure what that is. A black one with a white shell. Her... her buckle from her shoe!" I was surprised to see it had survived the fire. I picked it up and placed it in the palm of my hand. A subdued and saddened joy washed over me as I thought of her picking out her outfit to die in. "*Mom... I want my school shoes,*" she insisted. My thoughts drifted. "Her life will never fill them but at least I can hold this memory in the palm of my hand *now, and forever in my heart.*"

Like I was performing a religious ritual, I returned the ashes to the bag and placed it inside the container. Keeping those few pieces out, I poured them into the small envelope with the cremation certificate. I wanted to keep them for myself, not return them to the sea. I put the envelope on top of the ashes, secured the lid, and put the container in my room for safekeeping. I thought, "How ironic. *This* container holds what's left of Amber's body while Amber's body was the container for her soul... for her spirit." It gave me comfort to know she was with me. From now on, she would always be my "Guardian Angel" and an angel to all the others who knew her as well.

Winter was fast approaching and soon the ice would trap Sea Wing at the dock. "I need to spread Amber's ashes in the Sound," I told Gary. "Why don't we ask Jim Motavalli if he'd like to come with us?" Jim had written an article titled *Amber Has Cancer for the New Haven Advocate*. It was subtitled ... *and the 'War' on the Disease is Making Slow Progress. Why?* He'd done his homework, reported on the state of cancer and the doctors who were open to various cancer treatments, not just the "big three": Surgery, radiation, chemotherapy. He explored the world of cancer and the "Cancer Industry" itself. His heart was touched by Amber; his mind reached out to save her.

We planned to sail to the middle of the Long Island Sound with just a few close friends and scatter most of her ashes there. It was a cold, blustery day as Harry and Diane motored their sailboat out of the Housatonic River and raised the sails, just as we entered the sound. Jim Motavalli, Bob and Joyce, Gary and I, silently sailed past the breakwater, all of us lost in our own thoughts. Mine returned to the past. This river held so many of our memories: The day Amber and I met Gary and Todd at Brown's Boatyard, moving aboard and watching Gary collect oysters from the warmth of the companionway of Sea Wing, many evenings spent sitting in the cockpit as a family while we watched the sun set.

When the time felt right, Harry turned the boat into, then downwind. I walked up to the bow and opened the plastic bag, allowing her ashes to blow with the wind and settle on the surface of the water. The wind was pushing the boat forward, forcing me

to say my good-byes to her body now resting at sea and heading towards my future.

A week later, Gary and I returned to the Bahamas to pack up the apartment. It felt odd to be there without Amber. Although my spiritual life had been uplifted, my physical life was devastated. My senses were floundering... groping for her. I wanted to *see* her... *touch* her... *smell* her... *hear* her. Emotionally, I was a pendulum swinging back and forth: First feeling my loss, then all I had gained from knowing her. I held on to the fact that at least I was *moving*, if not fully living.

We packed up two huge duffel bags with the things we didn't need, but someone else would: Amber's clothes and toys, household goods, and food. We took a cab to the village of Williamstown, on the outskirts of Freeport, and distributed them among the local Bahamians. Afterward, we walked down the road to the Traveler's Rest, a local roadside cafe across from the ocean, and reflected on the day. Both Gary and I felt so fortunate to *have* the things so we could give them away. We knew Amber wanted that, too.

I was reminded of Amber's Angel, Mrs. N., who had so generously paid for our stay at the clinic. When I thanked her for all she had done for Amber and for us, she modestly told us why. "Patti, it's not *MY* money it's *GOD'S* money. I'm just here to distribute it for Him." That sentence changed my life. From then on, I would redistribute God's money, too.

I returned to the 'States ready to do battle... ready to redeem Amber's death. I was going to fight for all the people who were suffering from cancer. I plunged into that world, without so much as a thought, and certainly not a plan. I lived at the library; searching for *all the* information that existed about cancer. I contacted *all the* organizations that existed *because cancer existed*: The American Cancer Society, The National Cancer Institute, hundreds of citizen action groups and others. I read *every* book I could get my hands on, watched television shows that interviewed knowledgeable guests, and attended seminars and lectures.

I did nothing halfway; there was no middle, no compromise, no balance. The energy of my grief, my burning desire to save the world, and my sense of injustice, all mixed into the pot. It was

simmering with the rage I'd buried for so many years. I learned to "keep the lid on." It would take many years before I was safe enough to boil over. But the pressure needed to be released and I wanted to scream to the world, "My daughter suffered and died in vain!" I got a call from the *National Enquirer*.

"Hello, Mrs. Calistro," the reporter said, "We've been following your daughter's battle with cancer and we'd like to do a story." We made an appointment for them to come interview me. I kept the tape recording running during our interview to resolve any possible questions that might arise. On January 20, 1981, Amber's story was told: *The Love that Death Couldn't Steal*. It didn't soothe me; it made me more determined than ever to "save the others."

I discovered the dark side of cancer; the one most people don't know (or don't *want* to know). Those that do, either want to forget or have been forgotten. It was a world fueled by money, greed, and power. People who were suffering with cancer and were desperate to live were willing to try anything. They were turned into guinea pigs and used in "clinical trials"—experiments—to further a particular research facilities' "hope for a cure." They stopped being people and were turned into statistics and those statistics were manipulated to make the public think that great strides were being made toward eradicating this dreaded disease. Once the drug companies' press releases were fed to the media and the public "bought it," more money was released to those research facilities to continue the cycle.

"But *are* there 'great strides'?" I continued to dig deeper. I wanted to know. The optimistic side of me needed to know that my daughter's death was not in vain; not the result of the futile War on Cancer. The same war that claims *ONE PERSON EVERY MINUTE... OVER HALF A MILLION PEOPLE EVERY YEAR!!!*

I read Ralph Moss' *The Cancer Syndrome* (now *The Cancer Industry*) and Samuel Epstein's *The Politics of Cancer*. I was in shock, unwilling to rest until *everyone* knew what I knew. I learned that CHEMICALS caused cancer... chemicals, our immune system's inability to withstand their bombardment, with a touch of "heredity factor" thrown in for good measure. "Oh, my God,

chemicals are everywhere!!! They're in our food, water, air, clothing, schools, homes, cars, workplace... in our world!"

It made sense to me: "If they know what *causes* cancer, then they know how to *prevent* it." I set out to prevent the millions of others from the agony that Amber had suffered. I continued to dig. The more I looked, the more I found. I collapsed under the weight of my newly discovered knowledge and its implications.

My feelings of anger and impotence fueled the fire that was under the "pot." Rather than lose control or boil over, I went into hiding. I stayed at home, pulled the shades down, and cried. I cried, not only for the fact that my only child had suffered and died, but that she didn't *have* to die. I cried for Amber, for me, for anyone who had ever died from cancer, for those who suffered that day, and those who would learn someday that they had cancer, too. I cried for the celebrities who died from cancer and for the homeless person that secretly died alone. I cried for the families they left behind; those who stood by and watched their loved ones suffer, unable to stop the pain, unable to stop them from dying. I wanted to cry myself to death. I wanted to join my little angel who now lived in God's house on the other side of the rainbow.

It was December. The leaves were gone. The world looked dead and I *felt* dead. Any life that I had, was buried deep inside... too deep to feel. I didn't want to celebrate the holidays and I was mad at the world because everyone else *was*, despite the fact that Amber was dead. "Let's just erase Christmas this year," I told Gary. He wanted to help me heal. He needed to focus on something positive and could not understand that I didn't. He even put up a *tree!!!* So I was mad at him, too.

One morning as I awakened from a deep sleep, I heard Amber's voice. "It's okay, Mom. I love you. Love means wiping away someone's tears." She was helping me to heal... teaching me how to live, the same way I taught her. "No need to hurry. This will take a very long time."

Putting my anger aside, I returned to the studio to find my way back to the world. Working long hours, Gary and I remodeled the space that we had abandoned to move to the Bahamas and care for Amber. We decided to divide it into three