Damocles’ Wife

the inside story of cancer caregiving & long-term survival in the midst of motherhood, marriage & making life matter

by Shelly L. Francis

Foreword by Clarissa Pinkola Estés, Ph.D.
Damocles is pronounced
DAM-uh-kleez

(The author would like you to know this because
as a little girl she once read a storybook about mosquitoes
and the whole time thought the strange word was MOSS-kwee-toes.)
Part One: Crescent Moon Coping

I wish you didn’t need to find this book. I wish you didn’t find yourself one day in a new role, needing to know how to survive as a caregiver while your loved one fights cancer. I wish cancer was a thing of the past, but until it is, we’re going to be busy.

If you suddenly find yourself wondering how in the world you’re going to manage all this—finding the right doctors, the right treatments, taking care of your kids, plus your household and the rest of the family, paying the bills, moving one foot in front of the other, keeping the faith, needing peace, and ensuring when it’s over you’re still standing strong—you’re going to need help. Please know you’re not in this alone. I hope our story will encourage you with glimmers of light, both practical and, let’s say, spiritual, to add to your own inner strengths that I know you can summon.

If you’re wondering how someone survives brain cancer, here’s the story of how my husband did it—and how he could not have done it without me and the rest of our caregiving crew. If you wonder what happens inside the caregiver as she learns to see how courage and fear coexist, to imagine a way beyond worry, to let go of the past and have faith in the future, to become a survivor herself, here’s my story.

Once upon a time, not so long ago, a young family lived...
Let choice whisper in your ear
and love murmur in your heart.
Be ready.
Here comes life.
—Maya Angelou

1
Setting Intentions

Three days after surgery, on that Tuesday night, I was sitting next to Scott’s bed in his private room on the neuro ward. I was near the end of Richard Bach’s book Illusions where the Messiah’s Handbook concludes: Everything in this book may be wrong. I said out loud, “I love this part.”

Just then the neurosurgeon came through the door. I moved to the wide window ledge as the doctor examined Scott’s head, unwrapping, peering, poking, and rewrapping the bandage. Then he pulled up a chair and sat down. Realizing he was here to give us Scott’s pathology report, I pulled out my bookmark to write on, an empty purple envelope from a get-well card.

“It’s a slow-growing astrocytoma,” he explained.

The brain tumor had been named—astrocytoma—and I rolled the sound around in my head. Astrocytoma. Then I heard him say that the tumor was malignant, but only a grade two, two out of four, where grade four is the most aggressive.

“That’s good news,” he tried to reassure us. “There’s a big leap between grade two and three. Of course, it could degenerate into a more aggressive tumor at any time. This type of tumor can never be cured completely, but we can keep it in check with radiation, perhaps chemotherapy, and it likely won’t recur for years. My recommendation is that you have radiation, which can start as soon as we remove the staples from your scalp, in a couple of weeks.”

He named a few specialists to contact as our next assignment. The neurosurgeon left the room, with a backhanded wave saying he’d check on Scott the next morning and decide when to send him home.

Alone again, Scott and I just looked at each other. I turned to a blank page in my big spiral notebook, dated the page “Tues 11/17/98—6 p.m.”,
and transcribed my notes in clear handwriting onto our permanent record. With that we realized that Scott’s brain tumor treatment had barely begun.

Not long after, I left Scott alone to sleep for the night—or to not sleep and consider the words of the neurosurgeon and the pathology report. “No cure...can manage the disease for two to five years, maybe ten.” After that moment, I never recalled “maybe ten.”

I can’t recall walking down the hall, into the elevator, across the large hospital lobby, or through the parking garage. I must have been on autopilot to maneuver the car past the ticketing booth and out onto the streets. My guardian angel, who made sure I survived driving at night and through crying jags, was surely on duty, clicking the traffic lights to green and clearing the roads for me until I arrived at my parent’s house. The trip might have lasted all of ten minutes. Once parked, I gathered my purse, my spiral notebook, and my backpack of all-day-at-the-hospital necessities, and I stepped out of my car, looking up at the second story windows of the welcoming house that had been home most of my life. The front bedroom lights shone, meaning Wil was still awake inside.

I took a deep breath of cold November night air and glanced up and down the block. Our house at 360 South Corona was six houses from the corner of the tree-lined street, two blocks northwest of Washington Park. The neighborhood was a mix of Craftsman bungalows and post-Victorian homes spaced no more than fifteen feet apart—kitchen windows looking into dining rooms next door. Our 1917 Denver Square was a clay-red brick with a deep front porch that spanned the full width of the house. The porch swing was empty now, of course, but full of memories of summer evenings, Sunday mornings, and countless afternoons talking with neighbors, reading alone, or swinging with best friends while planning our futures or weekends. We moved here a week before Christmas in 1970, halfway through my kindergarten year, and here I was, just shy of full circle, 360, coming home that night to my own son, who would soon start kindergarten himself.

Glancing up at the sky, I hoped to see some of the meteor showers that the newscasters explained came once every thirty-three years. Despite the dark of the moon, Denver’s lights were too bright to see any shooting stars. I wondered if thirty-three years ago, when Scott was born, if the meteor showers were visible above the Michigan farmland where he grew up—but then I realized that no, he was born in Chicago and the city lights even then might have been too bright for stars. I sent a mental note to the sky, Thanks for the meteor showers even if I can’t see them. It’s nice to know they’re there.
walked up the wide concrete porch steps and entered the house with a sigh. Home.

Sure enough I heard splashing bathtub water, Wil’s giggles, and my dad’s soft voice spilling down the oak staircase. I could picture Wil’s bubble beard matching Dad’s white one, their round cheeks giving credence to genetics. Wil’s face at four looked just like the tinted sailor-suit photo of Dad at that age, the difference being Wil’s blond widow peak wasn’t black and his eyes were bright blue, not hazel. The saucy grin was the same.

I unloaded my armful onto the third-step landing and checked my eyes in the narrow antique mirror. Pure exhaustion stared back at me. As much as I hungered for a hug from my son, I was relieved that Dad had him occupied for now. The living room on my right was empty, but the kitchen light was on. Mom stepped into view and said, “I’m making hot tea. Would you like some? Did you eat dinner?”

“I’m not hungry. Tea sounds nice, but no caffeine. I want to sleep tonight.”

I sat down on a kitchen chair at the yellow Formica table with curved metal legs that had been in her mother’s kitchen, and I leaned against the wall. For a minute I soaked up the sounds of a happy boy getting cleaner upstairs and the comfort of my mom’s kitchen, the safest place on the planet. Thank goodness I’m not driving home to Highlands Ranch tonight, I was thinking. It will be nice to sleep upstairs in my old bedroom, snuggle with Wil, and let someone take care of me for tonight. And it will be a much shorter drive back to the hospital in the morning.

Mom put an empty flowered mug in front of me, a plate of sliced banana bread, and her bright red teapot full of hot water. I had a choice of decaf Constant Comment, Celestial Seasonings mandarin orange, or chamomile. As usual, I picked mandarin orange and she poured hot water. Mom sat down across from me and reached her hand over to mine.

“How is Scott doing tonight? You?”

“He’s okay. I’m tired,” I said, dipping my teabag in and out of the water, watching the water seep darker. Without looking up, I said, “We got the pathology report back tonight.” She squeezed my left hand and waited.

I repeated Scott’s prognosis, having already memorized the words of the neurosurgeon. “He said this type of tumor can never be cured completely, but they can keep it in check,” and I spat out that phrase, “for two to five years. Keep it in check? What does that mean?” I felt my anger beginning to boil like the tea kettle that had been whistling minutes before.
“Oh, Shelly,” Mom said, emotion welling up and spilling out her brown eyes. “Oh, Shel.” She took a deep breath before continuing.

“It means you have options for treatment—radiation, chemotherapy—lots of options that your surgeon might not even know about. Those numbers are only statistics. They don’t necessarily define what is going to happen to Scott.”

I looked at her and knew she was right. I sipped my tea and took a bite of banana bread, not tasting either. I was too overwhelmed to consider Scott’s survival options just then. All I could think of was the deadline on his life, our life together. I burst into tears and in between blubbers I uttered, “I don’t want to be a widow.” Sob, gasp. “I don’t want to be a single mother.” Sob, sob, gurgle. “I don’t want him to die.” Sob, sob, sob, snort. “I…need…a Kleeeeenex.”

“Oh honey.” Mom scooted her chair around the table to be closer, then stepped in and out of the bathroom to hand me a roll of toilet paper. “It’s going to be all right,” she said, patting my leg while I unrolled a long piece, folded it, and blew my nose. I leaned into her shoulder and cried for several more minutes, while tears streamed down her face, too. Upstairs, Wil was still splashing in bubbles but the sound seemed more muffled, as if Dad had put up a shield to protect Wil from my fears.

When I stopped crying and started breathing again, my mom took the plates to the sink. I felt an energy swirling around the kitchen, this kitchen full of our lives for almost twenty-nine years. This kitchen held all the magic of eating sourdough pancakes with chokecherry syrup on Saturday mornings, sisters and neighbor kids standing on stools to wash dishes so we could hurry up and play after dinner, sitting on counters kicking the cupboards below waiting for popcorn to finish exploding in the pressure cooker on the ancient gas stove, walking around twirling the cord of the wall phone while giggling about boyfriends and haircuts, bumping elbows with aunts, uncles, and cousins as we filled our cups and plates for Easters, Christmases, and graduations, lingering talking as grown-ups at this same kitchen table on weekends home from college or on vacation back home when we lived in Tennessee. My whole life of being fed in this kitchen was spiraling into a storm, funneling all our dreams and hopes for the future into a raging tornado.

Mom turned around and said with a catch in her voice, whispering her greatest wish as a mother, “I wish with all my heart you didn’t have to go through this.”
If mothers could protect their children with a wish, it would have come true right then and there without any more pain. Instead, something caught inside me like a hook in a trout and I felt myself standing up from the chair, pushing it back, defiant, and flipping out like that fish deciding to live.

“No! If I have something to learn from this, I’m ready for it. We’re not going to just give up without a fight. Scott is not a statistic. There must be a reason for all this shit. So let’s figure it out. Bring it on, I say!”

Bring it on. Fighting words to the gods. If somewhere in the universe you can hear a noise when someone shouts an intention like that, it might have sounded like a high-pitched squeal and the echoing CHUNK of a monstrous metal cog settling into gear, locking into place your new direction. Something in me shifted then, refusing to be a victim before the battle had begun.

Mom stepped closer for a tight hug and affirmed, “Okay, bring it on.”

I went upstairs to kiss a prune-skinned Wil goodnight. He and Dad were waiting, snuggled under the covers reading from my childhood pages of Richard Scary’s *Busy Town*. Then I tiptoed into the small study off of my parent’s bedroom where, by the light of a desk lamp, I caught up on incoming email. One announced baby-cousin Jack’s happy arrival on Earth (okay, Minnesota). Another was from my friend Julie, reporting that after only two chemo treatments, the tumor in her breast had shrunk by an amazing fifty percent! I scanned the subject lines of the many emails awaiting and left them marked as unread until I had more time and energy. It was enough to know they were full of good wishes.

With what I had left, I typed my day into words and sent them through cyberspace to be heard.

Sent: Tuesday, November 17, 1998 8:45 PM
Subject: Pathology Report on Scott

Dear Everyone, (and please forward the message for us)

I am at my parent’s house tonight, 10 minutes from the hospital, to get a long, snuggly night’s sleep with Wil and then return to the hospital to be with Scott tomorrow. I wanted to let you all know that the neurosurgeon gave us the results of the pathology report tonight.

Here's the news. Scott's tumor is called an astrocytoma, which is made up of the "support cells" of the brain (as opposed to the thinking cells). Of the possible 4 grades of such tumors, where 4 would be rated as the most aggressive, Scott's rates as a 2. (The surgeon's first impression from the MRI 10 days ago was that it
was certain to be a 4—nice surprise it wasn't.) As further comparison, he says there is a large difference or leap between a 2 and a 3, so 2 is pretty good. On the down side, however, this type of tumor is not completely curable and could become more aggressive (a 3 or 4). HOWEVER, it can be "kept in check" for YEARS through radiation, possible more surgery someday much later down the road. And that is good news.

So, our next step is to seek opinions and select a team of oncologist, radiation oncologist and also a gamma knife specialist (this is a newer, different type of radiation that MIGHT be appropriate in Scott's case). Scott will start some type of radiation treatment in the next week or so. One scenario if we can't have the single-dose gamma knife treatment would be 6 weeks of radiation, 5 days a week. That means we might be done right around Xmas.

Soooooo, we're not done yet but are content that we now have passed through another waiting period and are on to the next phase. Scott and I KNOW that your positive thoughts, prayers and massive doses of love sent our way helped us through the surgery on Saturday and will keep us going as we continue to battle whatever remains of this dragon.

I would like to share a dream Scott had in recovery, which he told me today. The first part was of himself "slaying" and killing whatever was left inside after surgery, and the second part was of him inside his brain repairing the damage caused by surgery, "hoisting the girders back into place." He is so confident in this imagery, believing that whatever remains are simply remnants and carcasses that need to be vaporized. :)

Wil came to visit Scott at the hospital today. From now through the radiation treatment, we want Wil to know that Daddy will be having a healing light shining on his head to finish making him all better. As a near-5-year-old, that's all he needs to be told. Beyond that he needs lots of hugs and reassurances.

Scott is regaining his strength and is starting to catch up on two weeks without sleep. Scott will come home from the hospital either tomorrow (Wed.) or Thursday. Because we are all EXHAUSTED and emotionally worn out, we will not be answering our phone much nor having visitors for awhile yet. But we sure do welcome your emails, cards and more than anything, continued loving thoughts and prayers.

Thank you again for accompanying us on this hard journey. It would be a lot lonelier and much harder without you—thanks for lightening our load. We love you and appreciate you SO SO much.

Talk to you soon,
Love, Shelly
May is National Brain Tumor Awareness Month!
June 8 is World Brain Tumor Day
November is National Caregiver Month

We hope you enjoyed this sample chapter of *Damocles’ Wife: The Inside Story of Cancer Caregiving & Long-Term Survival in the Midst of Motherhood, Marriage & Making Life Matter* by Shelly L. Francis.

The printed book is available for ordering from your favorite local bookstore or online at [Amazon.com](http://www.amazon.com) (US, UK, DE), [BN.com](http://www.bn.com) and other sites.

If you have questions or comments, send email to shelly@caregiverhope.com or check out the resources for caregivers at CaregiverHope.com.
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