



**LONGER THAT EXPECTED:  
ADULTHOOD AFTER LIFE-THREATENING CHILDHOOD ILLNESS**  
*A Wising Up Anthology*

**III. RECONFIGURATIONS**

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## **JANICE POST-WHITE**

### **FACING FEARS**

“Mom, could I have died?” Brennan asked me as I walked into his bedroom after just getting home from work. I was surprised to find him in bed. I quickly scanned him from head to toe assessing for any illness. He was lying in bed reading *When Mom Has Cancer*, a book I was using for a research study. I had left it on the kitchen counter that morning.

I lay down next to him, our bodies soaking up the late-afternoon summer sun as we stretched ourselves out like the legs of a clothespin. I watched as his slim eight-year-old fingers skillfully turned to the sixth chapter. I let my silence usher him on.

“It says here that the mom has breast cancer, and that 10 to 20 percent of women die from it.” He pointed to the paragraph as proof. “I had cancer too. Could I have died?”

“Yes,” I admitted quietly, with a hint of relief that we were finally talking about this reality. I looked up; his eyes averted from mine. “Some children who get leukemia do die,” I said. “That’s why it’s so important to start treatment as quickly as possible.” I avoided pointing out that he was only three months off treatment and relapse remained a real danger.

“She has a port-a-cath too, but she only has to go in once a week for treatment. I had to go in every day some weeks!”

I couldn’t tell if he was feeling pompous or envious. I hesitated. “Yes. That was a lot, wasn’t it? Different cancers are treated with different medicines and schedules, but most people with cancer are treated with some type of chemotherapy because it kills the cancer cells. It also kills some healthy cells, which is why you—and this mom—lost your hair and had mouth sores and nausea. You need some time off in between treatments.”

The cancer expert and teacher in me monopolized my intention. I struggled to put myself back into his world, to think about why he was asking these questions. Why was this so hard for me? Was I afraid he would shut down? I thought about the mothers with breast cancer and their children, the eight- to twelve-year-olds in our study. “She has children your age; I wonder what they are thinking.”

“When she is done with treatment, will she live?” he said, more wondering than asking.

I didn’t know if he was responding on behalf of the children in the study, asking if their mothers would survive breast cancer, or if he was identifying with the mother as a fellow cancer survivor and asking if he himself would live. I wish that I would have probed further, but he had just come off treatment. After three and a half years, I was so relieved to be thinking about living each day, reclaiming the childhood we had missed out on. It wasn’t *his* reticence to face death, it was mine.

###

When he was diagnosed at age four and a half, I buried my feelings and flew into action, analyzing the options and advocating for my son. As a cancer nurse,

researcher, and educator, I felt responsible and competent. I was in survival mode, doing whatever it took to save my son.

But my cancer training hadn't prepared me to be a cancer mom. My professional knowing see-sawed against the emotional intensity. I couldn't find the center, the lever, to balance my familiar roles with my unspoken fears. I'm not even sure I knew what I was struggling against. The darkness swallowed me that first week in the hospital. I wanted to flick a switch to shine a light on everything happening around us at warp speed. Inevitably, I lingered in the darkness for the first two weeks, where just surviving had its purpose.

As we marched along the treatment road map, filling in dates and turning pages every twenty-eight days, I couldn't ignore my fear of life-threatening infection, liver disease, and early relapse, the anguish of neurotoxic driven outbursts, gut-bursting constipation, and the exhaustion of steroid-induced frenzy and constant worry. "Who is this child?" I cried out in frustration one desperate day.

Eventually, I learned to take each moment as it arrived, in all its haziness. It wasn't easy to just "be" rather than feel I had to "do" or even "see." At night, as I lay awake in bed, I tried to call on my past training in imagery and hypnosis, breathing in rays of white light—omnipresent energy from the universe—to cleanse each cell of my body and reignite the candle in my solar plexus. Some days the light flickered and other days I couldn't even find it.

Many days, I simply did what my patients had taught me. I got off the elevator, putting one foot in front of the other. As cancer patients and survivors, they had learned to trust the process to unfold. Light follows dark; hope emerges from despair.

But stress responses can become habitual, and when Brennan came off treatment, I remained hypervigilant. If he relapsed, he would need a bone marrow transplant; the few patients I had nursed through transplant had died. As had our friend's daughter the previous year. My fears lingered.

###

Five months after coming off treatment, Brennan had surgery to remove his port-a-cath. Sara handed it to us in a clear Ziploc bag. I tucked it away in a box, alongside his curly blond hair from his first haircut, his first baby tooth, and his childhood cancer survivor gold ribbon from the 1998 White House Christmas tree. I tossed the medication bin that had sat on top of the fridge for three years and eight months. We were free! Third grade here we come!

Before we knew it, his brother, Tyler, had started kindergarten, our nanny, Beth, had left for medical school, and super-energetic Christopher had joined our family team, engaging the boys in after-school activities—football, baseball, basketball, tennis, and homework. We were six months off treatment, and we were moving on.

Third grade also brought crises for our small, close school community. In the midst of our celebrating, Brennan's classmate, Sam, died of his cancer.

At Sam's funeral service, the first week of school, Anna's mother told me that Anna, the other third-grade cancer survivor from Brennan's class, had transferred to another school. She seemed relieved to have her daughter distanced from her unspoken history, the cancer that had stolen her eye at birth but was never acknowledged in her family. I was glad to see her there, supporting Sam's family and feeling as if she was

still a part of our community. I felt a sense of closure. We could leave cancer behind now.

And then, that same year, tragedy struck two other school families. Brennan's friend's sister, a ninth grader, died suddenly after a brief respiratory illness during the holiday season. Surprised to see her name in the obituaries, I ran, breathless, into the family room with the newspaper, where Brennan and a friend were playing a game on the floor.

"No, I didn't know his sister was sick," Brennan said. "That's too bad." He went back to playing Risk.

I carefully cut out Natalie's picture from the *Star Tribune* and smiled back at her carefree grace, then tucked her obituary in a plastic sleeve in Brennan's school portfolio. To others this might seem inconsequential, as if her death were just another milestone event in elementary school—but it wasn't to me. For weeks after I imagined her family and the healthcare team struggling to sort out the symptoms, to find a cause, and to treat it. Acutely labored breathing is frightening to experience and to watch. And to lose a child, suddenly, under any condition, was inconceivable. Or perhaps it was because I could imagine it that I felt it so profoundly.

And then Tyler's classmate's younger sister was diagnosed with astrocytoma, a brain cancer originating in her spinal cord. Despite surgery, chemotherapy, and radiation therapy, Kami couldn't walk, and yet she still delighted in attending the same kindergarten classroom Brennan and Tyler had. The teacher, Molly, commented to me in the hall one day as she wheeled Kami back from assembly, "She has such a beautiful spirit. It's a joy to have her in class." Molly was the same teacher who had been able to see Brennan's optimism through his prednisone outbursts when he was on treatment.

We had Kami and her family over for dinner early on in her treatment. At one point, Kami, trying so hard to be like the other kids, lost her balance and tipped to the floor. Frustrated and crying, she curled up in a ball. Her mom stalwartly picked her up and gently wrapped her arms around her, whispering soothing reassurance as she caressed her daughter's shiny black hair. I paused in my cooking, watching this mom's strength and confidence—and her gentleness. After dinner I cheered as Kami's two siblings chased our boys around the house, shouting orders and laughing out loud. *Just let them be kids*, my heart pleaded.

Kami lived for two years with progressive deterioration and intense family sacrifice and loving care.

There was so much cancer and so much death in one little school.

I vacillated between being supportive and caring and distancing myself as a form of self-protection. My son was off treatment, but he was still at risk for relapse. I still felt vulnerable.

People would ask me if he was "cured," which was such a nebulous term in my mind. I wondered when I would consider him free of potential relapse. Some experts considered children cured if they survived without any evidence of disease five years after diagnosis. That sounded like a long time, but it was less than two years away. Would I feel secure that soon? Others pointed to the five-year mark after treatment ended, which made more sense to my conservative, logical mind, especially since our friend's daughter had relapsed after four and a half years off treatment. Would I ever

completely breathe a sigh of relief that my son was not at risk of relapse? To a researcher, 100 percent certainty isn't a real statistic. Some probability always exists.

I was incredibly grateful for my son's life, and yet despairing that these other children didn't live. These early lessons in death and grief and disability and loss had to have slithered into Brennan's psyche too. How can you ignore your fears when they are mirrored back to you, over and over again?

###

Starting sometime after he came off treatment, and for years afterward, Brennan dreamt of death. His death. When I asked him to tell me more, he usually said, "I don't remember much, other than I died," or "I died falling off a cliff," or "I fell into a deep, dark hole." The dreams didn't seem unusual, except that his dying was consistent and persistent. From the age of eight to eighteen, his dreams, or his memory of the dreams upon awakening, became more explicit. I never knew what to do with the information. I kept hoping that if he talked through them, they would eventually stop.

After one night of restless sleep, when he was around twelve, Brennan said, "It isn't like I wake up knowing I'm going to die. I see myself dead and then I wake up." He looked directly into my eyes, making sure I understood.

"That's unnerving," I said, sitting on the edge of his bed, trying to imagine what it would be like seeing your own body lying lifeless on the ground. I had always thought people woke up from dreams when they were in danger, before they actually died. I waited for more.

Silence followed.

"Tell me again how you died?" It felt better to have something specific to ask. But why couldn't I just ask him how the dream made him *feel*?

"Most of the time I get shot or attacked. Sometimes I'm in an alley and I get shot in the back or get caught in crossfire. Other times I face the perpetrator." He hesitated; I was looking at him quizzically, intrigued by his word choice. He was dissociated from any feeling, like an observer watching a movie. "But I always die. I see myself lying on the ground, not breathing, blood everywhere."

I wasn't sure what to make of the graphic finality. I had asked for specifics and he had answered. He had circled back to the important message, seeing himself dead. I had left that fear dangling.

He would sometimes ask me to analyze his dreams. On four sequential nights one summer, he dreamed that he died in Boston. "What does that mean?" he asked the next morning at breakfast.

"I don't know," I admitted, "I don't know that the place is so important." I was more concerned by the pattern of his being a victim. But I don't think I ever mentioned my concern to him, which seems dismissive. How could I help him if I was avoiding my own feelings and concerns?

The dreams continued for years, although I was never quite certain of their frequency since he only talked about them occasionally, every few months.

When he was in his late teens, Brennan asked me about the detail in his dreams. "I notice everything," he said, "even the wrinkles on a person's face, the color of their eyes, and the make and model of the cars driving by."

"You're a detail guy," I said. "You notice these things in real life, so your subconscious processes them too." I was just guessing. "I'm not a dream expert," I told him.

But I was intrigued. Dreaming of death can mean change, new beginnings, and leaving the past behind. Of course, I paid attention to what I most wanted to hear—that the dreams meant a positive direction, a “moving on” kind of future. I needed time and distance to allay my concerns and to calm my son’s fears without minimizing them.

“I’m not afraid of dying,” he insisted over the phone while at college. “I think that’s why I dream about death so much.”

“It’s a game,” I suggested, relieved to know that he had at least considered his fears, even if he ruled them out. He was always so logical, so analytical. “You play a game with life and a game with death. Strategy is your forte.”

And then he told me about a dream in which he had flown to Paris to meet a publisher. They were having lunch in a café on Rue St. Honoré and someone drove a car through the window. He said, “I’m sitting with my back to them, but I know from past dreams that the car crashes into the restaurant and hits me, so I dive to the floor, as far from the impact as I can. It’s totally a reaction. I don’t have time to process things, which is why working it out in a previous dream helped me respond. I’m conditioned to think about self-preservation. I just act.”

I thought back to those three years of my being in survival mode. Of course he had felt it too.

He went on to tell me that in the dream he left the restaurant scene, unscathed this time, and walked into a local market on his way back to his hotel, only to be caught in an armed robbery. This time he was prepared, and he safely interrupted the holdup. It wasn’t until he was flying home and the plane depressurized and the oxygen masks didn’t descend that he panicked. He had never confronted this problem and had no idea how to mechanically pry open the oxygen compartments. He died in his dream, along with everyone else on the plane.

He told me about the dream the next day. By then he had searched online and figured out how to get the oxygen compartments open, just in case he dreamt it again. “Maybe I am setting myself up for my next dream,” he admitted.

“Maybe you’re setting the stage for your first novel,” I retorted.

He laughed lightly, not yet ready to move on.

“It takes a lot of time and energy to be prepared for everything that could possibly happen in life,” I said. I couldn’t tell if the game of outrunning death kept him engaged or if the dreams haunted him until he figured out a solution. This was the first time I’d seen his direct determination to conquer death in his dreams. What was his motivation? If he could figure out how to circumvent death through strategy, why couldn’t he program his mind not to dream of death at all? If the dreams reflected subconscious fears, perhaps talking about them would bring them into awareness so that he could consciously let them go. But it had been thirteen years and he still dreamed.

He was like a samurai warrior, preparing for all the things that might go wrong, imagining and practicing his way out of any situation. Samurai use this strategy to stay cool and calculating in battle. Nothing surprises them because they have prepared themselves for everything.

But can we ever be prepared for death? Or cancer?

Each day in the United States, forty-three parents are told, “Your child has cancer.” Nine of those children will have leukemia. As a parent, and even as an oncology nurse,

I never ever imagined that my child would be one of the 0.004 percent. I could not have knowingly prevented leukemia, and now I could not predict or control what the future held for my son. I lived with a new awareness, a new vulnerability, knowing that I couldn't protect him from the hurt of having to go through cancer treatment or facing the potential late effects, including a second cancer.

"It is a game," he eventually agreed. "I work out in my dreams how to stay alive and how to die."

"How is it that you always lose?" I asked.

"I don't lose," he said, "I win."

As I pondered his perspective on winning, I was reminded of a conversation we had late at night when he was sixteen and in high school. I had walked into the shadowy family room, lit only by the computer screen on his lap and the television across the room. I leaned over the back of the stuffed leather chair that he sat in sideways, his size fifteen feet, clad in threadbare athletic socks, dangling midair over the arm. He glanced up at me and then quickly flicked back to the screen on his lap. I watched him play his game in the dark—football, soccer, basketball, tennis, golf, one of those—it was always a sports game. The late-night show echoed from the television in the background. This twilight zone was our time, when his dad and brother slept. "Hey, how's it going? What are you playing?"

He answered, and then suddenly, as if in defense of his passion for sports games, he blurted out, "I just can't get myself to play war games or violent video games where I know I'm going to die."

I nodded understandingly. He knew I detested guns. When he was six years old, he had come home from a comedy movie with a friend and said, "You wouldn't like it, Mom. The guy carried a 'you know what.'"

After a pause and the click of a few more plays with the computer arrow keys, he added, "If I do play, I hide to protect myself. Like behind a barrel or a wall. I just can't set myself up to be killed."

"Unlike Tyler," I said, and we both nodded, thinking of how his brother spent hours every day playing war games, dying and clicking himself back to life as he built his dynasties.

"You sometimes play *The Godfather* with Tyler," I reminded him, cringing at the images of shooting human beings in their homes and cars.

"Oh, that's easy to beat," he said, clicking another play on his computer.

"So winning is important."

He agreed.

The violence seemed less distressing to him than the vulnerability involved in putting himself at risk. He was happier playing sports, where losing didn't cost him his life.

I still don't understand, though, how he wins when he dies in his dreams. Perhaps it's because he allows himself another chance, a replay in his next dream. The will to survive motivates him to figure out a solution. He's still in the game. He's got another chance.

###

Brennan's dreams of death were never about leukemia or illness, but they always involved something external—and random—happening to him. I could see how

thwarting death in his dreams and video games was another way to regain control over vulnerability.

Figuring things out fosters a feeling of control. And feeling in control can be empowering, as long as it isn't an escape or defense. Reverend Alla Renée Bozarth cautions in *Life is Goodbye Life is Hello* that holding on tightly to control can be a way to avoid feeling fear or any uncomfortable emotion, allowing feelings to simmer unannounced. "You need to feel the fear before you can release it," Bozarth advises. And since our natural tendency is to avoid our fears, we resort to control.

Shortly after coming off treatment, Brennan wrote about having leukemia for a class assignment. "This event taught me how capable I was of doing things I didn't think I could do. It gave me confidence in myself because I had gotten through this whole thing . . . [it] taught me to believe in myself and to believe in my abilities to do things."

His mastery and confidence had come with practice, experience, time, support, and a positive outcome, a result he had little control over. He had learned resiliency while facing cancer, but did he know what he feared? Did our dreams give us both away?

I thought it was death that Brennan feared. So I was surprised several years later when I came across a paper he had written for his high school English class, titled, "My Greatest Fear: Europe on my Sixteenth Birthday."

I sat down, paper in hand. *This* was his greatest fear? His first trip to Europe? A fifteen-day family vacation in three countries? I leaned back on a stack of pillows on the window seat. He hadn't shared this paper or these feelings with me.

It wasn't the smoothest trip, I admit. Our connecting flight was canceled, Brennan fell asleep and forgot his birthday *Mad Men* DVDs under the seat in the airport, it took two hours to get the rental car in Geneva, and the roads to our hotel in Bern, Switzerland were closed for the Euro Cup Fan Zone. But Brennan didn't mention these hassles in his paper. And he didn't say anything about the responsibility of being designated the chief navigator and German translator.

His dad and I had purposely paced activities on the trip, allowing time for hanging out as a family. We followed Brennan as he led the way through the crowded Fan Zone, snapped pictures of him in front of the statue of Freddie Mercury (of Queen), played life-size chess and mini-golf in the park, and spent hours at the Duomo, checking out every dark corner inside and each spire and gargoyle outside in the summer mist. We jaunted through the Louvre during the day and raced down the Eiffel Tower stairs at night, trailing Brennan all the way. I wanted to take the boys into Notre Dame to light a candle and offer a decade-later blessing and thank-you, but they didn't want to go inside, so we didn't.

As the trip progressed, Brennan became increasingly sullen and resistant. I attributed his frowns in pictures and his abject apathy during long walks as a response to itineraries that weren't his, being tired, and being sixteen. He was out of his comfort zone, in unfamiliar countries, facing new and novel experiences. Three months later, however, when he processed his feelings on paper, this is what emerged:

*One of my least favorite things is change, or when I don't know where I am, where I'm going, or what I will be doing . . . I wanted to have a fun, planned out trip, where all of our activities were laid out ahead of time. I always liked to know what would happen next, but in this new environment I was being forced to face my fear of lack of order,*



*of uncertainty. I had no control anymore . . . I was forced to follow my parents every move, beat into submission by uncertainty.*

I set Brennan's paper in my lap and stared out the family room window, visualizing the streets of Bern, Menaggio, Milan, Venice, and Paris, and sighed. The lack of structure had tripped him up. We had changed his environment, his routine, and his role, sweeping away order and stability. He could speak German but he couldn't grasp flexibility.

If uncertain vacation itineraries were so stressful to someone who thrived on order and predictability, what must it have been like to have cancer? Or was this defense a consequence to that experience, an ongoing attempt at control?

And that's when it struck me: Brennan wasn't afraid of death in his dreams, he was afraid of losing control.

###

Brennan and I both liked to plan, to know what was going to happen next. An analytical mind wants to order things, make sense of things, make the unknown known.

"What's the plan?" Brennan would ask each day as he hopped down the stairs.

"What's the next step?" I would ask our oncologist at every visit.

Leukemia didn't change who we were; we just learned to adapt when fevers or illness or fatigue changed our plans for us. We still traveled on vacation, although we inevitably ended up in the local emergency room on every trip. I continued to work, juggling meetings, classes, and writing time around his appointments. My nursing students and medical colleagues knew the unpredictability of cancer and were understanding when Brennan got sick and I had to cancel. Together, we established a new normal, one that allowed us to be flexible.

The treatment road map directed our daily routine, but how we lived was up to us. Cancer was only part of our identity; it shaped us, but it couldn't define us. We were a family living with cancer, not just a cancer family fighting to survive. We were survivors.

And yet, eleven years after he came off treatment, I dreamt that Brennan had died. It was as if fear had weaseled its way into my cells, lurking in my DNA, regenerating insidiously. I had answered the door in my dream, allowing entrance to my subconscious fears. I had no idea what the circumstances of his death were. It didn't seem to matter. It was the ominous void that haunted me. For the first time I could remember, I felt helpless. I couldn't save my son.

Fear isn't logical or rational. It invents the worst that can happen and then smolders through the day, licking away at energy, confidence, and faith, leaving ashes in its footsteps. When events sort themselves out, as they usually do, fear retreats and we go on our way, none the wiser. Unless we turn back and ask fear what we can learn from it.

And that is what I did. I turned around to face my fears, and I began to write. I had to acknowledge my fear of losing my son, however possible or improbable, if I wanted peace from the vigilance and a truce with my regrets. I had to quiet myself so that I could listen to and feel whatever came through, without directing, managing, or suppressing. Forgetting doesn't heal; remembering does.



JANICE POST-WHITE is a cancer nurse, researcher, and writer, and the mother of two millennial men, the oldest a childhood leukemia survivor. *Facing Fears* is a chapter adapted from her recently completed memoir, *LEAF HOUSES*. Other publications include numerous academic papers and book chapters and an essay, "Renovating," published in *Snapdragon: A Journal of Art and Healing*. She has a PhD in Nursing and completed a two-year apprenticeship in creative nonfiction at The Loft Literary Center in Minneapolis, MN.

## INTERVIEW

**What kinds of misperceptions do people have about the *kind of illness* your child had?**

"Is he in remission?" some people asked innocently. I always hesitated. I appreciated them asking – it showed they cared and were trying to understand, but I was unsure how to answer. For a long time, my real concern were his high liver enzymes, but I would dutifully reply, "Yes, he's in remission," and then often add, "he has been since day twenty-eight." And then I would have to explain, since my son had 1,200 days of treatment *after* going into remission for acute lymphoblastic leukemia. As a teacher, I felt compelled to inform them that remission, while critical to survival, is a short-term goal, and that survival without recurrence, complications, or late effects was equally important as the ongoing, life-long goal.

**What do people misunderstand about *your own experience*?**

That having a child with a life-threatening illness is not the same as having a spouse or other family member diagnosed with cancer. You can't really understand unless you have been a parent with a critically ill child.

**What is an important *source of strength* you have found through this experience of childhood illness that has helped you as a survivor/family?**

Three months off treatment for acute leukemia (ALL), my then eight-year-old son told an audience of cancer professionals: "What really helped me the most was having my family with me and believing in myself, knowing that I could get through it...I knew I could do it."

I never doubted my son's strength and determination. He showed us daily! And the times when he was sick and vulnerable, I welcomed the opportunity to reassure him and be present for him, which made me feel stronger. And when I felt vulnerable, I relied on my belief that we could get through this, through anything, together. We found courage and strength within ourselves and through each other. We aren't unique; we just learned to be strong and courageous early in life.

**What is a *question that you would like people to ask you about your experience that they rarely do*?**

Sometimes I wish people would ask about any lingering effects of treatment, or if there are any ongoing risks after treatment. Cancer is perceived as an acute illness, one to survive and be cured of. Unless there is a visible disability, most people are unaware of any long-term effects, such as second cancers or cardiovascular disease.

What's more important to me, however, isn't *what* people ask, but *if* they ask. Asking a question and allowing me to answer is more meaningful to both of us than making (often incorrect) assumptions or comparisons.

**How has your son's experience of a life-challenging illness at an early age *changed your own understanding of what it means to be an adult*?**

