

# Never Leaving Wonderland

Category: Stories

written by Jacqueline Dooley | January 15, 2016

## **Jacqueline Dooley**

Three years ago I spent the entire month of September by my daughter's side in her hospital room. From Ana's window, we watched summer fade into fall as we waited, day after day, for her to be discharged, which finally happened in early October.

During her forty days in the hospital, Ana was diagnosed with an obscure, slow-growing cancer called inflammatory myofibroblastic tumor. The tumor, roughly the size of a cantaloupe, engulfed her liver. Her oncologists formulated a plan of action involving chemotherapy, steroids and a Herculean attempt to save her liver so that she wouldn't need a transplant.

Ana was eleven years old and about to start sixth grade when she was hospitalized. She loved singing, drawing and being with her friends. Her long brown hair was her pride and joy, hanging nearly to her waist. That was the year she wanted to be Katniss from *The Hunger Games* for Halloween and braid her hair just like the character, but she lost her hair a week before the holiday, so she had to wear a wig.

That hospital stay was my family's initiation into Wonderland, where everything is upside-down and there's no easy way out.

I'm going to admit something that I never thought I'd say: I miss the first few months of Ana's diagnosis. As horrible, terrifying and heart-wrenching as that time was, it was also filled with hopeful expectation that she would eventually get better—that our stay in Wonderland was only temporary.

The chemo didn't work. In February 2013, six months after Ana's hospitalization, she got a liver transplant. She enjoyed seven glorious months of remission. She was able to return to school. She started growing again, after a year of being so malnourished and sick that she'd stayed the same height. She finished the school year looking robust and healthy. We thought that we'd left Wonderland mostly behind us.

But in September 2013, a follow-up MRI showed suspicious masses in Ana's abdomen and lungs. A CT scan confirmed our worst fears: Her cancer had returned, and it had spread.

Cancer recurrence wasn't something we'd thought about in any tangible way. Ana's original oncologist definitely hadn't alerted us to the possibility. Like many people without prior experience of pediatric cancer, we viewed the disease in a very simplistic way: A child had cancer, received treatment and was cured, or died. Getting cured only to have the cancer return wasn't part of that script. At least, not in my mind.

We'd been told Ana's tumor rarely returns after being removed, and that it almost never spreads. I used to feel angry at her doctors for not preparing us better for this eventuality, but three years of living in Wonderland have changed my perspective.

I now understand that Ana's doctors had to balance knowledge with hope. It's a common scenario in pediatric oncology clinics and children's hospitals across the world. Playing out what-if scenarios only makes figuring out a plan of action that much harder. If they had told us that the transplant might not cure her, then we may not have gone through with it, and she wouldn't be here today. So, although we knew there was a chance that her cancer would return, we chose to hear what we wanted to hear—that it most likely wouldn't.

As I've said, I miss that early optimism. I long for it, just as I longed for the healthy childhood Ana left behind the day she was diagnosed.

Since then I've learned how relentless cancer can be, how it defies treatment after treatment, and I feel amazed that I ever thought we'd be free and clear of Wonderland.

Now I'm in mourning—perpetually, relentlessly in mourning. The cancer's recurrence has dragged us back into Wonderland, only this time it's impossible to feel naively hopeful about words like “cure” and “remission.” Cancer doesn't care about these words.

My husband and I try to get through the days and to function like everyone else, but it's like walking through quicksand. We're mired, sinking.

We want nothing more than to leave Wonderland for good—but only if we can take Ana with us. And now we know there's no guarantee of that. Wonderland is a place filled with unhappy endings. So, although we've learned to navigate its strange landscape, we find no comfort in our newfound understanding. In fact, the terrain is even more hostile and unyielding than when we first got here.

Ana started high school this past fall. She's learning guitar, performing in shows, and making new friends. She's managed to avoid further chemotherapy (for now), and since June of 2014 has been maintained on various targeted drugs. She doesn't want to deal with cancer. She only wants to be a kid. She leaves the worrying to me.

I'm writing about this now because, although relapse and extended treatment often mark the long journey of pediatric cancer, they aren't something we (as a nation) talk about much. We focus on statistics—that childhood cancers make up less than 1 percent of cancers diagnosed each year, that more than 80 percent of children will survive five years or more past diagnosis (compared with 58 percent in the mid-Seventies). But statistics don't tell the full story. They don't speak to relapse, secondary illness or permanent disfigurement and disability.

In the early days of my daughter's illness, I was focused on one thing and

one thing only—making her better. Now I don't know if she'll ever get better.

This painfully bleak realization has been digging into my consciousness, making it almost impossible to function. Some days, like today, I'm too tired to think about the long fight in front of us—another surgery, more chemo, more pain for my child who has been through too much already.

I'm resolved to find the strength I need for her, and for her sister, who is three years younger, but it's a struggle to remain optimistic. I can't suppress the thought that keeps repeating over and over again in my mind: *We're never leaving Wonderland.*

*Postscript:*

On November 27 Ana had extreme and sudden pain in her pelvis, so we took her to the emergency room. A CT scan revealed many new tumors that hadn't been present on her previous scan, just six weeks earlier. On December 12, Ana had extensive surgery to remove as many tumors as possible, including two near her liver (a procedure that required two incisions). She was able to return to school on January 5, quite a bit thinner and weaker, but determined to resume her life. The surgery didn't cure her. It revealed new tumors in her intestine and didn't even touch the multiple tumors in her lungs. Ana will likely be starting low-dose chemotherapy infusions in the near future to try to slow the progression of her disease. I'm grateful for her brilliant medical team at Morgan Stanley Children's Hospital, in Manhattan, who keep fighting right along with us. I'm also grateful that Ana got to spend the holidays at home this year. Each day with Ana is a gift, even in Wonderland.

**About the author:**

Jacqueline Dooley is a self-employed internet marketing consultant and independent author living in New York's Mid-Hudson Valley. In August 2012, her eleven-year-old daughter was diagnosed with a rare form of cancer called inflammatory myofibroblastic tumor (IMT). Jacqueline has written extensively about navigating the landscape of childhood cancer on her blog [www.healingana.com](http://www.healingana.com) (now offline) and, more recently, as a blogger for the Huffington Post at [huffingtonpost.com/jacqueline-dooley](http://huffingtonpost.com/jacqueline-dooley). In addition to blogging, Jacqueline has written two young adult novels, [\*Doorways to Arkomo\*](#) and [\*Doorways Home\*](#), which feature a protagonist struggling with cancer. Jacqueline is currently working on her third novel, *Spiritwood*, an epic fantasy featuring a teenager who also happens to be a three-time leukemia survivor.

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