

Finalist, Non-Fiction

Searching for the Right Words  
By Wendy Kennar

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*How do you talk to a child about an invisible disability?* That's the question I've been asking myself lately.

When my son was in kindergarten, I picked him up one day from school to find both his knees covered with large bandages. He told me he had fallen during lunch play time. He had worn shorts that day, and his uncovered knees bled when he fell and hit the asphalt. He told me he cried. He told me his friends helped him tell one of the grown-ups in charge. He told me he went to the nurse's office where his knees were cleaned and bandaged.

And that night, as we got ready for bed, he asked me if he now had "boo-boo legs" like me.

"Your boo-boos are on the outside of your legs. See, how your knees already have scabs?" I pointed to them.

He was sitting in his blue plastic Ikea chair. He looked down at his knees, afraid to touch the new scabs.

I continued, "That means your body is already starting to heal itself. My boo-boos are on the inside of my legs. You can't see them. And so they don't heal the same way regular boo-boos do. But soon, your knees will be back to regular."

And though my son is now eight-years-old, he still refers to my legs as "Mommy's boo-boo legs."

My illness began in 2010 when my son was two years old. At the time, the easiest way for me to explain why I couldn't play, why I had to sit, why he couldn't crawl up onto my lap was to tell my son I had a "boo-boo in my legs." Over time, that got shortened to "my boo-boo legs."

It took almost a year for me to receive a diagnosis to explain the pain and heaviness I was regularly feeling. I told doctors it felt like my legs were being hit with hammers. That my left calf felt as if it was being squeezed by a giant set of pliers. That it felt as if an elephant had taken up residence on my legs. That I walked slower because I felt weighted down by invisible shackles. A world-renowned rheumatologist finally told me I was suffering from an autoimmune disease called Undifferentiated Connective Tissue Disease. He told me there was no cure; there were only treatments to try; treatment plans that would most likely need to be re-evaluated and changed over time.

Most people don't know when I'm hurting; most people don't know there's anything wrong. My disease is invisible, and I walk without an assistive device. I look okay, so I try to pretend I'm okay.

Driving home from the library the other day, I pointed out my doctor's office building and told my son I'd be there in a few days for an appointment.

"Dr. Wallace needs to check my legs and maybe change some of my medicines," I told my son.

"How'd you even get this?" he asked.

"I don't know. No one knows. Sometimes people get sick, people get illnesses, just because," I told him.

“So you didn’t do anything wrong?” Ryan asked.

“No. It just happened. And now I just try to handle it the best I can,” I told him.

It was an honest exchange, though it felt incomplete. But I don’t have any other answers to give Ryan. I don’t have any other answers for anyone.

During first grade, Ryan really began expanding his reading choices. During our weekly library visits, he began checking out a lot of biographies -- Neil Armstrong, Jesse Owens, Sally Ride, George Washington, Hillary Clinton, Abraham Lincoln, Elizabeth Blackwell. It was through his reading that he learned that people die at different ages and for different reasons. George Washington got old. Abraham Lincoln was shot. Sally Ride, the first American female astronaut, got sick. She died from cancer, not because she did anything “wrong,” but simply because she got sick, and doctors couldn’t make her better.

The fact that I have an autoimmune disease somewhat contradicts the message I send to Ryan about taking care of himself. He knows all the right things to do, and he knows all the things his body needs to continue growing healthy and strong.

I did those things too, but I still got sick. Not Sally-Ride-sick, but sick.

Every day I struggle. I struggle with the demands and details that are a part of taking care of a family. I struggle with physical pain and fatigue. And I struggle because I’m not sure how to be completely honest with my son without scaring him. I don’t know how to fully show him my pain and vulnerability, while making sure Ryan feels safe and knows that he is taken care of, that even though I’m hurting, I can and will still take care of him.

By definition, autoimmune diseases are often unpredictable. Some days, or even parts of days, can be much worse than others. I don't know how I'll be feeling from one minute to the next. I don't know which activities will trigger a flare-up (sometimes a trip to the market does but not always) and which ones I can do with relatively minimal pain (sometimes gardening is relaxing, and sometimes it's pain-inducing). And sometimes it's the more mundane parts of the day (loading soap in the dishwasher or trying to reach a bowl from a high shelf) that can trigger pain.

One of Ryan's second-grade classmates lives two doors down from us. Earlier in the school year, this classmate broke his leg and was in a cast for several months. He couldn't play outside during that time, and he missed out on a class field trip. But now the boy's leg is healed; he's back to playing and running, and swinging and jumping.

My legs won't heal. My legs won't get back to the way they were before.

It's been six years since all this started. Six years ago when I had naively thought I had a temporary problem with my left leg that would eventually go away. Instead, it's been six years of appointments, medications, lab tests, a muscle biopsy, and scans. In those six years, our family has had to make a number of adjustments. We now drive to places in our neighborhood that we used to walk to. We plan family trips carefully, trying to determine how much walking is involved and how I can best navigate it. And, I've become a full-time, stay-at-home mom.

Even after my diagnosis, I continued teaching my fourth-grade students. I tried to pretend I could keep doing it all. But it was my doctor who finally told me I couldn't keep pushing myself, that the stress of public school teaching wasn't compatible with the

stress involved with living with a chronic medical condition. After a twelve-year career, the state of California approved my request, and I officially “retired due to a disability.”

At that point, Ryan was four and attending preschool. Ryan asked me why I was home, why I wasn’t going to school to teach the big kids anymore. And I told him that my doctor said I needed to stop teaching and rest my boo-boo legs.

But, it’s hard to turn off the teacher mind-set. I’m used to being in charge. I’m used to being stoic and strong and taking care of business -- whether it’s teaching fourth-graders how to compute equivalent fractions or helping my son construct a rhino beetle out of pipe cleaners, cotton balls, and toilet paper rolls.

Ryan’s now about to enter third grade. He’ll learn cursive writing, multiplication, and his teacher won’t conduct lessons while the students sit on the rug. They’ll be “big kids,” sitting at their desks all day.

Which means Ryan is a big kid, and it may be time for us to develop a new way of referring to my legs, a different term besides “boo-boo legs.” Like most things in parenthood, I don’t think I can necessarily plan for a new term or a new way of discussing my illness. It needs to evolve through our natural interactions. Although I have been trying to stop myself from saying things I used to say. Instead of “My boo-boo leg hurts,” I say, “My left leg is hurting.”

It’s a start.

When adults have asked me about my medical condition I tell them that having an autoimmune disease basically means my body is attacking itself, through no fault of my own. It

means that my body can't just heal itself. It means that my pain isn't evident to others. And it also means that I'll most likely be dealing with pain and tiredness in my legs for the rest of my life.

But while saying it like that is true, it's depressing. And though I want to be honest with my son, I think he deserves a slightly different explanation.

Having an autoimmune disease, an invisible disability, is a lot like the wind. You don't see wind. Instead, you see and feel the effects of the wind -- leaves blowing, branches scraping against the window, wind chimes jingling on the back patio, kites soaring, stray straw wrappers moving along the sidewalk, hair blowing in front of your eyes.

You don't see the wind, but you know it's there. You know it's strong, and powerful, and forceful, and you need to pay attention to it. There are times you need to keep the windows closed, times you need to hold on tighter to the paper in your hand, times you need to take your hat off so it doesn't blow away.

*How do you talk to a child about an invisible disability?*

Over-time. Developmentally. Honestly.