

When the Foo is on the Other Shüte (I Mean When the Shoe is on the Other Foot)

By Joyce Fichtenbaum, PhD

I have been a Rehabilitation Psychologist for over 20 years in a greater metropolitan area on the East Coast. I treat individuals with spinal cord injuries, disorders of consciousness, and cancer and help them and their families, who have received devastating diagnoses, cope with the unknown and unknowable. I support them in trying to balance hope with uncertainty while they are in an indeterminate state.

But nothing in my professional life prepared me for Friday, June 10, 2016, or for the 11 days that followed, when that shoe, from the idiom, attached itself to my other foot. It began when my son's school called. I needed to pick him up immediately and take him to his optometrist because Myson, who was 13-years-old and near-sighted, had lost vision in his left eye. It worsened between first and second period when he couldn't see the left side of the conductor of the symphonic band.

The optometrist referred us immediately to an ophthalmologist who was a retinal specialist: "He's fitting you in..."—a phrase implying emergency. His evaluation yielded the same diagnosis that the optometrist had made: optic neuritis and multiple sclerosis (MS). *As a teen, with no other symptoms, I thought, a single episode of neuritis puts one at risk of developing MS?* Before Myson left the ophthalmologist's

chair, he had Googled both optic neuritis and MS. The next step was an orbit and brain MRI (magnetic resonance imaging) with and without contrast: "They will fit you in"—a phrase that instilled fear and horror in me. I couldn't believe my son needed an emergency brain MRI. And they did fit him in. After thirty minutes of driving, we were waiting in an outpatient imaging center. Fifteen minutes later, Myson had an IV placed in his arm and he went in for an hour-long MRI. I sat in the room with him although he could neither see me nor hear me speak to him. We were told the results should be available early tomorrow morning. *We can wait 15 hours*, or so I thought. Once home, I watch Myson from the hallway outside his room wondering if this is the moment that changes everything. The thought brings me to tears he doesn't see. But that same Friday night, Myson begins to have nightmares of being tortured. In each nightmare, the torture remains the same. The torturers are different. He screams. I run in. I sleep in his room so I can wake him up at the first sign of distress. Other than lessening the time in his nightmarish state, it doesn't help.

The wait ensues. Waiting is unlike any other time in the medical sphere. This is particularly true if it

involves your young child whom you don't want to scare any more than the "Doctor Google" whom he already consulted via the internet. I tell him (as I try to tell myself) that it will be okay; a meaningless euphemism.

Waiting is an active process. Some people sleep or escape into a book or TV. I cannot. I get out of bed Saturday, June 11, the next morning, at 5:30 AM. Waiting is visceral, deep-seated, gut-wrenching. Noise heightens. Time slows. As 9:00 AM approaches, I transition to the process of anticipation. My anticipation is fueled by apprehension and begins when the expected phone call is imminent. It is static, paralyzing and mind-numbing even as my heart races, my blood pressure rises and my head aches. It reminds me of the feeling I get when I hear a police siren right behind me and wonder if they are looking for me to stop. The phone rings at 9:15AM. It is the Ophthalmologist's office. The imaging center cannot find the films. When located, a half hour later, the radiologist had already left for the weekend. I return to waiting, texting my colleagues and friends, that results will not be available until Monday. Texting is a blessing. Neither seeing a face nor hearing a tone of voice makes communication easier. Those who asked me to let them know what happens were multiplying, and it was becoming a burden. I knew that in my current emotional state I wouldn't recall who might be waiting for news.

Since it's Saturday, the Sabbath, I go to Synagogue to pray for my son's health and the strength to cope. People offer a clasp of a hand, a hug, referrals, or a lollipop for my son—gestures worth a thousand words. I feel disappointed by people who tell me of others they know who were diagnosed with MS with optic neuritis being their only symptom. I want to yell *Shut up*, but instead I walk away. I stand to say the

prayer for the sick. Instantly, a life can change, and the present with its everyday minutia and worries, and the hopes and dreams of the future, fall into the muck of the unknown.

Upon returning home from Synagogue hours later, I wait. I try to watch reruns of TV shows I know by heart. I think in staccato bursts. I am internally distracted. I probably shouldn't drive. I have no place to go anyway. I ask Myson to do his homework and practice saxophone; activities that require reading and concentration. We agree the situation can't be too serious if it doesn't prevent him from doing routine activities.

I think about the difference between *wanting* and *needing*. I decide that I *want* to know that his brain isn't involved. I *want* to know what it isn't- that MS is ruled out. I *need* to know what it is, a diagnosis, to be able to plan. *Why did the visual field cut develop suddenly? What does it mean? How will life change?* My clarity about *wants* and *needs* is inspiring. I begin to wonder how to apply it to my work with rehabilitation patients and their families. Goals, when we ask patients for them, are tantamount to asking what they want. How can I help others differentiate wants from needs?

I think about the difference between *waiting* and *anticipating*. *Waiting* occurs during the time that news is not possible. Once I knew I wouldn't hear from the ophthalmologist until Monday, I could occupy my time with short, finite, concrete tasks. *Anticipating* occurs when you know the information is imminent.

I realize that *waiting*, *anticipating*, and *planning* are three separate phases that weave in and out. Of the three, *planning* is more concrete. It requires knowing. Adults plan for *if*/becoming *when*, by assigning health care proxies and powers of attorney, and writing wills and living wills. We share decision-

making with our physician and follow treatment protocols given to us. *Waiting* and *anticipating* are far more difficult as during that time, there is nothing you can do to affect the outcome. Health care professionals who recognize the inherent difficulties during the *waiting* and *anticipating* stages will better serve their patients and their families.

Monday, June 13, finally arrives. I send Myson to school in the event I have a strong reaction to news I hear from the ophthalmologist we saw on Friday. At 9:30AM, I begin the transition from waiting to anticipating. I stand, phone in hand. I listen to my heart race and feel the adrenaline flow through my body. I call the doctor's office at 9:45AM. "The radiologist is still reading the MRI. It should be an hour or so. The doctor will call as soon as he gets the results." The phone rings, two hours later. I leap towards it. *Will this be that moment when life's trajectory changes?*

"It's not optic neuritis. There are no plaques or lesions. There are no restrictions to Myson's activities." He is referring us to a neuro-ophthalmologist. He will fit us in. That phrase again. The neuro-ophthalmologist office calls an hour later. What is usually a six-month wait will only be a week. Out of the forest but not the woods, I believe.

I return to work Tuesday, June 14, the following day. I can barely look at patients and their families. We share shoes. My eyes are weary and dull just like their eyes. I turn away from them in case they wonder if the sadness in my eyes reflects bad news I heard about myself or them. I have a deeper empathy for those who are waiting for biopsy results, the spinal cord injured awaiting prognosis, those who are vent dependent and don't know if they will wean, and families of patients with disorders of consciousness who wonder if their

loved one will return to the land of awareness. I, like them, are in the land of not knowing. I prefer that no one asks me how Myson is doing. There is nothing to say in response.

It's Friday, June 17, one week later. At work, I can be with patients and families as I can now compartmentalize my emotions and fully empathize. Once home, my heart breaks even though Myson reports some improvement in his vision and can continue with his daily routine both in and out of school. We wait for the neuro-ophthalmology appointment on Tuesday, June 21, and hope for a diagnosis with a good prognosis.

Tuesday's neuro-ophthalmology appointment approaches slowly. I start a list of questions. *Will Myson's vision get better? Is there brain involvement? Is it chronic? How will he play sports without getting hurt? Will summer camp allow him to come if asked to keep an extra eye on him? What if this doctor sends us for more brain or spine tests?* Once we park at the doctor's office, waiting will move towards the anticipation stage with all the emotional and visceral responses. My gut will be in knots. I will be hyper-vigilant. I will try to slow my heart rate down as it will be pounding in my ears.

Anticipation will become full throttle once Myson's name is called in the waiting room. It will be a familiar feeling. Before the doctor gives us his diagnosis, I will briefly stare at my son and weakly smile wondering if I should take his hand or if this will further alarm him.

As I write this narrative on Sunday, June 19, two days before the neuro-ophthalmology appointment, I don't know the end of this story. I am afraid. I am weary. I will try to protect my son whom I love dearly, from seeing my fear. I have support. So, while my thoughts and emotions run amok in my head, I am not truly alone. In fact, I suppose that you, the readers, are also

waiting with me.

ADDENDUM:

It is February, 2017, and Myson's vision has improved. 8 months, 5 doctor visits, 6 computerized eye tests and 2 MRI's later, we still do not have a definitive diagnosis. Our next appointment with the neuro-ophthalmologist is in June, 2017, which will be a year

since this horror began. We hope and pray the tests and examination yield a favorable diagnosis and prognosis that brings us closure.

As the June appointment nears, a few months from now, waiting will turn to anticipating with familiarity and Myson's nightmares will return in full force. At least I know what to expect, when that foo (i.e., shoe) once again attaches itself to my other foot.

About the Author



Joyce Fichtenbaum, PhD

Joyce Fichtenbaum, PhD, is a Rehabilitation Psychologist with over 20 years of experience. She received her PhD degree from Columbia University, NYC. She currently works with individuals and families who have experienced a life-changing medical diagnosis, including spinal cord injury, cancer and disorders of consciousness, in an inpatient rehabilitation setting. The personal experience she shares about the health of her son, Myson, changes her understanding, empathy, and treatment of individuals and their families who are trying to cope with life-altering injuries.



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