WHEN THE CARETAKER BECOMES THE PATIENT

Lessons learned while receiving and providing care.

BY TAIA DELANO, OD, FAAO

Whether a patient needs glasses for driving or is experiencing sudden vision loss, it is our job to evaluate, diagnose, and explain. It's an understood concept that it is our duty—our *job*—to take care of others. But who takes care of us when we aren't well?

In the back of our minds, we all have that worry that at some point we will be the one in the examination room, anxiously waiting to meet the person who will care for us—trusting that they paid attention in school and genuinely care, hoping that their bad day or personal lives won't interfere with our care. If it's up to luck or God our biggest problem will be cataracts. (I say luck because for most, it is a surgery only needed in advanced years.) I happily tell my patients that cataracts are a rite of passage and "good news" because it means they have been blessed with more birthdays. But what about health issues that go beyond cataracts? It is easy to see how we continue through our day without the consideration of our own mortality when so much of what we see can be fixed with a simple surgery.

MY BACKSTORY

After a trip to the neurologist in early 2017 because of frequent headaches, I was diagnosed with a type 1 Chiari malformation (see *The 4-1-1 on Chiari Malformations*). With bilateral clonus in my lower extremities and concern for further neurologic damage from my 18 mm herniation, I received a posterior fossa decompression. Scary as it was, I healed and married a fellow Illinois College of Optometry graduate 9 months later.

Fast forward 3 years. We have been blessed with two babies and have enjoyed (or survived) the two-under-two phase. Shortly after my youngest turned 1 year old, my headaches returned. Assuming it was an issue with the Chiari malformation, I scheduled a repeat cine-flow MRI to assess the flow of my cerebral spinal fluid.

A NEW DIAGNOSIS

I was in between seeing my morning patients when I got the results through an online patient portal. The brain scan showed a 3 cm lesion on my left inferior temporal gyrus.

Differentials were discussed, but none of them were good, each carrying a prognosis worse than the one before. Oligodendroglioma, ganglioglioma, astrocytoma. Even as a medical provider I wasn't sure what each of them meant, but I knew I didn't like the "-oma" at the end of each possibility. Within 2 weeks I was scheduled to have a craniotomy to remove and biopsy the lesion.

Between the initial scan and surgery, I had two neurosurgery appointments, a neurology visit, MRIs for my brain and cervical spine, an MRI spectroscopy, and a functional MRI. All of these took place while I continued to fit contact lenses, refract low vision patients, manage uveitis, and assess diabetic retinopathy. More importantly, I continued to change diapers, make dinners, read *Pete the Cat*, and watch Cocomelon. Life kept going, even when I felt mine was on hold.

The day before surgery, I snuggled my babies, desperately prayed, and cherished being an optometrist to my last patient who was none-the-wiser about me undergoing brain surgery. The surgery, due to the possibility of a disabling speech deficit, could prevent me from ever fitting those contact lenses, refracting my patients, or reading *Pete the Cat* again.

RETURNING TO WORK

I took 1 month off from work to try to reconnect brain circuits that were damaged by the tumor and the craniotomy. I spent 1 month pretending that was even possible, awaiting pathology results and getting misdiagnoses, coming to terms with the 7-year prognosis that came with the diagnosis of a grade 3 astrocytoma, and questioning the point in returning to work at all.

I picked a noble career, one in which I care for people, make a difference, and provide for my family. I planned to retire and travel with my husband and pay for dance lessons for my daughter, my son's first car, and family vacations. I acknowledged that I would unlikely be able to retire with my husband and that I probably wouldn't see my son learn to drive. It felt as though I was working just to pay off my $300,000 student debt—a debt that would likely outlive me.

At first, every day at work was just another day not spent with my family. Work was hard. Empathizing about presbyopia and mild dry eye was hard. Leaving my kids at day care so I could help people I didn't even know was harder. But each day I grew stronger mentally and emotionally. I had to hope that I could beat this, I had to continue to live as if I would. To quit a job I love would be defeat. It would be acknowledging my limited years and not acknowledging my will for a life beyond this.

I showed up for work every day. I conscientiously gave it my all to help my patients despite what I was going through. Appearing to be healthy offered me a unique vantage point. People were coming to me to fix their problems while having no idea about my own.

REALITY CHECK

You wrongly assume that every provider, nurse, and person you meet throughout your day is healthy. Your ego believes that the patient is the sick one and the provider is healthy. That's how the doctor-patient relationship works—or so we've been led to believe.

My experience made me realize that I had no idea what the people taking care of me were going through. Maybe my neurosurgeon has diabetes. Maybe the MRI technician has breast cancer. I hope not, but I don't *know*. Regardless of their health status, I

THE 4-1-1 ON CHIARI MALFORMATIONS

A *Chiari malformation* is a condition in which brain tissue extends into the spinal canal and occurs when part of the skull is either misshapen or smaller than normal and presses down on the brain, forcing it downward.

CHIARI MALFORMATION TYPE 1

This type of malformation develops as the skull and brain are growing; therefore, signs and symptoms may not emerge until late childhood or adulthood.

CHIARI MALFORMATION TYPES 2 AND 3

These are pediatric forms and are present at birth.

Chiari malformation is rare, and treatment depends on the type, severity, and associated symptoms. Monitoring, medications, and surgery are treatment options, but some cases require no treatment at all.

Source: Chiari malformation. May Clinic. www.mayoclinic.org/diseases-conditions/chiari-malformation/symptoms-causes/syc-20354010. Accessed February 3, 2022.

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expect them to show up and take the best care of me. That's what they were trained to do.

And that is how each of my patients see me. I am there to help *them*. I get to be their answer, just like my neurosurgeon and neuro-oncologist are for me. My patients don't know why their eye hurts or why they can no longer read without glasses. They don't know whether they have diabetic damage to their eyes or whether their Crohn disease has caused uveitis. But I know, and I have been trained to evaluate, diagnose, and explain.

All medical providers learn as much as we can about a certain topic because no one person can learn it all. We divide and conquer. The doctors I trust to save me are also the ones referring patients to me. Patients need me and my expertise, regardless of what I am going through. At the end of the day, we are all just people taking care of other people. There's something very beautiful about that.

BEING PRESENT IN THE PRESENT

It has been 6 months since my surgery, and although my prognosis has improved, it remains unclear. I choose to focus on the possibility of more *Pete the Cat* and meaningful patient encounters. This experience, although not concluded, has reminded me to not only cherish the family vacations and snuggles, but to also cherish the gift of being able to care for others while also being taken care of myself. ■

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