

## One Family's Journey

*“Even if our own family may not beat this disease, we can take what we're enduring and use it to raise awareness that eventually will lead to great progress.”*

### **Bryan and Ruth Wichmann, Port Washington, WI**

#### **Life as you know it Changes**

The Wichmann's journey started gradually three years ago. As a couple in their early 50's, Bryan and Ruth had plans for early retirement. Ruth was a teacher for Kindergarten and 3<sup>rd</sup> grade for over 20 years, but that all changed. The first thing they started noticing was that Ruth was having a hard time driving at night. But being in her early 50's, it was easy to assume this could be a natural part of aging and “normal.” Her vision seemed to be deteriorating and eventually she couldn't drive during the day. “The changes were subtle and very gradual,” says Bryan. “In hindsight it makes sense, but at the time you don't know it. We were very healthy people and didn't see this coming.”

After a visit to an ophthalmologist with a misdiagnosis of cataracts, the Wichmann's went to the Froedtert Eye Institute. In April 2019 Ruth was diagnosed with posterior cortical atrophy (PCA), which is a form of dementia which is usually considered an atypical variant of Alzheimer's disease. The disease causes atrophy of the posterior part of the cerebral cortex, resulting in the progressive disruption of complex visual processing. Because it affects vision, you don't go blind, but you struggle to see where things are. Over time her disease has progressed and more typical memory issues are presenting themselves.



#### **Mourning the Future**

Ruth's mother passed away from Alzheimer's disease so there was a family history. With her mother's journey, the Wichmann's were very aware of the devastation and challenges their future held for them. “Because we knew how this was going to play out, it was very emotional to know what was coming,” says Bryan. “It's hard for you to put your best face on, but you know you have to make decisions.”

“We had so many plans, but that has all changed,” says Bryan. “I have to balance our desire to really live our life before Ruth declines, but I'm limited because I have to work and support my family. In your head you go around and around in circles, which can be paralyzing. But I'm all out of tears and we just take it day by day.”

Bryan and Ruth go through phases of grief and have open discussions about their fears. Like many couples experiencing a dementia-related diagnosis, they have made ground rules for when they may or may not discuss some of the hard parts of their future.

#### **A System Not Set Up for Dementia**

“It's a huge problem that our system is not set up for this,” says Bryan. “Everything is hinged around a physical disability (often around a specific injury) and not adapted for cognitive disabilities, that are more gradual.” With PCA specifically, it didn't impact Ruth physically at first, so it was difficult for the Wichmann's to navigate the system. The paperwork process is overwhelming for caregivers seeking resources – disability, retirement, social security, life insurance – all center around physical disability. “There needs to be some new definitions for the system,” says Bryan. “Ruth's condition did not have black or white answers, based on how the system defines disability.”

Caregivers face road blocks at many steps. “Ruth voluntarily gave us her driver’s license,” says Bryan. “We learned later that this was a mistake (when trying to get social security and disability) and she should not have given it up voluntarily, but waited until it was taken away by a professional. You are trying to do your best and you fail.”

## **Challenges for Working Caregivers**

According to the Alzheimer’s Association, 6 in 10 caregivers were employed in the last year and 57% had to leave work early to tend to caregiving demands. Bryan is an Application Engineer at Crescent Electric Supply, which is one of the largest electrical supply distributors in the U.S. “It’s been very hard to balance work with medical appointments for Ruth,” says Bryan. “And it’s difficult to be motivated to go to work and make money, only to funnel it off to the health system.” The Family and Medical Leave Act (FMLA) has been another challenge for Bryan. “FMLA is not set up well to support intermittent leaves from work,” says Bryan. “The paperwork is very burdensome and the system is set up for longer chunks of continuous time off, which doesn’t meet the needs of our situation.”

Bryan’s company has been supportive of his families challenging needs and has worked with Bryan. “It’s a challenge for working caregivers – you want to quit to take care of your spouse, but you need to stay working to take care of your spouse.”

## **Moving Forward**

Bryan and Ruth want something good to come out of her diagnosis. “If we can help even one person learn from the things we struggled with, to make their path easier, then we’ve done something,” says Bryan.

For Ruth, she lives life day by day. She has learned that this disease doesn’t define her and she works to find ways to separate her own human self from the disease. They have learned that her disease moves slowly and a daily routine will change without notice.

“If there was any positive thing to come out of my mother-in-laws Alzheimer’s, it was that I knew we couldn’t do it alone,” says Bryan. “If we hadn’t been through that, I may have thought I could handle it without a larger network.” Over time Bryan and Ruth have shared their challenges with their close circles of friends and continue to grow that circle to support not only Ruth, but Bryan. They rely on their family and friend networks for ongoing support.

Bryan and Ruth have 3 children; a son who recently graduated college, a daughter in college and a 16-year old daughter in high school.

Bryan has also gotten more involved with the Alzheimer’s Association since Ruth’s diagnosis. They both attended the Wisconsin Advocacy Day and it opened their eyes to the efforts being made. “A lot of people only think the Alzheimer’s Association is about research, but there are so many efforts being made to improve the lives of families dealing with dementia,” says Bryan. “Until you walk the walk, you have no idea of the needs this community has and how policy change is needed.” Bryan has also participated in a caregiver support group where he was surprised at how much he appreciates going to that group. “Just being in the presence of others who are walking the same path and being able to share experiences without needing to explain your feelings is way more valuable than I thought it would be. Even if you have an awesome support network amongst your friends, these groups are a different kind of comfort and centering that I need.”