

Alzheimer's & Brain Awareness Month
Defining Perseverance

Karen Squiers, Cudahy, WI

For Alzheimer's & Brain Awareness Month we celebrate community heroes who represent hope, strength and perseverance. For caregiver Karen Squiers, perseverance is how she looks at each day. "I just have to keep putting one foot in front of the other one," says Karen. "We don't get to pick what obstacles life puts in our way and the only way I can live, and not look back with regret, is to keep moving forward. There are certainly days I fail epically at that, but it's about recognizing that you've fallen off your path and getting back up and dusting yourself off and keep going."

Karen cares for her husband of 38 years, Larry. He is living with frontotemporal degeneration (FTD) and early stage Alzheimer's. The last five years have been a journey for the Squiers. In 2017 Larry and Karen fulfilled a longtime dream of hitting the road in an RV. In early 2017, they put their house on the market, sold virtually all of their things, bought an RV and hit the road for 14 months. Once they were on the road Karen started noticing more changes in Larry. He started to withdraw and he became uncomfortable with the new places they were going. And his decision-making skills were diminishing, leaving everything to her. On the road, Larry was diagnosed with depression, but doctors suggested further evaluation. At that time, Karen first experienced the Alzheimer's Association through the 24/7 Helpline. Her call led her to resources that she could utilize to find a psychiatrist, in order to confirm her suspicions that they were dealing with something much more than just depression. They ended their RV adventure and settled in Cudahy to be near a geriatric psychiatrist and also family.



Shortly after coming off the road in the summer of 2018 they had Larry tested again and early stage Alzheimer's was showing up, as well as severely impaired attention and focus. She made another call to the Alzheimer's Association 24/7 Helpline for support and they suggested a care consultation. Because of that consultation they started attending the support group for Early Stage Dementia and enrolled in the Living with Chronic Conditions Workshop. It was here that they made friends with several other couples that they actually met with once a month for lunch before the pandemic and now keep in touch through group email. This made a huge impact, since the Squiers were new to the area. Many people find that they lose their friends through this diagnosis, but they found friends through the Alzheimer's Association. The support group helped Larry recognize that he was not alone or crazy and he made a connection through shared life experiences. Karen found that the support group helped her keep their life in perspective as she listened to others struggles and could find grace in the fact that they weren't quite there yet. In this last year, further testing revealed Larry also showed signs of frontotemporal degeneration, in addition to early stage Alzheimer's.

The Need for Awareness

Awareness is a fundamental part of Alzheimer's & Brain Awareness month. "Dementia, above other types of health issues, is one people need to pay more attention to," says Karen. "Everyone knows common things that can be bad for health – smoking, no exercise – things you can control. But you just never know when dementia is going to hit. We don't know why you get it or how to prevent it. Because it's such an unknown, the more people that can pay attention to this disease, the better prepared they will be in the eventuality that someone they know is impacted."

"There is a huge misconception with dementia that it's purely about memory loss and people wandering off," says Karen. "It's important to educate that there is a whole lot more to it than that. The beginning stages of this disease are just as devastating as the end stages people typically think of. Realistically, everyone probably already knows someone with dementia, but you just don't know it, yet."

Message to Caregivers

"I would encourage other caregivers to take time to breathe," says Karen. "It is easy to get caught up in everything going on around us. It can become very overwhelming very quickly. Be mindful of that and find ways to step back from all the noise to take care of yourself – be proactive about that. It's easy as a caregiver to just focus on your person. But if you're not taking care of yourself first, you can't do as good of a job. Keep going. Today is just a day. Find small moments of grace and be grateful."

Karen participates in the Alzheimer's Association FTD support group as well as the Early Stage Group and recently took the Savvy Caregivers Workshop. "These resources help tie me to a community of like-minded individuals who get it," says Karen. "Being able to hear their stories, helps keep your own situation in perspective. It's a monthly reminder that you're not alone."

Life after COVID-19

Karen and Larry's routine has been altered due to the epidemic. The Squiers household had to reinvent what normal looks like. Karen uses a white board and puts up a weekly schedule. Previously, Larry was going to Makerspace several days a week where he could work with woodworking and other tools. That has been replaced on the white board with "garage time" where he works on miscellaneous projects. Instead of their regular gym trips, they are doing outdoor exercise. While they have adapted, it's been difficult because now Larry isn't "out in the world," so to speak, and it worsens isolation.



Karen always tries to stay positive with Larry and is an example to all. "It's all about the journey and moving forward. All you can do is live the best life you can, one moment at a time!"

This June we salute the perseverance Karen has as a caregiver and thank her for being an amazing example of a community hero.