

## National Family Caregiver Month

*"An Alzheimer's diagnosis is not the end; it's the beginning of another journey."*

### Monty and Kuei Johnson, Waukesha

#### Love at first Sight

Monty and Kuei's life together began overseas. After he graduated from college, Monty wanted to serve his country during the Vietnam War, and enlisted in the Air Force in 1969. He was stationed at Tainan Airbase in Taiwan as a Veterinary technician – his primary work focused on food service and inspection and helping at a small animal clinic.

Monty met Kuei for the first time at the Happy Souvenir Store. Monty and friends would visit the store in their leisure time and talk with the clerks (who wanted to practice their English). Kuei worked at the store, and when she met Monty, it was love at first sight. They met in April of 1970, were engaged by July and married in December. Monty's original assignment was for 15 months, but he extended his assignment a total of 24 months, and they ended up staying on the airbase just over 3 years before moving back to the U.S.

Once they settled back in the U.S., Monty worked for the Veteran's Administration and then at the Equal Employment Opportunity Commission, where he stayed until his retirement. Kuei participated in many classes and eventually got her GED and a High School Diploma.

Monty and Kuei have an adult son and daughter, and two grandchildren.



#### Their Journey

Kuei was diagnosed with Alzheimer's disease in 2003, when she was 55 years old. Monty shared that the first 12 years of her diagnosis were early-stage, but the last 5 years, she has declined significantly. "I feel very fortunate that I was able to retire shortly after Kuei was diagnosed," said Monty. "This gave me the time to focus on her. Most people couldn't do that and would need to keep working."

The Johnson's also benefited greatly from long-term care insurance that they signed up for 6 months before Kuei was diagnosed. "Without that insurance, there is no way I could care for Kuei at home," said Monty. "The costs associated with Alzheimer's disease are overwhelming for families. The long-term insurance was somewhat new at the time, and we are very lucky we have it."

"A caregiver is on duty 24/7," said Monty. "Currently, I have caregivers from three different in-home care providers assisting me, but I am always with Kuei and do all of her transfers." Kuei also has regular nursing visits from a home hospice company.

"A lot of people view this diagnosis as a dark cloud and focus on what's missing, but there is so much still there," Monty shared. "An Alzheimer's diagnosis is not the end, it's the beginning of another journey. There is so much life still to savor. Even now, Kuei has a sense of humor and understands what I'm saying to her. We still interact and enjoy each other's company." The Johnson's have a 3-season porch that they enjoy together. The hospice company has volunteers come out to sing and entertain them (standing in the yard outside the porch).

## Taking Advantage of Alzheimer's Association Services

Monty and Kuei have been very active in Alzheimer's Association programs and services. "My only regret is that it took me so long to get involved," shared Monty. "We were many years in before I started reaching out for support, and there are so many resources that are available to caregivers."

The couple first got involved by participating in a Memory Café, which is a social engagement for those living with early-stage Alzheimer's or dementia where they can go with their care partner to socialize with those on a similar journey. "The friends we met through the Memory Café have become our network over the years," said Monty. "Several of them were with us this Fall (socially distanced) to celebrate Kuei's birthday." Out of the Memory Cafés, the group created the Purple Canoe Club, which is another social engagement where they meet up weekly at local restaurants (now virtually).

Monty has taken part in Alzheimer's Association education programs, support groups, social engagement opportunities and in-home care consultations throughout the years. He has also participated in several State Advocacy Days and Letter to the Editor campaigns to raise awareness for the needs of those living with Alzheimer's.



## Self-Care for the Caregiver

Monty has been a caregiver for over 17 years. While he is grateful he is able to keep Kuei at home, he also understands the importance of self-care. "It's critical that I take care of myself, because caregiving is demanding and will wear on you," shared Monty.

Monty has an oasis in his basement where he has a home gym, a den, and a computer area. He reserves 8:00 p.m. – 12:00 a.m. every day for himself (after he puts Kuei to bed). "I set this time aside every day so I can get my mind off of things and just focus on things I enjoy – genealogy, computer games, exercising and reading," said Monty.



"Caregiver's need an outlet," said Monty. "It's also a pressure release to talk with someone, frankly, about your situation, and I have reached out to friends and counselors in the past, and encourage other caregivers to do the same."

Monty also stressed the importance of socializing. "I would get together with 3 other guys pretty regularly," shared Monty. "Talking about things, other than your situation, is a healthy outlet."

## Advice for Caregivers

"I would encourage caregivers (especially in the early-stage) to get as much information as they can from the Alzheimer's Association early on," said Monty. "The Savvy Caregiver education course was very helpful and opened my eyes, so I knew what to expect. The course covers the stages of Alzheimer's and common behaviors, so it made the journey run more smoothly because I knew what was coming."

Monty also suggests planning and researching about the disease so you can avoid crisis situations, by having things in place. The Alzheimer's Association 24/7 Helpline can also provide resources to prepare caregivers.

"Savor the time you've got during whatever stage they're in," says Monty.