

## ***Celebrating Community Heroes Alzheimer's and Brain Awareness Month Teena and Kim's Journey***

Teena Racheli, Washburn, WI

For Alzheimer's & Brain Awareness Month we celebrate the heroes in our community who show strength, hope and perseverance in our current environment. Caregiver Teena Racheli is the definition of this mantra as we celebrate her unrelenting love for her husband Kim.

Teena and Kim have been together for 20 years. They came together as older adults and have had a beautiful marriage. Teena describes Kim as "a smart, loving, playful man." Kim used to work in the financial market, but left that to fulfill his passion of becoming a bread maker and purchased a Great Harvest Bread Company bakery. In Denver, where the two met, he was instrumental in creating The Network Coffee house for homeless people to come and have a safe place to rest and enjoy coffee and bread. "This is just the type of person Kim was," Teena says.

Teena and Kim decided to trade in the big city for a small community and moved to Northern Wisconsin. A year before Kim was diagnosed, strange things started to happen to his memory. Kim's father had Alzheimer's, so they knew this could also be in his future. They spent a year ruling everything out, before in 2011, Kim was diagnosed with early onset Alzheimer's. They were told that he had 4 years until he was in a nursing home and would no longer recognize family. "The first thing we did was take the Alzheimer's' Association 6-week class "Living with Alzheimer's," says Teena. "It equipped us with tools, hope and ideas." To a caregiver who is new to this diagnosis, she would say "Yes it's scary – the person you love with all your heart is changing and going to change. That is real. That person is still going to be there. We need to stay connected with them. Lean into help, resources, friends and support groups. They will be a lifeline for you"



Teena feels strongly that the small town (literally a one Main Street town) where they live has been very beneficial to their journey with Alzheimer's. "Washburn became a care center for us," says Teena. "The care team I relied on would take Kim out – to the bank, hardware store, grocery store – and everyone in the town greeted him and welcomed him. It gave him a sense of place and community." In addition to their small town support, Teena focused on diet, exercise, medications and mental stimulation (they put together at least 75 puzzles) early on in his diagnosis.

The last few years, Teena began to fear it wasn't safe for Kim to be at home anymore. He was more restless and confused and she feared he would wander away from their home. In August 2019, Teena made the decision to move Kim to a secure memory care facility that would be sensitive to his needs, Court Manor in Ashland. "When Kim was diagnosed, he told me that when he couldn't care for himself, he didn't want me to have to do it and he wanted to go to a care center," says Teena. "He was not afraid and he didn't want me to have any guilt. He gifted me that. I promised him that I would always keep him safe and be with him always."

Kim's transition to memory care was seamless. The staff who work with the dementia patients are well-versed at working with their residents and he adapted well. Teena modeled to the staff what worked best with Kim and they patiently followed her guidance. After a few weeks, Teena developed a schedule and focused her time with Kim when he was "sundowning" (also known as "late-day confusion" where those living with dementia are

more confused and agitated – commonly between 4:00-7:00 p.m.). She would help him with dinner, they would make up stories and listen to music. Knowing Kim was in a safe place allowed Teena, who is a United Methodist pastor, to balance her duties to the 4 churches she serves. The memory care facility also gave Kim a sense of purpose. Staff told Teena that Kim would look for anyone who seemed down and put his arm around them and reassure them that they would be alright.

Their beautiful rhythm of life all came crashing down with COVID-19. In mid-March the care facility had to implement a no visitor policy. Teena coordinated with the care facility that four times a week before Kim sundowned, a non-essential staff person would help to have Kim and Teena meet through his outside window.



They play a CD Kim loves and staff sit next to him as he and Teena tell stories (the staffer holds a tablet with the speaker on, and Teena is on her phone). While this routine started OK, Teena has noticed a swift decline in Kim emotionally and cognitively. He has increasingly shown more confusion in their meetings and she feels helpless that she cannot be there to comfort him during the most difficult time of day. To further seek support, Teena has attended an Alzheimer's Association support group for "Family of loved ones living in a facility" during COVID-19. "The group is so well facilitated and attended by amazing caring people who listen to each other," says Teena. "It's very powerful and has been a life-line to many of us."

Teena has been driven, now more than ever, to try to affect change for Kim and those dementia residents **who are safe, but emotionally failing** due to COVID-19. Teena still visits Kim and has been respectfully, but firmly communicating with the facility her need to be creative and find ways to connect with him. There has been a reliance on communications through video and other technology for residents to speak with family. However, some dementia residents are unable to access digital platforms for communication with their families; cognitively they cannot make the connection that someone is communicating with them via technology and it's more frightening than helpful.

She is advocating that there be a provision where trained family members (complying with all rules) can support the small group of dementia residents who are emotionally most at risk, out of compassion. She contends that family who regularly come to the unit to be with their loved one, are not actually "visiting", rather they are supporting them during the time of day when one-on-one support is needed (mealtimes, or in Kim's case, when he has "sundown-like" behaviors). While Teena is very complimentary of staff, she suggests there aren't enough of them and that there are benefits to having a family caregiver be present on a regular basis. Her recommended proposals are based upon several of the Governor's Orders and the Department of Health Services guidelines (calling for volunteers, and also one advocating for the hiring of "COVID-19 Emergency Non-Registered Nurse Aides" (the DHS outlined a 16-hour training program). She suggests that real suffering can result for the resident from the unmet cognitive and emotional needs that family caregivers provide for the person in the care center.

This June we applaud the heroic efforts of Teena and the thousands of other caregivers like her who represent the mission of the Alzheimer's Association.