

Impact of COVID-19 on those Living with Dementia

Karen Przybylski, Milwaukee

Karen's family has been on a journey with Alzheimer's since her father, John, was diagnosed six years ago. He was living in La Crosse at the time, but moved to Milwaukee so Karen and her sister could better support him. "When he was first diagnosed, I went right to the Alzheimer's Association website and signed up for a 3-week training class," Karen shared. "It was so helpful, so we would know what was coming."



Lockdown

When COVID-19 arrived, Karen and her family felt helpless. "Even though I knew a lot about the disease, the restrictions with COVID-19 posed a whole new level of learning for a family struggling with dementia," Karen shared. "One of my first calls was to the Alzheimer's Association 24/7 Helpline to figure out how to manage."

Her father and uncle shared a room in a long-term care (LTC) facility. They both contracted COVID-19 in March, 2020, very early in the pandemic. After a brief hospital stay, her father recovered from the virus. But what John was not able to shake was the social isolation that virtually ground his life to a halt.

The COVID-19 restrictions prevented Karen and her dad from taking the daily car rides they had been accustomed to for the past five years. "We would listen to old-time music and talk," Karen said. "Now we could no longer go on our car rides and I could only communicate with him through a window. He developed panic attacks and couldn't breathe. Eventually a geriatric psychiatrist had to give him medication for his panic attacks." Karen felt helpless as she watched her father's rapid decline.

Impact of Isolation

"The isolation of COVID-19 is devastating to so many living with Alzheimer's and dementia," Karen shared. "For my dad, the isolation really made his Alzheimer's progress. During the past 5 years, his Alzheimer's was somewhat stable and he continually scored the same when he had his yearly Alzheimer's exam. Despite his diagnosis, he was positive. This past September, his score fell by 3 points and honestly, I thought it would be more. He was actually talking about not wanting to live. Isolation is killing our loved ones, especially those with Alzheimer's and we need to create awareness for this tragedy. It's terrible to not be able to see your family."

Adjusting to Meet Their Needs

For many individuals living with Alzheimer's and dementia, routine is critical. "The daily rides with my dad were important to help manage his anxiety," Karen said. "He knew I was coming and he had a purpose. My family had worked so hard to keep him stable and that was all being stripped away."

"While it wasn't recommended, eventually I moved my dad to a new facility. Since he has moved, his disposition has changed," Karen said. "He is so much better. We've



resumed car rides and he doesn't talk about wanting to die anymore. He's back to being grateful and says he's so happy he has his two daughters. On our rides we listen to the radio and he's back to telling stories of living on Milwaukee's East side. He's still anxious, but hasn't had any more anxiety attacks. His LTC is still on lockdown, but they work with me to make his daily rides possible. His room is close to an exterior door for easier access. We limit rides if cases spike, but they work with me." Her father has received the COVID-19 vaccine.

Increased Caregiver Burden

COVID-19 has also dramatically impacted the lives of family caregivers. In October, during her father's move, Karen, who works as a data analyst for a major mortgage investment corporation, received a promotion at work. She found herself tasked with new career responsibilities and a deeper learning curve. And yet, COVID-19 and her father's Alzheimer's journey did not go on hiatus. "As a caregiver, it's been extremely stressful to watch the last year of COVID and the impact it has," Karen said. "COVID-19 has forever changed my dad now. Even though he is in a better place, his decline has been so significant. He will call me 50 to 75 times a day. My voice mail is full of messages from him asking me to pick up cigarettes. He doesn't remember that he doesn't smoke anymore. At times he will leave me a message forgetting that we just went for a ride. The damage has been done in some ways."

Advocating for those with No Voice

Karen became involved in Alzheimer's Advocacy shortly after attending her first caregiver class over five years ago. During that time, she has attended several Alzheimer's Impact Movement Advocacy Forums in Washington D.C. where she has urged her federal legislators to support increased funding for Alzheimer's research and support legislation for individuals living with Alzheimer's and their family caregivers.

The Alzheimer's Association provides support for families with loved ones in long-term care facilities. The 24/7 Helpline 800.272.3900 is staffed by professionals who can offer support and suggestions for families. The Alzheimer's Association Wisconsin Chapter also hosts a weekly virtual support group for "Families with a Loved One in a Long-term Care Facility."

