

Coronavirus and Alzheimer's: A Precarious Relationship

By

Ira Asherman

One cannot underestimate the impact of the Coronavirus on our society. The number of people who have died and will continue to die is heartbreaking. There is a group of us for whom the problem is even more complicated. We are the caregivers for those people living with Alzheimer's. The Coronavirus has had a three-fold impact on us

First: For many of us in NYC the greatest relief came with attending the wide range of Alzheimer's programs available here. These included a rich array of programs sponsored by museums, artists, dancers, musicians, and day programs at community centers. What all these programs provided was a safe place for Alzheimer's patients and their caregivers to relax, be with friends, and go home having had an enjoyable experience. In addition, it provided a safe haven for us caregivers, knowing that we were among friends: no judgment and everyone was there to help. COVID 19 ripped all of that away. No more programs, no more dancing, singing or eating with friends and clearly no emotional support.

Prior to COVID, my wife spent several days a week at a day program full of music, exercise and just being with others. Weekly she attended rehearsals for a chorus for those with Alzheimer's. She loves to sing and still knows the words to many songs. On a monthly basis we might attend a museum-based program, a concert, or go dancing at programs specifically sponsored for people living with Alzheimer's and their caregivers.

Now, with COVID, everything is virtual. As hard as everyone is trying, it is just not the same and never will be. Online programs are by their very nature one dimensional. I see, with a heavy heart, the change in my wife. While I have no illusion about where she is with the disease and what the

future likely holds, I see the difference. She frequently reaches out to our computer in an effort to touch, to make contact with people she recognizes. She is sleeping more, eating less, and is just not stimulated in the same way.

Second: There is justified fear of having others in our homes. Including friends and family members. This has led many people to eliminate home health aides helping them out. Bottom line: a great deal more stress. These aides can make all the difference in our lives. They provide the bridge helping people to participate in the available on-line programs and finding other programs that one is likely to enjoy. They also give us, the family members, time to rest and revive. With luck, the aide is someone who is pleasant to be around for both the person with Alzheimer's and the caregiver. We are so fortunate that this is the case for us.

A physician friend summed up the problem in the following terms: "When I think of COVID-19 and dementia, it's the extra strain on caregivers that really concerns me. The pandemic has either stripped them of the necessary tools they use every day - like small group activities or senior centers - or it's made them fearful of the personal attendants they depend on for help. That's a double whammy that can only lead to poor outcomes for the loved ones with dementia."

Third: The situation is dire for people living in nursing homes or residential memory facilities where ability to visit has been severely curtailed. No longer are we able to sit with our loved ones to talk and to touch. COVID has reduced much of the process to face-time calls or window visits. And, it has reduced the time people were allowed out of their rooms to communicate and eat with others. As a result, many residents end up in virtual isolation without understanding what has happened.

To quote a friend who works in a memory care facility "As a team member who has worked throughout the pandemic (sometimes six days a week) I have seen the decline in our residents, especially the memory care folks. It is eye opening to see how much resident engagement, team member chats, and touch really made the difference." As the world has

begun to change and restrictions have been relaxed, even temporarily, she has noted: "I have watched the residents smile again. It is so satisfying to see the families able to re-connect with their loved ones after six months or so of visiting through window visits."

Under the very best of conditions being an Alzheimer's caregiver is a difficult and unforgiving task. In the era of the Coronavirus it is even more complex and demanding. You are on call 24/7. You do not leave. You do it because of your love for the other person, you care and as Arthur Kleinman said in closing his recent book *The Soul of Care*: "Caring is what makes life worth living; it is a source of beauty and goodness."