

Because Loneliness Kills

A few years ago, I spoke with a hospice chaplain who said, "You know, I don't believe people die from dementia. I believe people with dementia die from **neglect, loneliness and grief!**" I will never forget those words because they so accurately describe the cruelty of this disease.

Late last February, assisted living and memory care facilities began to close to the public, setting in place quarantine systems to keep their residents safe from COVID-19. Suddenly, residents were isolated even from their own families, many of whom previously visited regularly to assist with their care. Now, more than six months later, we are beginning to witness the cruel outcome of isolation, especially for individuals living with dementia who do not have the cognitive ability to understand why this is happening to them. Many are declining more rapidly than they should, and some are dying alone without the support of their families.

Facilities have tried to compensate with window visits, online meetings, and other novel methods of keeping residents in touch with their loved ones. But these are poor substitutes for closeness and real human touch, and for people with dementia they likely create more confusion than relief.

When these survival tactics were established, none of us had any idea how long this situation would continue, and now we find ourselves horrified that there appears to be no end in sight.

Something happened in Florida in July that brought this situation into the light of day. A woman named Mary Daniel, like other loved ones, was cut off from her husband who was in a memory care facility, and she could see how badly the isolation was affecting both of them, individually and through their relationship.

Daniel noticed that the staff could come and go, and she applied for a part-time job as a dishwasher. As a result, two days a week, after her shift, she could visit her husband and even lie in bed with him as he went to sleep, just as she had done before COVID-19.

Daniel's bittersweet story struck a chord! The news media picked it up and soon even Florida's governor was talking about her. Daniel grasped on this unexpected publicity to create an organization called Caregivers for Compromise, a grassroots initiative to ask governments and the senior care industry to look for new, compassionate and humane solutions.

Caregivers for Compromise put up a Facebook page that attracted 6,000 followers in 24 hours. Within two weeks, chapters had formed in every state. Clearly, Mary Daniel was not alone.

The message of Daniel and her group is, if we cannot change this pandemic, then we must change how our senior care industry responds to it. Why this change is urgent and imperative is expressed in Caregiver for Compromise's motto: "Because isolation kills too!"

This is not a confrontational movement. Daniel has set its tone with the word "comprise." Let's find ways to work with — not against — the professionals and government regulators to make it better for each and all of us. As a result, several states have already begun to review their regulations to address this issue.

The pandemic has given us another opportunity to learn and improve. I am optimistic we can come out of this crisis with a more compassionate, more flexible, more creative senior care industry.

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