

COVID-19 kept Kaci Johnson away from her mom, who slipped further away

Broken Bow — For weeks, Kaci Johnson wondered if “eggs and bacon” would be the last words she’d hear her mother speak.

Even they felt like a breakthrough, coming as they did in the 10th month of a pandemic that had left Johnson’s mom, Marlyn McCullough, 77, isolated and alone in the Brookstone View Skilled Nursing and Rehabilitation here.

McCullough was still lucid before COVID cut off her off from Johnson and her two sisters. In that time, McCullough’s dementia had taken firmer hold. By the end of the year, she was confined to a wheelchair, unable to lift her arms.

“The last year has been hell,” Johnson said. “I know what dementia is and what it does. I just can’t help but wonder how the isolation that these people have had to go through has sped up that process.”

The coronavirus has killed over 2.5 million globally, including more than 500,000 in the U.S. It has hit the elderly particularly hard. According to a New York Times [database](#), 42% of the deaths in Nebraska have come at assisted-living facilities.

To protect their residents, care facilities have increased testing, stocked up on cleaning supplies, and restricted access of visitors.

But the new rules, necessary to slow the spread, came at a steep cost. Isolation increases [the risk](#) of a host of health problems, including neurocognitive issues. A Washington Post [analysis](#) found that dementia patients were dying at a greater pace since the pandemic, and not only from COVID.

For most of the year, Johnson’s connection to her mom was limited to Zoom calls or awkward meetings outside a window that seemed to just confuse her mom more.



Marlyn McCullough with her grandchildren Kailey Johnson, 19, and Camryn Johnson, 15, and daughter Kaci Johnson. Credit: Kaci Johnson

“How do you explain to a person with dementia why their loved ones are standing outside waving to them?” she said. “It’s impossible. She just looks at us, like, what the hell are you doing outside?”

Brookstone allowed in-person visits for a few weeks in July, September and early December, but always with six feet in between.

When Johnson and her family would come, facility staff would hand out flyers reminding them that touching was prohibited.

“It takes every ounce of willpower that I have to not jump in her chair with her every time I see her,” Johnson said. “I just want to shut the door and just break every rule, every single time.”

Johnson and her two sisters, visiting from Denver, were able to visit for two consecutive days in early December. Johnson said she could see the difference in her mom almost immediately.

McCullough sat up straighter and seemed to pay more attention to her daughters’ conversation. It was then that she answered the question of what she had had for breakfast that morning: bacon and eggs.

Johnson said the Brookstone staff was “incredibly caring, kind and understanding.” While she was frustrated by the restrictions, her real anger is directed at state and national leaders she says did a poor job managing the crisis. Their indifference and inaction made it easier for Americans to ignore the risks, helping the virus spread, she said.

According to AARP, 35 states had [mask mandates](#). Nebraska isn’t one of them.

“I just feel like this entire generation of people has been let down,” Johnson said. “I feel like these residents have had some of their basic rights and freedoms just trampled all over.”

Her mother deserved better. McCullough worked hard all her life, in tough jobs like road construction, as she raised her three daughters.

When she and Johnson’s father owned a café, McCullough’s day started at 4 a.m. and ended late at night. After Johnson’s dad died when she was just 15, her mom went to work at hospital in the kitchen and in housekeeping.

“She really poured her heart into that, and it was really all just for us kids,” Johnson said. “She would have given us the shirt of her back, you know. I just always remember my mom as happy and smiling. She always loved it when the family was all together.”

She was humble and selfless. She loved to decorate.

Johnson, who is an administrator at the local community college, has the burden and blessing of being the closest daughter in proximity to her mother. She’s been able to spend more time with her mother as her disease progressed. But its stressful to visit and then relive the experience, explaining her condition to family members.

The news she’s had to relay has grown steadily worse. By mid-February she had lost her appetite. She slept most days. McCullough hasn’t spoken since that day in December.

After residents and staff were vaccinated in February, Johnson was allowed to come back into the facility.

While space restrictions remained in place, a sympathetic aide led Johnson to her mother’s room and closed the door, leaving the two alone. After a year of not touching, Johnson raced to the bedside and grasped her sleeping mother’s hand in hers.