

During the isolation of COVID, a mother's dementia took a firmer hold

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

They came in December, nearly ten months into a pandemic that had sealed off Marlyn McCullough, 77, inside a nursing home and, increasingly, inside herself.

Before COVID-19, McCullough’s dementia had been progressing, but slowly. She still recognized her daughters. She could hold a conversation. Then the virus arrived, and with it the rules: no visitors, no contact, no touch. 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 these people have had to go through has sped up that process.”

The coronavirus has killed millions worldwide and more than half a million Americans, hitting the elderly especially hard. In Nebraska, roughly 42% of deaths have come in assisted-living facilities, according to a *New York Times* database.

To protect residents, facilities like Brookstone View Skilled Nursing and Rehabilitation locked down. They ramped up testing, stockpiled cleaning supplies and barred visitors.

The measures slowed infections. But they came at a cost.

Isolation is known to accelerate a range of health problems, including cognitive decline. A *Washington Post* analysis found that dementia patients were dying at higher rates during the pandemic — not only from COVID itself.

For most of the year, Johnson’s connection to her mother was mediated through screens and glass: Zoom calls that rarely landed, visits conducted through a window that only seemed to confuse her.

“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 are you doing out there?”

There were brief reprieves — a few weeks in July, again in September, then early December — when in-person visits were allowed. But even then, families stayed six feet apart. Staff handed out flyers reminding them: no touching.

“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 break every rule.”

In early December, Johnson and her two sisters, visiting from Denver, were granted two consecutive days with their mother. The change was immediate. McCullough sat up straighter. She followed the conversation.

And when asked what she’d had for breakfast, she answered: eggs and bacon.

It felt, Johnson said, like a breakthrough. It would also be the last time her mother spoke.

Johnson is quick to praise the staff at Brookstone as “incredibly caring, kind and understanding.” Her frustration lies elsewhere — with what she sees as a broader failure of leadership that allowed the virus to spread unchecked.

According to AARP, 35 states adopted mask mandates. Nebraska did not.

“I just feel like this entire generation of people has been let down,” she said. “Their basic rights and freedoms have just been trampled.”

Her mother, she said, deserved better.

McCullough spent her life working hard — in road construction, in cafés, in hospital kitchens and housekeeping — raising three daughters, often on her own. After her husband died when Johnson was 15, she kept going.

“She really poured her heart into it,” Johnson said. “It was all for us kids. She would have given us the shirt off her back.”

Johnson remembers her mother as happy, smiling, always happiest when the family was together.

Now, as the daughter who lives closest, she carries both the privilege and the burden of witnessing her mother’s decline up close — and of relaying it to her sisters. The updates have grown steadily worse. By mid-February, McCullough had lost her appetite. She slept most of the day.

She has not spoken since December.

After residents and staff were vaccinated, the facility began allowing limited visits again. One day, a sympathetic aide led Johnson into her mother’s room and quietly closed the door.

For the first time in nearly a year, there was no glass, no distance, no one watching.

Johnson crossed the room quickly and took her mother's hand.