

# When Dementia Meets the Coronavirus Crisis

Disruptions in routines and the need for hands-on care are among the special challenges for dementia patients and their caregivers.

By Julie Halpert

March 26, 2020

As the coronavirus advances, it is taking a particularly harsh toll on the many who are caring for a loved one with dementia or Alzheimer's, the most common form of dementia. According to a report by the Alzheimer's Association, more than 16 million Americans are providing unpaid care for those with Alzheimer's or other types of dementia. For them the virus is "really a double whammy," said Lynn Friss Feinberg, a senior strategic policy adviser at AARP's Public Policy Institute. "You're worrying about your own health and that of your family member."

While the disease itself does not necessarily place patients at high risk for contracting the virus, they and their caregivers face a range of special challenges. Dementia patients are typically very sensitive to changes in routine and often require a great deal of hands-on care, both factors that are hard to manage now. Family members who usually rely on day care programs or visiting caregivers may be finding themselves with full-time responsibilities, while others whose loved ones are in facilities are unable to visit them now.

Among the greatest challenges is how to minimize disruption in care that is intensely personal. "Care for dementia patients is 'high touch,'" said Peter Lichtenberg, a professor of psychology and director of the Institute of Gerontology at Wayne State University. He recommends that caregivers take measures to avoid their own exposures by having provisions delivered, disinfecting surfaces and employing proper hand-washing techniques.

K.C. Mehta has been caring for his wife, Sumi, since 2013, when she was given a diagnosis of Alzheimer's at the age of 59. A former engineering executive at Chrysler, Mr. Mehta, who is 72 and lives in Rochester Hills, Mich., spends each day focused on maintaining his wife's routine. Twice during the night, he changes her diaper. When she awakes, he bathes and dresses her.

He prepares her meals that include fresh vegetables, hummus and Babybel cheese as well as homemade fruit smoothies.

## Latest Updates: Coronavirus Outbreak

- [Trump effectively ousts the top watchdog for the \\$2 trillion in virus relief.](#)
- [Major challenges remain in grappling with the virus amid some encouraging signs.](#)
- [New York records the largest number of deaths in a single day.](#)

[See more updates](#)

Updated 8m ago

---

More live coverage: [Markets](#) [New York](#)

Intent on reducing his wife's risk of getting infected, he has temporarily let her evening caregiver go. He's conflicted about reducing risk in a situation where touch is essential. His wife can't fall asleep unless he is beside her. "She needs that comfort," he said. "I cannot keep a safe distance from her. When she gets agitated, I pull her head upward to give her a kiss on the forehead or cheeks. This calms her down. For her, it is a kiss of love. For me, it could be a kiss of corona."



The Mehtas take indoor walks around the basement of their Rochester Hills, Mich., home. Peggy Ketor

Dr. Ken Langa, a professor of medicine and co-director of the Institute of Gerontology at the University of Michigan, said that while dementia patients, whose social network tends to be small, may be at lower risk than the overall population of contracting the virus, they can be in greater danger of complications if they get it. Most dementia patients are in the high-risk older population; the Alzheimer's Association report found that one out of 10 people over 65 suffer from Alzheimer's. And many have chronic conditions that could make them more vulnerable to complications from the infection, Dr. Langa said.

Beth Kallmyer, vice president of care and support for the Alzheimer's Association, said that if they do get sick, people with dementia often can't articulate their symptoms; agitation or a change in behavior can be a warning sign. If caregivers are the least bit concerned, they should call their health care provider immediately, she said.

Ms. Feinberg said that because routine is so crucial for dementia patients, caregivers should provide security and comfort as much as possible. "It's a time to help the person with dementia have the most normalcy in this most unnatural time," she said. This could include trying not to watch the television news, playing soothing music and participating in small tasks together, like folding dish towels or winding a ball of yarn. Going for regular walks to get fresh air, even if it's just in the back yard, can be helpful as well, she said. Staying in the present with something you have control over, Ms. Kallmyer said, "is the best way to get through the day with those you're with."

Sign up to receive our daily **Coronavirus Briefing**, an informed guide with the latest developments and expert advice.

[Sign Up](#)

Sherri Snelling, a corporate gerontologist and chief executive of the Caregiving Club, which provides consulting services to employers on caregiver wellness, especially Alzheimer's caregivers, said it's important to acknowledge the changes to routine with your loved one and address them. For example, if a caregiver is sick, you could say, "Susie is sick, so Jane is coming to help us out. You'll really like her." Or if bingo and arts-and-crafts outings have been canceled, you could say, "Everybody is off, so we'll do those activities at home today."

Those who do not live with their loved ones may feel anxious that they are not able to visit them at long-term care facilities now. Ms. Kallmyer suggested using phone calls or video chats, and she urges families to keep in mind that staying away is best for the health of those residents. "It's hard, but you need to keep them safe," she said.

Dr. Langa said the priority for caregivers should be to keep themselves healthy and act like emergency medical workers, "because if they get sick, two people are going to be in trouble." He urges caregivers to get out, take walks by themselves and set up a pool of people who might be able to come in and give them breaks, perhaps while the patient is taking a nap. He acknowledges that this can introduce a risk of exposure, but says the downsides can be significant. Going it alone means "you're putting yourself at risk of burning out and in danger of getting exhausted," he said.

Mr. Mehta has kept his morning caregiver and asks her to take her temperature and change clothes when she arrives. Ms. Snelling says getting support from others through virtual support groups can be extremely beneficial. "In this crisis, there's a fear of the unknown. If we can share those fears with other caregivers and get their insights, that is really key." She says caregivers can also take time to practice mindfulness as a way to stay calm for their loved ones in a high anxiety environment.

Mr. Mehta said his greatest fear is that he and his wife could be infected simultaneously and that he would not be in the position to take care of her. Though he has a power of attorney and guardianship for his wife, he fears those documents could get lost if he is not with her, should she be taken to the hospital. He worries that if she becomes agitated, his wife, who is unable to communicate and takes no medication, could be medicated with anti-psychotic drugs.

To safeguard against this situation, Dr. Langa recommends developing a contingency plan outlining the logistics and points of contact if the patient or caregiver gets sick. Ms. Kallmyer said advance directives are essential. “Wherever the patient goes, those should go with them,” she said.

Mr. Mehta acknowledged that he has no choice but to take each day as it comes. He says he has managed to overcome many challenges in the seven years he has cared for his wife. “What I thought was a cliff was just another plateau — a new normal,” he said. “But now, I am uncertain of what this new normal will turn out to be. I am like the single pole of a tent taking care of my wife. It is scary to think what would happen if this pole crumbles.”

---

**The Coronavirus Outbreak** >

## Frequently Asked Questions and Advice

Updated April 4, 2020

- **Should I wear a mask?**

The C.D.C. has recommended that all Americans wear cloth masks if they go out in public. This is a shift in federal guidance reflecting new concerns that the coronavirus is being spread by infected people who have no symptoms. Until now, the C.D.C., like the W.H.O., has advised that ordinary people don't need to wear masks unless they are sick and coughing. Part of the reason was to preserve medical-grade masks for health care workers who desperately need them at a time when they are in continuously short supply. Masks don't replace hand washing and social distancing.

- **What should I do if I feel sick?**

---

**READ MORE** ∨