

May 4, 2020

The Honorable Alex M. Azar
Secretary
U.S. Department of Health and Human Services
Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, DC 20201

Dear Secretary Azar:

On behalf of UsAgainstAlzheimer's and the 5.8 million Americans living with the disease, I write to ask that you ensure immediate COVID-19 testing of all residents and staff of long-term care facilities such as nursing homes and assisted living communities. The safety and health of older adults in such communities, including people living with Alzheimer's Disease and related dementias, requires urgent action.

The Centers for Disease Control and Prevention's new list of indications for COVID testing will not protect people who lack the cognitive capacity to report many of these symptoms. And the Coronavirus Commission for Safety and Quality in Nursing Homes that was announced last Thursday is a good step, but will not even begin meeting soon enough to save lives.

People with Alzheimer's disease, even in its earliest stages, often rely on a loved one to be their advocate and to notice changes in health and behavior. According to survey released last week by UsAgainstAlzheimer's, 91% of caregivers cannot visit loved ones living in a long-term care facility due to restrictions on visitors, so patients with dementia must rely on you to keep them safe.

In order to control the spread of COVID-19 in long-term care settings, UsAgainstAlzheimer's urges the Department to implement policies that require testing of all residents in and employees of long-term care facilities. Testing must include new residents before entry and periodic retesting of long-term residents and staff.ⁱ Currently, testing policies can vary from facility to facility and from state to state, so leadership must come from the federal government to establish uniform national testing guidelines and to make such testing possible.

We appreciate actions the federal government has taken to expand testing across the country, yet many states indicate they still lack adequate testing capability.ⁱⁱ The federal government should make more tests and related supplies available, expand capacity of testing labs, and ensure that adequate funding is available to pay for the cost of testing.ⁱⁱⁱ ^{iv} We urge the Department to expedite development of tests that are appropriate for individuals with cognitive and sensory issues. We also call on the Department to issue guidance specific to individuals with dementia in long-term care settings.^v

These critically important steps are necessary to address a serious national issue. As of April 23, more than 11,000 deaths have been associated with long-term care facilities.^{vi} In six states reporting COVID-19 data, more than 50% of all COVID-19 deaths can be attributed to long-term care facilities.^{vii} More than 1 in 6 facilities nationwide acknowledge COVID-19 infections among residents or staff, according to an analysis by the Washington Post published April 29th.^{viii}

Testing some patients and staff is not sufficient. Much of the challenge in controlling COVID-19 transmission results from asymptomatic transmission of the virus, as you know.^{ix} When a skilled nursing facility where an outbreak occurred in Washington state tested residents, more than half of the residents who tested positive were asymptomatic at the time of testing.^x

The only solution is testing everyone, using a means of testing that is acceptable to dementia patients.

More than 1.3 million Americans currently reside in long-term care settings, and residents with Alzheimer's disease and their caregivers face unique challenges as they face the current public health emergency.^{xi} On behalf of UsAgainstAlzheimer's and the millions of families affected by Alzheimer's and dementia, I urge you to take action necessary to ensure the safety of everyone in long-term care environments during these difficult times.

Sincerely,



Russ Paulsen
Chief Operating Officer
UsAgainstAlzheimer's

-
- ⁱ “Asymptomatic Transmission, the Achilles’ Heel of Current Strategies to Control Covid-19,” *The New England Journal of Medicine*, April 24, 2020.
- ⁱⁱ “Virus Test Shortages Undermine Drive to Restart U.S. Economy,” Bloomberg news, April 28, 2020, <https://www.bloomberg.com/news/articles/2020-04-28/virus-testing-shortages-undermine-drive-to-restart-u-s-economy>
- ⁱⁱⁱ “Why America’s coronavirus testing problem is still so difficult to solve,” Vox, April 24, 2020, <https://www.vox.com/recode/2020/4/24/21229774/coronavirus-covid-19-testing-social-distancing>
- ^{iv} “Long Term Care Industry Calls for Expanded Testing and Funding for Nursing Homes and Assisted Living Communities,” American Health Care Association, April 29, 2020, https://www.ahcancal.org/News/news_releases/Pages/Long-Term-Care-Industry-Calls-for-Expanded-Testing-and-Funding-for-Nursing-Homes-And-Assisted-Living-Communities.aspx
- ^v “Implementing COVID-19 Recommendations for Residents with Dementia,” *Provider* magazine, April 27, 2020, <http://www.providermagazine.com/reports/Pages/2020/Implementing-COVID-19-Recommendations-for-Residents-With-Dementia.aspx>
- ^{vi} “11,000 Deaths: Ravaged Nursing Homes Plead for More Testing,” *New York Times*, April 23, 2020, <https://www.nytimes.com/aponline/2020/04/23/us/ap-us-virus-outbreak-nursing-home-testing.html>
- ^{vii} “State Reporting of Cases and Deaths Due to Covid-19 in Long-Term Care Facilities,” The Kaiser Family Foundation, <https://www.kff.org/medicaid/issue-brief/state-reporting-of-cases-and-deaths-due-to-covid-19-in-long-term-care-facilities/>
- ^{viii} “Number of Nursing Homes with Publicly Reported Cases of the Coronavirus Soars,” *Washington Post*, April 29, 2020, https://www.washingtonpost.com/investigations/number-of-nursing-homes-with-publicly-reported-cases-of-the-coronavirus-soars/2020/04/29/7375941c-898c-11ea-ac8a-fe9b8088e101_story.html
- ^{ix} “Asymptomatic Transmission, the Achilles’ Heel of Current Strategies to Control Covid-19,” *The New England Journal of Medicine*, April 24, 2020.
- ^x Ibid.
- ^{xi} Ibid.