



**Joint Senate Aging & Youth and Health & Human Services Committee
Hearing on Nursing Homes and Challenges During COVID-19
May 7, 2020**

First and foremost, on behalf of the Alzheimer's Association, we would like to take a moment to acknowledge the health and direct care professionals, emergency response personnel and all other essential workers that continue to work around-the-clock to provide for the health and safety of all Pennsylvanians during the COVID-19 pandemic. We are so grateful for their dedication and acknowledge the sacrifices they are making during this time. We also would like to thank Governor Wolf, Secretary Levine, other state government leaders and staff and all the members of the Pennsylvania General Assembly for your leadership in confronting the COVID-19 pandemic, an unprecedented and monumental task that will continue into the foreseeable future.

Thank you, Chairwomen Ward, Collett, Brooks, Chairman Haywood and members of the Senate Aging & Youth and Health & Human Services Committees for convening this informational hearing on the impact of COVID-19 in Long-Term Care (LTC) facilities. LTC is an essential care service supporting people as they age and their loved ones. As the COVID-19 pandemic continues to spread across Pennsylvania, the virus is disproportionately impacting the most frail and vulnerable members of our community - those who live in nursing homes and assisted living communities. With over two-thirds of the total deaths statewide occurring within these care settings, the Alzheimer's Association is gravely concerned. We are deeply appreciative of your commitment to protecting residents in nursing homes and assisted living communities and the care workers who support them. The Alzheimer's Association has been in frequent contact with state officials and has been a strong advocate for an increased focus on the impact of COVID-19. We look forward to working with you to find solutions to protect the health and safety of residents and staff in LTC facilities.

Challenges of Alzheimer's and Dementia During the COVID-19 Pandemic

The Alzheimer's Association continues to focus on our mission to maximize quality care and support for the 280,000 individuals living with Alzheimer's and the 677,000 unpaid caregivers in Pennsylvania, especially as we navigate the many challenges facing our constituency during the COVID-19 pandemic. Dementia is characterized by a group of symptoms that include a decline in cognitive abilities, loss of memory, poor judgment, changes in personality, disorientation and problems with abstract thinking. Alzheimer's disease is the most common cause of dementia, accounting for 60% to 80% of all cases. As the disease progresses, people living with dementia will need additional assistance to complete activities of daily living.

Roughly 48% of residents in nursing homes and 42% of residents in residential care facilities, have Alzheimer's or other dementias. Overall, people with Alzheimer's and other dementias living in long-term care residential settings are at a particularly high risk for COVID-19 because of their age, decreased cognition, increased likelihood of co-existing chronic conditions and their frequent interaction with facility staff and other residents. As a result, they require additional assistance and consideration during the implementation of an emergency plan.

Due to their decline in cognition associated with dementia and their living in a residential facility close to other residents and staff, people with dementia may be unable to follow guidance on social distancing, hand-washing and other preventive measures. They may have difficulty articulating how they feel or explaining the symptoms they are experiencing. As their environment and routine continues to change rapidly, they may become more confused, frustrated and agitated, all representative of dementia-related behaviors.



People with dementia have unique care needs that fluctuate on a daily basis, challenging professional care staff to pivot care delivery and adapt to the individual's needs. Under "normal" circumstances, family members, friends, volunteers and other caring community members are available to help monitor and assist in meeting these care needs. However, due to the (necessary) visitation restrictions, families are not able to communicate with their loved ones and are unable to see first-hand their physical and emotional health status. Multiple staff changes at the facility (exacerbated by COVID-19) further challenge a resident with dementia to remain calm during a particularly stressful time. New staff may not understand the unique needs of people with dementia and effective communication strategies to support them.

Of significant concern is the inability to ensure that residents with dementia are receiving safe and high quality care. The Long Term Care Ombudsman Program regularly advocates on behalf of residents and their families and can mediate concerns with providers but they, like all visitors, are currently restricted from facilities. Adult Protective Services (APS) investigators are also unable to address many issues unless there is concern of serious bodily injury, sexual abuse, or serious physical injury - all of which are hard to identify if there is limited external communication and no visitation.

While state officials are making decisions to slowly re-open the Commonwealth, we know that residents and staff within these care settings will remain at an increased risk for weeks and months to come. We appreciate the leadership of our state government partners, we understand the need to make decisions allowing providers more regulatory flexibility during the COVID-19 pandemic, and we honor all the staff who work tirelessly in these care communities. Even through these best efforts, the Commonwealth is falling short in protecting our most vulnerable citizens and we must turn our attention to policy considerations to protect the health and safety of the residents and staff within nursing homes and assisted living communities, especially as infection rates and deaths in these settings continue to escalate at an alarming rate.

POLICY CONSIDERATIONS:

Broader Public Transparency and Communication With Families and Care Partners

Currently, the Department of Health reports county-level data on the number of facilities with cases, number of cases among residents, number of cases among employees and number of deaths. On April 19th, the Centers for Medicare and Medicaid Services (CMS) issued new regulatory requirements to require nursing homes to inform residents and their representatives of positive COVID-19 cases and to provide weekly updates that include mitigation efforts. At this time, the Department of Health has not issued guidance about how this will be enforced. Additionally, since CMS only addresses nursing homes, it is imperative that the state also provides needed guidance to assisted living communities. Information about infection rates and deaths by facility should be made public and posted on the Department of Health's website, instead of just county-level data. In some instances, families are not aware of current outbreaks in a facility where their loved one is living and even after asking, their questions often go unanswered.

We are aware of a tragic case where a family was notified after death that their loved one tested positive with COVID-19 but the family was never informed prior. Families are desperate for information that will help guide their decisions on care for loved ones and this can literally mean the difference between life and death.

Recommendation: All licensed long-term care facilities should proactively maintain communication between residents and families or other key support individuals, either by telephone, video, email or other communication means.



Recommendation: Within 24 hours of notification of a COVID-19 positive case at a nursing home or assisted living community, the facility shall report the case to public health authorities and inform the representative of each resident of the facility.

Adequate Testing and Personal Protective Equipment (PPE)

Given that over two-thirds of Pennsylvania COVID-19 deaths have occurred in nursing and personal care homes, coupled with high infection rates among residents and staff, high priority should be given to distributing PPE and COVID-19 testing kits to protect staff and residents and prevent further spread of the disease. We continue to receive reports from providers, residents and staff that they do not have adequate access to PPE and COVID-19 testing is only being done to symptomatic residents and staff. Testing all residents and staff will prevent further spread by detecting asymptomatic and pre-symptomatic individuals and initiating quarantine protocols. West Virginia became the [first state](#) to require testing of all residents and staff and [Maryland](#) and [Wisconsin](#) recently announced similar measures.

While we were pleased to see the Department of Health's [COVID-19 Guidance on Distribution of PPE](#) update on April 27th to include prioritization of nursing homes, personal care homes and assisted living residences ("congregate care settings"), it does so only when there is an identified **and** investigated need. The sheer number of cases and deaths in these settings indicate a clear need for ALL congregate care settings to have adequate PPE to protect and **prevent** the spread of COVID-19 and in planning for a potential second wave.

Testing Recommendation: Pennsylvania should require COVID-19 testing for all residents and staff of nursing homes and assisted living communities, regardless of whether or not they are symptomatic.

PPE Recommendation: Prioritize PPEs for all nursing homes and assisted living communities and not just those that have already been identified as hot spots.

Rapid Response or Strike Teams

Similar to [Maryland](#) and [Rhode Island](#), Pennsylvania should consider developing rapid response or strike teams to dispatch into long-term care facilities where there is a COVID-19 outbreak to provide additional support. The rapid response teams should be made up of a Long-Term Care Ombudsman and Adult Protective Services staff, public health infection control experts, regulatory staff from the Departments of Health or Human Services, doctors and nurses, and members of the National Guard to help triage and treat patients accordingly. Upon making an assessment of overall status and needs in a facility (resident and staff testing, PPE, infection control and quarantine, staffing, communication with families, etc.) they can then establish a plan to access the needed resources and develop protocols for implementation. These efforts can lead to development of best practice models to use for future communicable disease outbreaks or public health emergencies.

Recommendation: Establish rapid response/strike teams to assess individual facility needs, triage resources and develop implementation protocols.

Person-Centered Care Approach for Persons with Dementia

Person-Centered Care is an approach that focuses on the person's emotional needs and care preferences, consistent with their lifestyle. It considers the person's relationships and the impact that other people, practices, physical care and the environment may have on the individual. Under the current circumstances, it is important to minimize changes in routine, environment and daily structure and to keep

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as much of a person-centered care approach intact for individuals with dementia. We acknowledge that providing this type of care is extremely challenging during this time, especially as providers are struggling to address staffing shortages, keep their workforce healthy and meet the ever-growing and fast-changing demands of business operations.

The Alzheimer's Association has developed an [emergency preparedness guide](#) to assist care professionals working in long-term and community-based care settings to better care for persons living with dementia during the COVID-19 pandemic. Recognizing the rapidly changing dynamic of any emergency, including COVID-19, the guide is designed as a reference tool to support all staff, including non-licensed staff and lay people who may become involved in direct care during a major emergency, with quick, high value solutions.

Recommendation: All nursing homes and assisted living communities should develop, document and make available COVID-19 dementia care protocols consistent with the emergency preparedness guide (attached for reference).

Long-term care and senior living providers are an essential part of the continuum of care for people living with Alzheimer's and other dementias and their families. We must ensure we are doing whatever is possible to maintain the health and safety of residents living within these settings and the families and care providers that love and support them. The Alzheimer's Association appreciates the work already underway to protect all Pennsylvanians, and we stand ready to work with our state leaders and community partners to identify and advance policy solutions today that will save lives and enhance the care of tomorrow.

Thank you Chairwomen Ward, Collett, Brooks, Chairman Haywood and members of the Senate Aging & Youth and Health & Human Services Committees for taking the time to review our written testimony and consider our recommendations. If you have questions or would like additional information, please don't hesitate to contact either one of us, or Jen Ebersole, Director of State Government Affairs at jaebersole@alz.org or 717.678.6464.

Respectfully Submitted,



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During the COVID-19 pandemic, the Alzheimer's Association has maintained a number of informational resources available for people living with dementia as well as their care partners that have been especially valuable during the statewide stay-at-home directives.

- ***Free 24/7 helpline for individuals with dementia and their caregivers at 1-800-272-3900***
- ***COVID-19: Tips for Dementia Caregivers***
- ***Support group communities available online at alzconnected.org/***
- ***Free online training resources at training.alz.org, including upcoming live webinars and professional conferences***