



August 26, 2021

Lori Gutierrez, Deputy Director for the Office of Policy
PA Department of Health
625 Forster Street, Room 814 Health and Welfare Building Harrisburg, PA 17120
Submitted via email to: RA-DHLTCRegs@pa.gov

Re: Rulemaking #10-221 (Long Term Nursing Care Facilities, Proposed Rulemaking 1)

Dear Ms. Gutierrez,

On behalf of the Delaware Valley and Greater Pennsylvania Chapters of the Alzheimer's Association, we appreciate the opportunity to submit comments in response to Rulemaking #10-221 (Long Term Nursing Care Facilities, Proposed Rulemaking 1). We are pleased that the PA Department of Health is moving forward with long overdue and urgently needed revisions to Pennsylvania's nursing home regulations. The Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support, and research. Our mission is to eliminate Alzheimer's and other dementia through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. Together, our Pennsylvania Chapters focus on carrying out our mission for the nearly 400,000 Pennsylvanians living with Alzheimer's or other dementia, the 500,0000 Pennsylvanians providing unpaid care for them and countless others impacted by this devastating disease.

Since the onset of the COVID-19 pandemic, those living with dementia have been disproportionately impacted, which has been especially troubling for us considering nearly half (48%) of all nursing home residents are living with Alzhiemer's or other dementia. The need for a complete rewrite of the regulations were necessary prior to the COVID-19 pandemic and unfortunately, the devastation witnessed in Pennsylvania nursing homes throughout the pandemic has brought into sharp focus the need for comprehensive changes and quick movement to final regulations that should take effect immediately upon approval.

Given the Department's approach to submit five separate regulatory packages, it is difficult to understand the full scope and impact of this first package when we have yet to review how these changes will correlate with subsequent packages. Generally speaking, the Alzheimer's Association supports the Department's goal to provide consistency between state and federal regulations and expressly stating a facility is in violation of the state regulation if they violate federal regulations. We do have some concern with fully deleting the definition of "abuse" and how this might impact the state's authority to carry out critical protective services and law enforcement functions to protect residents

<sup>&</sup>lt;sup>1</sup> Alzheimer's Association 2020 Alzheimer's Disease Facts and Figures, https://alz-journals.onlinelibrary.wiley.com/doi/epdf/10.1002/alz.12068



from various forms of abuse, neglect and exploitation. We recommend the Department reconsider deleting this definition outright, and instead cross reference with appropriate state and federal regulations and statutes.

Alzheimer's and other dementias require a wide range of evolving care and services, and as the disease advances the needs of those living with the disease change and individuals often require more specialized care. The Alzheimer's Association believes that person-centered care is the foundation of quality care in nursing homes and the final comprehensive package of regulations must be grounded in this principle, along with other important health and safety measures aimed to improve the overall quality of life for all nursing home residents and the staff who care for them. The single most important determinant of quality dementia care across all care settings is direct care staff,² who help to shape the daily lives of people with dementia and assist with all aspects of physical care for those with the disease. Through their close interactions with people with dementia, direct care workers gain an in-depth knowledge of the individual with dementia, including their preferences, behaviors and functioning. However, the ability of these health care professionals to provide quality dementia care is jeopardized due to high levels of turnover and job dissatisfaction due to low pay, poor working conditions, inadequate training and few opportunities for career advancement, all of which has been exacerbated by the COVID-19 pandemic.

Therefore, as the Department continues to move forward with the next four proposed regulatory packages, we urge the Department to include systematic changes to direct care staffing across the spectrum of recruitment through retention to better support this critical workforce and that the level of care for each resident is determined based on need and acuity as outlined in their care plan. We encourage the Department to consider the principles and facts outlined in the Alzheimer's Association Dementia Care Practice Recommendations related to dementia care, and consideration of the following: (1) staffing levels should be adequate to allow for proper care at all times — day and night; (2) staff should be sufficiently trained in all aspects of care, including dementia care; (3) staff should be adequately compensated for their valuable work; (4) staff should work in a supportive atmosphere that appreciates their contributions to overall quality care because improved working environments will result in reduced turnover in all care settings; (5) staff should have the opportunity for career growth; and (6) staff should work with resident families. Additionally, we know that consistent assignment is an important component of quality care for staff working with residents with dementia.

As we review these nursing home regulatory packages, the Alzheimer's Association will ground our advocacy in a person-centered approach to delivering quality care, which will include the latest in dementia-care practices with an emphasis on the need for competency-based dementia training for all professional care staff and administrators. We will also build upon our comprehensive set of long-term care policy recommendations released last year that focus on testing, reporting, surge activation and

<sup>&</sup>lt;sup>2</sup> https://academic.oup.com/gerontologist/article/58/suppl 1/S103/4816757



additional support to residents and staff, all of which will further support efforts to navigate the COVID-19 pandemic and future emergencies.

The Alzheimer's Association is committed to advocating on the resident's behalf to ensure they receive high quality care while preserving their overall health, safety and well-being. We would again like to reiterate our profound support to the Department for initiating this long overdue process. We look forward to working with the Department, the PA General Assembly and other stakeholders to move this process forward as quickly as possible.

Respectfully Submitted,

Kristina Fransel, Executive Director

Alzheimer's Association, Delaware Valley Chapter

klfransel@alz.org

Kit Francel

Clay Jacobs, Executive Director

Alzheimer's Association, Greater Pennsylvania Chapter

ciacobs@alz.org