From: Deborah Strafuss <DebS@theagingspacema.com>
Sent: Thursday, May 15, 2025 2:12 PM
To: Sullivan, Francis P (ELD) <Francis.P.Sullivan2@mass.gov>; Travascio, William (ELD) <william.travascio@mass.gov>
Subject: FW: Advocacy Day concerns for assisted living communities

Forwarding my comments and concerns for Assisted Living Dementia Care Units from the ALR Hearing today. This is an email I forwarded to myself from my personal account to a work one where I participated today on my work laptop.

Again – Assisted Living communities are a good industry, filled with much thought and excellence of care and are much needed, but there really is a lot of room for improvement. The below issues arise specifically for residents with dementia – usually advanced mid stage – and occur due to rising levels of need around dementia care. If these communities had to share a plethora of responses from their residents and their families, including dementia patients, it would be interesting to see, agency by agency, what areas of concern are highlighted.

My proposals would increase time and ability of carers to interact with residents in positive and meaningful ways and are not meant to restrict individuals' agency or freedom but provide safety and sociability for those with advancing dementia, better training for staff and more involvement and communication with family caregivers of the same.

Thank you.

From: [redacted]>
Sent: Tuesday, March 4, 2025 2:16 PM
To: 'ltsamant@alz.org' <ltsamant@alz.org>
Cc: 'cgordon@alz.org' <cgordon@alz.org>
Subject: Advocacy Day concerns for assisted living communities

I am an Alz Assn trained caregiver support group facilitator, author of a book chronicling my mother's journey with Alzheimer's, an Alzheimer's advocate, and work at an Adult Day Social program for early AD as well as working as a Thoughtful Engagement Specialist with

The Aging Space. As such I constantly interact with the need for balance between individual agency and safety and standards of care for those in care and for their family caregivers. I have been active in Alzheimer's care one way or another since 2006. I have been in a regular round of 8 weekly remote caregiver support sessions with 3-4 weeks off, three sessions per year since 2020. This intensive rate of connection and support has yielded a dedicated core group who are now very educated and supportive around their journeys. As some of these core attendees have continued over several years, many are now moving towards or have already placed their loved ones in care.

The concerns about memory units here are from their stories and experiences along with some of my own with my mother. I am advocating for more oversight and regulation of assisted living memory care units. These units are more medically and behaviorally involved with their residents' care than assisted living residences due to the ravages of dementia, which is in a category by itself when it comes to care.

Firstly, I want to say that the validation of caregivers as vital parts of a person with dementia's care team in acute settings being considered in current ALZ Assn sponsored bills needs to be extended to all facets of dementia care in assisted memory and nursing facilities. Proper acknowledgement of and working with families is essential in dementia care . Placement of a loved one does not end caregiver responsibilities and concerns. Family caregivers are the ones who know the individual in care intimately and over time. They are necessary to care.

Some of our recommendations learned through painful experiences:

1. We need more state reporting for disease and symptom/behavioral management in assisted memory units. The state needs to know what is happening in these memory units to make good decisions about future legislation and current population trends.

2. Continuing and required ongoing dementia training for staff to maintain proper dementia awareness and skill levels – the level of "dementia" training is abysmal in some cases and there seems to be no consistency and too little required training, often left up to the facility to decide.

3. A smaller caregiver to resident ratio is needed due to the amount of time and engagement for ADL's and the disorientation and communication issues presented by those with dementia. Current ratios provide for insufficient care for residents and create an undue burden on caregivers.

4. Clear care plans and required family communication on a regular basis is needed in memory care. Clear reporting on progression of symptoms and recommended disease management to family caregivers so they can make plans and informed decisions for future care. I find this lack of information and communication as I listen to family members ongoing issues in care.
5. Pre-disclosure of additional billing for extended levels of care and appropriate (including outside) referrals for increased levels of care when needed
6. Clear information and contacts for after-hours notifications and communications should be required if it is not

7. Dementia attendants for transport: Currently loved ones with dementia are sent to emergency rooms with no attendants for extended periods of time (which is what ER is all about) often without caregiver pre-notice so they can accompany – to which I can personally attest as purely and simply not safe. Recently we had one caregiver race to the ER to spend 48 hours with her husband caged on a gurney because the assisted memory unit sent one smallish young girl to clean up a rather large and known to be resistant resident when he soiled himself. The resulting attack was clearly a lack of proper care and planning – including pre-medication for well documented agitating ADL's along with improperly assigned staffing. (see #4) The gentleman did not need to go for Geriatric Eval for further dosing and the care facility would not allow him back unless he went 48 hours with no incident. He was never hospital admitted, and his wife stayed by him in ER for 2 days until she could return him to care.
8. Relationships in dementia: One of our caregivers came to visit her dementia impaired husband on a memory unit to find him in bed with another woman and the staff giggling about it. Dementia care professionals should know how to handle relationships diplomatically, especially with FTD residents, and family caregivers' needs and wants should be listened to, not laughed at, as they usually have legal

jurisdiction, just as with a child or otherwise impaired dependent. This staff did not appear to know that.

9. Accuracy of facility assessments: more in-depth questions and conversations to help caregivers disclose care needs when looking for possible placement. More truth in assessment needed. Those “assessing” for a facility are more likely to assess into their care when perhaps the level of care they can provide, and the level of care truly needed, are not congruent. These types of mismatches produce turbulent facility stays and more medical interventions than necessary, yet facilities market to make money on numbers of residents and caregivers can be reticent to share their caregiving challenges with staff for fear of refusal.
10. And of course, caregiving staff need livable wages, decent break periods and employee support.

I am sure there are other issues you are aware of but wanted to offer these as each one represents an individual’s experience or experiences within our group.

Thank you for taking the time to read this email. I am available for any further communication and my group members are very open to discussing the challenges of memory care life as well.

Deborah Strafuss

Caregiver Support Group Facilitator

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