To: ALR Commission

Date: May 28, 2025

From: [REDACTED]

To: Francis Sullivan and William Travascio

Subject: May 15, 2025 hearing – additional testimony

I wanted to provide some feedback after our experience with two memory assisted living residences. As an addendum, I provide detailed background on SJM’s experiences.

Brief Background

My husband, SJM, was diagnosed with Alzheimer’s in June 2023. He was able to live at home without additional help above what I provided through November 2023. After a hospitalization for a urinary tract infection (UTI) in December 2023, he spent several weeks in rehabilitation (rehab), during which time the social worker recommended memory assisted living. At that time, SJM could get up from a chair by himself and walk with a walker while being shadowed. SJM spent two periods of time in memory assisted living facilities, the first from February through April 2024 at ALR#1 and the second for the month of February 2025 at ALR#2. We removed him from both residences due to the inability of staff to keep him safe. While home, we provided and still provide 24/7 caregiving. For further details on SJM’s journey, please see the Addendum to this testimony.

What Worked

Both residences developed strong senses of community and provided activities geared towards residents with memory problems. At both, SJM was on the higher end of cognitive functioning. At ALR#1 we would have liked more challenging activities; at ALR#2, they were appropriate and excellent. The only deficit at ALR#2 was that residents had to be brought upstairs for concerts and, since SJM’s mobility was a challenge, this provided more risk of falls. Similarly, at ALR#1, residents were brought downstairs for selected concerts. Overall, we appreciated that SJM was in a situation where he could succeed, whether it involved reading aloud short biographies of well-known people, exercising, or singing and appreciating music. Caregivers at both residences were caring and competent. The food was excellent at both facilities.

Staffing levels

In our experience, although they met State requirements, neither facility had sufficient staff, especially for SJM. SJM required shadowing while walking. At ALR#1, SJM was still mobile enough to walk by himself with a walker. He often would walk out of the view of staff and then he would fall. He fell eight times in a three-month period. One fall led to a hospitalization and two-week rehab stay.

By the time SJM entered ALR#2, he was no longer able to get out of a chair without help. Yet, he was still able to walk with a walker. However, staff left him in a transport chair rather than help him exercise. Again, in my opinion, there were simply not enough staff to attend to the needs of all residents. SJM fell four times in a one-month period at ALR#2. One fall led to hospitalization. He was hospitalized a second time for Norovirus, all within the one-month period at ALR#2.

SJM required help toileting and, although this was specified in his care plan, at both residences, during my visits, I had to prompt staff to care for him.

Evaluation, Marketing and Cost

We chose ALR#1 quickly and knew of it as my dad lives there in Independent Living. It was affordable (about $10,000 per month); the community fee was waived. As noted above, SJM was assessed by their medical staff twice, once prior to entry and once after he completed rehab. Still, it did not work out for SJM, and we were able to secure a live-in caregiver through an agency we were familiar with; so we brought SJM home in May 2024, after three months at ALR#1.

ALR#2 met our budget by discounting rent to arrive at $15,500/month. However, they charged a community fee, though they waived half of it. It was not exactly clear how this community fee amount was calculated. It was the same for all residents. When we left, they prorated it, so we received a partial refund as we were there for less than 90 days.

In retrospect, I feel that ALR#2 drew us in by negotiating the cost. Their medical staff and unit director assessed SJM, and they assured us that they could care for him. I feel that, given my reporting of his behavior and their observations, that they either should not have accepted him or should have told us first to work with a psychiatrist to steady his mood. Or they should have acknowledged that he would need private care to supplement their staff. When I decided to bring SJM home because he was not being kept safe with their staff alone (as I had to bring in private care), they refused to take any responsibility for under-assessing his needs.

Financial implications

ALR#1 was able to work with me to return half of the last month’s rent after we moved SJM earlier than originally proposed. ALR#2 refused to return the last month’s rent and only returned a small portion of the community fee. Although we had signed a contract, I felt that because of SJM’s difficult experience in the ALR#2 community, they should have bent over backwards to satisfy our requests. In addition to these costs and the costs of private care, I spent another $3,000 on moving costs for moving in and out of both facilities.

Conclusions:

For some people, memory assisted living seems to work well. However, in our experience, the State-required level of staffing was insufficient to care for SJM. I do not think he is that unusual. I would hope that staffing level requirements can increase. I also felt that the marketing at ALR#2 was misleading. They easily met my budget by discounting the rent and community fee; but because they could not care for SJM, I ended up spending much more money than projected on private care. I feel strongly that they mispresented their ability to care for SJM. Though caring for SJM at home has its own challenges, as a result of these experiences at memory assisted living facilities, SJM suffered through several hospitalizations that he might have avoided had he remained at home.

I have been working with a geriatric care manager through all of this, paying for her to visit the prospective facilities and visit SJM once residing there. SJM cannot be so unusual. I feel that professionals might have predicted he would not do well in the memory assisted living setting. In fact, the very first recommendation to place him in memory assisted living was a bit odd, given that even then, the physical therapist recommended that SJM be shadowed while walking. And, clearly, memory assisted living facilities do not provide that level of care.

For the time being, SJM is doing well at home. But should he require a move to a facility, it will have to be to a skilled-nursing one.

In my opinion, the United States health system has to do better and provide help for families like ours – financial help to manage long term care, including live-in help for home care. The government also has to incentivize training for home care workers and raise their pay. We are lucky that we have long-term care insurance which covers about half of the cost of caregivers, but we only have a little over two years worth of coverage and we have already used up a little over one year’s worth. After another year, we will be on our own.

Thank you for listening to our experience. I hope this helps with your assessments of assisted living residences.

Addendum – Details of SJM’s experiences at ALR#1 and ALR#2

Background:

My husband, SJM, was diagnosed with Alzheimer’s in June 2023. He was able to live at home without additional help through November 2023. Then, he had a urinary tract infection (UTI) for which he was hospitalized in December 2023. After discharge, he spent several weeks at a rehabilitation facility. The social worker recommended memory assisted living as he needed quite a bit of cueing for activities of daily living (ADLs) and had mobility issues due to chronic back problems. I was taken aback but found a spot at ALR#1. I knew about that residence as my dad lives there in Independent Living. As I felt under time pressure, I did not do any research on alternatives. Although the caregiving team was competent and friendly and the living space was well-designed and the food was high quality, I was disappointed with the activities they provided. Even more disturbing was the fact that SJM fell eight times in the three months he was there, leading to one hospitalization and a two-week rehabilitation facility (rehab) stay.

At about this time, we were given the opportunity for a live-in caregiver and so, SJM came home on May 2, 2024, after which he had 24/7 caregiving. During 2024, even at home with 24/7 care, SJM had two additional hospitalizations due to UTIs, one of which was followed by a two-week rehab stay, and one ER room visit due to agitation. The later (ER visit) followed my absence for five days, during which time SJM’s illness seemed to progress and his temperament to change.

I found providing care at home to be difficult psychologically. Because SJM’s behavior had changed so dramatically in November 2024, it was also difficult to keep a consistent caregiving team to cover our live-in caregiver’s off days. We researched three different memory assisted living locations, and, on February 7, 2025, we moved SJM into ALR#2. During the month that SJM was at ALR#2, he fell four times and was hospitalized twice, once due to a fall and once due to Norovirus. We had to hire private care to supplement the ALR#2 staff since this was difficult financially, we moved SJM back home on March 5, 2025. As at ALR#1, the ALR#2 staff were generally caring and competent. There were simply not enough of them.

We were able to rehire our live-in caregiver and cover her away time with a consistent team of three caregivers, two hired through the agency that supplies our live-in help, and one hired privately. After working with a psychiatric nurse practitioner, we were able to find a combination of medications that helped SJM’s mood and behavior.

Home is also not perfect. In addition to the two hospitalizations mentioned above, during the period of May 2024 through February 2025 and March 2025 through May 2025, he has sustained two or three soft falls. But overall, the experience at home with the one-on-one care is much better than the ALR experience.

ALR#1

Financially, ALR#1 was affordable, costing about $10,000 a month. They waived the “community fee” as my dad lived in Independent Living. However, as noted above, I was disappointed in their activities. Although memory unit residents were invited to concerts in the main activity area, for the most part, the memory unit-only activities were not very stimulating nor easy for the residents to follow. SJM was more mobile when he lived there – he could get up from a chair by himself and walk with a walker or rollator. However, he really needed someone to shadow him, and they did not provide that level of care. Although they had the required level of staffing, in my opinion, this is simply not sufficient. Although we had to give a month’s notice when SJM left, the administration was flexible and as they had someone who wanted to move into SJM’s room, they allowed us to leave early and recover some of the last month’s rent.

ALR#2

ALR#2 came highly recommended. Before signing a contract, we visited three times and attended their activities and met their staff. I had a lawyer review their contract. We were especially impressed at their activities and how they tailored them to the needs of their community and used a high-level interactive computer program to do so. They told us about an electronic surveillance system they had recently installed to detect falls. In addition, they met our budget, discounting monthly rent to achieve an overall rate of about $15,500 per month.

Before signing the contract, the medical staff and memory unit director came to our home to evaluate SJM. I was very transparent about his behavior issues and fall risk. As they left, I asked “Are you sure that you can take care of him?” to which the reply was “Yes.” However, from the moment SJM arrived on the unit, problems began. SJM became agitated and called out. When their caregivers were helping him toilet on the first day, he had the first soft fall.

I had arranged for our private caregiver to be with him the first few days, but when she stopped staying with him, his behavior worsened. Previously, we had been meeting remotely with a general psychiatrist. It was clear he needed different medications, so we began working with a nurse practitioner specializing in geriatric psychiatry. As the days passed and I continued to hire private care, I tried to ask the unit director how long I would need to. Her answer was “Until his meds kick in.” Since that could be an indeterminate amount of time, we decided to pull him out and I gave 30 days’ notice. We could not afford the cost.

As I mentioned above, SJM fell four times in the month he was at ALR#2, and one fall led to a hospitalization with a laceration on his forehead. For two of the falls in the area with the electronic surveillance system, it was not operating; once because it had been inadvertently turned off by a repairman who I had called in; and once because ALR#2 did not tell me that SJM’s neighbor refused permission to use it in the entry area of the two rooms.

I was very angry about the whole affair and felt ALR#2 staff had insufficiently evaluated SJM. Given my description of his behavior, they should have recommended working with a psychiatrist prior to moving in and doing so, only after his behavior had improved. Or they should have said they could not take care of him without additional private care. In addition to the $15,500 a month, I was paying $36/hour for 24/7 private care.

Although they had discounted the community fee by half, and they refunded a small part of it, they did not return it in full. When I asked them to return my last month’s rent, they refused. They claimed the evaluation was a “snapshot” and they took no responsibility for SJM’s lack of fit.

As a result of ALR#2 not being able to care for SJM, SJM suffered an additional hospitalization, and I spent money to move SJM in and out of ALR#2 and lost the $8000 they charged for the last month’s rent.

Prior to deciding to move SJM into ALR #2, we had researched two other ALRs.

ALR#3

We visited and spoke at length to their representative. This facility is a bit further from our home and medically would have been in another network (for example, it is closest to a hospital other than the one we typically use). The price was between ALR#2 and ALR#4. We felt it could be a reasonable choice and heard it had a very good reputation, but we did not have them evaluate SJM as we had more or less chosen ALR#2. However, since, I have actually participated in their educational and support activities and continue to do so.

ALR#4

We researched ALR#4 quite carefully and they evaluated SJM. We visited several times and attended some of their activities. They indicated they could provide two-person assists. However, we decided against moving SJM there for two main reasons. First it was more expensive than ALR#2 (about $18,000/month). Second, we were concerned about SJM being a fall risk. Although they had a room close by the activities area and nurses’ station, we were not sure that SJM would be safe there. In retrospect, however, they noted that they would have developed a plan to help SJM adjust, which could have been beneficial.