

## Steven Sepe

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**From:** Shaun Gillis <shaungillis@hotmail.com>  
**Sent:** Monday, March 24, 2025 8:41 AM  
**To:** House Health and Human Services Committee  
**Subject:** Testimony SUPPORTING House Bill 5169

Dear Chair Donovan and Honorable Committee Members,

Thank you for the opportunity to submit this testimony in support of House Bill 5169. I can personally speak to the subject of this Bill as a care taker for my father. He is 66 years old, has dementia, diabetes, kidney failure, heart failure, has had seven (7) toes amputated, has to wear diapers full time, is on hospice care, and is suffering in a locked assisted living facility in Lincoln, RI. He worked the same dedicated job as a medical technician for forty (40) years. We had to move him into a facility three months after I received a call from his supervisor that he didn't show up to work for two weeks. It happened so fast!

He was first diagnosed with dementia at the young age of 63 and since then, it's been a full time job making sure he gets the care that not only he deserves, but anyone in his situation deserves. He didn't ask for this, no one does. I am so thankful he has my sister and I to make sure of this but I feel gravely bad for those that have no one to help care for them. This is the second facility he has lived at and has lived there for just over two years. Over the past two years, we've had a number of issues pertaining to cost of care and quality of care, but I will keep it fairly simple for you! It's been an absolute nightmare keeping his financial means aligned with his health decline.

Over the past two years, his rent has increased 10% and just recently 8% with just a thirty (30) day notice. He currently pays \$8,985 a month for just rent! We had thirty (30) days to scramble and figure out how he was going to afford the most recent increase of \$660 per month as his income is limited. We ended up defaulting on his two credit cards in order to afford this and are now dealing with the repercussions. Not to mention the extra costs associated if dad needs an extra load of laundry done one week, or the \$1000 extra per month for just 3.5 extra hours of care a week, which can be sprung on us with just a phone call. There is an extra fee for just about everything. Having an extra ninety (90) days to plan for rent increases would be substantially beneficial not just for my dad, but any family in similar situations.

We were never told about these enormous and often increased rents and fees upon signing a lease and moving him in. If so, we may not have moved him into this particular facility and would have moved him into a facility that would allow us to better plan his financial future. At this point, he will run out of money, he will need to apply for Medicaid (if that's even a thing anymore), and will have to move to a Medicaid accepting facility which further burdens my sister and I and even more our father. And just think, you work your whole life, contribute faithfully to your retirement fund, just to have to spend it all just to qualify for Medicaid! Oh, and when he does have to move, he's going to have a roommate as if he is confined to a hospital room for the rest of his life. That's not what he worked so hard his whole life for. After this most recent rent increase, I asked the facility manager for a copy of the operating budget and was declined.

I don't know how other family's are doing it for their loved ones. I have my own responsibility's and my own family including two kids ages 6 and 9. My sister has her own responsibilities and her own young family including my nephew who is just 1 years old. There are many many challenges we face having to take care of our father. We have so many questions that we have to try and answer ourselves to the best of our ability. Should we do this, should we do that, how do we do this, how do we do that, what is ultimately the best for our father, as he did for us. Which is why family and resident councils in assisted living would be extremely beneficial at a minimum to those in similar situations

I have story's and story's about my father's decline and his living situations over the past few years. I feel like I could speak for days about it but let me get straight to the point. Please pass House Bill 5169. If not for my father or the other residents living in the facility he does, but for your own loved ones that could be in a similar (not uncommon) situation similar to my fathers one day. I'm not a praying man but I beg that does not happen.

Thank you for your time in reading my email and please remember my father when considering House Bill 5169. If you have any questions or concerns, please do not hesitate to email or call me to further discuss my concerns with assisted living facilities. I wish you good health and happiness, something my father doesn't have.

Sincerely,

Loving son,  
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