

March 27, 2022

Hello,

My name is Joni Shaw and My 59 year old husband, Mark, recently passed away from Early Onset Alzheimer's Disease. He was diagnosed in 2014 at the age of 51. It was a devastating diagnosis and we owned a business and had 2 kids in college and 1 in high school at the time. The first 5 years were manageable but in 2018 Mark had a seizure and became violent and declined very fast. After several hospital stays, I had to place him in a long-term care facility. Mark declined very rapidly and eventually needed 24hour care.

I picked the facility based on several factors but the biggest being the private rooms and being able to be there at anytime 24hours a day. I was there every day and sometimes spending the night. He needed a lot of care and had behaviors that I helped diffuse. Most of the time there, Mark could not dress, eat, brush his teeth, shower or go to the bathroom without help. The last 2 years of his life, he was completely incontinent, wearing an adult diaper and could not walk or talk. Forget about him being able to push a call button or ask for help, he could not even get a drink of water for himself. This is why it was so very important for me to be there. That was all devastating enough and then here comes Covid. As much as I realize Covid was unprecedented and originally understood the shutdown of long-term facilities, the shutdown went on far too long. While staff were following the protocols, wearing PPE etc., residents were still dying...alone. No one wants to be in a nursing home and Covid or no Covid, this is the end of their life. I was tormented trying to figure out how I could bring my husband home. As much as I loved the staff, they were always short staffed, worn out and sick themselves and of course I wanted to be there for him. He wasn't actively dying, but he was dying a horrible, long death. Unfortunately, I wasn't able to bring him home.

No person should have to live their last days, months, years like this. I could have easily followed the covid guidelines and come and cared for my husband in a safer way than an employee who is taking care of several residents and therefore spreading covid more rapidly. As time went on, things started to open up. All the sudden, kids are able to play sports and go to sporting events etc. Nursing homes were last. Why would we allow others to run around breathing on others during an epidemic for the sake of sports but I could not wear PPE and be there for my husband at the worst time of his life? I can't tell you how mad I was and this should never happen again. This is why it's so very important that this bill is passed. Most people don't die in their sleep and there's a high possibility that either you or someone you love will need extended care. Can you imagine not being able to be there for them at the end of their life or if it was yourself, relying on a staff member to just give you a drink of water? Prior to my husband's diagnosis, Mark took care of himself and was healthy otherwise. No genetic disposition and he still got this sick. Please, I'm begging you to not put another person or family through this again. Please pass the bill so that future residents and the people they love can be there for them at the most vulnerable and such an important time...the end of their life. Isn't that what you would want?