

Chairman Cutrona, Vice Chair Gross, Ranking Member Somani, and members of the Health Provider Services Committee, thank you for allowing me to provide support testimony for HB 236; "The Never Alone Act."

My mom, Linda Lutz, was 73 years young when she died traumatically. She was retired after spending 30 years at Pepperidge Farm. Her health was important to her as she ate a vegan lifestyle and worked out one and a half hours five times a week at the local gym. She was a member of the Willard Moose where everyone called her a friend. An avid reader, she kept up to date on the latest political and world news. She loved sewing and crocheting and keeping tabs on what her 4 children, 12 grandkids, and 17 great-grandchildren were up to. It's two years after she has passed, but as I sit here writing this I am bawling because of what she went through in her final weeks, as well as what I went through. I still feel the deep intense grief.

August 18, 2021. Mom and I had coffee in the mornings 3 times a week. She was starting to sound like she was catching cold that morning and we discussed medications. We discussed it again Friday at coffee. The following Monday morning she wasn't up for the gym or coffee at my house so I went to visit her. She sounded bad. We saw our local doctor that Monday, August 23rd. She was tested for Covid, it came was positive. Luckily, we were sent home with instructions and over-the-counter medicine to go get. We were relieved as we did not want to go to any hospital as there were still covid horror stories. I spent all day with her the next 2 days, but by Wednesday her oxygen levels wouldn't stay above 90% and my Aunt Kathy, a retired nurse, urged me to take her to a hospital. I didn't want to, but her oxygen level was scary. Small town hospital here in Willard, OH (pretty sure they would ship her up to Toledo) or a neighboring town's hospital that I thought would keep her local (I was expecting the worst as far as being able to help her)? I didn't choose correctly.

August 25, 2021. I took mom to the Emergency Room at Fisher-Titus Hospital in Norwalk, Ohio. It was hell. I told them she had Covid. I wasn't allowed back with her. I sat in the waiting room as instructed. Registration finally came to me, and I made sure they had all her directives such as Medical Power of Attorney (which listed me). Registration told me I could use a phone on the wall to check on her since it had been 3 hours. The nurse back there didn't even know I was out there waiting, but she was pissed because my mom had pulled her IV tube and oxygen tube on her nose out and wanted to leave. ER nurse had obviously had a long day. Mean. She asked me if my mom had ever been diagnosed with dementia. I told her no, but I know that she seemed foggy which I assumed was from the lower oxygen levels. I told her I was on her Medical Power Attorney. She informed me that it didn't matter, as she hadn't been diagnosed with dementia. She did eventually get my mom to a phone so I could calm her down. One of the worst things I've ever done, convincing my mom she should stay in the hospital and not knowing if I should. The nurse told me they had to wait on the covid test result before they decided whether to admit her. I guess it didn't matter that she already had the positive test (they needed their money too). An hour later I was instructed to go home. They would be admitting her to the second floor as the ICU was full. I asked if I could put her cell phone with her stuff (though I wasn't sure she was coherent enough to use it on her own without help), but the ER nurse told me policy didn't allow it. Terrified to leave, but didn't have a choice?

That first night they move her to ICU. Her vitals stay fine if she keeps her oxygen in place, but she seems confused so she doesn't leave it alone. She can have an aide in her room to help her in ICU. I call every shift to check on her. I do find out they put her on remdesivir. That's scary, but I get no say. Evidently she's too confused to keep her oxygen in place, but she's allowed to consent to her medication? Sometime through that Thursday they put something in her IV to help keep her less agitated and the nurse claimed her lungs were starting to sound just a little better with the resting. Friday morning my call with the nurse said that vitals were good, x-ray still showed lungs were yucky, but they moved her back out on the regular floor. They needed the ICU room and evidently she's better? I bugged them until I got to talk to her that Thursday night before they moved her out of ICU. She was tired so short call. Friday during the day I managed to get someone to help her call me and she sounded out of breath, but more coherent. She doesn't want to be there. I cry. Saturday they back off the calming drug and she's a little more alert when I talk to her. Nurse says she did ask for something to eat, but he didn't think she ate any of it. Friday night she's agitated and the nurse is frustrated because she won't leave the oxygen in place. I convince him to allow me to come over and sit with her even though protocol is NO one on the second floor. He calls me back and got permission. I stay with her a little over 4 hours. While I sit there, we talk the entire evening. She's achy and fidgets in the bed a lot which is to be expected, I imagine. She's not trying to be a pain about the oxygen tube, but when she blows her nose, it moves. Then she's not strong enough right now to get it back into place. But with me sitting there, I take care of it and the nurses can do their stuff. I am to leave in the morning. Sunday was a good day for her, even had her up in a chair. Still not eating anything for which they aren't supplementing

her so I don't think that would be helping her get stronger, but I'm not included in her treatment. They don't move her or flip her like you hear about in some hospitals. I ask, but they say she's not strong enough. Hhmm? Can't they help? Vitals still good. Sunday night they let me in with her again. We talk again all night. She's weak, but vitals stay where the nurse says they're supposed to be. In fact, nurse doesn't even come to my mom's room ALL night, so not sure how she knows. The next morning I'm still there so I get to see one of the specialists, pulmonary I believe, who visits her. He says she's doing okay with where oxygen numbers and such are holding but still needs to be on that hi-flow oxygen as she has been. Then the aide or nurse comes in and realizes that my mom hasn't been bathed since...well never...and she checked in last Wednesday. It's Monday. Evidently between the back and forth of the ICU and regular floor, it just didn't get done. Respiratory comes in and says she's holding her own. The aides get her cleaned up some which does make my mom grumpy as she is achy. I talk with the nurses and get her on some pain meds for the achiness. She's calmer. She's settled back down and we're talking when all of a sudden a whole team of nurses come in and disconnect her from everything and wheel her and the bed out and to the ICU. (I guess a spot opened up. More money?) I'm literally left standing there in an empty room just looking around. Disbelief. She wasn't well yet, but nothing was worse. Why? Maybe I knew somehow I would never physically see my mom coherent again because I cried all the way home.

Nurses that afternoon were too busy to get back to me when I called to check on her. The middle of the night, I get a call from mom's ICU nurse and she's literally screaming at me. Mom does not want to take the medications they are trying to give her and will even try to bite them if they attempt. She wants me to talk to her. Mom's bawling and yelling that she wants to leave. I ask the nurse if she is keeping up on the Tylenol that took the edge off the achiness and kept her calmer like we had figured out with me being in there over the weekend. First she's shocked I was in there, and then she says she knows nothing about the Tylenol for pain. I ask if I can come in because it worked to keep her calm before. She says no. Now I'm bawling as she says she will have to sedate my mom for their protection. I never get to speak to my mom again.

August 31, 2021. Doctor calls and says we need to put her on a ventilator. Mom wouldn't want it. My Aunt insists people do survive it. I cry and discuss it with my siblings. We okay it, but looking back in her medical records afterward I don't think he needed our approval (it says something about having some universal power to do it in this situation). September 1-4, she stays in ICU at Fisher-Titus. I fight to get doctors to call and nurses to talk to me. No time for me. They run a whole myriad of tests from MRI's to scans looking for blood clots and possible strokes. She has a small infection. Sepsis they say, but no one knows why. Possible UTI? (Makes sense, she had a catheter but only bathed once?) They want to reduce her oxygen because appears to maintain her vitals on own but now afraid of kidney issues. If dialysis is needed they want her at a bigger institution. What? They have a dialysis unit here. Saturday, Sept 4th, they transfer her to UH Ahuja in Beachwood, OH. A blessing in disguise, but a little too late for my mom.

These people are wonderful. Someone can always be in the room with mom. They told us about her extremely severe bed sore wound. They watched her for kidney problems, but she was doing fine. The doctor called the very next day after she got there with an update. He was treating her with an antibiotic for sepsis, possible UTI, although he didn't know yet. He wanted to remove the ventilator but was concerned about her not responding or being alert enough yet. The first day he wanted to remove the ventilator!?! I sat with her everyday trying to convince her to wake up so they could take the ventilator out. After 11 days of tests and trying different meds and such to wake her, the doctors and her 4 kids decided it was time to let her go peacefully. We took her off the ventilator on Wednesday, Sept 15th. The worst decision for anyone to make. Her body was still healthy enough to hang on for 4 days until she died peacefully at a Hospice Home in Westlake, Ohio on Sept. 19, 2021.

I don't know why she fought so hard against the medicine that night at Fisher-Titus ICU? I don't know why that nurse was such a bitch to my mom and me? She's a nurse, it's her job to be patient with the sick. Should I have insisted mom come home? I think the nurse told me should would die if I took her. Maybe? But did the nurse traumatize mom so bad that night that she mentally just checked out because she couldn't do it anymore? But she was holding her own earlier that day when I was sitting with her on the regular patient floor. Why did they take her away from me? Why? She was even on lower oxygen that Sunday. If she hadn't been transferred to the ICU alone, would she still be alive? I think so. I should have been allowed to be with her through it all!!! This is proof that family needs to be there! And why did my Medical Power of Attorney get me nowhere?

Ohioans need the ability to have access to a loved one to advocate for and comfort them during a health crisis and at end of life. I ask the committee members to please vote yes on HB 236.