



caregivers *for* **COMPROMISE**

because isolation kills, too!

Visitation restrictions in place since March 13, 2020, meant to protect a vulnerable population, have resulted in wide-spread devastation as a result of the extreme weight loss, despondency, and rapid cognitive decline that comes from life in isolation and loss of desire to live.

Rights that are guaranteed in statutory laws and are federally protected by the 1987 Nursing Home Reform Act have been abridged and denied since March 2020. As well as being denied their federal right to receive outside visitors, long-term care residents have been denied the right to make decisions about treatment, choose their own attending physician, use personal belongings, participate in religious and cultural activities, engage socially within the facility, live free of physical restraint which includes being restrained from leaving a facility, or even receive a state inspector or representative from the state's long term care ombudsman program.

Residents have been denied equal access and protections under ADA by autonomous facility policies and have been denied the protection from abuse and neglect that comes from the ombudsmen, clergy, family, friends, powers of attorney, legal representatives, and court appointed guardians who would otherwise evaluate their care and advocate on their behalf. Enforcement, redress and recourse for violations of the few rights that remain to long-term care residents are all but non-existent.

We strongly contend that, after almost a year of isolation without access to their loved ones, residents in long-term care facilities cannot afford to wait while our government agencies decide whether it is safe to restore visitation. Too many people have already spent their dying days alone, separated from those they held most dear.

As a coalition of advocacy groups representing hundreds of thousands of residents living in long-term care facilities across the United States, we request the following considerations:

- Post-vaccine guidance discussions take place with urgency and that guidance does not penalize vaccinated residents on behalf of other residents and staff members who decline the vaccine. Those residents and staff members in long term care who choose not to receive a COVID-19 vaccine assume a risk just as those who refuse a flu or pneumonia vaccine do. While the diseases and their implications are different, the premise should be the same: the rights of those who accept the vaccine are not abridged by the existence of those who decline it.
- New visitation directives need to be issued in clear, direct, enforceable language so that caregivers can educate their individual facilities. In the absence of clear directives, facilities make their own rules which almost always fall short of the guidelines in place. We must be able to educate them and have them face penalties if they do not comply.
- No amended or future guidance regarding long-term care visitation take effect without a public comment process involving stakeholders that include the voices of residents and their families. We are the ones who will spot the flaws in public policy at the implementation level.

The Bottom Line

The physical and mental health devastation of the isolation protocols on the long-term care population and those who love them cannot be overstated. But, with administration of vaccines, we have an opportunity to change that which this country has gradually begun to accept as normal. It's time to start talking about what post-vaccine visitation looks like in a COVID-19 world.

Thank you for the opportunity to talk to you today. This is something many families have been trying to accomplish since shortly after Covid started. I am part of a group that is called Caregivers for Compromise. The group has added Isolation Kills Too to the name as currently, we are beyond just dealing with Covid. The national group was started on Facebook in Florida by Mary Daniel who got a job as a dishwasher in her husband's facility. That national group now has over 14,000 members. There are also groups for each state. Michigan's group has over 600 members. We understand the predicament that facilities are in. This is NOT a reflection on staff.

My name is Karen Lynema. I am an advocate for my mom, Pat Vander Weide. On March 11, 2021 she will be 78. On March 11, 2020 my brother and I brought a cake for mom and staff. March 12, the day our dad died in 2018, we also planned to visit. Mom and dad were married over 50 years. However, I received a call that the facility would be closed to visitors due to Covid. The facility had also been closed to visitors some time in Dec 2019 and Jan 2020 due to flu and gastro illnesses.

Please know that not all residents in long term care or skilled nursing are elderly. Some are young adults or younger. The decision to have a loved one go to a facility is usually not made lightly. Most often the level of care needed is more than what can be provided at home by family and friends. There are SOME resources available to assist with home care, but NOT ENOUGH. Our "choice" then becomes to find a facility with a good reputation, good staff to resident ratios, and a central location for family to visit AND all of this can cost thousands of dollars a month.

During this time, most of us as loved ones are lucky if we have been allowed window or glass door visits. These have continued even into the winter months. When my sister and I visited our mom on Christmas day by the glass door at the end of her hall, it was 21 degrees and blowing snow. Our loved ones are mainly in his or her room 24 hours/day other than a shower time. There is currently no communal dining and very limited activities. Our mom, even though she is not as verbal as she once was, has been and is a very social person. Residents are being physically protected, but at what mental cost to them and us?

When lockdown first started, the orders facilities were eventually given were to allow video visits. That was first on the list and where most facilities stopped. They were even given money to purchase or shipped I-pads. We were allowed to schedule Skype calls through the facility during business hours. This did not work for most of mom's 5 children. We eventually purchased a Grandpad senior tablet and pay a monthly fee to allow mom to video call or call us when she wants to....as long as it is charged and placed where she can reach it as she is now in a chair that does not allow her to move around her room. The chair was a change that was made during lockdown.

Mom has been offered a mechanical stuffed animal. A cat or a dog for companionship. It has not arrived yet. Even when or if she does get the lifelike cat, it is a poor substitute for human connection, family, and real pet visits that brightened her days.

March 12 will be a year. There should be better plans in place by now ESPECIALLY with the vaccines. The flu and gastro illnesses have become a yearly event already that keep visitors out. Covid is still relatively unknown. So far vaccines for flu and/or Covid have not allowed for visits. Right now, we will supposedly be offered indoor 6' socially distanced limited visits with masks and, more than likely, monitored. We still will not be able to hug or elbow bump our loved ones, even though staff is allowed to. Currently, there are so many restrictions and conditions from federal agencies for visits it will STILL be a long time. The rules may have changed slightly, however, they have been that if a staff member or resident tests positive there is a 14 day hold until visits can be allowed. We could get to day 13, someone tests positive and the count starts over. Now the threat level of our county also needs to be considered. I received one outdoor visit with my mom in August 2020. Our 2nd visit was cancelled and not rescheduled.

Technically, we are allowed to take our family members out of the facility. To not allow that would be cruel, inhumane, and a violation of their human rights, correct? For most of us, this is not a great option as many residents are not mobile enough to leave. This requires special transportation and several other accommodations that most families cannot make happen. When they get back, they may be quarantined again, but they are pretty much doing that already.

We are asking for an essential caregiver designation to be allowed to prevent this tragedy from ever happening again. This is not a designation that would have had to already be put into place prior to an event. It is not only for health reasons or end of life. We are asking that a resident is able to choose 1 or 2 family members or friends that would meet the same requirements and protocols for staff. We ask that this designation not just be for Covid, but a permanent and immediate change. There also need to be very clear rules for all facilities to follow and not open to interpretation.

Most facilities are already understaffed and under paid. Loved ones often helped with their resident, freeing up staff's time for other residents. We family members truly appreciate the care that is provided. We care about the mental strain that employees have also felt.

In conclusion, please consider: Families were kept out and Covid still got in. Our loved ones, some already near the end of their life, lost a year of knowing they have not been forgotten.

One final thought, how would you feel in our loved one's place?

Thank you for your time. We look forward to making plans that will work for all of us.