



Visitor restrictions in care communities have been in place in Florida since mid-March to mitigate and prevent the spread of COVID-19. While we understand the motive and intentions of this action, we MUST discuss the unintended consequences of this prolonged physical separation and isolation on our loved ones' overall health and well-being. Technology is not a substitute for in-person contact, especially for those with dementia, visual and/or hearing difficulties and mobility limitations who desperately need to maintain connections with their families.

"Before COVID many family members had been providing daily support and were an essential part of care plans and daily routines of care, including mouth care, eating and drinking, bathing, grooming, dressing, toileting, exercising, cognitive stimulation, and social interaction. There is mounting evidence throughout the health care system that the absence of these Essential Family Caregivers (EFC) has resulted in loss of mobility, cognitive abilities, socialization skills, health and well-being. The incidence of falls, fall-related injuries, mal-nutrition, dehydration, and pressure sores has increased dramatically in many facilities and for many at-risk residents. The use of sedating medications is on the rise and the return of the use of anti-psychotic medications is occurring."

*Teepa Snow, world-renowned dementia care expert
Owner, Positive Approach, LLC*

Additionally, there are wide inconsistencies among facilities in Florida. A stronger and more central voice and plan is critically needed to ensure all residents and families are receiving equal and reasonable support through this crisis.

As essential caregivers, we believe that our voices are not being heard and collectively we are asking Governor Ron DeSantis and the state of Florida to listen to our desperate cries for help.

We are asking for the following:

- A point of contact within the administration to keep us up to date on the progress of reopening so that we are not constantly blindsided by the ongoing continuation of this lockdown. We need information and communication so that we can make informed decisions based on facts, not hopeful speculation.
- The current plan of reopening our facilities in a "Safe. Smart. Step-by-Step" way including the specific criteria required to begin the process, the timetable for each step of that process and the necessary milestones for each.
- The implementation of an Essential Family Caregiver (EFC) designation program that is currently being implemented in Minnesota and Indiana. The specifics include:

- Designating a family member who, prior to visitor restrictions, was regularly engaged with the resident.
 - Visitation would be scheduled with time restrictions.
 - PPE would be required, physical distancing from other residents and staff, arrival screening as required of staff, and they must agree to limit contacts outside of the facility.
 - A preliminary negative COVID-19 test is required, and the EFC is subject to the regular testing required of the staff.
 - Restriction or revocation guidelines of the EFC status can be determined for those who fail to follow the established rules.
- An alternative to the Essential Family Caregiver designation would be outdoor visitation with PPE that is currently being implemented successfully in at least thirteen states including California, Colorado, Connecticut, Delaware, Illinois, Maine, Missouri, Nebraska, Ohio, Tennessee, Virginia, Washington and West Virginia.
 - As communities start to reopen, it will be important not to assume that new cases of COVID-19 are due to family involvement. Contact tracing will be essential in identifying the source of new cases so family members aren't denied access to their loved one who needs care and contact, unless they, in fact, are responsible for the COVID-19 transmission in the building. It is well established that staff members and hospitalized residents returning to the center are both primary sources of transmission. It would be highly ineffective and unfair to limit access once again to family members who have been consistently self-isolating in order to provide support and care to their loved ones.

The Bottom Line

Our loved ones are dying of isolation and loneliness and it has to stop. While we appreciate your efforts to save them from the virus there comes a point when the effects of isolation are more deadly than the risk of contracting COVID-19. Therefore, we respectfully ask that you announce a step-by-step plan for these recommendations by August 1st and you present that plan at a press conference, so it is clearly communicated to all caregivers. We all need to hear that you listened, that you care and that it is a priority to reunite us with our loved ones.

We are not going away. The families of the 142,000 residents in Florida's long-term care facilities are joining forces to advocate for our loved ones and we will continue to raise our voice through the national media to shine a spotlight on this issue.

Governor DeSantis, please, there has to be a better way!