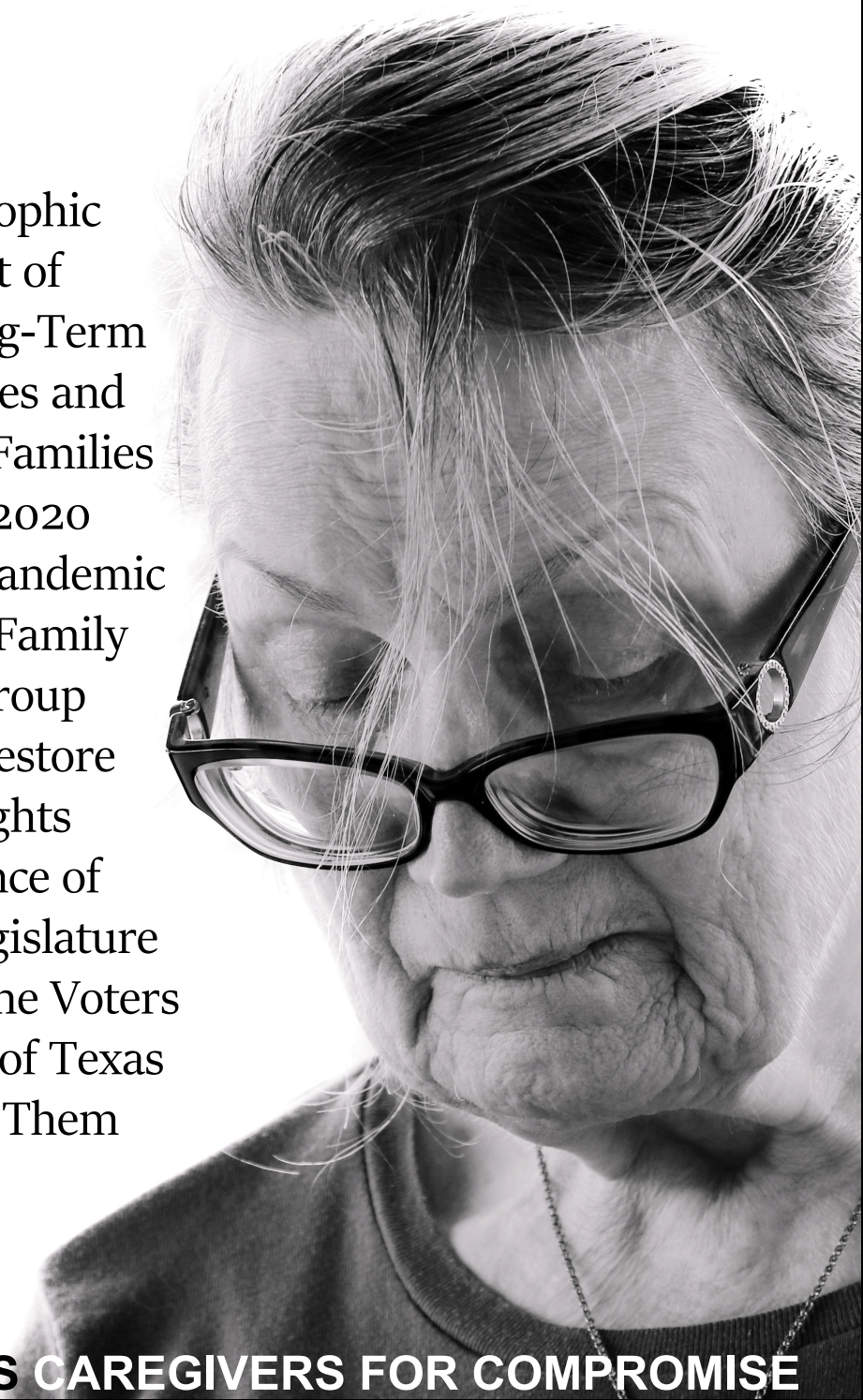


SAVING THEM TO DEATH

The Catastrophic
Human Cost of
Closing Long-Term
Care Facilities and
Separating Families
During the 2020
COVID-19 Pandemic
And Why a Family
Advocacy Group
Fought to Restore
Resident Rights
in the Absence of
a Seated Legislature
Elected by the Voters
of the State of Texas
to Do It For Them



TEXAS CAREGIVERS FOR COMPROMISE

SAVING THEM TO DEATH

Introduction

On March 12, 2020, family members said goodbye to their loved ones in long-term care facilities not knowing that the next day Governor Greg Abbott would announce that, in order to mitigate the risk of COVID-19, those same facilities would be off-limits to non-essential visitors including family members until further notice. So, we waited. But further notice did not come.

Frustrated by the closure of the government of the State of Texas and the inability of our elected officials to work on our behalf, family members began coming together on social media. A petition to allow family caregivers access to long-term care facilities began June 12 and a month later, on July 12, Texas Caregivers for Compromise was formed to advocate for the safe and reasonable restoration of visitation in long-term care facilities and the adoption of an essential family caregiver provision.

The State of Texas put long-term care in a safe bubble while addressing schools, churches, restaurants, professional sports venues, and hair salons. Yet every reopening discussion should have included long-term care since the staff who work in facilities also live in our communities as do their spouses and children. A special session of the legislature was neither called to address the COVID-19 crisis nor the 130,000 Texans living and dying in long-term care facilities.

Our loved ones have lived in emotional torment and died alone throughout 2020, never knowing why they were forgotten. They have self-harmed, starved, and dehydrated in their despondency, endured expedited cognitive decline, lost motor skills and the will to live, and then died wholly unaware of the end-of-life mercy visit granted their family members once they were comatose and hours or minutes from taking their final breaths.

The State of Texas removed the reason much of the long-term care population had to live. We strongly believe that legislation must be put in place to guarantee that the rights of long-term care residents cannot be paused or waived and that no future population's rights end the moment a pandemic begins.

Mary A Nichols

Mary Nichols
Texas Caregivers for Compromise

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Texas Caregivers for Compromise

Because Isolation Kills, Too

In June of 2020, family members in the State of Texas had already gone over 90 days without seeing their loved ones in long-term care facilities, loved ones who had no choice but to live in 24/7 supervised or skilled nursing to survive, when we began banding together. Met with both reluctance from some legislators to get involved in a controversial issue and the frustration of others who felt helpless with the legislature out of session, we formed our own advocacy group, developed our own essential family caregiver proposal, and then dozens of us made it our full time job to work toward the implementation of that proposal. Here is a little bit of the work we have done.

JUNE - A Change.org petition was formed for the safe re-opening of long-term care to families and was combined with petitions begun by others before we came together as a group.

JULY- Texas Caregivers for Compromise Facebook group was formed. We circulated our petition and began a letter writing campaign to the governor, HHSC, media, and legislators. We sent copies of a 4,000 name petition to Phil Wilson, Acting Executive Commissioner of HHSC, to Governor Abbott, then 5,000 and 8,000 name petitions to the same. The media picked up stories of our group members and our rapidly growing petition for essential caregivers. We collected isolation stories of our group members and made those public in our group for media and visitors. Then we scheduled a rally at the State Capitol for August 8 and began publicizing with media and social media. Meanwhile, our group was growing. Each group member was responsible for writing and calling his/her legislators, attending zooms, and staying informed.

AUGUST - Phase 1 Visitation was announced by HHSC August 7 with voluntary participation, stringent conditions, and a “failure to thrive” clause that allowed compassionate care visits for people lucky enough to live in Phase 1 approved facilities. Several hundred assisted living facilities qualified but only 90 nursing facilities of the 1223 in Texas qualified. On August 8, we held a rally at the State Capitol with much media coverage and two days later, our petition had another 2,000 signatures bringing us to over 14,000. We had over 50 television and radio stories about our group by this time. We called, wrote, and zoomed our cooperating legislators and attended every Q&A and webinar available regarding visitation or long term care. We became experts. We put together an essay on how Phase 1 was failing and put that in books with stories of people living in isolation in long-term care, and our proposal for an essential family caregiver plan. Those were sent on August 19 to Governor Abbott, HHSC, the House Human Services Committee, and the Senate Committee on Health and Human Services. Petition books with 17,000 signers were mailed to Governor Abbott and Cecile Young at HHSC on August 21. On August 22 we launched our “traveling sign” program fundraiser and had the signs bought, delivered, inscribed by volunteers and in the ground in Forney on August 31. These signs represented 300 names of residents who lived or died in long-term care. They began their journey around the great state of Texas, spending a few days in each location to call attention to our cause, get media attention, and then move to another part of the state.

SEPTEMBER - Our emails, calls, and Zooms with legislators continued, and we created a text-email blast that went out over Facebook and Twitter to our state house members and senators. Throughout this month, our media coverage was on-going in Austin, Lubbock, Houston, San Antonio and Dallas. Petition books with over 20,000 names were mailed on September 2 to Governor Abbott and Cecile Young at HHSC. Our group still grew and new group members were tasked with writing letters to their legislators, Governor Abbott, HHSC, and the media. The traveling signs were moving. In the month of September, they traveled to properties in Garland, Celina, Kilgore, Henderson, Palestine, Conroe, and Bryan. Each new location brought more media coverage in those areas and more people discovering that long-term care facilities were still essentially closed. Then, September 17, Governor Abbott announced that visitation would be expanded and essential caregivers would be allowed in long-term care facilities. It was not until September 24 that we saw the HHSC guidelines and realized that almost everything in our own circulated proposal was in those guidelines. Then we began the long wait while nursing facilities developed their policies. By the end of the month, it was evident that since assisted living and state supported living facilities were not mandated to participate, they were choosing not to and that nursing facility policies were so restrictive that they defeated the purpose of an essential caregiver as written in the HHSC guidelines. We relied heavily on the Texas Long Term Care Ombudsman Program who helped inventory facility policies and get that information to HHS as well as mediated with facilities. We also wrote a detailed explanation to HHSC listing all the issues with the new guidelines and the overly restrictive policies being put in place and how many facilities would not allow essential caregivers into their facilities unless HHSC stepped in and required it. HHSC addressed these issues in multitudes of webinars for long-term care facilities and downloadable training materials, guideline clarifications and adjustments, and a willingness to respond to our individual complaints expediently via email and telephone. As a group, Texas Caregivers for Compromise worked to make HHSC resources available to our members, helped educate facilities by sending them the guidelines and provider letter that HHSC already sent them, notify facilities of webinar information and resources, and lobby for change in assisted living facilities and state supported living facilities to make expansion visitation and essential caregivers mandatory.

OCTOBER - Our traveling signs kept moving. They went to Marion, San Angelo and Lubbock with more media coverage in those areas. We called attention to the ability for assisted living facilities and state supported living facilities to opt out. Meanwhile, Texas Caregivers For Compromise continued to remind facilities of the new guidelines and walk them through rules when they denied visitation to not only our group members, but family members all across Texas. Then, on October 16, HHSC announced that assisted living facilities and state supported living facilities must participate in expanded visitation and allow essential caregivers.

November - Texas Caregivers for Compromise presently functions as a source of information and education for families and long-term care facilities. We decipher the complicated, make it understandable, and work toward correcting issues in the existing guidelines. We are fierce advocates for ongoing change and are presently working toward making sure that our legislators take on long-term care visitation in January, 2021. We want no population to ever again experience the suffering we have witnessed since March of 2020.

Texas Caregivers for Compromise Requests that our Legislators Carefully Consider the Following:

No “ISOLATION WITHOUT REPRESENTATION” Legislation - Advocates should never again be put in the position of working alone and without the help of the elected officials put in place by the voters of the State of Texas. Our group has worked thousands of hours attempting to voice our concerns to our governor - the sole authority during the pandemic with the power to affect change - and failing to reach him, we used media, signs, social media, and other means as well as spent thousands of dollars to be heard. This is not the way our government is designed to work.

Legislation That Guarantees RESIDENT RIGHTS CANNOT BE PAUSED OR WAIVED - Both state and federal law provide for rights of residents in long-term care facilities. The residents’ Bill of Rights is required by law to be posted in nursing facilities in Texas. Not only has the resident’s right to receive visitors been waived but other rights have been infringed upon, paused and/or waived like the right to use their own physician, participate in activities inside and outside of a facility, be free of abuse and neglect, make their own choices about care and personal affairs, keep and use their own property, practice their religious beliefs, and refuse treatments. Many of these rights have been abridged and denied by the lack of the admittance of the outside caregivers, guardians, medical powers of attorney, and visitors. Rights of residents in long-term care should not be paused or waived but be as equally unalienable as any other population in the State of Texas.

Legislation or Constitutional Amendment to Require a SPECIAL SESSION OF THE LEGISLATURE to be called to act on behalf of the citizens of Texas in any emergency, crisis, pandemic, or other unprecedented situation that lasts longer than 60 days. The failure of the State of Texas to provide, preserve, or permit the republican form of government pledged in the Constitution of the State of Texas in the Bill of Rights has denied the people their right to participate in their own government through the public officials elected to represent them.

END ALL EMERGENCY RULES, Blanket Waivers, and Extension of Emergency Rules that perpetuate the separation of families, suspend resident rights, remove notification requirements of policy changes, establish the unequal application of limited visitation standards, and allow individual facilities to establish policies that determine the rights of residents. The mental and physical harm done to residents in long-term care and their families has created a mental health crisis both inside and outside long-term care facilities. The result of an agency attempting to write guidelines around emergency rules that restore incremental rights is inequity and discrimination. Rules should be universal and not the policy-by-policy and facility-by-facility standards in place right now where facilities decide the level of rights restored to long-term care residents. Presently, the only residents with the full benefit of the increments of their rights restored by the State of Texas are those lucky enough to have landed in the right facility.

INCLUDE LONG TERM CARE IN EVERY RE-OPENING CONVERSATION - Long-term care has been placed in a safe bubble off to one side while Texas has tackled other issues related to COVID-19. But every conversation about the re-opening of any part of Texas should include every population of the State of Texas including long-term care residents because it affects every population. Nurses, aides, contractors, vendors, physicians, and staff members that enter and leave facilities AND their spouses and children circulate in the communities where sporting events, large venues, and restaurants were reopened while residents in long-term care remain isolated to this day from family members living in those same communities. When the decision was made to reduce the number of people allowed to enter long-term care facilities, family members who were willing to test were given the lowest priority and the lowest margin for error. Physically and mentally disabled, deaf, and visually impaired people were forced to visit behind closed windows while family members, often senior citizens, stood in shrubs among ant beds and wasp nests in the scorching Texas heat shouting over roaring window units. But stadiums, concerts, and large venues were opened and people who attended those events live in communities and are free to work in facilities and/or expose people and families of people who work in them.

PROVIDE INFECTION CONTROL AND TESTING IN ALL FACILITIES - Free testing is available for essential caregivers in portions of Texas but not others. Rapid-testing is available in some facilities in areas with high positivity rates but not others. Some facilities provide PPE according to their own policy while others require essential caregivers to provide specific PPE that is unattainable and unaffordable. The State of Texas should provide testing in all long-term care facilities and a standard acceptable PPE. Since this is currently done at the expense of the facility or the essential caregiver, the facility's inability to obtain PPE and lack of knowledge regarding application processes or availability of funding is preventing essential caregiver visits.

REQUIRE PUBLIC COMMENT opportunities on emergency rules and waivers. Texas Government Code §2001.034, allows state agencies with rule-making authority to adopt rules with no public notice or public hearing. People insulated and distanced from the situation being regulated need input from boots on the ground. Had public comment been taken prior to the adoption of the Phase 1 reopening guidelines August 7th and expansion guidelines on September 24, Health and Human Services would have heard from groups like Texas Caregivers for Compromise who know the ins and outs of present everyday life in long-term care and would have alerted HHS to the holes in the dam. We would have objected to the "failure to thrive" provision as selective salvation in only those facilities approved for Phase 1 and we would have objected to assisted living facilities and state supported living facilities being given the ability to opt out of visitation expansion and essential caregivers. We would have insisted that end of life visits not be withheld until the resident is comatose and hours or minutes from death. Every delay in restoring even an increment of a right to people in long-term care is a matter of life or death so public comment related to long term care regulation is critical to success and costly if withheld.

PROHIBIT FACILITIES FROM DENYING long-term care residents access to hospice aides or nurses, clergy, the outdoors, off campus outings, exercise, their choice of physicians, essential caregiver visits, powers of attorney, legal representation, court-appointed guardians, or ombudsmen. If full visitation is not restored, essential caregiver visits should be allowed daily and for the minimum two hours allowed by HHSC unless a facility can prove a hardship or extreme health risk. Facilities should no longer be allowed to excessively restrict essential caregivers.

HOW WE ARE SAVING THEM TO DEATH

To **protect a vulnerable population** from disease, the State of Texas isolated long-term care residents from their communities, from the outdoors, and from each other. Keeping our vulnerable population safe made sense and seemed like the reasonable response to the COVID-19 threat in long-term care facilities. But the reality of the isolation protocol was devastating. Instead of safe and comfortable, long-term care residents felt punished, abandoned, unloved, and forgotten. Their only contact with the outside world was through closed windows, virtual devices that many of them couldn't understand or had no access to, or phone calls at the pleasure of the over-burdened facility staff because there were no phones in most residents' rooms.

While alternative visits were helpful for many long-term care residents, they were absent of benefit for many others. Adults with intellectual and cognitive disorders were traumatized by **window visits**. They did not understand why the person on the other side refused to come in or why they could not go out. Hard of hearing residents were frustrated and confused by **outdoor visits separated by six feet with both resident and visitor wearing masks**. They often could not hear over the nearby street traffic and parking lot noise combined with the muffled masks and they became angry and agitated when they were prevented from hugging or touching their family member. Plexiglass booths created the same communication barriers for the hard of hearing but were also terrifying cage-like experiences for people with intellectual and cognitive disorders. **Virtual visits** caused angry outbursts in some residents who heard a voice and could not locate their loved one while other residents were incapable of viewing the tablet as anything other than white noise. None of these visits benefited blind residents at all. These types of visits caused so many issues with residents and made it so difficult for the staff to manage their behavior that many facilities stopped allowing the visits at all.

The **isolation protocol** resulted in life threatening and life ending degrees of weight loss, despondency, and rapid cognitive decline. Residents lost the will to live and refused to eat or drink. They had no social interaction with friends in the facility, no entertainment from outsiders, no visitors, no exercise, no outings, and nothing to look forward to. They had no reason to get out of bed or get dressed and when coaxed to, their behavior was either lethargic or erratic. They gave up and longed for death. It was better than the utter loneliness and despair of daily life.

End-of-life visits are particularly cruel. Originally called "compassionate care" visits, end-of-life visits allow family members to be with their loved ones when they are minutes or hours from death. The compassion is extended to the family but not the resident. After months of separation, the family is allowed to see their loved one die but the loved one has already become comatose or non-responsive and is usually unaware of the presence of family. Facilities decide when an end-of-life visit is allowed, for how long, and how many family members are allowed so timing is everything and death is not always predictable. Facility policy often denies end-of-life visits at all or requires an administrative process causing delays that result in death before a family member is notified.

There are **130,000 stories to tell in the State of Texas** about how the months of isolation in 2020 have affected us and our loved ones in long-term care. Here are only 36 of them.

Herlinda Alcala

Died September 25, 2020

81 Years Old

Had I known my very first visit with my mother would be my last, I would have stayed longer.

With the exception of some weekends, I would visit my mother almost every day for as long as I can remember. We had a very close bond even as her dementia escalated and she needed 24/7 supervised and skilled nursing care.

I did not know that day in March would be the last day I would hug her or even touch her. I said my goodbyes and told her I would be back tomorrow. I was turned away the next day due to the pandemic.



I cannot imagine what my mother must have felt in those days. She would cry for me and wander the halls asking the nurses if anyone had seen me. I visited through the closed window

even though she would beg me to come in or ask to come out. She did not understand a thing. As the months passed, I was so depressed I would cry myself to sleep because I saw her decline. She eventually no longer cared if I was at the window.

Employees became ill with COVID-19 and the ones that cared for my mother left the facility. Now she had nobody she knew or that she felt cared for her. She had tantrums and the facility would call and ask me to calm her. But she wanted nothing to

do with me. She believed I no longer loved her, had forgotten her, and had abandoned her. I never did.

Then my mother's oxygen level dropped and I demanded she get a COVID test. The employees were still going on vacation and visiting bars instead of staying home like us family members who were waiting to be allowed in. My mother was hospitalized for two weeks and moved to a different facility. Upon her release. I was hopeful she would become her old self so I requested video chats and phone calls but she could hardly speak.

I found this amazing group, Texas Caregivers for Compromise, who worked to restore visitation and on September 24th I was finally able to see my mother as her essential caregiver. I truly believed I would be able to pick up where we left off, but she could no longer speak nor move on her own. My visit lasted about two hours but she was so non-responsive that I requested a hospice evaluation. I asked the administrator if my sister could come visit and he said no because she is not "actively dying".

I was getting dressed to go see her the next morning when they called to tell me she had died.

Had I known my very first visit with my mother would be my last, I would have stayed longer.

Veronica Alcala

Jane Anderson

79 Years Old

After seven months of isolation in her facility and no salon visits, the Valentine Queen has given up.

My sister Jane has been isolated in her nursing facility since February of this year, shortly after she was crowned Valentine Queen. She was vibrant, healthy, charming, put-together, happy, and oh, so beautiful when we saw her.



Jane came down with COVID-19 in August and although doctors told us to plan her funeral, she recovered with a plasma infusion. No one was able to be with her during her two and a half week hospital stay.

She has now become withdrawn and her dementia has worsened during her seven months of isolation. She rarely talks. Hairdressers have not been

allowed in the facility since March to cut and style hair so her basic grooming has been neglected.

Even though I am her essential caregiver, I am still limited to either window visits or outdoor six-foot separated, masked, no-touch visits.

None of our family has had a contact visit with her. Now, after seven months of isolation in her facility and no salon visits, the Valentine Queen has given up, and I fear that she won't remember me from one visit to the next.

Pauline Mountain



Ernestine B. Beck

81 Years Old

I went to the glass door every morning to visit but my mother looked away as if she didn't know me.

My mother has battled severe depression for decades. After suffering a stroke, she refused medical attention. When she began showing signs of vascular dementia six years ago, I was able to convince her husband to move closer to me so I could help with their care. He died three years later.

When she was misdiagnosed with pancreatic cancer and only given three months to live, I decided my mother needed 24/7 skilled nursing. I promised to never leave her side. Every evening, I went to the facility, helped with feeding and hygiene, exercised her arms and legs, put her to bed, and left her a note and a Bible verse to wake up to.

March 12, I told her I would see her tomorrow. But I lied. I did not see her tomorrow.

The first week of isolation, we tried virtual visits but she became so confused, emotional, and agitated that her dementia and depression escalated and she was put on an antidepressant.

I went to the glass door every morning to visit, but my mother looked away as if she didn't know me or she begged me to come inside. Before long, my mother simply stopped speaking at all. Then she stopped eating or drinking and lost twenty pounds in the first thirty days.

Day after day I went to that door thinking maybe it would give her hope or even give me hope. But instead, it resulted in damage to our mental health: both hers and mine. The sleepless nights were countless. I worried about how hungry she was or whether she would remember me or remember the promise I made to her on March 12 and never kept.

It was 208 days before I was allowed to see my own mother as her essential caregiver but only in the chapel, not in her room where I can assess her living condition and inventory her needs as I'm entitled and required to do as her legal guardian.

She can no longer feed herself, hold a spoon, hold a glass or chew her food. She's on a puréed diet because that's what happens when dementia escalates, something I am convinced only happened due to 208 days of separation from her daughter.

My hair is falling out and I've been put on antidepressants because, despite being an essential caregiver under the visitation guidelines adopted September 24, my visits are brief, public, and limited. I still cannot take care of my own mother the way I want and am required to by the State of Texas because it is the State of Texas standing in my way.

Beverly Damron

Janelle Binion

98 Years Old

This is not the way the HHSC guidelines read but many facilities are not learning or applying the rules correctly and all visits are on hold anyway.



We saw my mother March 8 on her 98th birthday. Then her facility locked its doors. She suffers from escalating dementia and simply cannot understand why her children do not come to see her.

Our family's story is the same as many other families with loved ones isolated for such a terribly long time. But the people we love are unique, created in God's image, loved by God, placed in the family He chose for them. They are mothers, fathers, husbands, wives, children, grandparents, and friends. Most of them lived their lives for us and now that they have come to the end of their lives, all that matters to them is seeing and being with those they love.

So much precious time has been taken from us all. Many ran out of time. My heart breaks for everyone who lost a loved one during the past months of isolation.

During these long months, only one resident and three staff members tested positive for COVID-19. This facility has been slowly opening, but I was finally given an appointment to see Mother in October but a staff member tested positive on her hallway. All essential caregiver visits were cancelled. This is not the way the HHSC guidelines read, but many facilities are not learning the new guidelines. My mother is now confined to her room for 14 days and thinks she is being punished.

I appreciate so much all of the hard working advocates in the Texas Caregivers for Compromise organization. Without their advocacy, we would probably be at square one.

While I wait expectantly for another appointment, we pray for those affected by this illness. We pray for the residents who have waited much too long to be reunited with their families and we pray for all those who, like myself, will not give up until I have my arms around my precious little mother.

Sharon Parker, Dub Binion, Ron Binion,
Randy Binion, Tony Binion, Mitzi Jones

Patricia Miller Calcote

Died September 28, 2020

78 Years Old

From the window, I could see her in bed, reaching up as if trying to hug an invisible someone.

August 22, I received a late night call informing me that my mother was not responding to the staff or any of the techniques they had used in the past. They feared she was transitioning and were allowing me inside to be with her.

Since March 13th, I had only been allowed to kneel in the dirt and fire ants in scorching Texas heat in hopes that she would be able to see and recognize me through a dirty window.

When I entered her room, she was staring blankly and the light had left her eyes. I took her hand and asked if she could see me. No response. The aides left the room to give us privacy. I worked with her the entire night. I talked to her, sang to her, washed her face and hands with a warm cloth, and rubbed her legs and arms with her favorite lotion. She remained motionless. Three hours of this and she suddenly heard me. She turned her head and stared directly at me, I lowered my mask and gave her my biggest smile. She smiled back. I took her hand and asked her if she was hurting. She stammered and said, "I'm just fine, when did you get here?"

I was allowed to stay in her room at her side in order to speak with the hospice nurse the following afternoon. She was met with my mom's big smile and even laughter. No doubt something had changed. She continued to improve the next few days as I was allowed to feed her and encourage her to drink. Here is the proof that our loved ones need

us by their side to let them know they are loved and not cast away in a dark room.

But days later, I was no longer allowed at her bedside and my window visits resumed. Several aides and patients had tested positive for COVID-19 so they would raise a window six inches I could yell at her from across the room. She began to decline once more, would not eat or take her medications. She had given up.

I feared she would die alone and my own health suffered. My Lupus escalated and ulcers formed in my mouth and stomach. From the window, I could see her in bed reaching up as if trying to hug an invisible someone.

On Sept 20th, her status was changed and I was entitled to "end of life" visits. I was at her side every day, for as long as they would allow. Despite my mother's brief moments back into the light, she passed away just hours before my regular essential caregiver visits would begin on September 28, 2020.

Roxana Calcote-Sanders

Daniel Carlo

He no longer has the fighting spirit in his heart he once had. He has given up. He is defeated.

My dear friend has Lewy Body Dementia and Parkinson's. He suffers from the effects of the progression of his diseases but combined with the isolation, Daniel lost the will to live.

Daniel said he felt imprisoned, confined to his room, unable to see anyone he loved, or go on his outings to Olive Garden and Whataburger. He has lost thirty pounds since March, falls frequently, develops urinary tract infections, and makes no attempt to get better.



He feels abandoned by his family and thought I had forgotten him. He no longer has the fighting spirit in his heart he once had. He has given up. He is defeated.

When I was allowed to see him again, Daniel said "miracles really do happen" and he looked like a new man when I gave him his first hair cut after seven months. He made a friend in another resident and found joy in watching her regain her ability to walk without her wheelchair, but there is no joy in his own life.

Hospice has taken over due to Daniel's advanced confusion, choking, and inability to swallow. He doesn't even try.

Lord, have mercy on us all.

Letty Lanzerio

Steve Christenson

63 Years Old

He had incidents and his behavior spiraled. Then one day, he asked, “so, are you just killing me?”

I took a cherry slush on March 9th and promised I would be back in a few days. But I wasn't back.

My husband Steve needs 24/7 care and supervision but isolation mandated as a result of the seven month lock-down resulted in confusion, depression, agitation, and boredom that turbo-charged his rare, Behavior Variant Frontotemporal Dementia (FTD). With a shrinking brain, his medications serve as maintenance that controls behavior and moods. They are the only relief available to FTD patients.

Prior to the pandemic, he was content, mild-mannered, and got along well with his roommate and nursing staff. We enjoyed two or three outings a week together for rides, movies, lunches, and errands. Although his executive functioning skills and word association needed

prompting, together we could communicate. As his wife of 26 years, caregiver, medical power of attorney, and liaison between Steve and the facility staff, I am his “person”. My job is to assess his living conditions and see that his needs are met.

Neither video calls nor glass door visits with phones allowed us to communicate well. Steve grew increasingly agitated and was unable to understand why he could not come out. He had incidents, accidents, and his behavior spiraled. His medications were increased twice and his frustrated roommate requested to be moved. Then, one day he asked me, “so, are you just killing me?”

I spent many days calling, writing, reaching out to politicians and policy makers; begging, hoping, praying for relief for Steve and others in long-term care. I lost sleep and blood pressure, stress, and fear steadily increased.

October 13, I was finally permitted in. He thought I was there for an outing and shrugged in confusion at everything I said but we muddled along until a little of his favorite music helped break through. He is more disconnected, dazed and confused than seven months ago and requires much more help. I had to move him to a different wing within the facility so he is watched more closely and unable to roam. He is now in a new form of lock-down. But, at least I can visit and be his caregiver again.

Jeanette Christensen



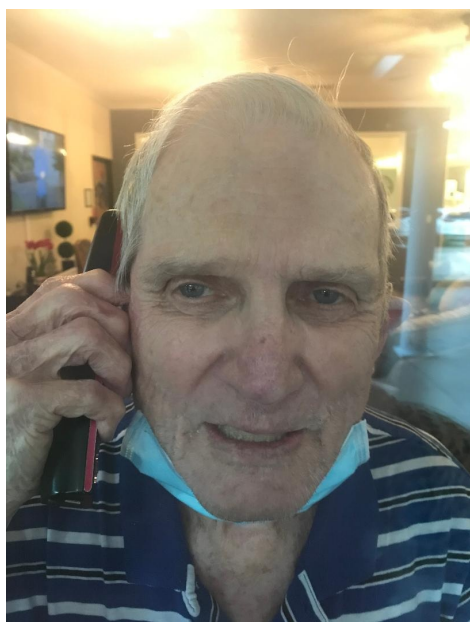
William Joseph Cobb

85 Years Old

He remembers my long absence and worries that when I go, I will disappear again and never return.

On March 13, 2020, I was notified by the nursing home where my dad lives that it was officially on lock-down and I could no longer come in to see him or take him out.

My dad has Alzheimer's, diabetes, and is very hard of hearing even with the assistance of hearing aids. During this time my dad's hearing aids were lost, his pacemaker transmitting device became unplugged, articles of clothing were lost, he wasn't transported to dentist appointments, missed doctor appointments, and never got a hair cut.



I would visit him at the window and talk over a phone but these visits caused us both frustration and anxiety. He struggled to hear and would cry every visit because he did not understand

why he could not go on our weekly outings or at least touch. Regardless, I showed up every week to remind him he was loved and thought about.

The worst part of all of this is the time he lost being with his family. His blood sugar increased probably due to his stress and because he wasn't eating or drinking well. His Alzheimer's disease has progressed significantly as confirmed by a CT scan during an emergency room visit.

The isolation has filled my life with anxiety, depression, and hopelessness. I have had multiple health issues due to the stress. I could do nothing for him. I could no longer do his laundry and when they eventually allowed me to bring him snacks, I had to drop them at the door. They were held for 24 hours and wiped down before the nursing staff took them to my dad.

Our whole existence felt regulated, watched, confined, and restricted.

October 2 was my first visit with my father in seven months. I was able to go in and actually hug and touch my dad again as an essential caregiver. While this has brought me some relief, neither my dad nor his family can ever get back the lost days from isolation. He cries every time I leave. He remembers my long absence and worries that when I go, I will disappear and never return. He still lives in a heightened state of anxiety.

All I can do is go see him every chance I get after a negative COVID-19 test every two weeks.

Rhonda Barber

Martha Louise Duncan

76 Years Old

202 days later, she had become a glassy-eyed shell of a human, choking daily, and waiting to die.

My brother and I said we would see her tomorrow. Then, we were not allowed to go back. By the time we set eyes on her again, 202 days later, she had become a glassy-eyed shell of a human, staring at nothing, choking daily on her own vomit, slowly drowning in her own saliva, waiting to die.

Despite being the legal court appointed guardian of a wholly incapacitated mother who suffers from end-stage Alzheimer's, Parkinson's and vascular dementia, I was stripped of the ability to participate in her care. Since she cannot speak, make eye contact, swallow, or turn her own head, there were no virtual visits, phone calls, or window waves.

Our mother was cut off from her adult children completely and we were denied the ability to assess her living conditions or quality of care or look for signs of abuse or neglect. Her facility became her ad-hoc guardian, making decisions about medications, hygiene, and her PEG tube nutrition intake without our input.

Prior to her descent into the Alzheimer's abyss, my mother had become so combative that my sister and I would stand in her shower and sing while aides bathed her. We spoon fed her every day, distracted her from her hallucinations and delusions, and took her to every X-ray, every eye doctor, neurologist, psychiatrist, and M.D. appointment until the State of Texas decided that we were no longer essential.

The separation has had serious health implications on her four adult children: anxiety, depression,

hypertension, sleep deprivation, and despondency requiring help from licensed physicians. We have been grieving a mother not yet dead while living with the guilt of abandoning her and our inability to provide the 24/7 skilled nursing required to keep her at home. A private hospice hospital would allow family but remove her lifesaving feeding tube.



Hasten her death and bring her home to die in the company of family or keep her alive and she may still die in utter isolation: this is the agony imposed on Martha Louise Duncan and the choice faced by her family.

Mary Nichols
and on behalf of Michael Batchellor, Melissa Roach, and Joanna Nasr

Nancy Haynes

Died October 19, 2020

90 Years Old

She would say that she had been kidnapped and was being held in a very nice hotel or in a hospital.

When Nancy celebrated her 90th birthday in January, she was healthy and strong enough to attend church, eat out, and travel for her big celebration. She was healthy and happy to be with family.

Until the COVID-19 lock-down, I visited my mother almost daily. After the lock-down, communication was minimal because, as a dementia resident, she was mostly unable to use phone calls or virtual visits and always wanted to know why her family wasn't with her. She would say that she had been kidnapped and was being held in a very nice hotel or in a hospital and asked when she could go home. She was concerned that her family did not know where she was. Prior to the lock-down, we had given her a journal in which family members would write a short note so that she could look back and remember that we had visited. There were no journal entries after the lock-down.

In May, Mom began to fall frequently and had a series of injuries and hospital visits for a broken nose, broken femur, cuts on her head and face and surgery. She needed skilled nursing and rehab prior to returning to her memory care facility in September. By then, she was rapidly declining, unable to self-feed, completely incontinent, too weak to walk without assistance, and unable to wake for physical therapy sessions. She grew increasingly worse by the day.

Outdoor and plexiglass visits became available but were complicated in her condition and caused agitation. She couldn't understand masks or no-touching and the thirty minute limit was not enough.

When Mom was “actively dying”, the family would be allowed access but she would be unaware by then so when she was discharged from the last hospital visit, we returned her to the family home. All of her family was allowed to come in our living room and be with her. Had she gone back to the facility, she would have been quarantined for 14 days with no visitors. Instead, she died at home, fully aware that she was in the presence of people who loved her.

Lori Haynes



Scott Hazelwood

55 Years Old

Plexiglass enclosures and window visits simply do not work for a deaf and blind man.

Deaf and blind and living in an intermediate care facility, my son's routine is the foundation of his life. With routine, Scott understands what is happening and what to expect. That routine includes a trip home every other weekend and going to his workshop during the week. But the workshop has closed and he cannot come home without going into quarantine for fourteen days.

When the pandemic began, I brought him home for two months. But, I am in my seventies and caring for him took a tremendous toll on me. His facility has only one other resident in a large group home. Scott is very unhappy and confused when I cannot bring him home so our temporary solution is to bring him home, per our routine, every other weekend. But the price is quarantine for the full two weeks until the next visit.

Quarantine is isolation, staff wearing gloves and mask, and Scott eating alone. Since his form of communication is tactile sign language, quarantine means not only no sight and no hearing, but limited human contact. It is inhumane.

Plexiglass enclosures and window visits do not work for a deaf and blind man, much less vehicle parades, virtual visits, or phone calls. The facility does not communicate their plans or policy to me, only refers me to the State of Texas guidelines.

Scott is incapable of understanding why his world went away. It's equally difficult to put into words

the level of mental stress and anxiety experienced by a parent who is utterly helpless.

Carolyn Kerr



Florence James

87 Years Old

We were notified a part-time staff member tested positive for COVID-19. A week later, my mom did.

Due to some health issues and a hospital visit, Mom agreed in January that it was time to find an assisted living facility. But the following month and another hospital visit due to degenerative spine disease and a multi-drug-resistant UTI, she needed a skilled nursing facility. We saw her that weekend and then long-term care facilities were locked down.

Mom was able to get around using her walker but when she fell and broke a finger, she could no longer use her walker and was confined to a wheelchair. Had we been allowed in the facility, we would have alerted the staff that she was unstable and her behavior was out of the norm. She ended up in the hospital in May after passing out at the nursing home and they determined that she was overmedicated. Again, had we been able to visit her, we would have seen her behavior was sluggish and her medications needed adjusting.

By June, my brother and sister and I knew that Mom had been showing signs of dementia and we were notified that a part-time staff member had tested positive for COVID-19. A week later, my mom did. By early July, she was not only battling COVID-19 but we decided to place her on hospice.

Mom survived both COVID-19 and the accompanying extreme upper respiratory infection. The neurologist put her on a medication to help with confusion but she had spent so much time in the wheelchair, her degenerative spine disease

accelerated. There is little hope she will ever walk with her walker again.

I feel certain that had we been allowed access to her facility, we could have identified the issues that contributed to her decline and she might still be walking with the help of a walker.

October was my first opportunity to visit her as essential caregiver in October but the facility's policy is so restrictive that it creates a hardship when I'm hours away. During the summer



when everything seemed hopeless, I was told about the Texas Caregivers for Compromise. I was able to focus my energies to support that group and work on making positive change.

More change is needed and it is my hope that our legislators will work to make sure that families are never separated like this again. Families notice the things that staff members do not.

Deniese James Itz

James E. Johnson

93 Years Old

Dining room restrictions stripped him of his role as “the candy man” due to potential contamination.

Seven months of isolation has exacerbated my father’s hallucinations and delusions due to Alzheimer’s. His phone calls are more confused and occur at odd hours of the night. Once, he thought he was in a combat situation with his troops and another time, he was back at a job he retired from decades ago.

Because two families broke the rules early into the lock-down and sneaked into their loved one’s apartments, none of the residents were allowed to take walks outside the facility for the first several months. My father was accustomed to walking twice a day but he has grown weak from lack of exercise and is now considered a serious fall risk.

My father has also lost weight during the lock-down. He was forced to eat alone in his room, three times a day, for months, so he refused to eat and threw many of his meals away. Without the social interaction, he just lost his appetite.

He has also lost his sense of purpose. Dad is known at the facility as “the candy man,” because after every meal he would go to all the residents at their tables and let them pick candy out of a container that he kept in his walker. That was his identity, his role, his purpose, and the thing about meal-times that brought him joy. He was buying between four and six bags of candy a week to hand out.

Even when group meals resumed, dining room restrictions stripped him of his role as the candy

man due to potential contamination and the joy it gave him to do this. Now, even though there are meals in the dining room with some restrictions, he’s still not allowed to resume giving candy to the other residents.

My father has not been able to attend church since March and there are no church service options within the facility. My sister used to take him to church each Sunday, and they would go out to lunch afterwards. This has been another loss to his weekly routine, making one day run into the next, which has removed his perception of time.

With removal of all activities and his sense of time comes additional confusion about time of day. He may sleep all day and shower at 3:00 a.m. All routine is gone so he has no way to tell time.

His greatest loss is not seeing his grandkids and great grandkids. Until normal visitation is restored, my father doesn’t know when or if he will ever see them again. And this makes him live in a perpetual state of grief.

Rebecca Pearce



Don Jones

89 Years Old

After only two weeks, he asked me why I had left him to die in this place. My heart broke for him.

39 years ago I married this sweet, loving, caring man, taking him "...in sickness and health..".

On June 18, 2020, he spent his 89th birthday alone. For the first time in 39 years, he spent a birthday without me and alone.



Nearly three years ago, I was forced to make the most difficult decision of my life and live separated from my soul-mate to give him the 24/7 skilled nursing that I cannot provide.

The skilled nursing facility tried to compensate for his birthday, but when I Face-Timed him, he sobbed about how lonesome he was and how much he wanted to come home. This was unbearable pain and heartache for us both.

Never in my wildest dreams did I ever believe the day would come that I would not be able to at least visit and care for my husband's personal and emotional needs. Honestly, if you had told me that I would go nearly 7 months without seeing him, I'd have thought it was a joke.

After only two weeks, he asked me why I left him to die in this place. Two days later he told me he thought I had divorced him. My heart broke for him. We had been inseparable for 39 years. The emotional toll this has taken on both of us is immeasurable. I pray I can see him on his next birthday but his mental and physical health has declined so much and he has lost the desire to exist without me. I doubt he will be here for his birthday in 2021.

Dorothy Jones

Petre Kirby

28 Years Old

He would hear my voice and then scream, cry, and bang his head when he couldn't find me.

When I hugged and kissed Petre goodbye on March 12th, I said, “see you later” as he finished his chocolate milkshake. Petre did not see me later. Normally “later” meant tomorrow or the next day. This time, “later” was 197 days.

For the three and a half years that Petre had been in a state-supported living center, I was there several times a week without fail. As soon as he saw the milkshake or Icee, he would jump up and drink it. We would hold hands and sit in Petre’s room on on the patio and listen music while I did a hundred other normal Mom things. I was an essential part of his life, not a visitor.

Petre functions at the level of a three-year-old, is non-verbal, and self-injurious. He is 100% dependent on others for his care and I did that. Since the day we met when he was four years old and only weighed 15 pounds, I did that. I was told he would never walk but he took his first steps at age six. He persevered despite his severely abused, neglected and then abandoned beginnings by his birth mother. It took years for me to gain the trust of this boy with severe PTSD and to prove to him that I would never harm or abandon him. Then I abandoned him.

His self-injurious behavior escalated during these 197 days. There were no window visits because I was required to wait at the gate of the multi-acre campus. Petre does not understand virtual technology although we tried. He would hear my

voice, look around the room, and then scream, cry, and bang his head because he couldn’t find me. Then the despondency began. He refused to get out of bed, quit going on walks, did not sit on the patio, and would not go to the dining room to eat. His weight loss was extreme.

I did see Petre twice when he self-injured and was sent to the emergency room for stitches. As the weeks and months went by, he resented my absence and lost an alarming amount of weight. When I saw him on day 197 as his essential caregiver, he did not jump up from bed and and rush to drink his Icee, would not hold my hand and made very little eye contact. He is not the same person I left on March 12th and I must work very hard to regain the trust of the little boy who was, for the second time, abandoned by his mother. Only this time, it was at the decree of the State of Texas.

Stephanie Kirby



Wanda Koonce

Died October 19, 2020

83 Years Old

She would have survived had she not suffered from despondency and severe weight loss.

For months, I drove two and a half hours one way to stand outside in the scorching west Texas heat and visit my one and only grandmother for 15 minutes by yelling through a dirty closed window. She could barely hear me over the roaring window A/C unit. Neither did she understand why we could not go in or she could not come outside.

Even through the window, I could see how quickly she was losing weight and the rapid cognitive decline as a result of her despondency.

Window visits from my children cheered her but my grandmother would also become agitated that she could not hug them. Confined to her bed, she was unable to even come to the window. Open window visits were not allowed without a Phase 1 designation so we were dependent on the staff to hand her a telephone. They rarely had the time or a portable phone available.

Her despondency resulted in refusal to eat or drink, and all the precautions did not keep her safe from COVID-19. Her facility staff members still worked other jobs, went home to spouses who circulated in the community and took care of kids who go to school and move around in the community. Somehow, the disease came inside.

When my Nannie developed symptoms and tested positive for Covid-19, we knew that we had to bring her home on hospice as soon as she was released from the hospital instead of returning her



to the nursing facility. Otherwise, she would never see her family members again.

After 200 days, she was finally home where everyone could see her. She ate every meal and even asked for ice cream. But it was too late to save her life. She shed tears of joy to finally see her family but died shortly after going home.

I am confident that she would have survived had she not suffered from the despondency and severe weight loss that weakened her immune system.

Amberly Koonce Herbertson

Edith Lagrone

Died May 22, 2020

95 Years Old

One day, she'd had enough. She said she did not want to live in a prison anymore. So, she didn't.

At 95, my mother was mentally and physically healthy and very active for the two years she lived in an assisted living facility. She spent many hours reading, visiting other residents, going to exercise classes, and writing the notes and cards to friends that she was so well-known in our home town for sending. She got up each morning, dressed, put her jewelry on, and went to the dining room. She enjoyed visiting with her table mates, Alexander and Ellen. Wednesday was beauty shop day, Saturday was family day, and Sunday was reserved for church and visitors.

I am retired so I was her main caregiver and saw her once or twice a week. I talked to her almost every day on the phone, did her shopping, straightened her apartment, and did whatever she requested or needed. We got one hour notice when the facility closed and we all live 45 minutes away.

The first time I visited her after the shutdown, we talked through an open window. She was dressed (with jewelry) as usual. The next week, I took supplies and we visited through a closed window using the phone to communicate. Each week, I could see a change. She wasn't dressed or her hair wasn't combed. She would say, "Why? I can't go anywhere." She went from walker to wheelchair in weeks and the last few times I visited, she didn't go to the window. She said "I can't really see you through the window and we have to talk on the phone anyway." Regardless, I continued to go and peer in the window.

Isolation was miserable for a person like my mom. She was restricted to her room, couldn't go to the dining room, couldn't socialize, had no exercise classes, and there were no volunteer entertainers. The staff was good to her but she had never gone more than a week without seeing family. She

compared her life to the Japanese Americans put in camps during World War II, "to protect the public."

One day she told me she'd had enough. She said she did not want to live in a

prison anymore. So, she didn't. The next morning I got a call that she was having difficulty breathing and they were transporting her to the hospital. She passed away May 22.

I am thankful we were able to be in the hospital with her. The nurses allowed me to stay each night so she was never alone. She tested negative and there were no COVID-19 cases in her facility, but I have no doubt the isolation killed her.

Cathy Nichols



Hortensia Lopez

90 Years Old

The last thing I needed was a phone call that Mom tested positive for Covid-19 and would be moved.

When we asked how long the facility would be off limits to visitors we were told, “indefinitely, for now”. That was an understatement.

My husband and I last saw Mom in February when we delivered the news that her sister in Nebraska had died. Mom suffers from Dementia and Stage III Kidney Disease and she looked forward to our weekly visits and family weekends. We sat in my garden and I would pamper her with her favorite meals, manicures, hair color, and a set because her appearance and red lipstick are a priority to her.



Then my mother’s whole world stopped: no more beauty shop appointments; no more bingo, social activities, or family time. Most importantly, her much needed dental care ended. In her own words, she felt like she was in prison. We called Mom twice a day, but she quickly lost the ability to

follow conversation. Her appetite waned and her self esteem plummeted.

In May, Mom fell and broke four ribs, suffered a concussion, fractured her left orbital wall, and required stitches above her right eye. When she was discharged from the hospital, she had to quarantine for two weeks. This was the beginning of her accelerated decline: throwing up, weight loss, refusal to eat, excessive sleeping, falling, weakness, and vertigo.

By August, she was a candidate for hospice and her weight has dropped from 113 to 93 pounds.

Mom doesn’t understand the cause of our separation and while I try to gently explain, I too am suffering from anxiety, guilt, sleep deprivation, and depression.

The last thing I needed was a phone call that Mom tested positive for COVID-19 and would be moved to another facility. The facility has no telephone in her room so our very brief virtual visits must be scheduled at the convenience of the facility staff.

I will continue my prayers that we, as essential caregivers, can get more access and time to be with our loved ones. Their lives depend on us.

Nellie Pennington

Martha Mass

83 Years Old

During the time we were banned, 35 employees and 77 residents tested positive for the virus.

My wife, Martha, had been in a nursing home for a year and nine months when I went to visit her as usual on March 13. I practically lived at the nursing home, visiting every day and spending each afternoon with my wife, bringing her snacks and taking her outside walking on nice days. She was only in the early stages of dementia and in excellent physical condition. The park where I took her walking was on a steep hill and she walked up and down the hills like a mountain goat, without getting out of breath.

On that fateful day, I was told that the governor had issued an order, effective immediately, barring all visitors from entering nursing homes. I never even had a chance to say goodbye or bring home some of my wife's things.

Within six weeks, I had my wife moved to another nursing home that was doing a better job helping families connect with their loved ones by means of virtual and window visits. I did get to see her at a doctor's office in June when she went there for an appointment, but that was the only time we saw each other except through glass until very limited "essential caregiver" visiting was allowed in late September.

While I was overjoyed to see my wife, I was also saddened by how much she had declined in six months. The woman whose legs had been strong enough to carry her up and down steep hills in March was now in a wheelchair, because she was

falling very often. I used to take her out to Jack in the Box for breakfast and she ate a hearty breakfast or I brought her a cheeseburger and onion rings from Burger King, but now she was on a pureed diet. Some of this decline was undoubtedly due to the fact that she had COVID-19, a mild case, but it still had its effects. Family was kept out to keep COVID-19 out of the nursing home but during the time we were banned, 35 employees of the nursing home and 77 residents tested positive for the virus. So, all of this isolation, separation, and heartache obviously had not accomplished its objective.

It is my hope that with repeated visits, getting my wife up out of her wheelchair to walk a little, and feeding her snacks, she will regain some of what she lost, but we lost six months' worth of interaction and emotional connection so the outcome is uncertain.

There are bright spots, though. When she saw me today Martha said: "There's my husband!" I was afraid she would forget me, so I am grateful that she still remembers me.

Warren Mass



Rena McConnell

94 Years Old

The loss of her Sunday family get-togethers has left her feeling bewildered, unloved, abandoned.

At 94 years old, my mother-in-law, Rena McConnell, was sharp, active, and social prior to the pandemic. But she does not understand seven months of no family or facility interaction with other residents. And, the loss of her Sunday family get-togethers has left her feeling bewildered and frequently unloved and abandoned.



My husband and I are everything to her: children, friends, family, parents, caregivers, providers, launderers, and links to her outside world. We are it. The withdrawal of those lifelines has resulted in confusion, weight loss, and cognitive decline.

As her adult children, we recognize that her years are limited and she doesn't have time to squander so prior to the pandemic, we saw her regularly throughout the week, took her on weekend outings, and brought her home every weekend to see her grand-children and great grand-children.

Big lunch or small, large group or few, Rena always knew that she was important and a valued part of the family. She knew she was loved, honored, and revered. The loss of that weekly time together has not only harmed her health, but it also leaves her son and me feeling guilty, helpless, useless, and overwhelmed by our inability to control the time lost day after day, week after week, month after month.

Rena has always been such a social person at the nursing facility, wandering every hallway and making sure she knows everyone else's business. Keeping her in one room is like trying to keep a happy puppy in one place. Not being able to go and do as she pleases makes her feel chained up and is a near impossible task for the facility staff.

And, we've seen the change. The woman so tough that she kicked COVID-19 at age 94 is sad, mopey, less communicative, and she seems lost. Her short term memory has suffered so much that at every essential caregiver visit, we must explain again where we have been and why we didn't come see her for so long. She remembers that we have been missing but it is difficult for her to remember that we have returned for one hour visits once a week. It's just not enough to restore what she lost over seven months. And, that's seven months her family will never get back either.

Becky McConnell

Florence McDaniel

80 Years Old

She lost the physical and mental progress she had made since I entered her life over four years ago.



Florence McDaniel has no family in Texas. She never had children. Her extended family is 1,500 miles away. Her one and only caregiver is me.

She has lost the physical and mental progress she has made since I entered her life over four years ago. No birthdays, weddings, funerals, church, or friends. Without a reason to get up and dressed each day, Florence no longer can.

Florence asks for me daily and even though I have visited from outside closed windows, I am unable to steady her on her feet, put my hands on that pair of tweezers she is desperately searching for, reassure her when she begs to go to the beauty salon to get her nails done, or explain why she has been isolated in her room.

With no interaction or stimulation, her short term memory declined the quickest. But her long term memory followed. Absent our memory care work for seven months, she has forgotten her deceased husband's name, a man she was married to for 25 years, and she believes her deceased siblings are alive. She will never regain the cognition she has lost.

Minus our group exercise twice a week and personal physical therapy that focused on walking, balance, and standing, she teeter-totters when she tries to walk or stand and sits in a free-fall.

Every day, I feel like she has died a little and I am consumed with thoughts of her floundering in her room all alone, not knowing how to ask for help, and forgetting to tell someone that she has a need.

Despite limited visitation now, Florence's life will never be the same. My life will never be the same. But we can make sure this never happens again in long-term care facilities in the State of Texas.

Karen Kammer

Daylene McEathron

81 Years Old

She said she knew she was losing her mind and was terrified of being alone. It was heartbreaking.

My mom was a lively, joyful person who loved her friends and family until the isolation protocol was put in place as a result of the pandemic.

Daylene McEathron's friends came several days a week to take her out for lunch, for a drive, to the theater or to visit their house for a game or craft and she would help a friend deliver Meals on Wheels for her church. As her only daughter living in town, I also visited three or four days weekly for walks, shopping, treats, or meals at home.

When visitation in long-term care stopped, so did the outings. She ate meals alone in her room, there were zero activities in the facility and she sat by herself all day every day. She began spending the day in bed and her cognitive health plummeted.

After several months, her facility began to allow scheduled and monitored window visits. While it was wonderful to see my mother, the change was alarming and significant. She needed help finding me, her own daughter, in the window. One weekend she was able to call me and called repeatedly, sobbing that she needed to see me, and that I needed to come right away. She said that she knew she was losing her mind and she was terrified of being alone. It was heartbreaking. How could I tell my distressed mother that I could not come and see her? My guilt and anxiety was overwhelming.

Mom's behavior became unpredictable and erratic. She would cry when she saw herself in the mirror

and made a friend in the form of a hallucination. She would adjust her bed covers and say she was "making a place" for her daughter to come and visit. Isolation was clearly taking a toll.

When the doctor diagnosed her with "failure to thrive", I was allowed to come in as a compassionate care visitor and saw first hand the impact of isolation. I decided to move her to memory care but there was a cost. I was no longer a compassionate visitor and became an essential caregiver. I was only allowed one hour twice per week during business hours.

I blame the isolation protocol for her rapid cognitive decline. We have lost seven precious months together that we cannot recover. She now lights up when I visit her, but she will never be the

same. As I write this, she sits alone in her room, disheveled, with her nightgown over her street clothes and mutters, "I don't feel good." No, I am sure she doesn't, and neither do I.

Laurie Evans



Elizabeth Middleton

87 Years Old

We visited our deaf and partially blind mother at an outside window in their glassed-in sun porch.

Like many families in Texas and across America, we had to make the excruciating decision to place our mother in an assisted living home. She was falling a lot and our father was unable to get her up without calling the fire department. He was able to care for himself but caring for her, especially during an illness, was more than he could handle. She is profoundly deaf and blind in her right eye.



Over the next five months, our family visited her three to five times a week. We did her laundry, tidied her room, stocked her with necessities, sat with her and talked using a dry erase board and an app on our phones called Live Caption. We ate

with her in her dining room and took her to doctor appointments and family celebrations. Some visits went great but others were fraught with complaints. She missed home, was unhappy, and couldn't make friends. But we knew she was safe there.

On March 13th, they locked the facility down. Suddenly, all of the things we did for her stopped. We understood the necessity and we prayed it would only be a few weeks. We visited our deaf

and partially blind mother at an outside window in their glassed-in sun porch, wrote messages to Mom on our phones and held them up to the glass for her to read but by June, we were weary of seeing staff members go in and out and knowing they'd go to Walmart and home to their families that circulated in the community. We saw untested technicians and healthcare people enter the facilities but we, who were willing to mask and test, were not considered "essential" to the mental and physical health, safety, happiness, or welfare of our mother.

We had trouble sleeping, cried, prayed, and wrote emails and letters. But when I found Caregivers for Compromise and Texas Caregivers for Compromise, we became advocates. We now had the contact information and things we could do to let our political leaders and state agencies hear about our loved ones' needs and how their rights were being stripped from them in the name of "safety." There were many nights I simply could not allow myself to read the posts made by the group members who lost their loved ones or had not been allowed to be with them at the end of their lives. There were no words that any of us could say that could take away their pain.

We're cautiously optimistic about visitation expansion and I pray my mother recovers from seven months of isolation.

Betsy Chambers

Margaret Nelson

78 Years Old

She has lost health, time, speech. She should not have had to lose her memory of her family, too.

When my dad visited my mother for the first time since March 15, it took our mother almost 45 minutes to realize who he was. Her decline is dramatic and noticeable. She mostly sits in silence now and hardly speaks. Our mother has lost so much: health, time, speech. She should not have had to lose her memory of her family, too.

Dementia and cancer are devastating illnesses for a family. Our family had to adjust to the loss of the mother we knew.

We discovered something was wrong when our parents were on vacation and suddenly our mother became confused and combative.

For the next two years, we struggled to confirm a diagnosis and get the proper treatment for Mom while our father continued to care for her at home. Toward the end of the two years, Mom was not able to walk. Not knowing she couldn't walk, she fell almost every day. It was a heart wrenching decision to move Mom to long-term care but it was the best care and safest option for her.

Since Mom was admitted to the nursing facility, she and Dad have been together almost every day until the lock-down. Dad would arrive in time for breakfast to make sure mom eats, visit with her, and help her eat her lunch.

Mom is easily distracted by her surroundings and having our Dad with her at meals is extremely important. Dad made a point to spend the morning talking with mom and keeping her engaged to help minimize her cognitive decline. Most weekends, my dad, my sister, and I would visit Mom and check on her health and living conditions.

All of that was taken away for seven months and only restored in a small increment.

Amanda Haynes

Maxine Onstead

91 Years Old

Then the phone calls started. She would have the staff call me so she could beg me to come get her.



My mother was separated from me for almost seven months while living in her nursing home. At age 91, seven months is a precious portion of her remaining life.

She was one of the lucky ones who did not suffer devastating physical decline. She is mobile and walks multiple times a day. But when residents were confined to their rooms, she was deprived of her physical exercise.

My mother suffers from dementia and never understood why I wasn't coming to see her. Outdoor six foot separated visits were not an option due to her hearing problems, especially with us

both wearing masks. She would also not be able to understand why she could not hug or touch her own daughter. This is particularly difficult for dementia patients. Closed window visits were equally illogical with her dementia and hearing problems. We used virtual visits but only when staff had time to accommodate us.

Our biggest issue with the lock-down was mom's depression. She became increasingly anxious and agitated as the months went on. Then the phone calls started. She had the staff call me so she could beg me to come get her.

The stress and anxiety on family members unable to calm or assist their loved ones is tangible. Add to that the guilt and frustration about being unable to remove her from the facility and bring her home and the past seven months were a time of mental health damage for people both inside and outside of facilities.

Thankfully, we are now able to visit my mother in her room an hour each day as essential caregivers. I'm thankful she was well taken care of. But I would ask every legislator to do whatever it takes to make sure this kind of separation never occurs again.

Janith Miller

Mary Ortega

81 Years Old

She cannot make eye contact and could not hear me through a closed window. Those were pointless.

My mother has been in the nursing home going on two years in January. Before the pandemic lockdown, I had always been involved with the caretaking of my mother. I would spend a lot of time at the nursing home, sometimes morning to evening.

She has dementia and can no longer speak, feed herself, or even walk so I would help feed and dress her, keep her fingernails trimmed, and perform other hygiene and caregiving tasks that dementia patients are often reluctant to allow aides to do.

Still, I know she knows me and knows when I am there and when I am not. I am her daughter. She hears my voice.

The lockdown was extremely hard for both of us. Even though I did window visits, she could not comprehend any of it. She cannot make eye contact and could not hear me through a closed window so the visits were pointless and heartbreaking.

Being left alone, separated from family, isolated from human contact, and not having any kind of stimulation is never the answer and I'm sure it exacerbated her condition. Dementia patients need family, hugs, and to know they are not alone.

I felt helpless until a friend told me about Texas Caregivers for Compromise. When I started reading other people's stories, it made a huge difference in my life and my perspective. I no longer felt

helpless. I took control and started making phone calls, writing letters, and telling our legislators and the people with the power to make change to do it and that isolation kills, too.

I thank God each and every day for leading me to every person who has been involved in getting visitation allowed in long-term care facilities.

Praise God! I am now allowed, with restrictions, to visit, see, and touch my own mother and once again be involved in her caregiving.

I am an essential caregiver. Isolation kills and we cannot allow this to ever happen again.

Cecilia Hoover



Iris Parnell

Died October 16, 2020

94 Years Old

During one window visit, she said she felt like an old piece of junk because nobody was going in to see her.

Had I not fought with every breath in my body for months to get essential family caregivers admitted into long-term care facilities, I know I would have never seen my mother alive again. I did my first media interview on May 12 and as a founding member of Texas Caregivers for Compromise, we developed a proposal that we put in front of the governor, HHSC, CMS, our legislators, the media and anyone who would read it. Once essential caregivers became part of expansion visitation guidelines on September 24, my mother's facility was reluctant to put the policy in place. So, even though I helped change long-term care in Texas, I was only allowed to see my own mother three times before she died.



Mom was already experiencing dementia and confined to a wheelchair when facilities closed but she was alert, reasonably healthy for her age, and looked forward to seeing me.

When she could only see me through a window, she became agitated, confused, and blamed me for not wanting

to come in and visit her. During one window visit, I was trying to reassure her that I would be inside to see her soon. She replied that no one is coming to see her, that she was just an old piece of junk. As the weeks turned into months, her frustration became fits of rage and then despondency and eventually quiet resignation and refusal to eat or drink.

Mom was evacuated to another facility during Hurricane Laura and needed the familiarity and comfort of her daughter. Instead, she was removed from everything she knew and put in a wholly unfamiliar environment with new nurses and aides, exacerbating her already fragile mental and physical state.

My own mental and physical health has suffered as I have lived with the anxiety of knowing my mother was incapable of alerting anyone to her needs or reporting any abuse or neglect and with the guilt of being unable to give her the 24/7 skilled nursing at home that she receives in a facility.

My mother deserved to spend her months and weeks in the company of her daughter and I am convinced that her death was hastened by her own hopelessness. I was her everything: her friend, her daughter, her provider, her protector. She was hardly even aware of my presence the day she died.

Mary Barnette

Dorothy Phillips

Died October 15, 2020

86 Years Old

Someone needs to fight for change in the laws. My mother deserved better. Every resident does.

By the time I got my mother to the emergency room, she had stopped eating and drinking. The damage was already done and her little body could not hang on much longer. She tried. She ate for me in the hospital. But it was too late. I was told she needed hospice.

Had I been allowed in the facility, I would have found the bed sores that had broken down and become infected. No wonder she couldn't move and didn't want to get out of bed for the last two weeks.

And now I live with regret that I placed my Mom in long-term care and the knowledge that she was in the wrong facility. If only I had it to do over again I would keep my Mom home with me but like most people who put their loved ones in long-term care, I did it because it was the safest option for her at the time and I believed she would receive far better care than I could provide at home.

Like other long-term care residents, my mother was in lock-down since March. Without family members, hospice aides, friends, clergy, powers of attorney and court appointed guardians, there are no extra eyes to prevent potential abuse and neglect. They are at the mercy of the staff.

The isolation protocol is not protecting long-term care residents. The staff still circulate in the community, have spouses that circulate in the community and have children that go to school and



circulate in the community. All the protocol did was decrease the number of people in facilities and the State of Texas chose family members as the least important.

My mother's fight is over but if I can help one person on their journey through dementia or Alzheimer's living in long-term care, I'm going to try. Someone needs to fight for change in the laws. My mother deserved better. Every resident in long-term care deserves better.

LeeAnn Phillips

Amber Reynolds

29 Years Old

Removing the guardian that protects her health and safety puts Amber's very life in danger.



Amber is 29 and suffering from a traumatic brain injury. She can only speak a few words like Mom, bubba, sissy, go, and Hi. She depends on the staff for all of her daily living skills and cannot read, write, explain her pain, notify anyone of her needs, or express her frustrations.

Isolation has resulted in an increase in her moderate psychosis, sleep deprivation, anxiety and stress. Any agitation or adjustment in her environment can bring on a severe or acute psychosis. Isolation is

extremely dangerous for Amber but the State of Texas decided that she is safer without the guardian that carefully monitors her behavior and responses to her medications, medications that have twice resulted in toxicity.

As her parent and guardian, I am the one that predicts behavior outbursts and calms her agitation. I discovered the MRSA and staph and other life threatening incidents that escaped the notice of staff members who care for hundreds of other residents at the state supported living facility where Amber lives.

Amber has no choice but to live with 24/7 supervision to survive. That's not my choice or hers. Living at home is not a safe option for her. Nor would she get the kind of medical supervision she requires to live with her brain injury. But removing the guardian that protects her health and safety put Amber's very life in danger. That's what the State of Texas did to Amber the day they decided I was no longer essential.

Angela Reynolds-Biggs

Patricia Rhea

90 Years Old

Had I been allowed to monitor her care, there would have been no hallucinations or paranoia.

When I was no longer allowed to visit my mother, she developed a mysterious laryngitis, which made it impossible to communicate over the phone. She began hallucinating, became defiant, and suffered from paranoia. She was also grieving the death of her roommate with no family to console her. The best we could do was leave messages with facility staff and hope they conveyed them to her.

Mom was not eating and her cognition was rapidly declining. When the doctor examined Mom, I asked when he thought he might come again. He told me, "Look, I'm 70 years old. My daughter is a physician too, and she doesn't want me out here seeing patients. I don't know if I'll be back!"

Packages sent via USPS were monitored, opened and restricted to two packages a month with the threat that if we went over the limit of two, she wouldn't be allowed packages at all.

In my mother's delusional state, she grew afraid of her new roommate, and her behavior became combative and unpredictable. She was even once found half naked in the hallway and refused to go in her own room so the facility moved her to another room against our wishes. Eventually, they realized that my mother wasn't being given her medication for dementia. Once we got her back on her medication, hallucinations and paranoia came to an abrupt stop. Had I been allowed in the facility to monitor her medications and care, she would not

have had to suffer through the hallucinations and paranoia.

We are heartbroken that Mom had to suffer unnecessarily and give up her beloved room and everything familiar to her.

Routine is critical to her mental health. Now, in her little world everything has changed:

neighbors, shower days, nurses, aides, hallway, room, meal time, and her roommate. But in spite of the weeks of isolation, her mental health is improving now that she is allowed essential family caregivers.

My mother and her fellow residents were stripped of their rights and keeping her from her family almost destroyed her mental health. Almost. How many long-term care residents were not lucky enough for an "almost"?

Connie Buenger



Anne Robinson

88 Years Old

I tried a window visit but Mom burst into tears and shut the blinds on me when I couldn't come in.

Prior to the pandemic, if you had spent time with Anne you would have had no idea Mom has breast cancer or Alzheimer's. Cheerful, smiling, quick to hide her physical deficits and a joy to spend time with, Anne was so chatty that it was hard to leave her as she would insist you "sit awhile".

Anne decided to move after 12 years from our home to an independent living facility. But, as her Alzheimers progressed, we chose to move her closer to us into an assisted living facility where we could visit three times weekly to monitor her care, memory, moods, living conditions, and basic hygiene needs. Then came the lock-down and we were completely cut off from and cut out of her life.

In the last seven months, Mom has become a shell of her former self as the isolation has exacerbated her Alzheimer's and accelerated her cognitive decline. There have been no social activities or entertainment and she is not allowed outside. She takes her meals in her room. She has no stimulation or reason to want to communicate.

I tried a window visit but Mom burst into tears and shut the blinds on me when I couldn't come in. We tried Zoom but Mom couldn't hear me or understand the virtual technology.. I resorted to writing letters. When we were allowed outdoor, 6 foot separated, masked and supervised visits, I was delighted to see mom, but she was hot and couldn't hear or recognize me through the mask.



Mom's doctor recently diagnosed her with "failure to thrive" and I was allowed to see her living conditions. She now slumps over, is unable to support her own weight, and relies heavily on a walker to move. Her functional and cognitive impairment is shocking. When she complained that her feet hurt, I found that her toenails had not been cared for and were painfully long.

Mom has no memory of her life, is withdrawn, sad, angry, and absent the joy of her pre-pandemic self. She has packed all her belongings and is waiting for someone to "get her out". I cannot imagine her emotional turmoil and suffering and I'm not sure I will ever recover from the guilt of the abandonment and imprisonment she feels.

Cindy Travers

Bob Shirk

74 Years Old

He begged me to raise bond money because he thought someone had locked him up in a jail.

February 2, 2020 was a warm spring day and my daughter's wedding day. She planned it in only 18 days so the ceremony could be held at her father's nursing facility since we all feared that he would not be on earth much longer and it was vital that he be at his daughter's wedding. I was extremely sick, probably with COVID-19. A week later, my husband did not even know who I was.



On March 13, 2020, I got up at my usual 4 a.m. and rode the bus two hours to the nursing home. After visiting for about two hours and assisting with morning group activities, I called the bus to take me home. At 4 p.m., the nursing home administrator called to say that Governor Abbott had locked down the nursing homes. After begging her, she got permission from her supervisor to lock me in instead of out. But seven days later, I came home lest we lose our apartment.

Two weeks later, Bob had three heart attacks in 24 hours. The next three weeks were a living

nightmare. Ten friends and residents died from COVID-19. Simultaneously, every medical procedure that they tried on my husband failed. We were locked out of the hospital and no family could be at his side.

When he was released, we were afraid to send Bob back to the home where so many had already died. As luck would have it, my taxi and his ambulance arrived at the new facility at the same time. I got 30 seconds to tell my husband how much he meant to me as they unloaded him and wheeled him inside.

My husband started calling me every morning. I remember one incredibly painful phone call when he begged me to raise bond money because he thought someone had locked him up in a jail.

The new visitation guidelines require hoops to become an essential caregiver and these are a hardship in Brownwood where the only place to get a COVID-19 test costs \$150. Since the nursing home schedule does not accommodate a bus, I was required to buy a car even though I had not driven in five years because of my eyesight.

Perhaps the hardest struggle of the whole thing was finding a way to tell my daughter, who was married at the nursing home, that she may never be able to hug her Dad again.

Ruth Shirk

Aida Smith

100 Years Old

The facility offered to let us watch her 100th birthday party through a closed window. We could not risk it.

Mom celebrated her 100th birthday without any family members present. We were allowed to deliver a cake and flowers and while the facility offered to let us watch her birthday party from a window, we could not risk putting our mother through the trauma of seeing us standing outside.

When I made the difficult decision to move my mother from her independent living community to assisted living with memory care, the facility told me that the lock-down was going to be lifted the following week and outdoor visits would be allowed. That didn't happen.

I tried a window visit, but Mom didn't understand why she could not come outside or I could not come in. She grew agitated and tearful when I left the window and I was tormented by doubts about whether assisted living had been the right decision.

We later tried an outdoor plexiglass visit. Mom couldn't hear us and lip reading was no longer an option since my sister and I were wearing masks. It was too hot outside, noisy, and once again, Mom was agitated and tearful. Virtual visits were helpful if someone remembered to give Mom her hearing aids, but they do not replace the hugs and the human touch she craved.

Mom's cognitive impairment has rapidly declined and she has forgotten things she has done for decades like put in her hearing aids. Her attention to self care has diminished and she is struggling to

remember family members' names. She says it feels like being in a prison when she is not allowed to feel the sunshine on her face.

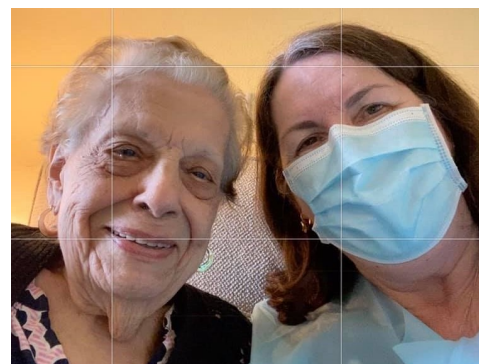
I feel helpless. I am allowed to see my 100 year old mother for one hour each week if there is an opening in the facility's schedule. How many weeks does she have left?

There is something fundamentally wrong with someone telling me that I can't see or help my own mother. I am willing to abide by the same infection prevention protocols required of the facility's staff. However, I feel that the facilities have been given too much flexibility to set unrealistic infection control and visitation policies.

I pray for the day that I can truly care for my mother again. More importantly, I need to remind her that I love her.

An entire segment of the population in Texas is being traumatized and it must stop.

Earlene Caldwell



Janet Smith

84 Years Old

She stopped eating and suffered from increased anxiety and depression. When porch visits were finally allowed, I saw first-hand the devastating toll isolation had taken on her health.

My last day inside my mother's memory care home was March 17th, 2020. I or her sister was always there to put her to bed seven days a week. We were committed caregivers, not visitors. Even though isolation was meant to "protect her", residents in her facility were exposed by staff members and three of the 118 in her facility died of COVID-19.

From a closed window, I saw my mother's daily decline. She stopped eating and suffered from increased anxiety and depression. When porch visits were finally allowed, I saw first-hand the devastating toll isolation had taken on her health and was able to get a "failure to thrive" diagnosis under the Phase 1 guidelines so I could help in her room. She has lost 22lbs since May, and even with appetite stimulant medication she is better no better.

My mother is fragile and prone to both stress and panic attacks. She falls easily but walks constantly because she says that is better than sitting all day. Her mind has declined and her body is struggling to keep up. She required a trip to the cardiologist when I realized her pacemaker battery was failing. The stress of being out and active caused her so much distress that it was like watching someone with PTSD experiencing a flashback.

There must be a better plan put in place for the mental health and physical safety of our loved ones and this can never be allowed to happen again. A portion of my mother's life has been taken from both her and me.

Cathy Randles

Paula Spangler

80 Years Old

My mom has one method of communication, touch, and I was forbidden from touching my mother.

With my usual hug, kiss, and wave as I walked out of her home, I told my mom I would see her later. Later would not come until October 5, 2020 when I became her essential caregiver.

My mom has advanced Alzheimer's and can no longer walk, talk or feed herself. She has more years behind her than before and lost seven months of time with me. For someone with Alzheimer's those precious moments are gone.

On March 13, 2020, the State of Texas declared that the risk of COVID-19 was so great to elderly persons in congregate living facilities, that persons living in those facilities were effectively imprisoned with no rights, and forbidden the protections once provided by family members, physicians, and ombudsmen. This was the date that triggered fear, anxiety, and sleepless nights in my life for months to come. This was the date that I was told that I could no longer see my Mom until she was actively dying.

Until then, I had accompanied my mom to every physician, dentist, hospital, or emergency room visit. I kept vigil following seizures and changes in her behavior, assisted her at mealtime, brushed her teeth, combed her hair, updated her wardrobe, did all her daily tasks, brought her surprises for her sweet tooth, decorated her room for the holidays, and knew when something was not quite right with her. But despite all this and having her medical

power of attorney, the State of Texas classified me as a "non-essential visitor".

I feared that my mom's final moments in life were going to be alone and as days turned into months, I sat outside her window, watching her try to make sense of my absence. She soon learned to raise her hand to mine, only to be startled by the glass between us. I watched hopelessly through the lens of a camera placed in her room – frightened that she thought family had abandoned her. My mother has one method of communication – touch – and I was forbidden from touching her.

On October 5, 2020, I became an essential caregiver and delivered my first hug to my Mom. On that date, my mom reached out to touch my hand. The State of Texas did not protect my Mom. The State of Texas isolated her from her own family. Human beings with physical and mental challenges deserve more.

Genny Lutzel



Billie Jane Stroud

Died August 10, 2020

91 Years Old

I could choose to see her one last time: alive while she knew me or later when she was about to pass.

My aunt would have liked that I am writing about her. She was a writer, poet, artist and astute business woman. She was 91 years old when she died, not from COVID-19 but because of COVID-19. My mother, her sister, died a year ago. Losing my aunt was like losing my mother twice.

We moved my Aunt from San Antonio to a small assisted living facility in Katy where I would go see her every day. She was happy, liked the people, and would text me to talk or remind me to bring something she wanted or needed.

When the facility said 'no more visitors', they took everything she knew. She was mentally sound and understood that I would be there if I could. I took her to two doctors appointments but getting in and out of the vehicle was so hard on her that she was assigned to hospice so they would take her.

As the days went by, she drew up into a fetal position and lost the will to live. She was almost deaf so virtual visits and phone calls didn't work, even with her hearing aid. Texting worked until her cell phone went missing and I stopped hearing from her. I would call and the staff would say she was fine, just sleeping a lot.

A month later, she died.

I was offered a choice of seeing her one last time while she still knew me or later when she was about to pass. I chose the former.

I will always bear the guilt of wondering what could I have done to prevent her rapid decline and death. I have frequent high blood pressure and sleepless nights. When I wake, my first thoughts are of her.

Cynthia Berry



Residents' Rights

Nursing Facilities

Residents of Texas nursing facilities have all the rights, benefits, responsibilities, and privileges granted by the Constitution and laws of this state and the United States. They have the right to be free of interference, coercion, discrimination, and reprisal in exercising these rights as citizens of the United States.

Dignity and respect

You have the right to:

- Live in safe, decent and clean conditions.
- Be free from abuse, neglect and exploitation.
- Be treated with dignity, courtesy, consideration and respect.
- Be free from discrimination based on age, race, religion, sex, nationality, disability, marital status or source of payment.
- Practice your own religious beliefs.
- Keep and use personal property, and have it secure from theft or loss.
- Choose and wear your own clothes.
- Be free from any physical or chemical restraints used for discipline or convenience and not required to treat your medical symptoms.
- Receive visitors.

Freedom of choice

You have the right to:

- Make your own choices regarding personal affairs, care, benefits and services.
- Choose your own doctor at your own expense or through a health care plan.
- Manage your own financial affairs in the least restrictive method or to delegate that responsibility to another person.

- Access money and property you have deposited with the facility and to have an accounting of your money and property that are deposited with the facility and of all financial transactions made with or on your behalf.
- Participate in activities inside and outside the facility.
- Place in your room an electronic monitoring device that is owned and operated by you or provided by your guardian or legal representative.
- Refuse to perform services for the person or facility providing services.
- Use advance directives as defined in the Texas Health and Safety Code, §166.002.
- Designate a guardian or representative to ensure quality stewardship of your affairs, if protective measures are required.

Privacy and confidentiality

You have the right to:

- Privacy, including privacy during visits, phone calls and while attending to personal needs.
- Have facility information about you maintained as confidential.
- Send and receive unopened mail and to receive help in reading or writing correspondence.



TEXAS
Health and Human
Services

Participation in your care

You have the right to:

- Receive all care necessary to have the highest possible level of health.
- Participate in developing a plan of care, to refuse treatment, and to refuse to participate in experimental research.
- Refuse treatment, care, or services.
- Receive information about prescribed psychoactive medication from the person who prescribes the medication or that person's designee.
- Have any psychoactive medications prescribed and administered in a responsible manner as mandated by the Texas Health and Safety Code, §242.505, and to refuse to consent to the prescription of psychoactive medications.
- Access personal and clinical records, which will be maintained as confidential and may not be released without your consent.
- Communicate in your native language to acquire or to receive treatment, care or services.

Transfers and discharges

You have the right to:

- Not be relocated within the facility, except in accordance with nursing facility regulations.
- Discharge yourself from the facility unless you have been determined mentally incompetent.
- Not be discharged from the facility, except in accordance with nursing facility regulations.
- Receive a 30-day written notice sent to you, your legally authorized representative or a family member.
- Appeal the discharge within 10 days of receiving notice in a Medicaid facility.
- Be readmitted to the facility as provided by nursing facility regulations.

Information

You have the right to:

- Receive a written statement or admission agreement describing the services provided by the facility and the related charges.
- Be informed of Medicare or Medicaid benefits.
- Receive a copy of the Statement of Resident Rights and to be informed of revisions.
- Be informed in a language you understand about your total medical condition, recommended treatment and expected results (including reasonably expected effects, side effects and associated risks), and be notified whenever there is a significant change in your condition.

Complaints

You have the right to:

- Complain about care or treatment and receive a prompt response to resolve the complaint without fear of reprisal or discrimination.
- Organize or participate in any group that presents residents' concerns to the administrator of the facility.

Your rights may be restricted only to the extent necessary to protect you or others, or to protect the rights of others, particularly those rights relating to privacy and confidentiality.

There are other rights or remedies a person may be entitled to, according to rules and under the law.

To learn more or to file a complaint, contact:

Complaint and Incident Intake

800-458-9858

hhs.texas.gov/incident-complaint

Office of the State Long-Term Care Ombudsman

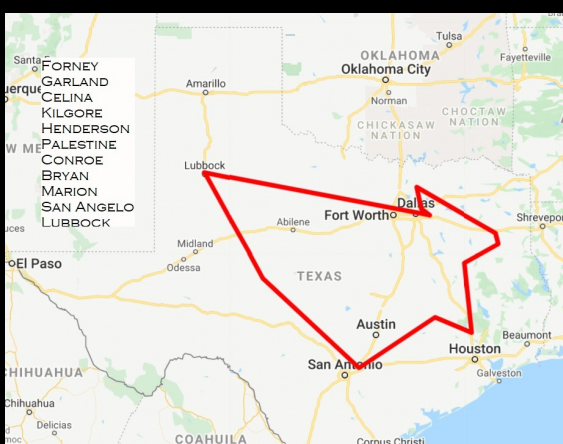
800-252-2412

apps.hhs.texas.gov/news_info/ombudsman



Caregivers advocacy group spreads message to ETX with yard signs

Texas Caregivers for Compromise started in July and has grown to include 2,600 Texans across the state.



DEDICATION

To these and all loved ones who died while living in long-term care facilities or as a result of the isolation protocol of 2020. May we remember the lives they lived and the lives they lost.

Alcala, Herlinda	September 25	Morgan, Doris "Catie"	August 26
Bannerman, Jim	July 25	Morton, Louis	July 29
Bernethy, Laverne	July 30	Newsom, Laverne	September 7
Billeck, Edward	September 13	Orr, Raybourn	October 23
Boddeker, Gammon	May 26	Parker, Rodney	August 6
Bond, Ola Mae	April 27	Parnell, Iris	October 16
Bonham, Charles	June 22	Parsley, Marilyn	July 18
Bruton, Martha	October 2	Patterson, Jimmy Ray	August 3
Carroll, Maxine	September 11	Pearce, James	November 2
Collins, Alma	April 3	Phillips, Dorothy	October 15
Cooper, Lorene N.	August 10	Polk, Billie	August 16
Cox, Donna	August 17	Popejoy, Glynadee Lewis	August 29
Cummings, Virginia	September 25	Rawls, Jeanne	April 16
Duvall, Anna	September 5	Reaves, Hazel Ellen Dill	August 19
England, Bob	July 20	Renneberg, Roland	July 22
Farrar, Alan	July 10	Robason, Betty	August 22
Fincher, Edith	May 7	Roth, Dilys	August 25
Fisher, Norma	August 27	Sellers, Ruth	October 4
Fyffe, Dolly Jean	July 11	Shaw, Betty Margaret	July 15
Gilbert, Linda	July 27	Sheldon, Madeline	September 24
Glock, Evelyn	August 14	Shitoskey, Audrey	March 22
Griffith, Pat	July 17	Sibley, J.B.	July 13
Guy, Nellie	August 16	Simpson, Betty	May 30
Harris, Sig	September 22	Smith, Mary O.	August 27
Hawkins, William "Willy"	September 25	Smith, Emory	July 15
Hawkins, Judy	July 12	Smith, Edna F.	July 2
Haynes, Nancy	October 19	Snider, Margie	May 27
Hemmen, Hattie	October 10	Stalbaum, Werner	June 29
Holloway, Mary Eris	June 8	Stephens, Charles	September 18
Hyndman, James	August 17	Stone, James III	October 10
Jasek, Melvin	July 9	Stone, Darryl	August 29
Johnson, Vivian	October 3	Stowe, Phyllis	September 16
Jones, Charles	August, 2020	Stroud, Billie Jane	August 10
Kelly, Marilyn	September 13	Tate, Larry D.	October 17
Koonce, Wanda	October 19	Thomas, Pete	July 22
Kramer, Robert Allan	July 7	Tolbert, Irene	September 2
Lagrone, Edith	May 22	Vickery, Mary Lou	August 13
Leija, Angelina	September 11	Villapondo, Estella	May 29
Lockett, Nelva	June 22	Watkins, Patty	June 28
Lyons, Anna M.	May 23	Weisblatt, Florence	May 16
Matthews, Louis Sr	August 4	Whaley, Paul	June 18
Matus, Mary Elizabeth	April 23	While, Marilyn	September 13
Mauldin, Joseph	August 12	Williamson, Mary Sue	August 25
McCuiston, James Walter	April 22	Wizoreck, Tom	April 16
McDonald, Glennys	September 8	Worden, Ronald	June 25
McDowell, Sue	August 26	Worth, Mary A.	September 27
Miller, Chloe	June 12	Yancy, John Wayne	July 23
Moree, JR	July 11	Yoakum, Alyne	June 9

Larry D. Tate

Died October 17, 2020

All he wanted was to go out for a good meal
and feel the sun on his face.



Friend and Advocate
Texas Caregivers for Compromise Member
Long-Term Care Resident