

Statement for the Record

RE: House Select Subcommittee on the Coronavirus Crisis Hearing
September 21st 2022

Melody Taylor Stark
Monrovia, CA

"This testimony is on behalf of my husband, Dr. Bill Stark and others who are, were, and will be in long-term care.

An upbeat, optimistic person Bill was a resident in a nursing home due to Post-Polio Syndrome. I'd come by the nursing home for my daily "good morning" and to hug and kiss my husband. I'd come back after work, and we'd spend the evening together. I was also with him on weekends.

*March 13, 2020, a call came that the facility was under mandated lockdown due to COVID. As days turned into months, **Bill had no contact with me except by phone.***

*I tried **all possible means to have more contact with my husband**, but everything, including video chats and window visits were denied. **The Administrator did not have approval from "corporate" nor LA County Public Health.***

***He became increasingly depressed. On our phone calls he'd say, "this is no way to live" and he would cry.** He had a drastic decline in both physical and mental health. Reports of this to the facility accomplished nothing. They placed blame on LADPH for blocking in person family support. When they were finally allowed in August, 15-minute window visits limited to 1x/month, were not enough to make a difference.*

*Several weeks before his death, **Bill told the LA Daily News: "... coronavirus "is nothing to fool around with" ... But (said) that didn't make briefly seeing his wife once a month, or the social isolation, any easier. "I'm in essence in a cell, a room," ... "I've got TV and the newspapers but that's it. ... I am not happy."***

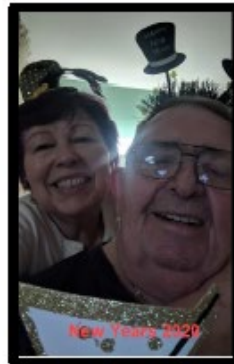
*On October 24, 2020, Bill was diagnosed with pneumonia. **It was discovered by me during a phone call. How could I notice a change in condition over the telephone when the staff didn't?** What type of care was he receiving? He was hospitalized on Nov 3 and readmitted to the nursing home on Nov 11. Calls from the nurses indicated his health was rapidly declining. **Again, my daily requests** for compassionate care visits were denied as they were not approved by "corporate" or the County Health Department. **I submitted multiple complaints to CDPH and LACDPH for compassionate care visits to no avail.***

*It was a dystopian nightmare. No one in the facility admitted that this mattered. It is not clear that they noticed. No one would take responsibility. **I had to stand by, helpless, as my husband declined.***

“As if” they were handing me a gift, on Nov 18, the nursing home allowed me a compassionate care visit for 15 min. Through full PPE (gown, mask, shield, gloves, sanitizer) and 6 feet away, **happy to see me in person Bill smiled and blew kisses.** As I was leaving I saw staff wearing the **same PPE as I** came into his room to provide very up close and personal support. **Yet his wife of 20 years had to stay 6 ft away.** That night, Bill was readmitted to the hospital as “systems were failing”. I got a call at 4am on Nov 22 that Bill had passed....

I did hug my husband one last time - It was when I carried his ashes from the car to the church for his funeral.

Health departments and the nursing home facility failed Bill. I formally request changes to the value of psychosocial support and the role of bio/chosen family in long term care to ensure, moving forward, other residents don't lose their life-sustaining right to meaningful human connection entirely as my husband did."



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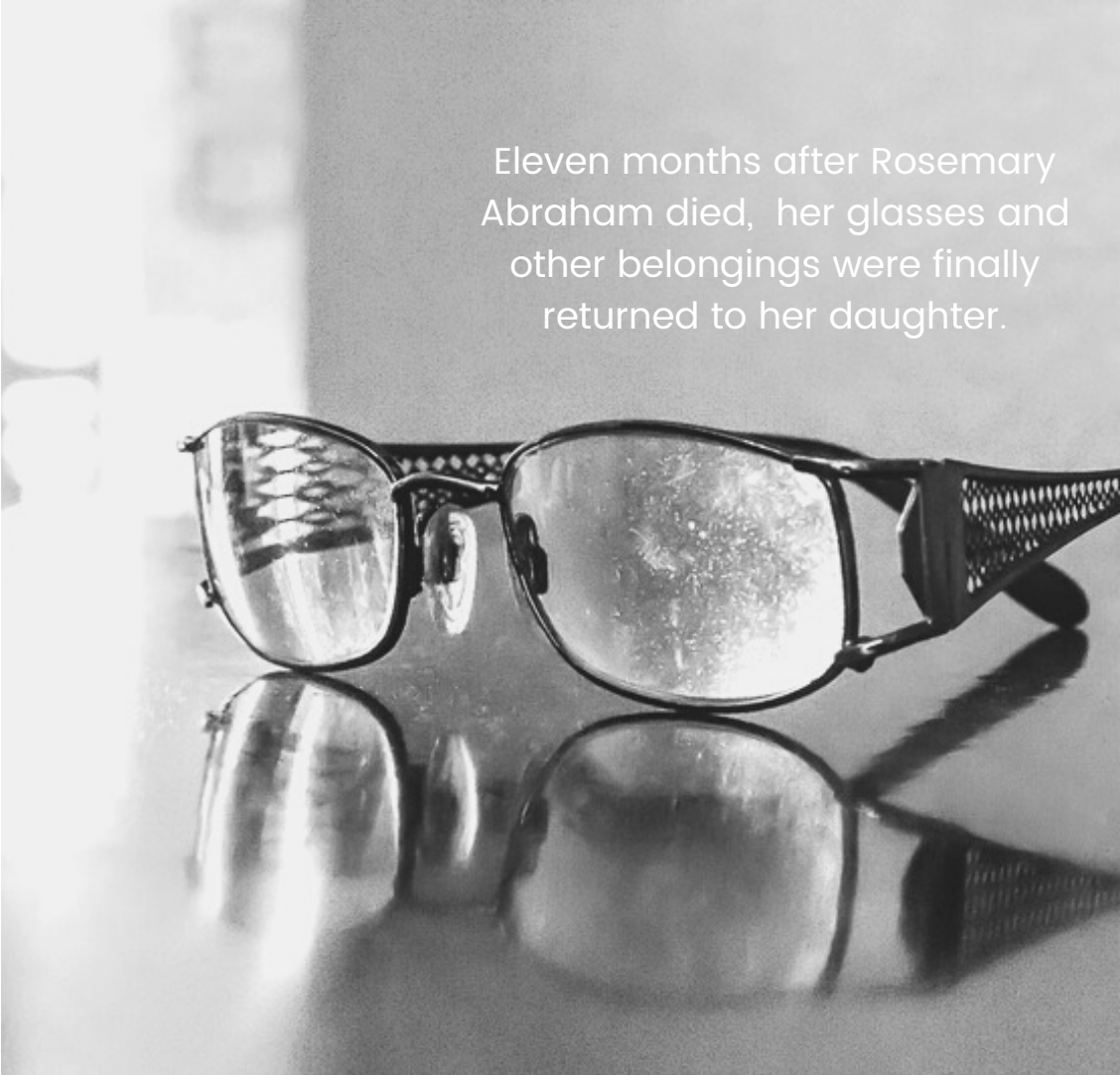
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Protecting Them to Death

THE IMPACT OF ISOLATION
IN LONG-TERM CARE

AN ESSENTIAL CAREGIVER MOVEMENT
ADVOCACY PUBLICATION



Eleven months after Rosemary Abraham died, her glasses and other belongings were finally returned to her daughter.

Protecting Them to Death

THE IMPACT OF ISOLATION IN LONG-TERM CARE

Loved Ones Shown On the Cover

Patricia Smith, Luke Smith, David Graham,
Elizabeth "Betty" Heard, Tom Manter, Masa Nakayama

Protecting Them to Death

THE IMPACT OF ISOLATION IN LONG-TERM CARE

Introduction

While COVID-19 mitigation decisions were made in good faith, in March 2020, families were not among the people considered essential enough to the health and welfare of long-term care residents to be admitted inside facilities. Extreme weight loss, rapid cognitive decline, self-harm, despondency, and preventable deaths were a direct result of isolation protocols put in place to protect long-term care residents.

Minus outside eyes meant to ensure protection from the potential for abuse and neglect and minus the presence of the guardians, resident representatives, friends, and family that serve as caregivers, many residents in long-term care suffered dehydration, infections, poor care, and preventable illness and injury while others lost rights to vote, receive mail, use their own property, choose their own doctor, participate in care decisions, practice their religion, access an ombudsman, or even leave the facility of their own free will.

Testimonies in this book are from family members with loved ones who either lived or died in long-term care facilities under isolation protocols. These stories demonstrate the urgent need for legislation that guarantees each person living in a long-term care facility will have the right to an essential caregiver or an essential support person, even in - and most especially during - a health emergency.

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W H Y E S S E N T I A L C A R E G I V E R L E G I S L A T I O N I S N E C E S S A R Y A T T H E F E D E R A L L E V E L

States have had eighteen months to come up with a solution to visitation restrictions in long-term care facilities and while some states have put essential caregiver policies and legislation in place, many of those laws and policies hand full discretion over to the facilities. By federal law - the 1987 Nursing Home Reform Act - long-term care residents are entitled to 24/7 visitation by a person of their own choosing.

H.R.3733 does not throw the doors of facilities open in the height of a health emergency but it does allow each resident to designate a support person called an "essential caregiver".

The very presence of that family member, guardian, friend, neighbor, clergy, legal counsel, or whomever the resident or the resident's representative chooses accomplishes three very important things we saw happening in facilities.

1. Essential caregivers hold bad actors accountable and keep good actors from back-sliding.
2. Essential caregivers prevent the extreme weight loss, rapid cognitive decline, and despondency that accompanies isolation protocols.
3. Essential caregivers make sure the residents' other rights are upheld.

During the current pandemic, residents lost almost every right guaranteed in the 1987 Nursing Home Reform Act, not just the right to receive visitors which is, of course, one of the them.

Essential caregivers are required to practice infection control and follow policies put in place by facilities including any training regarding the use of source control, proper hygiene, distancing, entrances and exits to be used, and any other safety measures put in place.,

HOW VISITATION RESTRICTIONS ARE BEING UNEQUALLY APPLIED

Unless families are very informed about and can discern the application of all local, state, and federal guidelines they assume the facility is correctly enforcing state or federal rules when they are turned away in violation of CMS or state guidelines, or state laws. Even informed families often hesitate to advocate out of fear of retaliation or the withholding of the visits that they went without for such a long time.

STATE HEALTH DEPT. GUIDELINES

Health Department Guidelines Can Be Enforced by the Public Health Authority

Must Fit under both CMS and any State Guidelines

Many States Simply Defer to and Adopt CMS Guidelines

Easily Waived and/or Amended

STATE LAW

State and Federal Law Can Be Enforced by Public Health Authority

Must fit Under both CMS Guidelines and any Federal Laws Like HR3733 if Adopted

Easily Waived and Can Be Amended Next Session

CMS

Can Be Enforced by Public Health Authority but it Rarely Happens

Subject to Broad Interpretation by Facilities

Facilities Able to Put Own Policies in Place That May Not Comply

Easily Waived and/or Amended

HR3733 FEDERAL LAW

Enforceable

Prevents Waivers

Not Easily Amended

Not Subject to Interpretation by Facilities

Allows Facilities to Put Own Policies in Place That Comply With Law

Encourages States to Put Assisted Living Requirements in Place

**L O N G - T E R M C A R E V I S I T A T I O N
R E S T R I C T I O N S T H R O U G H O U T
T H E C O U N T R Y T O D A Y**

SOME STATES REQUIRE ALL FACILITIES TO FOLLOW CMS GUIDELINES WHETHER THEY RECEIVE FEDERAL FUNDING OR NOT

SOME STATES REQUIRE ONLY FEDERALLY FUNDED FACILITIES TO FOLLOW CMS GUIDELINES WHILE VISITATION IN ASSISTED LIVING FACILITIES IS UNREGULATED

SOME STATES HAVE ADOPTED VISITATION LEGISLATION THAT DOES NOT RECOGNIZE ESSENTIAL CAREGIVERS WITHOUT A CITY, COUNTY, OR STATE DECLARED DISASTER EVEN IN A NATIONAL PANDEMIC

SOME STATES HAVE ADOPTED LEGISLATION THAT RECOGNIZES ESSENTIAL CAREGIVERS BUT IT IS OPTIONAL FOR FACILITIES

AT LEAST ONE STATE HAS A PROPOSITION IN THEIR UPCOMING ELECTION TO MAKE ESSENTIAL CAREGIVERS A CONSTITUTIONAL RIGHT IN LONG-TERM CARE FACILITIES

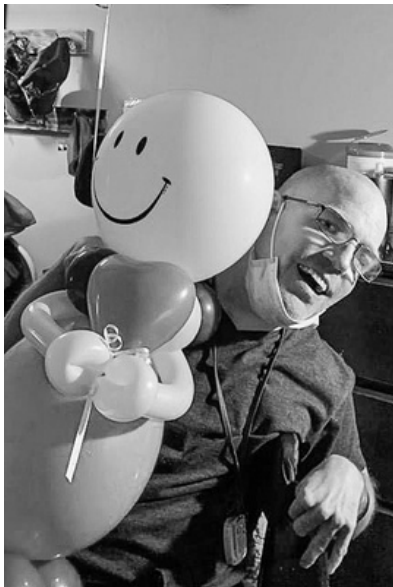
CHILDREN AND YOUNG ADULTS ALSO LIVE IN LONG-TERM CARE FACILITIES

Medically complex children and adults with developmental and intellectual disabilities also live in long-term care facilities. Some long-term care facilities serve only children and youth up to about age 21. Adults with developmental disabilities can live in a variety of long-term care facilities for most of their adult lives, some as long as 50 or 60 years.



Ivana Schnars
(top left)
Amber Reynolds
(top right)
Sammy DeAngelo
(bottom left)
Luke Smith
(bottom middle)
Christy O'Mara
(bottom right)





Jaxen Halfhill

(top left)

Petre Kirby

(top middle)

Jay Cannon

(top right)

Erik Schuetz

(middle left)

Jennifer Foushee

(middle right)

Scott Hazelwood

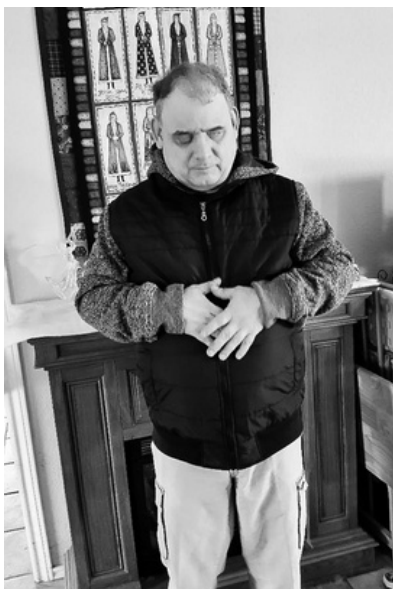
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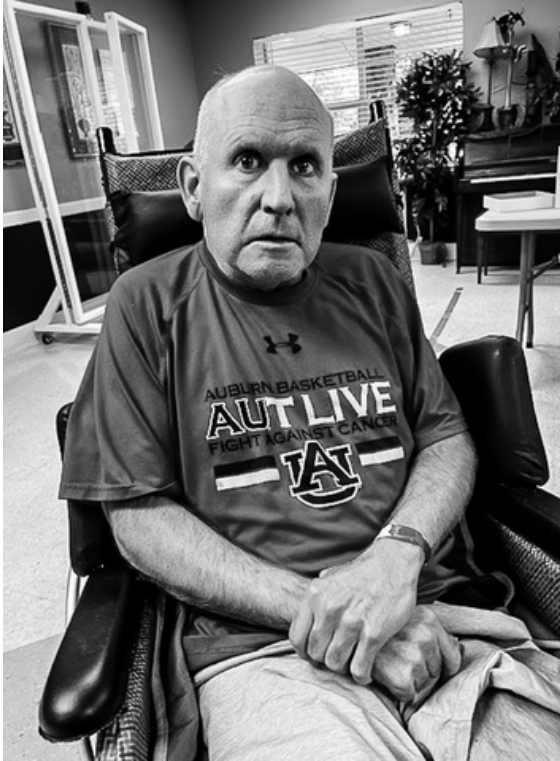
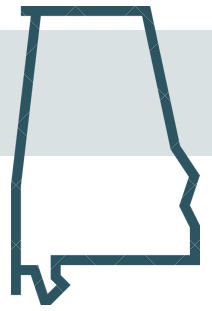
Lynn Ray

(bottom middle)

Jackson Ton

(bottom right)





VIRTUAL VISITS, PHONE CALLS, AND BOOTHS DO NOT WORK

My husband of 39 years, who is in the final stages of Younger Onset Alzheimers, has been in nursing care since 2016. Often confused, lying in bed waiting for his next meal, and unable to walk or talk, he looks forward to seeing me and his daughters. But, that didn't happen for the better part of 2020. Virtual visits, phone calls, and booth visits do not work for a late stage Alzheimer's patient. They understand touch, being read to, and the care of a loved one. I have not been allowed enough time with him to even evaluate whether I can handle his diminished condition at home. I'm at a loss to know what direction to go. I only know that he deserves better. **Bridget Graham**

MY MOTHER WAS MOVED SIX TIMES DURING THE LOCK-DOWN AND LOST THIRTY POUNDS

For the first six months of the lock-down, my mother seemed to accept the isolation without too many negative effects. But when a CNA gave COVID-19 to my mother, she was moved six times and lost thirty pounds. Her room and wing were turned into a COVID ward and while she did survive, it was not without heartache and an accelerated decline of her dementia. Thank God she survived COVID-19, but familiarity is necessary for the peace and comfort of a dementia brain. She was repeatedly moved and not only adjusting to a new environment over and over, but denied her own belongings and those things that provide memories and comfort. Nurses were worn out and going from the COVID-19 ward to other parts of the facility which, I am certain, spread the disease despite the best precautions. When I was finally allowed to see my mother for outdoor visits, she did not understand why we were separated and not allowed to hug. I was shocked at her appearance. My mother's roommate passed away alone and when my mother no longer had a companion, I was allowed a compassionate visit but I had to fight for it! **Denise Godwin**

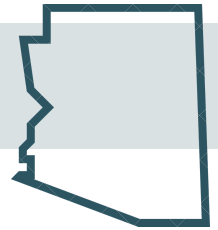


THE MOMENT THEY MOVED HER TO THE SECOND FLOOR WITH NO WINDOW VISITS, SHE GAVE UP

Ohana means family in Hawaiian and that no one is left behind. This word means a lot to us. My mother's skilled nursing facility was an hour away from her home and ours so they became her pseudo Ohana.



She was moved there by the State of Alaska when an employee brought COVID-19 into her extended care facility. She was able to see us through a window once or twice a week because she was on the ground floor at that time. We talked every day on the phone except for those days when she was too weak to answer my call. Last year, on her birthday and when she was in the final skilled nursing facility that the State had moved her to, we cooked her dinner outside her window, we sent it in via a CNA, my boys built her rock towers, and we sang "Happy Birthday" through the window. But the moment they moved my mother to the second floor, I think she gave up hope of getting stronger, of seeing the faces she loved through the window. It was her one connection to us that still seemed real and wasn't through a virtual visit. We lost her January 12, 2021. Denise Brown



HE NO LONGER SPEAKS AS A RESULT OF THE ISOLATION DURING THE PANDEMIC

My husband is in a memory care facility. He no longer speaks as a direct result of the isolation during the pandemic. He uses a walker because while he was confined to his room, he was unable to exercise his legs. All his physical abilities have declined significantly. Change of any kind takes a toll on dementia residents. Knowing that he spent seventeen days in a sterile room in the COVID-19 ward of his facility is heartbreaking. He had very few symptoms but lost twenty pounds. I am praying this never happens again. Linda Thompson



I WAS ACTUALLY RELIEVED WHEN THEY TOLD ME SHE HAD CONTRACTED COVID



Every time I visited my mother, she looked like a zoo animal behind the patio door. She would mouth that she was hungry or motion for what I had brought to drink. The blueberries I left got moldy, the almond milk grew stale, and the canned organic soups gathered dust. Nobody was giving them to her. My Dad gestured at the closed patio window how much he missed her and she avoided eye contact so as not to cry. Some days I was allowed to bring home-cooked meals and other days, I was not allowed to feed her. On the day she transferred to a hospice care facility, I was with her to say goodbye and could see particles in her dentures that had not been cleaned in weeks and blackened food underneath her fingernails from trying to eat with her bare hands.

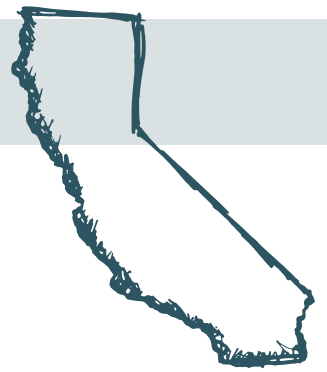
I was actually relieved when they told me she had contracted Covid shortly after being vaccinated. Nobody deserves to spend their last years, months, weeks or even days alone in a facility without their loved ones at their side. Anne Martinez



MY GOAL IS FOR HIM TO HAVE SOME SENSE OF PEACE IN THE DAYS TO COME

My dad is 70 years old and has lived his life on his own terms. My goal is for him to have some sense of peace in the days to come. The concern is finding truly an exceptional nursing home which cares about this demographic of life. Lack of continuity and communication plays a major role in the isolation of residents because basic care and best practices are less important now than COVID-19 mitigation resulting in shifts not communicating with each other. The fear of COVID-19 has put staff safety ahead of resident health, well-being, and safety. *Veronica Myers*





HE CONTRACTED PNEUMONIA THREE TIMES AND THEN COVID-19

My son suffered a massive brain hemorrhage nearly six years ago. He is helpless, bedridden, immobile, cannot speak, is on a trach, and is on a feeding tube. During the ban on visitation, he contracted pneumonia three times and then COVID-19. After all he has been through, don't you think he has served his time? If his visitation rights are not fully restored, he should be entitled to access the family members that try to protect him. [Nancy Klein](#)

THE LAST TIME I HUGGED MY HUSBAND WAS WHEN I CARRIED HIS ASHES FROM THE CAR

On March 13, 2020, as I'd been doing for almost five years, I stopped by the nursing home on the way to work to say "good morning" and hug and kiss my husband. The plan was to pick up a nice take-out dinner that afternoon to take to the nursing home for our usual "Friday Night Dinner Date". But, the nursing home called that day to tell me about the mandated lock-down for non-essential visitors and that only virtual visits were allowed. What we thought would be a couple of weeks turned into months and months. There were no virtual or window visits facilitated and it felt as if everyone except families were wholly unaware of the impact of isolation, depression, lack of psychosocial support. Over time, my husband's mental and physical health drastically declined.



During the ensuing months, my usually optimistic husband sounded increasingly sad and said things like, "this is no way to live" and he would cry. Over time this led to drastic decline that affected his physical health as well as his mental health. By November 22, 2020, his health had declined to the point that he was hospitalized and passed away. He did not die from COVID but from failure to thrive due to isolation in long-term care. The last time I hugged my husband was when I carried his ashes from the car to the church. [Melody Taylor Stark](#)

California



SHE DIED ALONE AS HER FAMILY WATCHED FROM THE PORTAL

My mom still loved her life and everyone around her at the time of the lock-down. But, the three of her five daughters that came regularly were necessary to her quality of life, her well-being, and her physical care. We met her psycho-social needs in ways no other caretaker could. When we were locked out, the normally happy, joyful, and grateful mom became depressed, withdrawn, and solemn. The Alzheimer's accelerated at an alarming rate. Mom was soon put in diapers, rarely walked anymore, and had little to no interaction with other residents as she was confined to her private room. Three days before

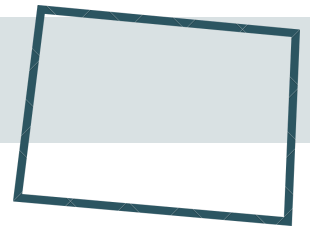
Christmas mom was moved to the COVID-19 ward after she contracted the disease from a staff member. We were not allowed even a window visit. By Christmas Eve, she was non-responsive. On Jan 7th 2021, Mom took her last breath as her family watched and sobbed from the portal. She was completely alone and one week away from receiving the vaccine. *Denise Bogan*

HE WAS DENIED THE HOLY SACREMENTS BY OUR PRIESTS

My husband was a Vietnam combat veteran and a San Diego police officer for 33 years. As a retired San Diego police detective, I was allowed in-person visits with inmates but not my own husband. By December, after only being allowed door visits, closed window visits, his kidneys began to fail and I got four visits per week outdoors for twenty minutes while he was on hospice. During this lockdown, he was denied the sacraments normally given by our Catholic priests, he lost a dangerous amount of weight, his vascular dementia accelerated, and he quickly lost lucidity.

On February 2, 2021, two days after my last visit, I received a call from my husband's hospice nurse to tell me that he passed away. He was denied being surrounded by family members during his final moments in life. *Dee Massey*

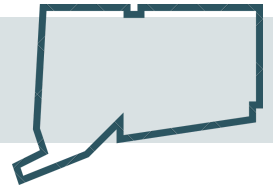




HE WAS MOVED TO A SECURED DEMENTIA UNIT WHERE HE WAS NOT ALLOWED TO GET HIS HEARING AIDS

This past year has been a disaster trying to care for my dad. After a fall in his independent senior living facility required rehab, he moved into a skilled nursing facility. There, his memory faded quickly and dementia took over as he could not see family or friends. He kept trying to leave so he was moved to a secured dementia unit where he was not allowed to get his hearing aids and we were not permitted to take him out for appointments. We moved him, but the forced isolation caused depression and his behavior changed. Instead of spry and alive, he was withdrawn, lethargic and didn't engage anymore. He went from a gentle person who knew and held conversations with his family to a delusional, sad, and despondent man. [Michelle White](#)

Connecticut



SHE MISSED HER GLAUCOMA INJECTIONS AND CAN NO LONGER WATCH THE METS

Since the pandemic, my mother has been left to stare at the ceiling in her room, extremely isolated and lacking any socialization. The decline in my adopted grandmother has been worse. Once able to pedal herself around in her wheelchair, vibrant, and an enthusiastic Mets fan well into her 90s, she is a different person today and I am 100% certain her condition is due to my absence all of these months. She has glaucoma and after missing several doctor's appointments for injections to preserve her eyesight, she can no longer watch her beloved Mets. Her hearing aids disappeared so she cannot even listen to her Mets. Her joy is gone and quality of life has diminished. She is now on palliative care only but this was preventable had I only been allowed to assist in her care. [Amy Badini](#)



SHE DIED AFTER LOSING SIGNIFICANT WEIGHT AND ALL QUALITY OF LIFE



Our mother, a precious friend to many, suffered a stroke in May 2016 that landed her in a skilled nursing facility. Then, four years of daily family support ended on March 10, 2020. She got thirty minute virtual and 20 minute supervised window visits but no human touch. She never understood why she was being punished, why her family abandoned her, or why she spent the last eight months of her life in isolation. She suffered multiple infections and significant weight loss and died on November 3rd having lost all quality of life. [Elizabeth Stern](#)

My mother lost fifteen pounds, developed two infections and three pressure ulcers, was not allowed outside, and went months without nails trimmed or teeth brushed. [Irma Rappaport](#)

On March 9 when I went to see my mother, the door was locked and the voice on the intercom said simply, "You can't come in; check your email." We lost her from the isolation, not COVID-19. [Lynn Norman](#)

It was five months before I was able to see Mom in person. [Elisabeth Quigly](#)

Our first supervised visit, my dad was brought to a closed window in a wheelchair. I was horrified. Only three months earlier, he walked into his new home with only a cane. [Cynthia Hadden](#)

We would press our hands up against the window together and he would cry, "All I want to do is hug you, why won't they let you in to see me?" [Ginger Andreoli Muscarella](#)



THERE HAD TO BE A BETTER WAY THAN TO JUST LET PEOPLE DIE OF LONELINESS

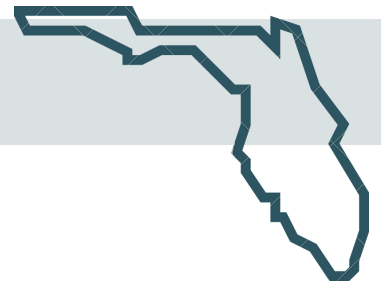


My father was getting better until that horrible day March 12th when they shut down his facility and his dementia began progressing crazy fast. I had seen him every day since he got pneumonia and he was gaining weight until the doors shut. When his pulse dropped to 40, the facility let me in because they thought he was dying. After a week in the hospital and seeing me, he rallied and as if he didn't have dementia at all but when he returned to the nursing home and to isolation, his oxygen plummeted and he returned to the hospital. He opened his eyes when I arrived, squeezed my hand, mouthed "I love you" and then shut his eyes forever. There had to be a better way than to let people just die of loneliness. [Bernadette Fisher](#)

SHE LOST TWENTY POUNDS IN THREE MONTHS AND BY THE TIME I SAW HER IN PERSON AGAIN, SHE WEIGHED ONLY 82 POUNDS

Overworked and understaffed, her facility couldn't give my mother the social support she needed. Until the lock-down, I saw her weekly and my father, her husband of 45 years, saw her daily. We also hired someone to go in and do activities with her twice a week. Suddenly, she was alone and confined both to her room and a wheelchair so she would not walk the halls independently. She lost twenty pounds in three months and by the time I saw her in person again, she weighed only 82 pounds, unable to speak, and unable to recognize me as her daughter. Now that she has been allowed to see her husband and daughters almost daily for four months, she is gaining weight, smiles again, and motions for us to sit beside her. Most importantly, when we say "Hi", her face lights up and she instantly starts talking to us. [Heidi Socash](#)





WE NOW KNOW BETTER, WE NEED TO DO BETTER



My husband was diagnosed with Alzheimer’s in 2013 at the age of 59. I tried to be patient when the facility said, “you can’t come back” but I knew I was losing priceless time with my husband while he still knew me. When the days turned to weeks and the weeks turned to months, I got vocal and the local press picked up our story. In late June I got a call from the facility’s parent company offering me a part-time job. I took it without even asking what the job was and happily worked my first shift as a dishwasher on July 3, 2020 – 114 days after I last touched my husband. When I walked into his room, the first word he said was “Mary,” I wasn’t too late. The bottom line is that the lock-down of long-term care facilities didn’t work. The virus did get into facilities and people died because of it. Governor DeSantis initiated an Essential Caregiver designation in September of 2020 and it did work, allowing caregivers back into facilities under safe conditions. This model should be a model for the entire country. We are the United States of America. We now know better, we need to do better by passing the Essential Caregivers Act. **Mary Daniel**

SHE WAS SKINNY, UNABLE TO WALK, AND BARELY SPEAKING

My mother had Alzheimer’s and was healthy, alert, talking, and interacting when the March 2020 lock-down came. She couldn’t understand virtual communication so contact was almost zero. She quit eating, lost weight, stopped getting dressed, or even getting out of bed. Her food was brought to her and there was no visitation for nine months at her assisted living facility. When we were finally allowed inside wearing full PPE, she was skinny, unable to walk, and barely speaking. She was placed on hospice care in November and passed in January. Isolation most surely was the reason she declined so rapidly. **Marlene Chestnut**

Florida

When I was finally allowed to see my 86 year old mother as her essential caregiver, she was soon thereafter asked to leave her assisted living facility without explanation. My advocating for her physical and mental health clearly played a role. It is critical that families are never again forced to sit on the sidelines watching their loved ones from afar and unable to evaluate their care or give them the attention they need. [Diane McMillan](#)



My husband suffers from Alzheimer's disease and was living in a small memory care community when the lock-down occurred. He had no idea why I wasn't coming to see him anymore, and had no recollection of when I was there last due to his memory impairment. Seeing my face on a tablet made no sense to him and it was difficult to talk because he doesn't really speak anymore. [Lisa Warren](#)



Our beloved mother was 97 years old when she was limited to visiting family through a closed window even though she could not hear us. There were no in-person visits, no hugs, no kisses, just separation from her family including her 98 year old husband, our father, shown in the photo watching her from his wheelchair. She died alone in her assisted living facility in January, 2021 and our father died three months later. Isolation most certainly played a major role in their failure to thrive. [Margaret Melzer](#)

My mom was not even allowed window visits because her window faced an interior courtyard. They allowed somebody inside to clean the fish tank but I was not allowed to hold my dying mother's hand. She lost over thirty pounds and when she died, I had to identify her body from a photograph. [Rosemarie Petrilli](#)

My husband suffered a devastating stroke that required rehab and, ultimately, long-term care. All progress he made was lost during isolation and then he got COVID-19 and lost 30 pounds. He is only just now beginning to smile again. We cannot let this happen again to our loved ones. [Kelly Dommel](#)

My sister and both parents all live in the same skilled nursing facility. To see my parents through their window, I would have to stand on an old 2x4 with protruding nails that must have been left from boarding up the window at some point. My sister suffers from a traumatic brain injury and is unable to go to her window since she is bed-bound. If I pressed my face right up against the window, I could sometimes see her but she could not hear me. [Kathy Raines](#)



TOO MANY FAMILIES WERE NOT ALLOWED TO BE WITH LOVED ONES BEFORE THEY DIED



Mother, at one time, was one of only six in the entire building to never get COVID-19. As soon as the vaccine was available, she received it. I was there every day prior to the pandemic when her dementia was not severe. But months of minimal social interaction has escalated her confusion. We abide by the rules to protect her and others, but protection involves more than just the physical precautions. How much damage this isolation has caused Mother mentally and emotionally, we will never know. **Harriett Barrow**

Viral encephalitis landed my mother in the pulmonary rehab unit of a skilled nursing facility where she was allowed unrestricted window visits. Her improvement was noticeable and during one window visit, a CNA asked, "Are Chris and Emily here to see you?" Our mom said, "Yes. They're good about coming to see me." But, when she was moved into the long-term care setting at the facility, communication became difficult with both her and her caregivers. I was told to hang on because better days were coming. Instead, my mother passed away and a nurse found her dead during a routine check. **Emily Main**



My husband is 73 and I am 68. We have been married sixteen years this May. For sixteen months, I could not visit him at all. Both of us suffer from Parkinson's, a truly treacherous disease. Both of us have had significant declines in our health due to the stress of it all. Way too many families were not allowed inside to be with loved ones before they died. **Gail Manter**



Standing outside my mother's window in 95 degree heat as she begged me to come inside caused pain for both of us. I would see her dry cracked mouth and pound on her window to ask the staff to give her a drink or transport her to the hospital. The lock-down felt like a slow daily death to my mental own well-being. **Karen Hood**



TO RECEIVE THE HIGHEST AND BEST, SAFEST AND HEALTHIEST CARE, HE MUST SACRIFICE HIS FAMILY RELATIONSHIPS



Within weeks of my father arriving at his facility, it was locked down due to the virus. My mom, married to my dad for 52 years, was relegated to drive-by parades every couple of months. The pain of being allowed mere seconds to see him as she passed by in a car took weeks for her to emotionally recover from especially since he looked increasingly weaker and more confused with each parade. Updates from the facility were infrequent and photos of him weren't shared with us. The only reports we received were from an agency we paid \$4000 per month to provide him with one-on-one care and that was on top of the \$11,000 a month that the facility cost. Two months in, my dad was transferred to another facility due to his deteriorating physical and cognitive state. He was able to walk and talk when he arrived but within two months of isolation, he could do neither. A full year later, they finally began allowing 30 minute visits in the courtyard, once a month, by appointment, one person only, masks on, six feet distance maintained, and no touching. Since his vaccination, access to my dad has not improved much: one hour every two weeks so my mother has to surrender what little time she has with my father in order for him to see his daughter and wait a full month to see him again.

My mother is going to great expense to make sure my father receives the highest and best care in the safest and healthiest environment possible because he cannot get that at home. But, to receive that care, he must sacrifice his family relationships. My dad is dying — alone. This should not be. [Melissa Fisher](#)

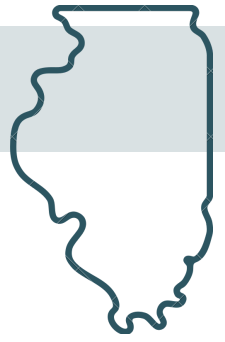
Idaho



On March 11, 2020, I walked out of the facility with my normal “see you all tomorrow” and then walked into my house to a ringing phone. It was the administrator telling me they just went into total lockdown and no one was allowed back on the campus until further notice due to COVID-19. The next time I saw my husband was April 6, 2020, through the dining room window. With his poor eyesight and hearing loss, he didn’t really see or hear us through the closed window, and since nobody under the age of 18 was allowed on campus, the little girls were left out. For two months, I felt like I was watching an animal in a zoo. My nonverbal husband was denied our communication through touch and music and there were no COVID cases in his facility up to this date. On June 28, 2020, a worker tested positive and the entire house went dark, literally. All residents were isolated in their rooms, meals were eaten in their rooms, and no activity took place at all. It was spooky. Questions went unanswered like how many have tested positive. When my husband tested positive, I asked for a window visit. Absolutely not. I asked them to take a picture and text it to me, No. By August, he was in a wheelchair because he had forgotten how to walk after seven weeks in a recliner or bed. In September, we were allowed brief patio visits and in October, daily fifteen minute plexiglass visits which are frightening for anyone with dementia. In December, he had a seizure and we decided he needed to be transported to our local hospice house where the whole family could be with him. He passed on December 20, 2020, and we are so thankful we had that last week with him. Our hearts are broken, and life will never be the same. The system is broken, especially where dementia is concerned. I’m hopeful we can fix this if we work together on legislation. [Pat Ferriola](#)

I ASKED FOR A WINDOW VISIT. ABSOLUTELY NOT. I ASKED THEM TO TAKE A PICTURE AND TEXT IT TO ME. NO.





I WAS KNOWN TO SHOW UP IN THE MIDDLE OF THE NIGHT JUST TO CHECK ON HIM

My 33 year old son (pictured right) was born with a rare seizure disorder called Sturge-Weber Syndrome that has required multiple surgeries to make his seizures manageable. So I can be his almost full-time caregiver, we bought a house two blocks from the facility that provides him with the highly skilled care his condition requires. Prior to the pandemic, I would frequently be there to have breakfast with my son, help bathe him, or get him ready for bed. I was known to show up in the middle of the night just to check on him. But, that stopped in March of 2020 and even his doctors have commented on the visible rapid physical and mental decline resulting from his limited access to the care he once received. While I am now permitted to see him, I cannot provide any direct care for my own son unless it is something I am capable of doing alone because I must remain distanced from the staff and most care duties for him are a two-person task. Without regular extended access to their loved ones, these residents are being sentenced to a slow, painful decline and eventual death from isolation, failure to thrive and loneliness. *Carrie Lejedal*



STILL, THEY BOTH GOT COVID-19

My mother entered a long-term care facility on March 18, 2020, following a stroke after she made good physical progress in an acute hospital rehabilitation and family was present with her every day for therapy homework, helping with her personal care and supporting her emotional well-being. We knew once she was transferred to the long-term care rehab facility that there would be limitations but, like most people, we believed those would be temporary and a solution was forthcoming. My mother-in-law was a long-term care resident of this same facility in the skilled nursing wing where my husband and I had visited regularly prior to the pandemic so we were comfortable that her needs would be met. But they were not because neither of them could hear through window visits or understand virtual visits. My mother had a stroke which I am convinced was brought on by the isolation and then she passed away after contracting COVID-19. While my mother-in-law survived COVID-19, she ate alone in her room and experienced despondency and malnutrition from isolation protocols. Essential caregivers can follow the same infection control measures required of staff and prevent unnecessary suffering. *Tamara Holland*

WHEN HE WAS NO LONGER RESPONSIVE, I WAS ALLOWED TO ENTER THE FACILITY

My husband had Alzheimer's and I spent time with him every day at his memory care facility until March of 2020. I shaved his stubble, cut his hair, cleaned his glasses, brushed his dentures, and monitored his health. I tried window visits and virtual visits, but he just wanted to know why I didn't come into his room and was not part of his life like I had been for 32 years. Outside visits six feet apart in the summer heat were difficult and his mental and physical health declined. Then he tested positive for COVID-19 in October and was hospitalized. He returned to his facility on hospice care and when he was no longer responsive, after eight months and 24 days, I was finally allowed to enter the facility and comfort him with physical touch until he died three days later. *Lucille Powell*



FORCED TO FEEL DESERTED AND ALONE

The last time I was in my 90 year old mother's room in her private assisted living residence was March 13, 2020. Since then we have had window visits, a few outdoor visits and some 30 minute scheduled visits. She is afraid to leave her facility. She continues to decline physically and now mentally. I firmly believe this is due to the isolation she has been through. At a time in life when the support of a loved one is crucial, residents have been relegated to window visits and ultimately forced to feel deserted and alone. *Kathy James*



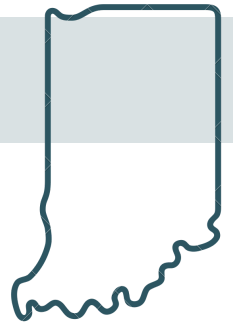
HOW CAN ANY TODDLER BE EXPECTED TO KNOW HIS MOMMY STILL LOVES HIM IF SHE WILL NOT TOUCH OR HUG HIM?



Two hundred and twenty four days is how long I waited to touch my own son. The reasoning for this lengthy separation was that I might be a danger to him and give him COVID-19. I followed the rules, never came in contact with anyone, only visited through the windows, and he still ended up getting COVID. He was not infected from me or anyone else's family member but from a COVID-19 positive staff member who came to work sick and passed it on. My son is twenty-two years old but he is developmentally at the level of a three year old. He loves Barney and Caillou. Tell me, how can any toddler be expected to understand that his mommy still loves him if she will not touch or hug him? [Fran Smith](#)

Little did we know that when our dad died in the hospital of COVID-19 in November, 2020, and my 94 year old mom went into a skilled nursing facility to recover from COVID, we would not be allowed to see her until April of 2021. After that five agonizing months and endless perseverance, we finally received compassionate care visits with the help of our ombudsman. My mother's physical, emotional and mental health has declined dramatically due to isolation and her inability to grieve my father with her family. The changes were shocking and she will never fully recover. There will always be lasting effects of this isolation on my mother. [Gail Siciliano Grazian](#)

My brother sustained a life threatening injury which left him quadriplegic and vent dependent. As a result, he became a resident of a long term care facility where he could receive the 24/7 skilled attention that he requires. Prior to the lock-down, I visited my brother almost every day for up to four hours. When my care and attention stopped, his physical and mental health deteriorated. He developed pressure ulcers and life threatening infections as well as clinical depression. His isolation was compounded by his inner room away from a window and his condition which limited his options. I am my brother's support system and I am essential. Legislation is needed to put an end to the numbers of residents in long-term care facilities who are failing to thrive and dying due to isolation. [Bernadine Chapman](#)



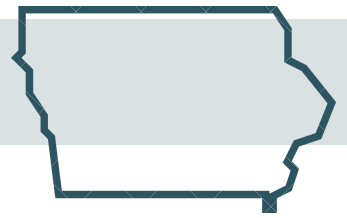
MOM THRIVED ALL HER FRIENDS WERE BURIED

By the time the COVID-19 lock-down struck in March 2020, Mom had suffered broken vertebrae in two different, consecutive facilities in two different states. Extending way beyond our capacity, we saw no other option but to figure out a way to remove her from long-term care and return her home, purely for safety's sake. Having experienced what she had, we knew Mom would be wheeled out of our sight at any nursing facility and the likely outcome the next time we were allowed to see her would be unacceptable.

In Nov 2018, my 73 year young mother had developed a brain infection, an empyema in her right frontal lobe required an emergency craniotomy to drain the abscess and flush the fluid from around her brain. Four days after surgery, we were advised to take her off the ventilator and say our good byes. But, she survived the "devastating brain damage" and experienced an incredible recovery over the next few weeks. She needed a bit of rehab to restore some strength before heading home, yet her progress indicated that she could likely expect to return to an independent lifestyle eventually. A series of illnesses, errors, and discharges from facilities ensued as we continued to pursue, and pray, for ultimate and appropriate recovery options for Mom, ultimately making the excruciatingly difficult decision to take her home where her complex care was initially miserable. But, over the next sixteen months, we watched Mom steadily improve, as she had access to family, various physicians & specialists, and meaningful activities that she would have been denied in long-term care. Her zest for, and purpose in, life happened because her family - her essential caregivers - made that happen. Meanwhile, every single person that was on the long-term care floors and wings with Mom during that sixteen months perished. "Failure to thrive" was the common cause of death.



Mom thrived. All her friends were buried. Essential caregivers are absolutely essential. The absence of family means absence of life. [Michelle Sanchez](#)



WEIGHT LOSS AND LACK OF PREVENTATIVE CARE LED TO UNTIMELY DEATHS

What I thought was a routine indoor visit on March 12, 2020, was my last visit with my mother for a very long time. Her facility tried to accommodate window visits and phone calls but not everyone can communicate through a window for medical reasons, because they live on upper floors, or because they are bed-bound. Lock-down questions went unanswered like how many residents have tested positive. Weight loss and lack of preventative care led to untimely deaths, which ironically are what the lock-down was intended to prevent. Protocols did not provide the emotional and mental support needed to combat the isolation impact. We caregivers must be allowed inside to advocate for our family and loved ones who cannot speak for themselves. [Jodi Granger](#)

IT IS AS IF HER ALZHEIMER'S CLOCK WENT ON FAST FORWARD PARTLY BECAUSE WE WERE NOT ABLE TO BE WITH HER



After exhausting all of our efforts to keep Mom in her home and with no openings for a Medicaid patient in our hometown, my siblings and I chose a nursing home in a small Iowa town about forty minutes away for our mother with Alzheimer's. Mom seemed to adjust pretty well in the beginning. We spent lots of time with her and she made friends with other residents. Then came March of 2020 and COVID-19. The nursing home allowed us to see Mom only through a window which upset and confused her. She would beg us to come in and the staff to open the door. In her dementia, she had a difficult time understanding who we were behind our masks. Then, a healthcare worker brought COVID-19 into the facility and Mom got the virus. Our last window visit before Mom got sick would be the last time we saw her on her feet.

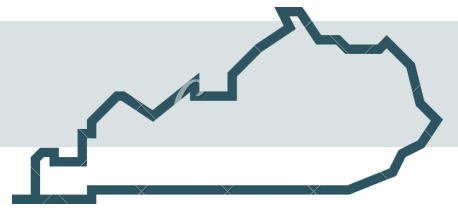
Mom came through COVID but hasn't been the same since. She lost her ability to walk, to form a sentence, and to recognize us. It is as if her Alzheimer's clock went on fast forward partly because we were not able to be with her through the changes and stimulate her memory and communication skills. No human should ever be forced to live without the touch of a loved one. [Sandra Vogt](#)



SHE WAS ONCE SO DESPONDENT THAT SHE SAID SHE WOULD RATHER DIE THAN GO ON BEING ISOLATED FROM HER FAMILY

A year-long struggle to see my mother caused irreparable harm to both my mother and me. Before the lock-down restrictions were in place, I was an essential caregiver to my mother. I took her to all of her doctor appointments, made her favorite foods, did her laundry, and assisted with personal grooming. I was an almost daily presence in her life and in her care. The staff at her facility worked with me to make my mother's life as fulfilling as possible. But, as a result of visitation restrictions, I was unable to spot signs of decline in my mother's condition. She lost over 20 pounds and is skin and bones, has lost almost all muscle mass, is extremely weak from sitting in her chair or bed for days with no socialization, and her dementia has progressed so much that she can barely hold a conversation. Her macular degeneration progressed unabated due to medical appointments she was denied and, even with her cochlear implant, she is too deaf for virtual visitation via electronics. She was once so despondent that she said she would rather die than go on being isolated from her family. She has not recovered from the isolation and lives in constant fear of being denied access to her family again. At present, she is only allowed two visits per week and she counts the hours and the minutes until those visits. Kim Eastman





ESSENTIAL CAREGIVERS PROVIDE QUALITY OF LIFE AND SHOULD NOT BE OPTIONAL



When end-of-life visits were discontinued for my husband with Alzheimer's, I took a job as a nursing home aide so I could be with him before my shift, during lunch break, and after hours. That position was defunded after three months, so I took a housekeeping job that allowed me to see him daily for another three months. When he gave up, I moved him to a hospice facility where he died three days later. I saw first-hand how overworked and underpaid the CNAs and nurses are. A CNA may be assigned up to thirty residents. An essential caregiver fills a void, advocates for the resident, and is their eyes and ears. Essential caregivers provide quality of life for residents and should not be optional. Sue Fowler

SHE MAY NEVER REGAIN THE ABILITY TO WALK BECAUSE HER MUSCLES HAVE DEGENERATED

Before the pandemic, our mother had mild dementia and walking difficulties but was able to bathe herself, fix her hair, get dressed, and move about the facility on her own. After a mild case of COVID-19 that put her in total isolation for thirty days, she became almost catatonic and lost the ability to follow simple commands or answer "yes" and "no" questions. We have since learned critical medications had been stopped without informing us, including a thyroid medication that doctors say put her in a myxedema coma. She may never regain the ability to walk because her muscles have degenerated too much and the shunt to drain spinal fluid caused by undiagnosed hydrocephalus was inserted too late to help. Todd and





SHE SUFFERED A 17% WEIGHT LOSS AND A PRESSURE SORE THAT WENT ON FOR FIVE MONTHS LONGER THAN NECESSARY



Mom had emphatically stated that when the time came, her wishes were to live in a memory care facility. Obviously, she expected that her family and friends would not only oversee her care, but also be frequent visitors. Neither of those things were possible during the lock-down. While the government and the rehab facility “kept her safe from COVID,” her quality of life was nonexistent. She and I were robbed of precious time together. In March 2020, she knew that I was her daughter, Beth. By August of 2020, she only knew that I sometimes seemed familiar. She suffered a 17% weight loss and endured a pressure sore that apparently went on for five months longer than necessary. The physical suffering would have been completely avoidable had I been allowed to see her, oversee her care, hold her hand, look in her eyes, and explain what was going on. Some other things that are hard to get over: that a random moving guy with a 10-day-old negative COVID test, dozens or hundreds of paid employees, and a rehab worker that met me at the door for a laundry exchange were all considered safer to interact with my own mother than I was. The fact that I could unilaterally be banned from seeing my mother has shaken me to my core. When Mom’s weight loss and increased dementia qualified her for hospice care, I moved her to my house and she died five months later. In my home. Holding my hand. Long-term care facilities need to know that families will monitor and advocate for the care of their loved ones. We cannot do it from behind locked doors. **Beth Frith**



NOT UNTIL FIVE HOURS LATER WAS I OR EVEN A DOCTOR CALLED AND BY THEN, IT WAS TOO LATE TO STOP THE BLEEDING

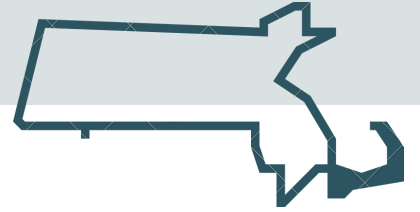
Two months into the lock-down, my dad was already having a very hard time with his isolation and my absence from regularly caring for him when the nursing home staff found him at 7 a.m. having suffered what they believed to be a stroke. Not until after 12:00 p.m., five hours later, was I or even a doctor called and by then, it was too late for medication to stop the bleeding. There was no hope of reversing the damage. He passed away on June 20, 2020. Stroke is listed on his death certificate as his cause of death but it was the isolation that killed him. It was the restriction of family that allowed the facility to dismiss his distress, prevent me from participating in his care, and delay decisions that were mine to make. He had dementia and often forgot what used to come easily to him. He had thoughts he couldn't always express but if I leaned in close and watched his eyes, I knew what he was feeling. Sometimes, although his words were lost and unspoken, I watched his lips and could catch some of them, almost as if his mind had forgotten how to say them but his lips remembered. Some visits he didn't know me. Some visits, he was angry at me. Some visits, he smiled and nodded as if I was no more to him than a random person in his space. But, I made a promise and I think somewhere in him there was a sense of safety in my presence even if he can't recall our conversations. [Dawn McBreairty](#)



WITHOUT THE ESSENTIAL CAREGIVERS ACT, MY MOTHER WILL CONTINUE TO HAVE MISUNDERSTOOD AND UNMET NEEDS AS SHE LIVES A TORTURED LIFE IN HER OWN MIND

My mother will soon be 100 years old and I, her only child, have been principally overseeing her care for over 21 years. She developed dementia approximately 25 years ago and it has been a long, hard road that I have had to mostly walk alone. My mother's journey was greatly improved, before COVID-19 appeared, by using a music therapy process that awakens a path in the brain and allows dementia patients to communicate better to the outside world. Communication helps ease her anxiety without drugs and helps me, as her caregiver, to better understand her pains and problems, as well as help medical professionals better determine the most effective treatments. Once COVID restrictions locked me out, her full personal music therapy was interrupted. My mother became riddled with anxiety and agitated due to the loss of this method of communication. When I am not there, the music does still provide comfort and reduce tensions, which the staff that closely works with her appreciates. But they are not familiar with my mother's past and cannot provide the time or the life experiences that I provide. Without the Essential Caregivers Act, my mother will not receive effective therapy and will continue to have misunderstood and unmet needs as she lives a tortured life in her own mind. [Elmer Dengler](#)





SHE OFTEN THOUGHT WE HAD ABANDONED HER AND SHE CRIED HYSTERICALLY EVERY DAY



In late April 2020, my mother who has mild dementia suffered a second stroke which required her to enter a skilled nursing facility for rehab. Her temporary stay became a permanent stay. She had the very bad luck of arriving at her long-term care facility during the beginning stages of COVID-19 lock-downs.

During this time, we were shut out completely and unable to hug her, kiss her or be anywhere near her. For my mom, someone who was always so close to her husband and daughters, this was extremely difficult. She often thought we had abandoned her and she cried hysterically every day.

Fast forward to almost an entire year later when we were able to physically hug her. She missed a year of our lives in the period of hers when she needed her daughters and husband the most. This not only took a toll on my mom mentally but also my dad who has, himself, significantly declined physically and mentally and now lives in the nursing home as well. Please hear us families and never allow this isolation to happen to our vulnerable population again.

Mandy Braga





“SHIKATA GA NAI” IS TO ENDURE THE UNENDURABLE WITH DIGNITY AND PATIENCE



My mom was among the 120,000 Japanese Americans incarcerated in internment camps during World War 2. The Japanese have a phrase, “shikata ga nai”, which loosely translates as “it cannot be helped” or “to endure the unendurable with dignity and patience”. I believe this phrase best describes how my mom was able survive the first months of the pandemic before her health deteriorated. She couldn’t understand why I missed my daily visits, she gradually quit eating and drinking on her own and, since she was unable to use a telephone or watch television, her only human contact was with tired and overworked caregivers who could only provide the bare minimum. She was existing in a dark and lonely world while slowly starving for both nutrition and interaction. The pandemic may not have been the ultimate cause of her death on July 27, 2020, but the restrictions and isolation were major contributing factors. Nancy Falbo



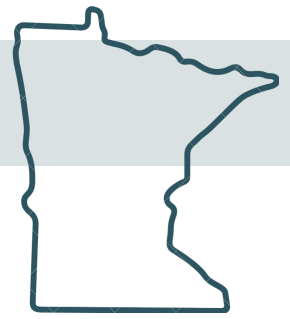
SHE EXERCISED THE ONLY CONTROL SHE STILL HAD OVER HER LIFE

Eleven months after the lockdown began, my mom died after she decided to stop eating. We had made every effort to see her indoors with physical contact according to the CDC guidelines but the facility administration repeatedly denied compassionate care visits. Mom no longer wanted to live in isolation so she exercised the only control she still had over her life and let it go. Jamie Nicholson



Every time a staff member at the nursing home tests positive for COVID-19, it stops other families from seeing their loved ones indoors for another fourteen days. Loretta Watters

My husband lost the ability to feed himself. I was allowed fifteen minute visits once a week. His home, like most homes, was completely closed to all visitors, except for end-of-life situations. Anita Hack



ON HIS 62ND WEDDING ANNIVERSARY, MY FATHER-IN-LAW ONLY SAW HIS WIFE THROUGH A CLOSED WINDOW

My 86 year old father-in-law was a veteran and life-long resident of St. Cloud, MN. He was diagnosed with prostate cancer that progressed slowly over the last five years. Last year, it metastasized and became terminal, a condition that required hospitalization and recovery in a nursing home. His wife of 62 years was able to see him briefly and sporadically while he was a patient in the hospital. But, since he was transferred to a care facility for rehabilitation at the height of COVID-19, his sons and his wife were unable to enter the facility and spend time with him. On his 62nd wedding anniversary, my father-in-law only saw his wife through a closed window. Not being able to see his family and enduring isolation during the last lucid days of his life caused him heartache and extreme loneliness. Only when he was on hospice care and actively dying were his wife and three sons allowed by his side.

Carol Wenner

THE STAFF SHOULD NOT BE ALLOWED TO DECIDE WHO IS WORTHY AND WHO IS NOT

During the pandemic, my significant other lost the use of his legs from being kept in bed all day. After his stroke, I had been at his side almost every day up until his transfer to another facility. Then, I was denied essential caregiver status by the facility and required to visit at a closed window. Staff did not understand that he compulsively shook his head 'no' even when his answer is 'yes' and without me there to help interpret, he was often misunderstood by staff. Essential caregiver guidelines in Minnesota give the facility the ability to decide who can and cannot be designated. The staff should not be allowed to decide who is worthy and who is not, or decide that only blood relatives can be essential caregivers. That should be the resident's choice. Donna Lower

Mississippi

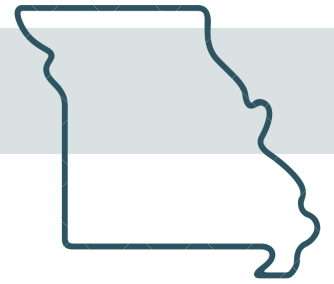


SHE BELIEVED THAT WE HAD DROPPED HER OFF SOME PLACE JUST TO ABANDON HER AND LOCK HER AWAY



My mom was still physically able to eat when she died, but her body was shutting down and she did not have much desire for food in her last weeks. She did not die of Alzheimer's-related complications like pneumonia or because her brain had "forgotten" how to swallow or eat. Mom still knew who everyone in her life was and could carry on conversations. But, forced isolation and the resulting failure to thrive that stems from it is a humanitarian crisis of our elderly and disabled children and adults.

On her bad days, my mom forgot about the pandemic. Angry and devastated, she believed that we had dropped her off some place just to get rid of her, to abandon her, and to lock her away. She would essentially ask us to prove that we weren't doing those things, by coming and getting her out and we couldn't do that. Window visits are a disaster for someone with a cognitive disability, so we could not have them often. Mom's cell phone battery died one day when we were "talking" through the closed window. No one would answer the phone in the facility so I could not ask anyone to help her plug her phone in so we could continue the visit. Mom became angry, cried, banged on the window, and demanded to know why I wasn't calling her so she could hear us. Her young grandkids witnessed all of this. I had to walk away and leave her at the window, weeping, with no means of calming her down. She died of failure to thrive on December 26, 2020. [Kim Prachniak](#)



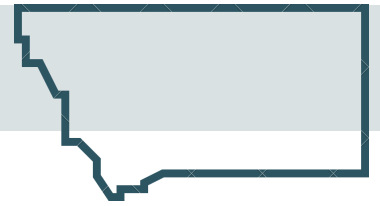
MY NEGATIVE COVID-19 TEST THAT VERY DAY ONLY QUALIFIED ME FOR A VISIT AT THE PLEXI-GLASS "HAND HOLDING" BOX



When, on September 2, 2020, I received a call that my husband had suffered a seizure, I was also denied entry into the facility to see him. My negative COVID-19 test that very day only qualified me for a visit at the plexi-glass "hand holding" box. Three weeks later, since he was no longer allowed out of his room to use the phone to talk to me. I had a device installed in his room so he could communicate with me. But, the facility removed it. I asked the sheriff to do a welfare check and they denied him entry. HR3733 needs to become a reality so my loved one's access to me is not subject to the authority of facilities who interpret guidelines at their discretion. *Rebecca Portman*

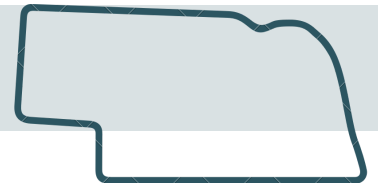
THE RAPE OF A CNA OCCURRED IN MY WIFE'S OWN BED WHILE SHE WAS LYING IN IT

I fear for my wife in long-term care because I am not there to protect her and have no idea what is really happening behind those closed doors. When the lock-down began, the rape of a CNA occurred in my wife's own bed while she was lying in it. I was not immediately notified. What else am I not being told? There is no oversight from family members as staff members come and go. Eventually one of them exposed my wife and she tested positive for COVID-19. I am to this day still not allowed to visit her room and see the condition of her bed or inventory her belongings. She has been moved five times during the lock-down and because she is considered "end of life", I am now allowed to sit beside her. She is still alive and my visits must be "supervised". No private time at the end of her life. *James Blundell*



RATHER THAN SEND HER TO REHAB IN A FACILITY WHERE WE COULD NOT SEE HER OR KEEP HER COMFORTABLE AND SAFE FROM INJURY, WE BROUGHT HER HOME TO DIE

When our mother/grandmother, who lived alone, began having alarming falls, she came to live with us in Montana. But she was healing from surgical wounds, contusions, and bruising and the wound from her vascular surgery reopened because the stint in the vein was infected. Following corrective surgery, she went to rehab where we were prevented from seeing her due to COVID-19 precautions. We spoke to her on virtual calls but she worsened each day. One day, she was shaking uncontrollably and unable to speak. She had had a fall while wandering in the rehab facility hallways that nobody had reported to us. The fall was followed by a severe stroke. We felt guilty and overwhelmed by our inability to be with her, to advocate for her, to communicate with her, and to keep her safe from injury. She was transported to a hospital and intubated to supply nutrients. This was inconsistent with her wishes that had been articulated and written in her living will. Rather than send her back to rehab in a long-term care facility where we could not see her or keep her comfortable and safe from injury, we brought her home to die. **Noy Holland**



SHE WAS LYING UNCONSCIOUS IN HER BED WITH HER VENTILATOR MASK ON HER FACE BUT IT WAS NOT TURNED ON

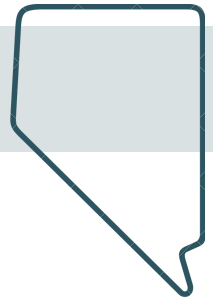
As a family, we decided to move our parents from an independent living community to a skilled nursing facility that has transitional care. We believed our father could visit our mother anytime he wanted by just walking to a different wing when the time came for our mother with Alzheimer's to move to a different level of care. But that was far from what happened to my parents.

My mother's life was a living hell because she believed she was being held hostage. During virtual visits, she would beg me to call the police. As her body declined, she could not use the phone on her own anymore and I was dependent on the nursing staff to take time and help her visit over a tablet or telephone. As a nurse that has worked in long-term care facilities, I know the staffing challenges and understand why we want to keep COVID-19 out. But resident quality of life is not being considered in many situations.

My breaking point was when the facility did not answer the phone for five days and I contacted the local ombudsman whom the facility did not respond to for another three days. I was finally able to get hospice onboard and allowed in after I threatened to sue the facility. The hospice nurse and I were shocked to find my frail mother lying unconscious in her bed with her ventilator mask on her face but not turned on. Her stomach was distended with a hard protruding abdominal mass, she had pressure sores on her coccyx and heels, and her unopened cards, unwatered plants, and family photos were in a corner where they could not be seen. She passed away two days later. [Becky Bogner](#)



Nevada



ISOLATION WEAKENED HER IMMUNE SYSTEM AND HASTENED HER DEATH

My beautiful mother was 80 years old when she passed away in January. When her long-term care facility went on lock-down due to COVID-19 in March of 2020, our daily phone calls helped her somewhat but she cried often and told us she was lonely. When, eventually, I was allowed 30 minute visits, I was shocked at her appearance and how much she had aged in a few months. We both cried when we were not allowed to hug as staff members stood by monitoring our visits to make sure we complied with visitation rules. We continued for several months with our scheduled and supervised visits until November when the CDC eased nursing home visitation restrictions. On December 3rd, I brought my mom to my home to celebrate her 80th birthday with a quiet dinner.

That was the last time I saw my mother because the facility had a spike in COVID-19 cases and went back into lock-down. My mother became very sick. I asked if I could visit and bring her fluids since I had already recovered from COVID and had antibodies. I was denied but was told she tested negative. Soon after, while mom was rinsing soiled clothes in the sink, she fainted in the bathroom from fever and dehydration. She had not eaten in almost a week. Every day I called to check on her and they said she was fine until, after seven days, I reached a breaking point and told the administrator that I was coming to see my mother. Meanwhile, Mom called 9-1-1 herself and had been transported by the time I arrived.

At the hospital, I was told she tested positive for COVID and had pneumonia. I was grateful for the two virtual calls that her nurse made to me while Mom was there but my precious mother died without any family by her side. No last words of love were spoken to her and I can only hope and pray that she was not as scared as I was. My question is this: why was I only allowed to sit with her after she passed away? I firmly believe that the isolation my mother endured led to her weakened immune system and hastened her death. Had I been allowed to see her, I would have gotten her medical care days sooner. Ultimately, the outcome may have been the same. I will never know, but I do know that I would have been able to hug her, tell her how much she was loved and help calm her fears. We **MUST** allow designated family to support and care for their loved ones even during times of a medical crisis because isolation kills, too.

Linda Giesler

New Hampshire



HE HAS TOLD ME THAT HE WILL GIVE UP AND DIE RATHER THAN LIVE THAT WAY

My dad is 97 years old and has lived in a skilled nursing facility for seven years. He is vibrant and life-loving but the forced isolation almost removed his will to live. He was afraid, alone, and regularly called me in a state of panic. When his roommate tested positive for COVID-19, he was moved and my dad was utterly alone for days. He is blind so television and books are not a way for him to pass the time. He was allowed no visitors, he received no news, and the only deliveries permitted were of food. Then, one day he called me and said, "They think I have COVID and are taking me to the COVID floor! I'm scared and I don't know what is going on!" He ended up in isolation and his belongings did not go with him. He had one slipper, no WiFi communication, no audio player and no audio books which are his only entertainment since he is blind. They forgot to bring him supper that day so he sat there, alone, confused and scared. He told me he didn't think he would make it through the isolation. Then he did test positive and he did survive. But, he has told me, that if there is a forced isolation like that again, he will give up and die rather than live that way. Today, I am only able to visit him outside one hour once per week unless I make a reservation for a designated indoor area. *Wendra Murphy*

SHE CRIED BECAUSE SHE FELT DESERTED AND NOBODY CAME TO COMFORT HER

When I went to drop off my mom's clean laundry at the facility on March 3, 2020, I was stopped at the door. Mom could walk with a walker and up steps that day. She could speak. She can no longer do either. Staff members went about their outside life and then entered the building but I, who was out of work and never left my house, was not around people and had access to gowns, face shields and N95 masks was not allowed to see my own mother. I was not even allowed a closed window visit or to set foot on the property. She was confined to a small room with nobody to talk to or share a meal with and when she cried because she felt deserted by her family, nobody came to comfort her. *Meg Deschenes*

New Jersey



HIS GRANDCHILDREN HAD TO STAND IN A FIELD 50 YARDS AWAY WHERE THEY COULD ONLY WAVE AT HIM

My father, who had a neurodegenerative disease which progressively affected his cognition and mobility, could not comprehend why I was not allowed to hug or hold him. We were given 15-minute monitored outdoor visits while my children – his grandchildren, ages 11 and 8 – were required to stand in a field 50 yards away where they could only wave at him. They were not allowed to see him in person inside or outside until March, 2021, when they got two short visits with him right before he reached his final days. When we were denied any significant time together by his nursing home while he was actively dying, despite both of us having been vaccinated, I brought him home. He died three days later. I feel sure that his isolation broke his spirit and his heart, and hastened his death. *Abby Grayson*



HER GRANDCHILDREN CELEBRATED HER BIRTHDAY ON THE LAWN AS SHE WATCHED FROM THE WINDOW

Our mother walked into the nursing home and a year later, having been denied physical therapy and the ability to freely walk about on her own two legs, she is now confined to a wheelchair and cannot stand on her own. She is depressed and stares blankly into space even though she is alert and aware of her surroundings. Our loved ones should not suffer again what they lived through this past year. Her grandchildren celebrated her birthday on the lawn as she watched from the window. The pandemic is not over. But the forced isolation of our loved ones should be. *Serena Swindell*

WE ARE STILL WORKING TO BRING HER BACK TO HER OLD SELF. BUT ISOLATION HAS PERMANENTLY CHANGED HER

Prior to the pandemic, my 96-year-old legally blind mother -- living in long-term care in New Jersey -- counted on the regular caregiving of her sons, extended family, and many friends. We supplemented the care provided by her facility. We are still working as a family to bring her back to her old self. But isolation has permanently changed her. We don't understand why we were kept out, why she had to suffer, why her quality of life was so diminished, and why essential care was denied. Why was she so alone when she needed her family most? [Bill Borrelle](#)

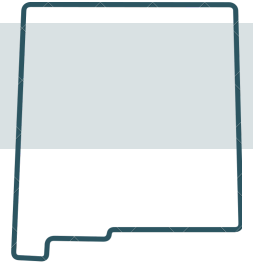
HER HEALTH DETERIORATED AT A RAPID RATE DUE TO ISOLATION AND SEPARATION FROM ME, HER PRIMARY CAREGIVER

During much of my mom's last year, while suffering the increasing effects of dementia, she lived alone, confused, and afraid. Her health deteriorated at a rapid rate due to isolation and separation from me, her primary caregiver. She was deprived the emotional and physical support of her caring and loving family. We knew my mom was going to die from dementia eventually but we were helpless to provide her love or support as she did. Only when she was at the end of her life was I able to provide the highest level of caregiving every person is entitled to from the family who loves them. [Ginger Vukas](#)



Over the months, my father missed Easter, Father's Day, summer barbeques, birthday parties, Thanksgiving and Christmas. He was all alone, in his room, isolated, not hearing the TV or radio due to the inconsistent charging of his hearing aids, and stuck in his wheelchair in one spot due to loss of limb strength. [Roslyn Sharkey](#)

The isolation was killing my mother's will to live. Window waves and phone calls were not enough to sustain her any longer. Without being with her family, she told me that she didn't want to eat so she wouldn't be alone anymore. [Laura Otten](#)

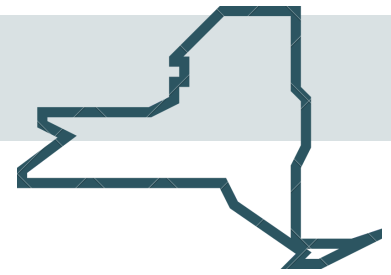


EVEN AS SHE WAS ACTIVELY DYING, HER DAUGHTER WAS NOT ALLOWED TO COMFORT HER IN HER FINAL MOMENTS

In March of 2020, when the door to my mother's facility was abruptly closed, instead of loving visits in my mother's private room, I was offered a single 15-minute window visit, once a week. Until then, I would visit with mom every day. We enjoyed meals together, took long walks and read magazines in the courtyard. I was her only connection to family and friends across the country. We would reminisce over old photos and I was her advocate, the one who reviewed her care plans with the staff.

My mother and I spoke via a staff member's mobile phone but otherwise simply stared at each other through a dirty window. I watched her health and mental acuity decline through these visits. She became quiet with an empty look in her eyes and began losing weight. Her legs atrophied so much so that she could no longer stand through the 15-minute visit. Staff members had to seat her in front of the glass where she would cry the entire visit.

Although it was extremely difficult caring for her, I brought mom to my home rather than watch her suffer from the other side of a pane of glass. My mother's friend at the facility was not as fortunate. She died, but not from COVID-19. She died due to "failure to thrive", the name they give the extreme weight loss and despondency that accompanies isolation. Even as she was actively dying, her daughter was not allowed to comfort her own mother in her final moments. There were similar endings for other residents at the same community. But not for my mom. Isolation was not allowed to kill her. [Dena Duncan](#)



GET ME OUTTA HERE THEY'RE GOING TO KILL ME

I was my mother's essential caregiver every single day prior to the lock-down. Suddenly, I wasn't there anymore and she was incapable of understanding why. She didn't understand why her husband of sixty years was not there any more. She was left to die alone in her bed and not from COVID-19. She said to me via virtual visit, "Get me outta here. They're going to kill me." And, kill her they did. I was denied compassionate care visits until Sept 27, 2020, when I fought for seven hours to get her to an emergency room where she was diagnosed with severe dehydration, sepsis, a stage three pressure ulcer, renal failure, high sodium levels, and swelling of the brain. She died one week later.



Had I been allowed inside the facility as her essential caregiver, none of this would have gone unnoticed and she would be alive today. [Karla Abraham Conley](#)

SHE NOW STRUGGLES TO STAND

During the lock-down, since she had no one to walk with, my mother experienced a significant physical decline. She now struggles to stand and, minus the music, talking, and reading we did together, her music major's brain was not stimulated and her dementia escalated so quickly that she went through a traumatic move to a memory care unit with no family to help her process what was happening. Families are essential. Nobody has a right to say otherwise. [Carol Wright](#)

When my father was assaulted in the nursing home, my mother was allowed to file a police report but not see him. Eight days later, after much pleading and threats to call Adult Protective Services, the facility permitted Dad to go to the hospital for evaluation. Before visitation was cut off, my family was with my father almost every day to help him remember to eat, provide clean clothes, keep him connected, and help him know how to live in the facility. Since the lock-down, my father has been assaulted twice by other residents, lost his belongings, and obtained bruises, bleeding skin, and two black eyes. His antipsychotic medication was increased without family consultation and to six times the amount he was taking pre-COVID-19. This is the cost of separating residents from family members. Families are essential caregivers who guarantee my father's well being and speak up when he is in trouble. Family members are not visitors. **Mikko Cook**

My wife had multi-infarct dementia. The thing she needed most was contact with people. That was the first thing they took away. During the lock-down, her primary doctor detected a heart murmur so I set up a cardiologist appointment. She wore a heart monitor overnight and when we returned the next day, I removed the heart monitor, and it was me who undressed and redressed my wife. It was the closest I had been to her in weeks. When I mentioned that I had just changed her clothes, the reply was, "It didn't happen in our facility." My wife of 62 years passed away Thanksgiving week. Isolation did not kill her but it definitely accelerated her death. **Martin Powers**

HE HAS BEEN ASSAULTED TWICE BY OTHER RESIDENTS



ISOLATION ACCELERATED HER DEATH

SHE DIED BECAUSE SHE NEEDED PHYSICAL THERAPY AFTER KNEE SURGERY

Our mother contracted Covid-19 in a rehabilitation facility when COVID patients were being admitted directly into the rehab wing of the nursing home where she was supposed to be getting stronger after her knee surgery. The hospital had suggested that a few weeks of therapy would do her good but we could never have foreseen that this advice would cost her life. As family members were kept out of the facility, we were unaware that she was located in a wing that put her life in grave danger. Our mission now is to see that no daughter or son will experience the depth of pain that has been inflicted upon us. Essential caregiver legislation would put in place safeguards to make sure no loved one will be denied the ability to care and advocate for a resident in a long-term or temporary care facility even in another public health emergency. *Vivian Zayas and Alexa Rivera*

SHE DIED ALONE

My mom passed away from COVID-19 in November of 2020. I was allowed one and only one compassionate care visit three weeks before she got COVID-19 and then she passed away six days later. I held my mom's hand and got to be at her side for twenty minutes. There were no family members with her when she died. Nobody held her hand and assured her that she was loved for a full three weeks plus six days before she died. *Terri Szafranski*



WITHOUT ME THERE TO HELP HER EAT, SHE SUFFERED A SLOW AND PAINFUL DEATH

My mom died scared, abandoned, and sad. I had been there every day for 442 days, checking on her care, making sure she was eating, and picking up her laundry. Without me there to feed her, she did not eat so she suffered a slow and painful death. Her primary care physician was not allowed inside the facility either. If her doctor had at least been allowed to continue to care for her, she would still be alive today, smiling and happy. *Dori Carlone*



THE FACILITY PUT TAPE ON THE FLOOR INDICATING WHERE I COULD NOT CROSS

My 87 year old mother suffered an anoxic brain injury due to cardiac arrest and lives in a skilled nursing facility. She has both a tracheostomy tube and a gastric tube and I have been her essential caregiver for three and a half years. She celebrated her 86th Birthday in March 2020, with family, friends and church members, and the facility was closed to those same people four days later. I visited her everyday outside her



closed window for up to five hours during the lock-down. Even when it was forty degrees outside, I wrapped in blankets and was there for her. I was finally permitted inside for compassionate care visits when my Mom developed shingles on her face and eyelid but the facility put tape on the floor indicating where I could not cross. I am the one who notices dehydration, infections, and pressure sores. I know her behavior and I know when it changes. Residents who cannot communicate rely on their essential caregivers to advocate on their behalf. **Marilynn Lester**

THERAPY WAS SUSPENDED AND HER MUSCLES WASTED AWAY



Shortly before the lock-down, my wife, Susan, had finally regained the ability to stand and use a walker without assistance. When therapy was suspended and she sat in a wheelchair for over a year, her muscles wasted away. She cried daily because we could not be together. She lost the ability to use her non-dominant hand to feed herself and to even use a fork or spoon. She developed multiple severe urinary tract infections resulting in five hospital

stays for as long as twenty days, was hospitalized twice more for dehydration, suffered kidney failure with sepsis, and was wholly isolated for fourteen days after each hospital stay. All of this took a toll on her emotional, psychological, spiritual and mental well-being. I know that staff members are tired, stressed, overworked, and even depressed, but my wife is damaged. Essential caregiver legislation is needed to protect her right to human contact that should have never been removed. **Bob Wilson**

North Dakota



WE HAD TO KEEP SAYING, "NO, DAD, WE CAN'T COME IN."

Prior to COVID, three of us kids visited my father seven hours every day, making sure his physical and emotional needs were met. During the lock-down, we were at the window for at least four hours every day. But, it was stressful on him. He would motion at us to come in and we had to keep saying, "No, Dad, we can't come in." Nobody was doing the things we had done for him. Almost daily, we reminded the facility to open his curtains and make sure he has access to his phone, TV remote, call button, grabber, tissues, and drinking water. He died on Thanksgiving, three days after his 90th birthday. *Lisa Moldenhauer*



I COULD TELL BY THE PHONE CALLS THAT THEIR HEALTH WAS DECLINING

My parents were 87 and 88 when the lock-down began. Telephone calls were their only bright spot on any given day. They were not able to use a cell phone or any other technical resources for virtual visits. As the days turned into weeks and then months, I could tell by the phone calls and their voices that their mental and physical health was declining. They were fortunate to have each other but they were not allowed out of their assisted living quarters for months and their meals were served in disposable containers as if they lived in an institution. When my mother became ill, the doctor asked that, since I am medically trained, I be allowed to go in for the night to care for my mother. I could even free up some staff time but the facility refused and my mother developed complications. The isolation, fear, frustration and helplessness continues to this day as none of us feels in control of their care, decisions, or their lives. *Barbara Johnson*

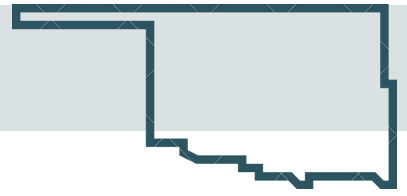


ON MY MOM'S 92ND BIRTHDAY I WAS STOPPED AT THE FACILITY DOOR

On my mom's 92nd birthday, March 15, 2020, I was abruptly stopped at the front door of her nursing home facility and told I was not allowed to enter. The facility was closed to visitors. I was distraught but complied. For over 400 days, I visited my mother at her window two or three times a day in all kinds of weather to reassure her that she was loved and remembered. I stood in a blizzard on Christmas Eve and had to send packages to her through the mail because nobody would carry them in to her. Staff members were frustrated with me as I tried to advocate on my mother's behalf through a closed window. Day after day after day I saw my mother sit in a recliner by herself, often with the door or curtain closed, and eating meals out of foam containers. She would ask me to come in and get her. A year later when I was allowed in her room for a compassionate care visit, I found her unopened mail and belongings stuffed here and there. It's a shame that our country couldn't come up with a better way to keep our loved ones safe. *Cynthia Woodburn*

FROM MARCH 12, 2020 TO MARCH 3, 2021 I SAW HER FOR A TOTAL OF 70 MINUTES

As a nurse married to an emergency room physician, I understand the medical thought process behind the COVID-19 precautions. However, I am an only child of a 95 year old woman who resides in an assisted living facility due to her beginning stages of dementia. I wasn't able to see or visit my own mother from March 12, 2020 until a window visit was scheduled on July 15, 2020 for 20 minutes. I had an additional two scheduled visits on July 29th and October 14th which was our first indoor visit, the first time I was able to physically be within six feet of my mom. From March 12, 2020 to March 3, 2021, I saw my mom for a total of 70 MINUTES. As weeks turned into months, she began losing weight and I could hear in her voice that she was slipping cognitively. When Christmas arrived and she learned that she wouldn't be spending Christmas with me, her response was "I have never not spent Christmas with my family. This is wrong." And she is absolutely correct. *Lynn Meldon*



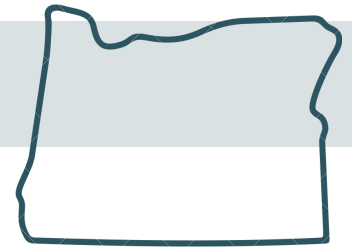
DADDY WAS ONE OF THE FIRST IN HIS FACILITY TO CONTRACT COVID-19 AND HE QUICKLY BECAME CRITICALLY ILL

We got the information on March 24th over the television, radio, and internet that COVID-19 was causing a statewide safer-at-home order that meant all “non-essential” businesses were to shutter their doors until further notice. This order effectively closed nursing homes to all visitors, too. We had celebrated my dad’s birthday with several of our family members on March 9th in the skilled nursing home for veterans where he lived and that was the last time I saw him for over a year.

Daddy was one of the first in his facility to contract COVID-19 and he quickly became critically ill. When he was transported to the hospital, they allowed only one person in to see him, gloved, gowned and wearing a mask and wristband. The nurse told me, “Tonya, he keeps asking for you” but I sent my mother in to be with her husband since we did not know if he would survive.

When he finally returned to his room, he had a new roommate because his had passed away from COVID-19 complications. We were not allowed to see Daddy in person so we spoke through a closed window and a telephone. He is hard of hearing, so it was very difficult for him to carry on a conversation. Mostly we just sang to him, and he cried, just wanting us to be able to touch him, wanting to go home, wanting to be with his family. The more he was separated from his family and deprived of physical contact, the more the dementia seemed to escalate. He gets confused about where he is and what he is supposed to be doing and whether or not the television show he is watching is reality. It is heartbreaking. He always knows our names the more we are allowed to see him, the more grounded he seems to be in reality.

We can not recover lost time and now we are seeing the ominous signs of a potential repeat of last year. It isn’t fair. Not to Daddy. Not to me. He is worth more than any amount of money to me. His time with me is worth the whole world. *Tonya Baldrige*



THE SIGN ON THE DOOR OF THE FACILITY THAT GREETED ME ONE AFTERNOON WAS A BIG RED STOP SIGN

Both my parents died during the pandemic. They lived in the memory care unit of an assisted living facility and I visited every day, sometimes twice a day, and spent several nights in a recliner when my mom was having a particularly hard time. Both my parents had Alzheimer's disease and my mom also had Lewy Body dementia which can cause a great deal of agitation, hallucinations and delusions. As if dementia wasn't bad enough, she was wheelchair bound due to peripheral neuropathy and suffered from debilitating anxiety and depression. Both my parents were in rapid decline, and had just been put on hospice when I was told they had 6 months or less to live. And then the lock-down happened.



The sign on the door of the facility that greeted me one afternoon was a big red stop sign. I knew of the staffing shortages that had long plagued this facility, so naturally, I worried about what might happen. So, I moved my parents into a group care home that was dedicated to memory care. It had a patio outside their window where I'd be sitting for the next 13 months, visiting only through glass. My mother passed away in May and we were allowed in one at a time to see her only during her final days. For the rest of that year, I visited my father only at the window, except for a brief, glorious period when virus cases were low and we were permitted to sit outdoors on the patio together. Christmas was the hardest. My sister and niece flew in from Texas, and they, along with me and my kids, spent a freezing day on the front porch as the caregiver wheeled my dad to the window to see us. It was the last time he saw his whole family together. He died in April. This lock-down was cruel in many ways to many people but I believe those with dementia suffered the most. It is inhumane to keep families from their loved ones.

Amy Massingale



I UNDERSTAND NOW HOW A PERSON COULD ACTUALLY DIE OF A BROKEN HEART

Before the pandemic I spent every day with my husband from noon to 7:00 p.m. Not only would I groom him, but I would also feed him his lunch and dinner. We would listen to music and I'd read to him. My presence, my touch and my hugs comforted and reassured him that he was loved and being well cared for. I understand, now, how a person could actually die of a broken heart. After being separated for fifteen months due to COVID-19 and only allowed window visits and a weekly telephone call, I was finally granted compassionate care visits on June 9, 2021 for three hours every day due to his evident physical decline. Residents absolutely need and deserve a family member, friend, or another person of the resident's choice to be their designated Essential Caregiver who will advocate for them to ensure the isolation experienced never occurs again. Not only did the isolation cause a decline for those in nursing homes but also for families who were unable to be with their loved ones. *Alice A. Stouffer*

WE LOST 200 PRECIOUS DAYS THAT WE CAN NEVER GET BACK



Due to her dementia, my 91 year old mother lives in a skilled nursing facility. Prior to March 2020, I was regularly inside the facility to feed her and assist with her care. She was walking with a walker, eating well with assistance, and somewhat responsive with her words. My Mom turned 90 that April and while I had the opportunity to see her through a window, she stared at me in confusion as if she no longer knew who I was. After 200 days of not being allowed to hold my mom's hand or hug her, the facility granted me compassionate caregiver visits and I saw my mother every day to feed her and assist in her care. In December, she tested positive for

COVID-19 and survived it so I was able to celebrate her 91st birthday with her this year. Although my mom is on hospice, she is thriving which I attribute in part to my presence but due to six months of separation, she has completely lost her ability to walk and to speak other than an occasional "yes". While I am grateful that I still have my mom in my life, we lost 200 precious days last year that we can never get back. Our loved ones need us. *Carolyn Michener*

Rhode Island



SOMEWHERE IN HER DAMAGED BRAIN, SHE KNOWS SHE WAS ABANDONED FOR A LONG TIME



Prior to March, 2020, we were always at my feisty Bronx mom's side as she learned to talk and walk again after a traumatic brain injury and even enjoy aspects of life. Blizzards couldn't stop us, none of us ever took a sick day. COVID kicked us out. No more Mom. We got it. The world was in a tailspin. But for over a year after our governor reopened casinos and strip clubs, we were still forced to advocate loudly for some safe, humane resumption of visitation in nursing homes. By the time we got the essential caregiver law passed in Rhode Island, it was too late for my dad. His Alzheimer's had accelerated into high gear with the loss of his visits with Mom. He could no longer fully appreciate being in her presence and she now looks to me and desperately tries to articulate her confusion as to why he can't respond to her anymore. My new mom won't allow us to let go of her hand or let us leave at the end of a visit. She may not understand much, but somewhere in her damaged brain, she knows she was abandoned for a long time. In her scrambled language, she pleads with me to care for her and not leave her alone again.

With residents and families now vaccinated, the benefit of a year and a half's worth of research and education, let's see if we can get it right this time and show some humanity to

the most vulnerable, voiceless population while employing the common sense safety precautions with which we're now all familiar. Let's see if we can pass merciful essential caregiver legislation. Mom clings to limited phrases, and a curious new one popped into her lexicon after our lockout. At the slightest indication of anything going awry, she now immediately looks at me and says, "I'm sorry!" Whatever precipitated this new instinctive reaction by my mom haunts me every day. [Charlie Galligan](#)

Rhode Island

PEOPLE DIED ALONE, FORCED TO SAY GOODBYE ON A CELL PHONE

Isolation had a devastating effect on my grandmother whose mental and physical health declined rapidly when she was no longer allowed close and regular in person contact with an essential caregiver from her family. She is visually and hearing-impaired and virtual visits were not beneficial to her like many with sensory or cognitive disabilities. She lost weight, suffered depression, and her overall quality of care plummeted without family to watch over her and ensure accountability and adequate care. She has never been the same. Families were never the cause of the infection surges. People died alone, forced to say goodbye to their families on a cell phone, if that. Legislation must be passed to ensure that our most vulnerable are never left behind in this atrocious way again. Isolation kills, too. *Keri Rossi-D'entremont*

ALL I WANT IS MY FAMILY

When I was finally allowed a virtual call with my mother, two CNAs physically supported her as she cried out to me, "Where are you? Get me out of here! I want to go home! All I want is my family! All I want is my family!" I tried to talk her out of her agitated state but dementia prevented her from understanding why visitation was halted. All of the restrictions were purportedly put in place to protect my mother from contracting COVID-19 but instead, they only served to diminish her quality of life. My mother died in the nursing home on January 16, 2021 from COVID, just four days after turning 101. *Barbara Tarczuk*

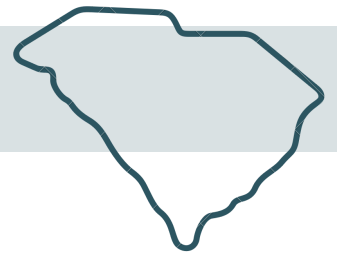
HE NEVER KNEW I WAS IN FRONT OF HIM

Until the pandemic, I was always at my husband's side. He requires human touch to know somebody is in his presence. When I was finally allowed to "visit" him, we sat outside in a garden in the heat, six feet apart, separated by plexiglass. I wore a mask and was not allowed to touch him. He sat in his "scoot chair" at the far end of the table with his eyes closed so I kept loudly repeating his name but he never knew I was in front of him. *Roni Ferraro*

HE DIED BUT NOT OF COVID-19

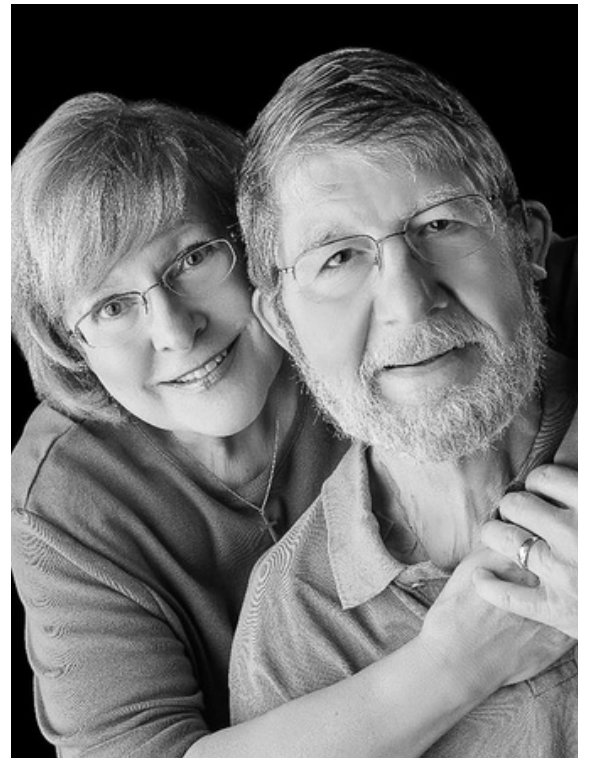
My dad died in a memory care unit but not of COVID-19. Prior to being locked out, I was my dad's advocate and voice, checked on him daily, and assisted with fluids, feeding, range of motion, skin care, mental stimulation, and of course, love. He suffered from dementia and I firmly believe that isolation, confusion, and my inability to supplement his care were significant contributing factors to his death.

Susan Hodgkin



I AM DEVASTATED THAT MY HUSBAND OF ALMOST 38 YEARS DIED ALONE

My husband was already dealing with progressing dementia when he was diagnosed with Parkinson's Disease. When he was admitted to a short-term rehab facility following a brief hospitalization, I was only allowed very short visits through his window. He was in the rehabilitation facility for ten days. Through his window, it was obvious to me that his mental and physical health was rapidly deteriorating. He did not even know who I was. The last time I saw him, he would not make eye contact with me. The night nurse went into his room early the next morning to check on him before shift change and found him dead. I am haunted by the likelihood that my husband felt abandoned by me which must have been bewildering and frightening. And, I am devastated that my husband of almost 38 years died alone. [Karen Basso](#)



THE NURSE SAID MAMA HAD SMILED AT HER, HAD TAKEN A BREATH AND DIED

At age 90, my mother chose on her own to live in a long-term care facility during her declining health. I visited her every day from the time she entered the facility in December, 2019 until the lock-down in March 2020. For 53 days, we could only talk on the phone. She missed her family. Then came that week. Monday, she was fine. Tuesday, she didn't feel well and didn't want to talk to me on the phone. Wednesday, the nurses couldn't get her to stay awake. Thursday, I asked them to take her to the ER. They agreed, but I was not allowed to see her. I met the ambulance at the ER door but I was not allowed inside. She was admitted into the ICU with septic shock. Friday, they still wouldn't allow me to see her. Saturday morning, her nurse said Mama was doing well and asking for her family to come. She missed us. That afternoon, the nurse called again, this time in tears, and told me Mama had smiled at her, had taken a breath and died. Alone, asking for her family. Maybe, had I been allowed in the facility, I would have realized that she needed to go to ER sooner. [Debra Hanna](#)

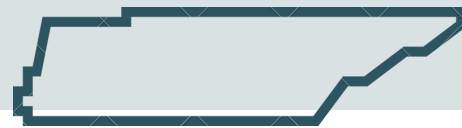


HOW IS IT MORE SANITARY FOR THE AIDE TO HANDLE WHAT I JUST HANDLED?

My mother's 85th birthday was held virtually. She held a tablet and sat next to a window where she could see everyone outside and we communicated via cell phone outside the facility. She did not understand virtual communication so instead of looking and listening to the screen, she watched us outside, the balloons, and kids drawing for her on the sidewalk. All this talk about using technology to accomplish contact simply doesn't work. My mom cannot plug in a cell phone, much less visit on one. This past summer, a staff member told us that my mom had asked if her family was mad at her because nobody comes to visit.

We have been allowed distanced in-house visits since June. I am allowed to visit 20 or 30 minutes at a distance and am escorted to the visiting area by an aide with the same mask I'm wearing who may or may not have had the same vaccine that I and my mother have had. I am not allowed to hand my mother the photos I bring to help her remember her family but must hand them to an aide who hands them to my mother. The aide is handling what I just handled. How is that safer or more sanitary?

The last time my mom was in a hospital, someone from our family was with her 24 hours a day. This was primarily due to her inability to understand and communicate. Somebody with dementia may not even know how to push a call button, and a hospital stay is confusing. That confusion is compounded for a person in long-term care. There are different doctors and nurses on different shifts and different days. People are in and out of the room taking vitals, weight, or temperature. Housekeepers clean, launderers pick up clothing and bedding, and kitchen staff bring trays in and out. Technicians and contractors make repairs and groundskeepers are right out the window. There are people everywhere but they are not family. Families understand the need for infection control and the fear of bringing disease into the facility. Residents do not understand. And that support person, the one who helps the resident communicate and feel safe, is essential. Vicki Franzen



ISOLATION CAUSED HER TO HALLUCINATE

At first, my mother did okay with the lock-down but then she had a doctor appointment and was required to isolate for two weeks. Then, the hallucinations began. When she moved back to her room, she improved but another doctor visit required another two week stint in isolation and more hallucinations. When her tonsil cancer was found which required treatment every three weeks, she lived for months in total isolation, crying and hallucinating until she no longer wanted to live. When we were allowed to see her one at a time, the hallucinations stopped. Nobody should be required to live like that. [Resha Oliphant](#)

COMPASSIONATE CARE VISITS DENIED

When my mother became despondent and dropped to only 96 pounds during the lock-down, I quoted the CMS guidelines and asked the facility for compassionate care visits. Denied. My ombudsman also asked. Denied. She escalated it to the state ombudsman. Denied. I insisted she go to a hospital where I hugged her for the first time in seven months and never left her side for two weeks. Her speech dwindled down to nothing and she would pull her blanket over her head and hide. What happened to my mother and tens of thousands of others must never happen again. [Tara Thompson](#)



HE ENDURED UNNECESSARY SUFFERING

My father's facility put an armed guard at the entrance. Dad was 89 and entirely cognitively intact. He was confined to his apartment for weeks and ate cold meals alone out of containers. The assisted living facility threatened to evict him if he went to his regular urologist appointments. They compromised with two weeks of quarantine in his apartment after each visit. Even though he ate well on outings, he lost over 30 pounds and his doctor could find no medical reason for it. The facility refused to allow him to go outdoors, something he did every day before the lock-down. Eventually they allowed him outside for one hour a week. He couldn't open his windows for fresh air because the facility screwed them shut. Eventually there was "visitation" behind a plexiglass wall but he couldn't hear well enough. At Thanksgiving he was able to manage liquids and soft solids without difficulty but six weeks later, he was unable to swallow anything and nobody in his assisted living facility noticed. He ultimately developed pneumonia. I requested several, but was allowed only one compassionate care visit, even though CMS guidelines plainly allowed for more. So, I took him home and he passed away a few days later. He never had COVID-19. His causes of death were pneumonia and failure to thrive and he endured unnecessary suffering due to my absence. [Nell Nestor](#)



ESSENTIAL CAREGIVERS WERE ADDED TO EMERGENCY VISITATION GUIDELINES IN TEXAS IN SEPTEMBER OF 2020

Visitation restrictions in my mom's small assisted living facility subjected my mom (pictured left) to 207 days of isolation from the one person she chose to protect her during her Alzheimer's journey. I was "non-essential". The only connection I had to my non-verbal, wheelchair bound mom was through the glass door of her back patio. The fear of never having an opportunity to deliver one last hug and kiss before my mother died was just as great as my fear of her exposure to a virus. [Genny Lutzel](#)

We visited our dying mother (pictured middle left) through an open window, shielded with plexiglass. Plexiglass visits are not enough—especially when loved ones, like my mom, are on hospice. She had a grandchild she was never allowed to meet. [Jamie Gallman and Marla Dorris](#)

My mom (pictured middle right) spent so much time in a wheelchair that her degenerative spine disease accelerated and she will never walk again. I feel certain that had we been allowed to visit her, we could have identified the issues that contributed to her decline, provided the items she needed like a platform walker and she might still be walking today. [Denise Itz](#)

My son (pictured right) has the mental capacity of a three year old and was incapable of understanding why his mother disappeared off the face of the earth. Virtual visits only made him look around the room and in the hallway for me. He has not regained what was lost through his developmental regression during the lock-down and I still don't think he trusts or believes that I won't just disappear from his life again. [Stephanie Kirby](#)



ESSENTIAL CAREGIVERS ARE STATUTORY

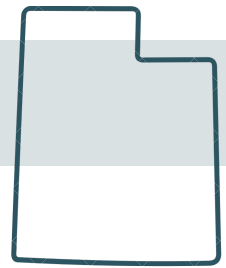
When Texas added essential caregivers to their emergency visitation guidelines on September 24, 2020, I was allowed to see my mother (pictured left), who has end-stage Alzheimer's, for the first time in 202 days. She no longer spoke, made eye contact, responded to my voice, moved her own limbs, or could turn her own head. I watched from the camera in her room as she lost the remnants of her cognition while living alone, curtain pulled, and nobody speaking a word to her. Essential caregivers are now statutory in Texas and may be amended into the Texas constitution if approved by voters in November. **Mary Nichols**

My brother (pictured middle left) has pervasive development disorder and intermittent explosive disorder among other conditions that require 24/7 supervision. Prior to the essential caregiver guidelines adopted in Texas, his birthday passed with no party, he missed our summer vacation, and he was not allowed to attend his own father's funeral. **Amanda Horner**

As a toddler, my daughter (pictured middle right) became gravely ill with viral encephalitis. We lived in Lima, Peru during a time of political unrest and we were not allowed to be with our daughter for 17 days. I promised her we would never be separated again. This was true for 43 years until March 17, 2020. Virtual visits and visitation through glass doors do not work for her. She requires physical touch. Our relationship with our daughter has been damaged and we are still working to regain the trust we lost during that time she thought she was abandoned. **Sue Venear Schnars**

My daughter (pictured right) suffers from a traumatic brain injury. She can only speak a few words and cannot read, write, explain her pain, notify anyone of her needs, or express her frustration. Isolation increased her moderate psychosis, sleep deprivation, anxiety and stress. Any agitation or adjustment in her environment can bring on a severe or acute psychosis so isolation is extremely dangerous for her. As her essential caregiver and guardian, I carefully monitor her and keep her safe. **Angela Biggs**



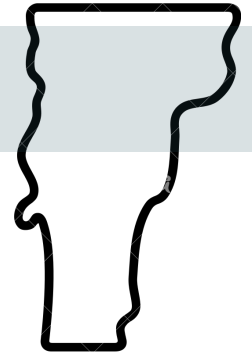


HE IS ONLY 46 YEARS OLD AND NO LONGER KNOWS HIS OWN WIFE AND CHILDREN

We were scheduled for a family photo session on March 14, 2020. But the facility was locked down the day before and the photos were cancelled. Then, my kids and I missed an entire year of my 46 year old husband's life. We were allowed window visits for a while until other residents' frustrated family members broke rules, which resulted in the privilege being revoked for all residents.



When limited visitation began, two of us were allowed fifteen minute supervised visits in a conference room and they watched us closely to make sure we didn't get near him. Video chats didn't work because he no longer knew how to use a cell phone or even carry on a normal conversation. If a helper facilitated a virtual call, he would simply cry in confusion. He was capable of walking on his own that day we were scheduled to take the family photo but now, he is wheelchair bound. He was eating by himself but now, he has to be fed. He knew who we were and called us by name. Now, he just knows that we are related somehow. My kids and I have missed that whole year of being with him and he has missed that final year when he knew his wife and children. I believe he would rather have seen his family and risked getting COVID-19 than to have lost that year and live alone today. The staff is tired and overworked. They don't have time to give their full attention to each patient. Even if they did, residents like my husband do not receive the same love and attention from a staff member that they receive when that familiar face - that family member - comes in and helps their loved one. [Jamie Gordon](#)



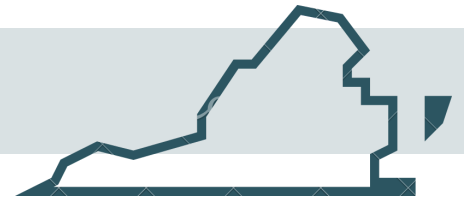
IF I HAD BEEN ALLOWED INSIDE THE FACILITY I DO NOT BELIEVE THAT MY MOTHER WOULD HAVE DIED

Seven months prior to my mother turning 87 in July, I had been told she was declining so much that she would not live more than six months. A few weeks after that birthday, she died of malnutrition. The death certificate noted it was malnutrition due to Alzheimer's dementia though my mom never forgot how to eat and never had difficulty swallowing. Her malnutrition was due to COVID -19 isolation.

When my mother, who lived in a skilled nursing facility, was admitted to hospice due to a sharp decline in her appetite, I was told that loss of ability to eat was part of the normal decline of dementia. However, once I was allowed outside visits and was given the time to encourage her to eat and allowed to feed her, she went from eating 25% of her meals to 95-100%. I attribute this to my ability to take the time to sit with her, to be patient while she ate, and to the fact that my mother was no longer depressed, lonely, and isolated.

During the height of the pandemic, the facility allowed online visits. While this might be an acceptable way for a person with full cognitive abilities to connect with loved ones, it does not work for most dementia patients. My mother was in bed most days, sleeping, and unable to focus on screens when she was awake. People with dementia face difficulties with perception and screens are noisy, agitating, and often nothing more than white noise. Dementia patients benefit from physical touch and a person's presence. In-person visits outdoors worked in fair weather but it was not wise to seat a frail, elderly person in the elements, especially hot and humid weather.

If I had been allowed inside the facility, as outlined in HR 3733, I do not believe my mother would have declined as much and as quickly or have died. My mother lived through one of the worst health emergencies in Vermont and did not get COVID but was put at greater risk due to her family being locked out. She died because of the toll isolation took on her. *Amy Saunders*



WE WATCHED OUR MEDICALLY UNSTABLE CHILD FROM THE WINDOW WHILE HE SEIZED



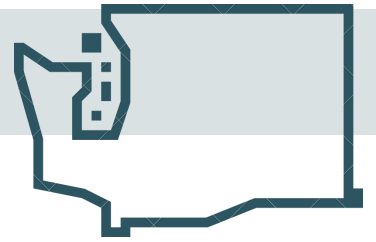
Our son has lived in a federally funded intermediate care facility for individuals with intellectual disabilities for the past seven years. We have been with him every day, attended every doctor's appointment, provided direct care for him - particularly changing his brief and brushing his teeth. We have been involved in his schooling and provided the continuity necessary to ensure that his safety and well-being are closely monitored so his care can be adjusted accordingly. But the COVID-19 pandemic separated us for months and then only allowed us thirty minute visits Monday through Friday for several additional months. Not only is his cognitive and physical regression caused by our removal from his life beyond measure, but we lost precious time with our child who is already on borrowed time. On his 13th birthday, he slept as we, from the window, tried to wake him.

We watched our medically unstable child from the window while he seized, he was stressed, confused, angry, and exhausted. Just before in-person visitation was allowed, he had stopped making eye contact with us. Throughout this pandemic we have spent hours talking with him about what has happened and why but talking and limited visitation are not enough to alleviate the impact of COVID-19 health policies on children and adults in long-term care settings. *Crystal Ton and George Mitzner*

A WINDOW OPENING SO NARROW THAT WE COULD BARELY SEE HER BEAUTIFUL FACE

My aunt lived her life to teach music. She was 92 when she entered her assisted living home but the following year, when COVID struck, we were only allowed window visits. If someone helped her open her second floor window, an opening so narrow that we could barely see her beautiful face. Deaf and suffering from dementia, she was incapable of understanding why we didn't come in and why she couldn't come out and enjoy the sunshine. As the year passed, she began refusing to eat. She was misdiagnosed with meningitis and caught COVID from a worker, hospitalized, and then released to home hospice. My aunt lived to be 94 and deserved better than what she received in her last year of life. *Carol Friedman*

Washington



AT 4'11" AND 105 POUNDS, SHE DIDN'T HAVE ANY SPARE WEIGHT TO LOSE



Initially going into the long-term care facility, my mom was exhibiting some mild dementia but nothing that caused us concern about her every day life at the facility or her time with us. But, after the lock-down, little by little, we could see the changes. By summer, she no longer remembered how to charge her cell phone or hearing aids and forgot how to change the channel on her TV. As the months wore on and the longer the residents were confined to their rooms for all meals and with no companionship of fellow residents, the less she ate and at 4'11" and 105 pounds, she didn't have any spare weight to lose. We put off taking her to the doctor over a stomach issue because it meant two weeks in quarantine upon her return. But when it could wait no longer, we took her to the doctor and then brought her home rather than force her to

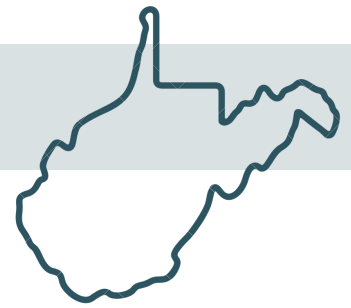
live in further isolation. She still has dementia but her teeth are brushed, her hearing aid is charged, and she gets the medical treatment she needs without two weeks of isolation. Laws need to be put in place so this never happens again. [Kim Miller](#)

EACH TIME AN EMPLOYEE TESTS POSITIVE THE FACILITY LOCKS DOWN AGAIN

My mom is a shell of what she was prior to the lock-down. She is 90% blind, has had two massive strokes, has diabetes and Parkinson's disease along with a handful of other health issues that make virtual visits, window waves, pen-pals, cards, letters, and encouraging signs outside of her window all useless. We were also only able to talk to her on the phone twice a month, if at all, due to staffing levels and COVID restrictions. A phone call required staff time to help her call, hang up the phone, and get back into bed.

When we finally saw her in person again, she had lost the ability to speak, could no longer walk, could no longer feed herself, and lost the use of her left arm and barely uses her right. Since she had not seen a doctor in a year, we do not know if she had a stroke. Each time an employee tests positive, the facility locks down again and she goes back into isolation, alone with the door closed and no longer able to even push a call button to summon help. [Kim Boekholder](#)

West Virginia



HE WAS SIX FEET TALL AND WEIGHED ONLY 80 POUNDS

Until the lock-down I visited my father every single day. He needed long-term care for his dementia and skilled nursing for his urinary tract infections. I was allowed to visit him three or four times throughout the lock-down, outdoors and distanced from each other. I was not allowed to touch or hug my own father. Regular phone calls to the nursing home went unanswered so I received no updates on his condition or care. Over the course of our outdoor visits, I noticed him declining physically and mentally. His dementia was accelerating from lack of family association, human

contact, and the comforting touch of his daughter. The isolation was killing him. On my last visit, he looked gravely ill and whispered "yes" when I asked if he needed a hospital. My father died a week later of a heart attack from severe dehydration and malnutrition. He was six feet tall and weighed only 80 pounds. He would still be alive today had I been allowed inside to make sure he was hydrated and nourished both physically and emotionally. The isolation killed my father. *Andrea Gould*

SHE COULD NOT EAT SOLID FOODS UNTIL THEY PUT HER DENTURES IN HER MOUTH

I saw my mother for up to seven hours a day prior to the lock-down in March of 2020. I assisted her with her eating, oversaw her diabetic friendly diet, helped her dress, took her for walks, and notified the staff of any irregularities in her expression or behavior. But, with COVID-19, I lost all contact. Virtual visits were limited to once a week. In June, I was allowed outside visits, distanced at six feet and closely supervised. But, that ended a month later and there was no visitation at all until closed window visits were allowed in September. Outdoor visits did not take place again until July 2021, a full year since they had come to a stop, and the visits were limited to thirty minutes. I could see my mother's physical and emotional decline through the window. She was unkempt and stared into space. She required assistance to walk to the window and was put on a diet of soft foods because they thought she couldn't eat solid foods. They were right. She couldn't eat solid food until they put her dentures in her mouth. Since I didn't see any other visitors, I asked for more than thirty minutes. Denied. Being locked out is a tragedy for us and our loved ones and restricting outdoor and window visits at the facility's discretion is inhumane. *Deborah Buchanan*

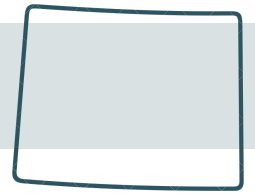


DURING THE FIRST TWO WEEKS OF THE LOCK-DOWN, HER ABILITY TO SPEAK COHERENTLY ON THE PHONE DEVOLVED INTO MEANINGLESS SINGLE SOUNDS

Mom had dementia and resided in assisted living. Until March of 2020, my brother, who lived nearby, visited almost every day. I lived further away and visited once or twice a month but called regularly. During a visit in February 2020, mom was dancing and singing to some oldies which, thankfully, I recorded and saved on video. Then the lock-down began.

Without regular face to face contact with us, mom deteriorated quickly. During the first two weeks, her ability to speak coherently on the phone devolved into meaningless single sounds. She stopped walking, eating, or even waking up. By mid-April, she was unresponsive, and even the staff was shocked at her rapid decline.

When she was placed in hospice, we were finally allowed to visit, but it was too late to bring her back. She passed away in early May. Even at her funeral, the lock-down denied us the comfort of family and friends standing with us in our grief. Laurie Griepentrog



THE SHORT STAFFED FACILITY DIDN'T ANSWER THE PHONE

My mother was the last resident in her nursing home to catch COVID-19 after every resident and every staff member had already caught it. She recovered and lived long enough to test negative but shortly afterward, had a stroke and passed on.

Before this lock-down, my brother and sister-in-law regularly visited her but I live in another state. We spoke frequently on the phone and she told me many heartbreaking things. I would hold back my tears and only cry after we hung up the phone. My brother and sister-in-law were allowed a few distant lawn visits and one in-person visit when she was in the hospital.

Towards the end, we did get to do virtual calls and the change in my Mom was alarmingly visible. I knew her physical and mental health was declining. She was anxious and depressed but trying to stay strong and put on a brave face for our sakes. Before long, though, she began calling my brother and begging him to help her because she couldn't leave her room and ask a staff member for help. All my brother could do was call the facility and relay her needs or stand on the lawn and tell an employee passing by when the short staffed facility didn't answer the phone and it just rang and rang and rang.

That this happened to the senior adults in our country after what they have contributed to our nation is unthinkable. I think of my mom day and night still and the suffering she endured and hope that some kind of legislation will be put in place so this doesn't happen to anyone else. **Candace Carne**



PROTECTING THEM TO DEATH ADDENDUMS

H.R.3733

*The Essential
Caregiver Act*

NURSING HOME RIGHTS

*Federal Rights As Outlined by the Centers
for Medicaid and Medicare Services Under
Residents' Rights & Quality of Care*



.....
(Original Signature of Member)

117TH CONGRESS
1ST SESSION

H. R. 3733

To amend titles XVIII and XIX of the Social Security Act to require skilled nursing facilities, nursing facilities, intermediate care facilities for the intellectually disabled, and inpatient rehabilitation facilities to permit essential caregivers access during any public health emergency under the Medicare and Medicaid programs.

IN THE HOUSE OF REPRESENTATIVES

Ms. TENNEY introduced the following bill; which was referred to the Committee on _____

A BILL

To amend titles XVIII and XIX of the Social Security Act to require skilled nursing facilities, nursing facilities, intermediate care facilities for the intellectually disabled, and inpatient rehabilitation facilities to permit essential caregivers access during any public health emergency under the Medicare and Medicaid programs.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

1 **SECTION 1. SHORT TITLE.**

2 This Act may be cited as the “Essential Caregivers
3 Act of 2021”.

4 **SEC. 2. RIGHT TO ESSENTIAL CAREGIVERS.**

5 During a public health emergency declared by the
6 Secretary of Health and Human Services under section
7 319 of the Public Health Service Act, a resident of any
8 skilled nursing facility (as defined in section 1819(a) of
9 the Social Security Act (42 U.S.C. 1395i–3(a))), nursing
10 facility (as defined in section 1919(a) of such Act (42
11 U.S.C. 1396r(a))), inpatient rehabilitation facility de-
12 scribed in section 1886(a)(1)(Z) of such Act (42 U.S.C.
13 1395cc(a)(1)(Z)), or intermediate care facility for the in-
14 tellectually disabled (as defined in section 1905(d) of such
15 Act (42 U.S.C. 1396d(d)) has the right to designate two
16 essential caregivers to have access to and provide assist-
17 ance and support to the resident at any time notwith-
18 standing any waiver made under section 1135 of the So-
19 cial Security Act (42 U.S.C. 1320b–5). The resident may
20 change who is designated as an essential caregiver.

21 **SEC. 3. REQUIRING FACILITIES TO PERMIT ESSENTIAL**
22 **CAREGIVERS ACCESS DURING ANY PUBLIC**
23 **HEALTH EMERGENCY.**

24 (a) **SKILLED NURSING FACILITIES; NURSING FA-**
25 **CILITIES.**—Section 1819(e) and 1919(e) of the Social Se-

1 curity Act (42 U.S.C. 1395i-3(c), 1396r(c)) are each
2 amended—

3 (1) in paragraph (3)—

4 (A) in subparagraph (D), by striking
5 “and” at the end;

6 (B) in subparagraph (E), by striking the
7 period and inserting “; and”; and

8 (C) by adding at the end the following new
9 subparagraph:

10 “(F) implement and maintain, during any
11 public health emergency declared by the Sec-
12 retary under section 319 of the Public Health
13 Service Act on or after the date of the enact-
14 ment of this subparagraph for the area in which
15 such facility is located and notwithstanding any
16 waiver made under section 1135, the essential
17 caregivers program described in paragraph
18 (7).”; and

19 (2) by adding at the end the following new
20 paragraph:

21 “(7) ESSENTIAL CAREGIVERS PROGRAM.—

22 “(A) IN GENERAL.—For purposes sub-
23 paragraph (F) of paragraph (3), the essential
24 caregivers program described in this paragraph
25 is a program implemented by a facility de-

1 scribed in such paragraph under which such fa-
2 cility shall—

3 “(i) allow each resident of such facil-
4 ity the unqualified ability to elect not more
5 than 2 essential caregivers (as defined in
6 subparagraph (D)) to have access to, and
7 provide assistance (as described in sub-
8 paragraph (C)(i)) to, such resident at such
9 facility, and allow each such resident to
10 amend such election at any time;

11 “(ii) permit each such caregiver so
12 elected by such resident to provide such as-
13 sistance to such resident at such facility
14 for 12 hours every day (or, in the case
15 such care is end-of-life care, for an unlim-
16 ited number of hours every day); and

17 “(iii) enforce the agreement described
18 in subparagraph (C)(ii) with respect to an
19 essential caregiver.

20 “(B) PRESUMPTION OF ELECTION.—For
21 purposes of subparagraph (A), in the case of a
22 resident who is unable, by reason of physical or
23 mental disability, to make an election described
24 in such subparagraph, the resident representa-
25 tive (as defined in section 483.5 of title 42,

1 Code of Federal Regulations) of such resident
2 shall be permitted to make such election for
3 such resident.

4 “(C) ESSENTIAL CAREGIVER DEFINED.—
5 For purposes of this paragraph, the term ‘es-
6 sential caregiver’ means, with respect to a resi-
7 dent of a facility described in subparagraph
8 (A), an individual who—

9 “(i) will provide assistance consisting
10 of activities of daily living, emotional sup-
11 port, or companionship to such resident;
12 and

13 “(ii) agrees to follow all safety proto-
14 cols established by such facility, which
15 shall be clearly specified in writing and be
16 the same as such protocols (including safe-
17 ty standards and entry requirements) ap-
18 plicable to staff of such facility.”.

19 (b) INTERMEDIATE CARE FACILITIES FOR THE IN-
20 TELLECTUALLY DISABLED.—Section 1905(d) of the So-
21 cial Security Act (42 U.S.C. 1396d(d)) is amended—

22 (1) in paragraph (2), by striking “and” at the
23 end;

24 (2) in paragraph (3), by striking the period and
25 inserting “; and”; and

1 (3) by adding at the end the following new
2 paragraph:

3 “(4) the institution implements and maintains,
4 during any public health emergency declared by the
5 Secretary on or after the date of the enactment of
6 this paragraph under section 319 of the Public
7 Health Service Act for the area in which such insti-
8 tution is located and notwithstanding any waiver
9 made under section 1135, the essential caregivers
10 program described in section 1919(c)(7) in the same
11 manner as if such institution were a nursing facil-
12 ity.”.

13 (c) INPATIENT REHABILITATION FACILITIES.—Sec-
14 tion 1866(a)(1) of the Social Security Act (42 U.S.C.
15 1395cc(a)(1)) is amended—

16 (1) in subparagraph (X), by striking “and” at
17 the end;

18 (2) in subparagraph (Y), by striking the period
19 at the end and inserting “, and”; and

20 (3) by inserting after subparagraph (Y) the fol-
21 lowing new subparagraph:

22 “(Z) in the case of an inpatient rehabilitation
23 facility that is located on the same campus (as de-
24 fined by the Secretary) as a skilled nursing facility,
25 nursing facility (as defined in section 1919(a)), or

1 intermediate care facility for the intellectually dis-
2 abled (as described in section 1905(d)), to establish
3 and maintain, during any public health emergency
4 declared by the Secretary on or after the date of the
5 enactment of this paragraph under section 319 of
6 the Public Health Service Act for the area in which
7 such institution is located and notwithstanding any
8 waiver made under section 1135, the essential care-
9 givers program described in section 1819(e)(7) in
10 the same manner as if such institution were a skilled
11 nursing facility.”.

12 (d) COMPLIANCE AND NOTIFICATION.—

13 (1) AUTHORITY.—No caregiver who meets the
14 definition of an essential caregiver in clause (i) of
15 paragraph (7)(C) of either section 1819(e) and
16 1919(c) of the Social Security Act and who upholds
17 the agreement described in clause (ii) of such para-
18 graph shall be denied access to the skilled nursing
19 facility (as defined in section 1819(a) of the Social
20 Security Act (42 U.S.C. 1395i-3(a))), nursing facil-
21 ity (as defined in section 1919(a) of such Act (42
22 U.S.C. 1396r(a))), inpatient rehabilitation facility
23 described in section 1886(a)(1)(Z) of such Act (42
24 U.S.C. 1395cc(a)(1)(Z)), or intermediate care facil-
25 ity for the intellectually disabled (as defined in sec-

1 tion 1905(d) of such Act (42 U.S.C. 1396d(d)) of
2 the resident involved.

3 (2) NOTIFICATION.— In the event of non-com-
4 pliance with either such clause, such facility must
5 first provide a warning to the essential caregiver and
6 resident in writing citing specific issues of non-com-
7 pliance and providing clear guidance for corrective
8 measures.

9 (3) ENFORCEMENT.—Should the essential care-
10 giver or resident fail to take corrective action, they
11 may be subsequently denied access. In such cases,
12 the facility shall provide to such caregiver and such
13 resident (or health care proxy of such resident), not
14 later than 24 hours after such failure to allow access
15 occurs, a written explanation as to why such care-
16 giver was not permitted to furnish such assistance to
17 such resident. Such explanation must include the
18 resident's and caregivers' options for appeal (as de-
19 scribed in subsection (e)).

20 (e) OPTIONS FOR RESIDENT AND CAREGIVER AP-
21 PEAL.—

22 (1) IN GENERAL.—During any period in which
23 any skilled nursing facility (as defined in section
24 1819(a) of the Social Security Act (42 U.S.C.
25 1395i-3(a))), nursing facility (as defined in section

1 1919(a) of such Act (42 U.S.C. 1396r(a))), inpa-
2 tient rehabilitation facility described in section
3 1886(a)(1)(Z) of such Act (42 U.S.C.
4 1395cc(a)(1)(Z)), or intermediate care facility for
5 the intellectually disabled (as defined in section
6 1905(d) of such Act (42 U.S.C. 1396d(d)) is re-
7 quired to establish and maintain the essential care-
8 givers program under section 1819(c)(3)(F) of such
9 Act, section 1919(c)(3) of such Act, or section
10 1905(d)(4) of such Act (as added by subsections (a)
11 and (b)), the Secretary of Health and Human Serv-
12 ices shall, not later than 15 days after the first day
13 of such period, establish and maintain a process
14 to—

15 (A) receive appeals from residents and
16 caregivers challenging a decision to deny access;
17 and

18 (B) investigate all such appeals within 48
19 hours of receipt.

20 (f) ENFORCEMENT.—With respect to appeals re-
21 ceived under paragraph (1), the Secretary of Health and
22 Human Services shall make a determination as to whether
23 a facility described in subsection (c)(1) violated a require-
24 ment or prohibition in this Act or in an amendment made
25 by this Act within 7 days of commencing its investigation.

1 If the Secretary determines that a facility has violated a
2 requirement or prohibition in this Act or in an amendment
3 made by this Act, the Secretary shall—

4 (1) require the facility to establish a corrective
5 action plan to prevent the recurrence of such viola-
6 tion within a 7- day period of receiving notice from
7 the Secretary; and

8 (2) impose a civil money penalty in an amount
9 to be determined by the Secretary if such facility
10 fails to implement the corrective action plan with the
11 7-day period specified in paragraph (1).

12 (g) REGULATIONS.—The Secretary of Health and
13 Human Services shall, after consultation with stakeholders
14 (including residents, family members, long-term care om-
15 budsmen, other advocates of nursing home residents, and
16 nursing home providers, promulgate regulations to carry
17 out this Act.

Your Rights and Protections as a Nursing Home Resident

What are my rights in a nursing home?

As a nursing home resident, you have certain rights and protections under Federal and state law that help ensure you get the care and services you need. You have the right to be informed, make your own decisions, and have your personal information kept private.

The nursing home must tell you about these rights and explain them in writing in a language you understand. They must also explain in writing how you should act and what you're responsible for while you're in the nursing home. This must be done before or at the time you're admitted, as well as during your stay. You must acknowledge in writing that you got this information.

At a minimum, Federal law specifies that nursing homes must protect and promote the following rights of each resident. You have the right to:

- **Be Treated with Respect:** You have the right to be treated with dignity and respect, as well as make your own schedule and participate in the activities you choose. You have the right to decide when you go to bed, rise in the morning, and eat your meals.
- **Participate in Activities:** You have the right to participate in an activities program designed to meet your needs and the needs of the other residents.
- **Be Free from Discrimination:** Nursing homes don't have to accept all applicants, but they must comply with Civil Rights laws that say they can't discriminate based on race, color, national origin, disability, age, or religion. The Department of Health and Human Services, Office for Civil Rights has more information.
- **Be Free from Abuse and Neglect:** You have the right to be free from verbal, sexual, physical, and mental abuse. Nursing homes can't keep you apart from everyone else against your will. If you feel you have been mistreated (abused) or the nursing home isn't meeting your needs (neglect), report this to the nursing home, your family, your local Long-Term Care Ombudsman, or State Survey Agency. The nursing home must investigate and report all suspected violations and any injuries of unknown origin within 5 working days of the incident to the proper authorities.
- **Be Free from Restraints:** Nursing homes can't use any physical restraints (like side rails) or chemical restraints (like drugs) to discipline you for the staff's own convenience.
- **Make Complaints:** You have the right to make a complaint to the staff of the nursing home, or any other person, without fear of punishment. The nursing home must address the issue promptly.

- **Get Proper Medical Care:** You have the following rights regarding your medical care:
 - To be fully informed about your total health status in a language you understand.
 - To be fully informed about your medical condition, prescription and over-the-counter drugs, vitamins, and supplements.
 - To be involved in the choice of your doctor.
 - To participate in the decisions that affects your care.
 - To take part in developing your care plan. By law, nursing homes must develop a care plan for each resident. You have the right to take part in this process. Family members can also help with your care plan with your permission.
 - To access all your records and reports, including clinical records (medical records and reports) promptly (on weekdays). Your legal guardian has the right to look at all your medical records and make important decisions on your behalf.
 - To express any complaints (sometimes called “grievances”) you have about your care or treatment.
 - To create advance directives (a health care proxy or power of attorney, a living will, after-death wishes) in accordance with State law.
 - To refuse to participate in experimental treatment.

- **Have Your Representative Notified:** The nursing home must notify your doctor and, if known, your legal representative or an interested family member when the following occurs:
 - You’re involved in an accident and are injured and/or need to see a doctor.
 - Your physical, mental, or psychosocial status starts to get worse.
 - You have a life threatening condition.
 - You have medical complications.
 - Your treatment needs to change significantly.
 - The nursing home decides to transfer or discharge you from the nursing home.

- **Get Information on Services and Fees:** You have the right to be told in writing about all nursing home services and fees (those that are charged and not charged to you) before you move into the nursing home and at any time when services and fees change. In addition:
 - The nursing home can’t require a minimum entrance fee if your care is paid for by Medicare or Medicaid.
 - For people seeking admission to the nursing home, the nursing home must tell you (both orally and in writing) and also display written information about how to apply for and use Medicare and Medicaid benefits.
 - The nursing home must also provide information on how to get a refund if you paid for an item or service, but because of Medicare and Medicaid eligibility rules, it’s now considered covered.

- **Manage Your Money:** You have the right to manage your own money or to choose someone you trust to do this for you. In addition:

- If you deposit your money with the nursing home or ask them to hold or account for your money, you must sign a written statement saying you want them to do this.
 - The nursing home must allow you access to your bank accounts, cash, and other financial records.
 - The nursing home must have a system that ensures full accounting for your funds and can't combine your funds with the nursing home's funds.
 - The nursing home must protect your funds from any loss by providing an acceptable protection, such as buying a surety bond.
 - If a resident with a fund dies, the nursing home must return the funds with a final accounting to the person or court handling the resident's estate within 30 days.
- **Get Proper Privacy, Property, and Living Arrangements:** You have the following rights:
 - To keep and use your personal belongings and property as long as they don't interfere with the rights, health, or safety of others.
 - To have private visits.
 - To make and get private phone calls.
 - To have privacy in sending and getting mail and email.
 - To have the nursing home protect your property from theft.
 - To share a room with your spouse if you both live in the same nursing home (if you both agree to do so).
 - The nursing home has to notify you before your room or your roommate is changed and should take your preferences into account.
 - To review the nursing home's health and fire safety inspection results.
- **Spend Time with Visitors:** You have the following rights:
 - To spend private time with visitors.
 - To have visitors at any time, as long as you wish to see them, as long as the visit does not interfere with the provision of care and privacy rights of other residents
 - To see any person who gives you help with your health, social, legal, or other services may at any time. This includes your doctor, a representative from the health department, and your Long-Term Care Ombudsman, among others.
- **Get Social Services:** The nursing home must provide you with any needed social services, including the following:
 - Counseling.
 - Help solving problems with other residents.
 - Help in contacting legal and financial professionals.
 - Discharge planning.

- **Leave the Nursing Home:**

- **Leaving for visits:** If your health allows, and your doctor agrees, you can spend time away from the nursing home visiting family or friends during the day or overnight, called a “leave of absence.” Talk to the nursing home staff a few days ahead of time so the staff has time to prepare your medicines and write your instructions. **Caution:** If your nursing home care is covered by certain health insurance, you may not be able to leave for visits without losing your coverage.
- **Moving out:** Living in a nursing home is your choice. You can choose to move to another place. However, the nursing home may have a policy that requires you to tell them before you plan to leave. If you don’t, you may have to pay an extra fee.
- **Have Protection Against Unfair Transfer or Discharge:** You can’t be sent to another nursing home, or made to leave the nursing home, unless any of the following are true:
 - It’s necessary for the welfare, health, or safety of you or others.
 - Your health has improved to the point that nursing home care is no longer necessary.
 - The nursing home hasn’t been paid for services you got.
 - The nursing home closes.

You have the following rights:

- You have the right to appeal a transfer or discharge to the State.
- The nursing home can’t make you leave if you’re waiting to get Medicaid.
- Except in emergencies, nursing homes must give a 30-day written notice of their plan and reason to discharge or transfer you.
- The nursing home has to safely and orderly transfer or discharge you and give you proper notice of bed-hold and/or readmission requirements.
- **Form or Participate in Resident Groups:** You have a right to form or participate in a resident group to discuss issues and concerns about the nursing home’s policies and operations. Most homes have such groups, often called “resident councils.” The home must give you meeting space and must listen to and act upon grievances and recommendations of the group.
- **Have Your Family and Friends Involved:** Family and friends can help make sure you get good quality care. They can visit and get to know the staff and the nursing home’s rules. Family members and legal guardians may meet with the families of other residents and may participate in family councils, if one exists. Family members can help with your care plan with your permission. If a family member or friend is your legal guardian, he or she has the right to look at all medical records about you and make important decisions on your behalf.

S U P P O R T E R S O F H R 3 7 3 3

Advocates for COVID Nursing Home Residents
Caregivers for Compromise Because Isolation Kills, Too!
California Advocates for Nursing Home Reform
Center for Estate Administration Reform
Center for Medicare Advocacy
Dignity for the Aged
Essential Caregivers Coalition
Elder Justice Committee of Metro Justice
FACE New Jersey
The Green House Project
Long Term Care Community Coalition
Louise Aronson, M.D., Author of "Elderhood"
National Association of Mental Illness (NAMI)
National Association of State Long-Term Care Ombudsman Programs (NASOP)
The National Consumer Voice for Long-Term Quality Care
North Dakota Advocacy for Long-Term Care
Our Mother's Voice
Voices for Seniors

T H A N K Y O U

GENEROUS DONORS WHO FUNDED THE PUBLICATION OF THIS CRITICAL BOOK

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PROVIDERS WHO CARRY THE BLAME FOR BAD ACTORS, WORK EXCESSIVE HOURS, AND
PUT THEMSELVES AND THEIR OWN FAMILIES AT RISK TO CARE FOR OUR LOVED ONES

THOSE HEALTH AUTHORITIES AND PUBLIC OFFICIALS ACROSS THE COUNTRY THAT
ARE WORKING TO DO BETTER NOW THAT WE KNOW BETTER

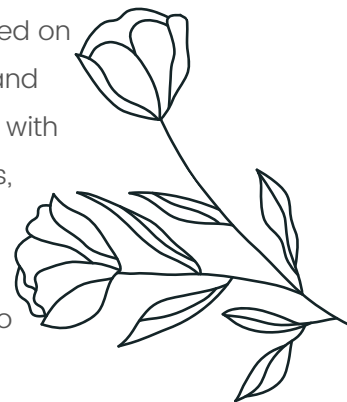
The Essential Caregiver Movement



The Essential Caregiver Movement is a group of grassroots advocacy leaders representing seventeen states across the country who work together to support visitation in long-term care facilities. Collectively, we speak for hundreds of thousands of families and residents living in long-term care. We are also the children, spouses, parents, siblings, and friends who were locked out of long-term care facilities on March 13, 2020 and declared non-essential. After months of waiting for our elected and appointed officials to come up with a solution, we joined together and offered one of our own: essential caregivers.

We believe that in the absence of visitors, each resident should have the right to designate at least one person - an essential caregiver or essential support person of his or her choice to help prevent the extreme weight loss, rapid cognitive decline, despondency, and death directly related to the implementation of isolation protocols designed to protect them. Essential caregivers are also those extra eyes that mitigate the potential for abuse and neglect as well as make sure other resident rights are not paused: voting, receiving mail, practicing religion, participating in care decisions, choosing a doctor, using their own property or even leaving the facility of their own free will.

Our group leaders have worked to pass state legislation, participated on task forces, helped develop state emergency visitation guidelines and long-term care policies, developed on-going working relationships with state and national legislators, agencies, commissions, departments, provider groups, and government staff members, testified in state hearings, written state and federal bill language, and worked with hundreds of state and national media outlets to bring awareness to the consequences of isolation protocols.



Essential caregivers must become part of permanent policy in long-term care facilities across the United States and this book shows why.