



TEXAS CAREGIVERS FOR COMPROMISE

BECAUSE ISOLATION KILLS, TOO!

SUBMITTED TO THE HONORABLE JAMES E. CLYBURN, CHAIR AND THE SELECT SUBCOMMITTEE ON THE CORONAVIRUS CRISIS

REGARDING THE IMPACT OF COVID-19 ON NURSING HOMES

Texas Caregivers for Compromise is a group of 3100 families of residents in long-term care. We are not lobbyists or attorneys, just families. I'm just a daughter that went 202 days without seeing her dying mother due to isolation protocols and made a decision to work toward solutions. We are one of a multitude of resident advocacy groups birthed out of the pandemic. Texas families have been very active and helped institute effective state legislation. But, we believe much is still to be addressed at the federal level. While we could report in excess and give pages of examples, we are concerned primarily about (1) in-person visitation, (2) an abundance of waivers, (3) loss of basic rights, and (4) immunity from prosecution for abuse and neglect.

THE WHITE HOUSE REFORMS We are grateful for the reforms proposed by the White House earlier this year and believe continued attention at the federal level and aggressive implementation of these reforms is critical. To be clear: nursing homes are NOT the enemy. COVID-19 is. We have worked very closely with providers in the past two years and are concerned for the future of the long-term care industry in the event of a future health emergency.

VISITATION Isolation protocols that prohibited in-person visitation were meant to protect residents from COVID-19. But, they had the unintended consequence of escalating disease and increasing deaths due to despondency, extreme weight loss, rapid cognitive decline, and general loss of a will to live. These deaths are attributed to "failure to thrive". We believe very strongly that there is a compromise that makes infection control a high priority but does not strip residents completely of their 24/7 federal right to all in-person physical and emotional support from friends and family.

- **EXACERBATION OF STAFFING SHORTAGE** Family members perform so many patient care duties that the complete removal or declaration of them as "non-essential" shifted their duties during the pandemic to CNAs. It was like adding a 40% work load or greater to each individual staff member who now had additional residents for whom they had to spoon feed, groom, dress, oversee minor wound-care, and perform a multitude of non-medical tasks.
- **PROTECTION FROM ABUSE AND NEGLECT** Outside eyes provide protection for all residents. The level of accountability, attention to the resident, and the level of care improves when outside eyes are in the facility.

LOSS OF BASIC RIGHTS In addition to extreme suffering due to confusion, loneliness, and feelings of abandonment, residents lost many very basic rights for six to nine months. Most of these rights were abridged or denied due to lack of outside eyes. But many rights were also denied as a matter of policy adopted by facilities and accepted as good infection control.

- The right to vote
- The right to wear their own clothes
- The right to use their own property
- The right to receive mail
- The right to practice religion or speak to their clergy
- The right to privacy
- The right to bathe, shower, shave
- The right to leave the facility
- Use of a telephone
- Access to an ombudsman or an attorney
- Palliative care and pain management from Hospice nurses or aides
- Participation in care decisions
- Access to POA and legal court appointed guardians
- Protection from physical and chemical restraint
- Access to a window or outside door
- Off-site doctor visits with personal physician, dentist, gynecologist, oncologist
- Annual physicals, screening, and treatments
- Right to decline treatments
- Right to access and control personal finances
- Proper nutrition & participation in dietary choices
- Access to Physical Therapy, Occupational Therapy, Speech Therapy

WAIVERS - An excessive number of waivers were granted for by CMS for extended periods of time for everything from minimum training and staffing to life safety, code, and inspection requirements. Examples - the following were in place until June, 2022:

- Physician Visits in Skilled Nursing Facilities/Nursing Facilities - 42 CFR §483.30. CMS waived the requirement to allow physicians and non-physician practitioners to perform in-person visits for nursing home residents and allowed substitute visits to be conducted via telehealth options which were inappropriate and wholly ineffective for many/most dementia patients, residents with intellectual and developmental disabilities, and veterans with traumatic brain injuries.
- Outside Windows and Doors for Inpatient Hospice, ICF/IIDs and SFNs/NFs – 42 CFR §§418.110(d)(6), 483.470(e)(1)(I), and 483.90(a)(7). CMS waived the requirement to have an outside window or outside door in every sleeping room so spaces not normally used for patient care and quarantine. This was extremely confining, isolating, and discriminatory when residents were only permitted closed window visits with friends and family.

- Paid Feeding Assistants for LTC facilities: 42 CFR §§483.60(h)(1)(I) and 483.160(a). CMS modified the requirements regarding required training of paid feeding assistants to allow that training be a minimum of one hour in length. This was harmful to residents unable to self-feed and accustomed to family assistance. Poorly trained staff increased choking and aspiration. pneumonia episodes likely resulting in the acceleration of disease and death.

We believe a closer look needs to be taken at these waivers and future waivers need specific expiration dates that are person-centered.

IMMUNITY FROM PROSECUTION

One of the most egregious trends that has taken place during the pandemic is blanket immunity from prosecution. While families agree that first responders and facility staff should be protected from inadvertently spreading COVID during routine care and while trying to save a life and similar circumstances, states have been granting immunity to all injuries and neglect, including intentional and criminal injuries. We do not believe short staffing is a defense if a facility fails to vet an employee that subsequently commits a sexual assault or beats a resident.

CONCLUSION

I reiterate that nursing homes are not the bad guys. COVID-19 is. We believe most facilities did the best they could under new and extreme circumstances. But numbers of new admissions have decreased significantly and trust in the industry has suffered. People are opting for substandard or no care rather than “risk” their lives or potentially being forced to live in isolation in a future health emergency. If we do not make necessary corrections and gain the public’s trust, I fear the long-term care industry itself may be one of our most devastating COVID-19 casualties.

Thank you for taking on this monumental review process and for demonstrating concern for our long-term care residents and industry.

Respectfully submitted,



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