

February 10, 2021

Jeffrey Zients
White House COVID-19 Response Coordinator

Re: COVID-19 Visitation Policies

Dear Mr. Zients,

The Coalition to Transform Advanced Care (C-TAC) and our members look forward to working with the Biden-Harris Administration on your comprehensive COVID-19 response efforts. To that end, we are **writing today to ask that the COVID-19 national strategy explicitly address ongoing visitation challenges for those with serious illness across care settings**. We have heard from our members, health care providers, clinicians, patients, and families about the heartbreak they all feel as a result of in-person visitation restrictions. Department of Health and Human Services Secretary-designate Xavier Becerra recently said “No one should ever have to die alone in a hospital bed, loved ones forced to stay away. That seems so contrary to the values of a great nation”ⁱ. We agree, and believe there is an opportunity for a strong federal leadership role on this issue, providing updated but flexible guidance to balance the safety benefits of visitation restrictions against the mental, emotional, spiritual, and physical harm they can cause patients, families, and providers.

C-TAC is a not-for-profit, nonpartisan coalition of over 150 members that works to ensure that all individuals living with serious illness, especially the sickest and most vulnerable, receive comprehensive, high-quality, person- and family-centered care that is consistent with their goals and values and honors their dignity. Visitation is a C-TAC priority not only because people with serious illness are at higher risk for complicationsⁱⁱ and death due to the COVID-19 virus, but also because they face unique challenges from visitation restrictions.

Increasingly available vaccines and the emergence of novel virus variants are complicating health care facilities’ in-person visitation decision-making. While past federal guidance from the CDC and CMS exists on this issue, it has not been updated in light of these new developments, and visitation appears not to be mentioned in any of the existing public-facing Biden-Harris COVID-19 planning resources. Additionally, there now exists a growing body of best-practices around how facilities can better accommodate visitation, despite the continued safety and transmissibility concernsⁱⁱⁱ. This changed pandemic environment calls for visitation guidance that is informed by the most up-to-date information.

We recognize and appreciate that facilities of all kinds are still challenged by shifting local conditions, infection rates, the availability of adequate PPE and testing materials, and the vaccines’ unknown impact on transmissibility. These are critical factors to consider in any visitation policy updates, and we encourage the Administration to continue supporting efforts to address all of them. However, given the suffering that visitation restrictions have resulted in, we believe there is a need to more fully consider their impact when making modifications to visitation policies. The uncertainty in the federal guidance on how visitation protocols could be updated in light of new circumstances adds to the stress on clinicians and health systems, many of whom have been at peak operational capacity for close to a year.

While health care facilities of all kinds are to be applauded for the creative ways they've been able to leverage technology for virtual visitation, these encounters are not a solution for all situations. From an equity perspective, many family members from underserved and low-income communities lack access to the resources needed to engage in virtual visits, such as broadband internet coverage or hardware such as smart phones or video tablets. Additionally, the mere act of connecting over a device can be difficult for patients with cognitive or functional issues, a challenge further exacerbated for those for whom English is not their primary language.

Further, with the limited information that can be gleaned from a phone or video calls, families struggle to make fully informed treatment decisions for those seriously-ill loved one who cannot make these decisions themselves. This complicates goals-of-care discussions or decisions to withdraw life support. It can also be culturally insensitive and even coercive^{iv} to make in-person visitation contingent on the choice to stop aggressive treatment and transition to comfort-focused end-of-life care measures. Although medical staff are trying valiantly to address this gap in communication, most are simply too busy during the pandemic to update family members as frequently as they normally would if visitors were physically present.

In nursing homes, where a large and disproportionate amount of COVID-19 deaths have occurred, visitation restrictions have been widespread. C-TAC appreciates CMS' updated guidance from September 17, 2020 that broadened the definition of a "compassionate care" visit beyond those for whom death may be imminent. This more inclusive definition should also be applied to existing hospital visitation guidance from CMS^v. However, while this update was a helpful conceptual change, there has not been robust enough education to facilities or oversight of this update, and many still narrowly restrict compassionate care visits to limited end-of-life scenarios. This has contributed to patient, family, and staff suffering as a result of disenfranchised or complicated grief, depression, anxiety, PTSD, and moral distress^{vi}.

We believe this visitation issue must be addressed in your Response Team's action plan, future guidance from CMS, and any COVID-19 legislation President Biden promotes. We note that the current National Strategy plan only calls to "strengthen long-term care facility guidance, funding, and requirements around infection control policies; support long-term care staffing levels sufficient to ensure patient safety and support the accelerated distribution of vaccines to residential care settings"^{vii}. Visitation is not mentioned nor are any health care facilities beyond these. President Biden's COVID-19 Bill includes "critical funding for states to deploy strike teams to long-term care facilities experiencing COVID-19 outbreaks"^{viii} but, again, does not address visitation for those or other facilities.

Specific actions the Administration could consider taking include:

- Refreshed national guidance from the CDC and HHS issued across states and facilities that encourages visitation policy updates as a result of changing on-the-ground conditions such as vaccination and the emergence of new COVID-19 variants.
- Additional funding for adequate rapid testing and PPE to support visitation across health facilities. With both, facilities could safely facilitate more in-person visitation opportunities.
- Acknowledgement of and additional funding for the Long-Term Care Ombudsman Program, which requires access to facilities to ensure the quality of care and advocate for residents and their families' rights.
- Consideration of designating family members or court-appointed guardians as "essential caregivers" that have legal rights to in-person visitation.

- Some state legislatures have implemented these policies in recognition of the vital role family members play in the care of their loved ones and the impact they have on their quality of life.

We at C-TAC and our members and partners stand ready to provide further information and support on this topic. If you have any questions, please contact Davis Baird, C-TAC Policy & Advocacy Manager (dbaird@thectac.org) or Dr. Marian Grant, C-TAC Senior Regulatory Advisor (mgrant@thectac.org).

Sincerely,



Jon Broyles

Executive Director, Coalition to Transform Advanced Care (C-TAC)

CC:

Andy Slavitt, White House Senior Advisor for COVID Response
Dr. Rochelle Walensky, Director, Centers for Disease Control and Prevention
Dr. Bechara Choucair, COVID Vaccine Coordinator

ⁱ <https://www.radio.com/kcbsradio/news/politics/biden-introduces-cas-xavier-becerra-as-nominee-to-lead-hhs>

ⁱⁱ <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/groups-at-higher-risk.html>

ⁱⁱⁱ https://www.argentum.org/wp-content/uploads/2020/10/Essential_Caregiver_Toolkit_Oct2020_Final.docx

^{iv} <https://www.thehastingscenter.org/you-can-see-your-loved-one-now-can-visitor-restrictions-in-the-covid-era-unduly-influence-end-of-life-decision-making/>

^v <https://www.cms.gov/files/document/covid-hospital-visitation-phase-ii-visitation-covid-negative-patients.pdf>

^{vi} https://www.atsjournals.org/doi/10.1164/rccm.200409-1295OC?url_ver=Z39.88-2003&rfr_id=ori%3Arid%3Aocrossref.org&rfr_dat=cr_pub++0pubmed&

^{vii} <https://www.whitehouse.gov/wp-content/uploads/2021/01/National-Strategy-for-the-COVID-19-Response-and-Pandemic-Preparedness.pdf#page=103>

^{viii} <https://context-cdn.washingtonpost.com/notes/prod/default/documents/9a786b76-2457-41ab-8c6a-eb0ea22d1de1/note/8bcf9ac3-3240-4b3b-9a2c-459a43c85760.#page=4>