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The Honorable Nancy Pelosi
Speaker of the House
U. S. House of Representatives
1236 Longworth House Office Building

The Honorable Mitch McConnell
Majority Leader
U.S. Senate
317 Russell Senate Office Building

The Honorable Kevin McCarthy
Minority Leader
U.S. House of Representatives
2421 Rayburn House Office Building

The Honorable Charles Schumer
Minority Leader
U.S. Senate
322 Hart Senate Office Building

Re: Recommended additional provisions to legislation addressing coronavirus pandemic

Dear Speaker Pelosi, Leader McCarthy, Leader McConnell, and Leader Schumer:

On behalf of Compassion & Choices, we thank you for the passage for the “Coronavirus Aid, Relief, and Economic Security (CARES) Act” (HR 748). Compassion & Choices is the nation’s oldest and largest nonprofit organization working to improve care, expand healthcare options and empower everyone to chart their own end-of-life journey. While we strongly support the expanded access to telehealth and the approximately \$1 billion that the Centers for Medicare & Medicaid Services (CMS) has allocated for hospice providers, we remain concerned that far too many individuals who have either a terminal diagnosis or some form of dementia remain particularly vulnerable during the coronavirus outbreak that further exacerbate existing barriers to patient-centered and patient-directed care at the end of life.

As you develop a fourth COVID-19 package to address our nation’s urgent needs, we ask that you: (1) remove barriers to electronic signatures (e-signatures) to effectuate advance care planning documents and authorization by healthcare proxies or those with power of attorney for healthcare decision-making; (2) ensure that hospitals and critical access hospitals participating in Medicare and Medicaid continue to provide information about their advance directive policies to patients consistent with the Social Security Act by prohibiting waiver of these provisions; (3) require nursing homes to provide virtual visitation for residents, their family and other loved ones via video conference or other technologies, and to provide funding that would allow nursing homes to do so.

THE CARES ACT AND BEYOND

When an individual has been diagnosed with a terminal condition or dementia, receiving care in their home removes many access barriers to medical care, such as hospice and palliative services. By increasing

flexibility to use telehealth and other virtual modalities, like remote patient monitoring and management, the CARES Act ensures patients covered by Medicare and Medicaid, as well as patients receiving services through federally qualified health and rural health clinics, are not forced to forfeit medical care or risk infection. We applaud the swift steps Congress has taken to increase healthcare system flexibilities in response to this crisis. These flexibilities should result in long-term modernization of healthcare delivery to reflect 21st Century capabilities and the values of patient-directed care. Informed by the evidence generated during this public health emergency, we encourage Congress to retain the expanded coverage where outcomes and patient experiences of care are the same or improved for patients with a serious diagnosis like dementia or a terminal prognosis.

HONORING PATIENT WISHES WHEN THEY CANNOT SPEAK FOR THEMSELVES

We strongly urge Congress to reverse the Centers for Medicare & Medicaid Services (CMS) waiver of laws that require hospitals and critical access hospitals (CAHs) to provide their covered beneficiaries information about the providers' advance directive policies. Specifically, the Administration has waived compliance with:

- Sections 1902(a)(58) and 1902(w)(1)(A) of the Social Security Act (for Medicaid);
- Section 1852(i) of the Act (for Medicare Advantage); and
- Section 1866(f) of the Act and 42 CFR section 489.102 (for Medicare).

Waiving this requirement will reduce a patient's choices and voice in the provision of their care. We are concerned with news media reports that hospitals will not honor patient advance care plans, nor physician's order for life-sustaining treatment (POLSTs). **The better policy is encouraging widespread adoption of advance directives now, while removing impediments to putting them into effect (such as through electronic authentication by witnesses and/or notary publics), as well as removing impediments to electronic consent by individuals who have been designated health care proxies or who have power of attorney for healthcare decision-making.**

Compassion & Choices is committed to empowering people to get the care they want during a serious illness or at the end of life. One way we do that is by helping individuals initiate open, honest conversations with their healthcare providers, memorialize their wishes and become strong advocates for themselves and their loved ones. We provide online tools that help patients consider and identify their personal values. These advance directives will be able to provide clear cut instructions to their loved ones, outlining their intentions through a personalized care plan. **During a pandemic, such as the coronavirus, it is important, now more than ever, to provide individuals information that enables them to make these informed decisions in terms that they understand and that they can take action to make happen.** To meet the needs of individuals, we have developed a COVID-19 Toolkit: [Understanding Your Options](#), [Using Telehealth to Reduce Your Risk](#), [Advance Care Planning](#), [Addendum to Your Advance Directive](#), and [Dying in the Age of the Pandemic](#). Advance directives advise physicians and the patient's family members about the patient's wishes if they are unable to direct their own care due to Alzheimer's disease or other forms of dementia.

Respecting and complying with patients' advance directives, POLSTs, and their healthcare proxies is particularly important during a deadly pandemic. Unfortunately, healthcare resource shortages are a harsh reality in certain areas of the country. Where clinicians must make tough decisions about who receives priority for care, they should do it in a way that is consistent with the wishes of the patient, to the

extent that is possible. These documents relieve clinicians from having to make the difficult decision to assess both the clinical status of the patient and the patient's wishes concerning care. When there is a systematic failure to seek or refer to a patient's advance directives, POLST or health care proxy and ensure easy and ready access to them, this failure should not be remedied by making unilateral decisions without input from the patient, or their healthcare proxy or loved ones if the patient is unable to speak for themselves.

This scenario raises the specter of post-COVID19 litigation for discriminatory decision-making, particularly when advance directives and POLSTs have been disregarded. There are already reports that clinicians are experiencing high levels of stress for making life-and-death decisions with limited input from patients, their healthcare proxies and families. Advance directives and POLSTs aid clinicians who may experience distress making unilateral decisions.

Prioritizing care for one patient over another is even more inappropriate when a patient's advance directive or POLST is available for consideration. Equally unacceptable is when another clinician with an established relationship with a patient has engaged in shared decision-making to develop a plan of care that is disregarded. We are also acutely aware that decisions concerning care made by someone other than the patient or their healthcare proxy or loved ones may be based on implicit bias or based on overtly discriminatory grounds. Again, the importance of listening to patients or their healthcare proxies or loved ones and honoring and respecting their decisions is more important now than ever.

VIRTUAL VISITATION FOR NURSING HOMES

We urge you to encourage nursing homes to provide virtual visitation via video conference or other technologies for patients and their families.

In sum, we applaud the swift action and your leadership as we face an unprecedented threat to the health and well-being of so many people in our nation. If you have questions, please contact Sylvia Trujillo, our Policy Director/Senior Legislative Counsel, (971) 219-6135-m or strujillo@compassionandchoices.org.

Sincerely,



Kimberly Callinan
President and Chief Executive Officer
Compassion & Choices