

July 20, 2020

The Honorable Nancy Pelosi  
Speaker of the House  
U. S. House of Representatives  
1236 Longworth House Office Building  
Washington, DC 20515

The Honorable Mitch McConnell  
Majority Leader  
U.S. Senate  
317 Russell Senate Office Building  
Washington, DC 20002

The Honorable Kevin McCarthy  
Minority Leader  
U.S. House of Representatives  
2421 Rayburn House Office Building  
Washington, DC 20515

The Honorable Charles Schumer  
Minority Leader  
U.S. Senate  
322 Hart Senate Office Building  
Washington, DC 20002

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

Thank you for ensuring that individuals with serious or terminal conditions are able to access end-of-life care as a result of a number of provisions in the first three COVID-19 response packages.

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. We urge Congress to make permanent a number of flexibilities authorized during the pendency of the coronavirus health emergency that have modernized health care, while authorizing several new policies that would empower patients to get care consistent with their values and priorities and limit the need for third parties to ration health care on behalf of patients, a practice that is universally opposed by people of all political ideologies.

Further, we strongly urge Congress to prioritize taking immediate action to reaffirm that hospitals must provide notice of their advance directive policies and clarify that moving forward the U.S. Department of Health & Human Services (HHS) does not have the authority to waive any portion of the Patient's Right to Self-Determination Act. This waiver could result in some patients receiving unwanted medical treatment and others not receiving treatment they want and desperately need to have a chance to survive.

The coronavirus public health emergency underscores the urgent need to modernize healthcare

delivery to leverage the existing and growing number of technology tools available. Taking these important steps will ensure that patients who have a serious or terminal diagnosis are able to access medical services and enable them to receive medical services (virtual and in-person) that reflect their preferences, values, and priorities in a sustainable and scalable manner.

## RECOMMENDATIONS TO PROMOTE 21ST CENTURY EQUITABLE END-OF-LIFE CARE

We offer the following recommendations to ensure that individuals are able to receive 21st Century end-of-life healthcare in an equitable manner. The current healthcare system is marked by fragmented and duplicative medical interventions. Although it should be centered around seriously or terminally ill patients where they are located, healthcare is built around physicians and health facilities. Further, mountains of paperwork and other administrative requirements delay or prevent delivery of care.

The barriers and burdens of an antiquated health-care delivery model fall heaviest on individuals who have a serious or terminal illness, their loved ones, and healthcare team. The resulting cost to the healthcare system of delayed care and overutilization in the highest cost centers of care (e.g. the hospital) continues to unsustainably climb when individuals consistently express interest in receiving care in their homes, which is less costly, yet difficult to access given current payment policies. In addition, the current healthcare delivery model is marked by structural inequality and inferior experiences of care and poor outcomes for vulnerable populations, which must be corrected.

Innovation and transformation of our healthcare system remains urgently needed to ensure that healthcare is patient-directed and patient-centered for individuals with a serious or terminal diagnosis. Healthcare at the end of life should be evidence-based, accessible regardless of the community or area of the country one is located, and guided by a patient's needs, values, and beliefs. While states and communities begin re-opening for business, individuals with a serious or terminal illness remain at heightened risk of a premature and painful death. Given this, the current flexibilities should remain in place during the public health emergency and some should be made permanent as they represent much needed improvements to the delivery of healthcare.

*We urge Congress to permanently extend and expand upon a number of flexibilities and waivers issued in response to the coronavirus public health emergency including the following:*

Remove barriers to patients accessing hospice services via telehealth. Permanently lift Medicare telehealth restrictions for hospice services (including certification and recertification) and the expanded coverage of providers (such as nurse practitioners, ) to deliver services via telehealth.

Improve patient access to palliative services in home and community-based settings. Permanently lift Medicare telehealth geographic and originating site restrictions for services in a targeted manner where clinicians certify the services are palliative and for patients with a serious diagnosis that is life ending.

*We urge Congress to authorize the following new policies:*

Increase access to hospice. Authorize coverage for nurse practitioners (NPs) to provide the initial certification of patients for hospice in Medicare, in addition to their current ability to recertify patients. As noted above, nurse practitioners are already temporarily authorized to certify hospice via telehealth; allowing them this option in person would be consistent.

Remove barriers to hospice services for individuals in underserved communities. Authorize payment by Medicare for services furnished to hospice patients by rural health clinics (RHC) and federally qualified health centers (FQHCs). **Specifically, Medicare payment limitation should not apply to services that: (1) would otherwise be physicians' services if furnished by an individual unaffiliated with rural health clinic or FQHC; and (2) are either arranged by hospice program or furnished by individual's attending physician, if not an employee of hospice program.**

Remove barriers to palliative care services for individuals in underserved communities through expanded hours of service. Lift restrictions on FQHCs and rural health centers RHCs that limit payment for palliative services outside of FQHC and RHC work hours.

Expand patient eligibility for hospice qualification. Extend the Medicare hospice benefit to terminally ill individuals with a life expectancy from 6 months to 12 months.

Ensure timely patient referral to palliative care. Provide Medicare incentive payment for referral to palliative care consultations when a patient diagnosed with a serious condition that is life ending.

Expand patient access to palliative care in underserved communities by expanding workforce skills and training. Include palliative care medicine as an eligible primary care service through the National Health Services Corp (PCHETA). **Expand the use of technology enabled collaboratives that allow palliative care specialists to advise and support other specialists, primary care physicians, and other frontline clinicians.**

**Ensure Medicare contractors waive restrictive Medicare eligibility requirements<sup>1</sup> and administrative burdens during COVID19 for home-based oxygen equipment as an alternative to hospitalization at the election of seriously or terminally ill Medicare beneficiaries. Seriously or terminally ill Medicare beneficiaries suspected of or diagnosed with COVID19 should be able to elect care in home supported with oxygen therapy. CMS has stated that the Agency will not enforce clinical restrictions in certain National coverage determinations and Local coverage determinations that would otherwise restrict coverage of these devices and services for COVID-19 patients during the public health emergency. According to CMS, clinicians will have more flexibility in determining patient needs for respiratory related devices and equipment and the flexibility for more patients to manage their treatments at the home but will need to continue to document those decisions in the medical record. Congress should codify this flexibility and make it permanent beyond the public health emergency and direct CMS to ensure Medicare contractors are consistently implementing.**

## RECOMMENDATIONS TO ENSURE PATIENT PREFERENCES AND VALUES ARE HONORED THROUGH MODERNIZED ADVANCE CARE PLANNING

---

<sup>1</sup> CMS Home Oxygen Guidance, [www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/Home-Oxygen-Therapy-Text-Only.pdf](http://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/Home-Oxygen-Therapy-Text-Only.pdf) and [www.cms.gov/files/document/covid-19-physicians-and-practitioners.pdf](http://www.cms.gov/files/document/covid-19-physicians-and-practitioners.pdf)

As COVID-19 cases surged, many doctors have been forced to triage patients with little to no information about the medical interventions their patients want. Evidence-based research overwhelmingly shows the need for more and higher-quality doctor conversations with their patients about their healthcare goals, preferences and values to ensure patients control their end-of-life care decisions. As the groundbreaking 2014 report “Dying in America” by the Institute of Medicine noted: most people nearing the end of life are not physically, mentally, or cognitively able to make their own decisions about care. The majority of these patients will receive acute hospital care from physicians who do not know them.

As a result, advance care planning is essential to ensure that patients receive care reflecting their values, goals, and preferences. A recent metaanalysis of published public surveys found that 80% to 90% of participants reported awareness of advance care planning. A similar proportion considered it important, but only 10% to 41% reported having named a proxy or completed a written document.<sup>2</sup> Due to the coronavirus, Americans are increasingly aware that too many people face the possibility that their healthcare providers will not know or honor their values and preferences at the end of life.

Congress is able to take steps that remove the many impediments individuals face to completing advance directives. Many states have antiquated laws that govern the implementation of advance directives and designation of a proxy.<sup>3</sup> For example, many states require in-room witnessing of the patient’s signature by two people. A number of states still require notarization of an advance directive and proxy designation. Digital signatures are not universally recognized in states, even where they are allowed for executing contracts. Even when a state authorizes notarization remotely, it is expensive. Due to the coronavirus public health emergency, some governors have issued Executive Orders authorizing the use of modern digital technologies during the pandemic to help residents prepare advance directives. These are temporary.<sup>4</sup> While efforts are needed at the state level, Congress is able to advance a national strategy promoting best practices, standards, and model policies. We recommend the following provisions to modernize advance care planning.

**Remove barriers to advance care planning in the Medicare program. Waive patient co-pays and deductibles of Medicare advance care planning services and expand the professionals able to provide advance care planning services to include clinical social workers, as well as hospital clergy. In addition, clarify that advance care planning is included in the Medicare annual visit, so it is not subject to co-pays.**

---

<sup>2</sup> Grant MS, Back AL, Dettmar NS. Public Perceptions of Advance Care Planning, Palliative Care, and Hospice: A Scoping Review [published online ahead of print, 2020 Jul 2]. *J Palliat Med*. 2020;10.1089/jpm.2020.0111. doi:10.1089/jpm.2020.0111

<sup>3</sup> The American Bar Association offers “A Guide with an Easy-to-Use, Legal Form for All Adults” to designate a healthcare proxy. However, even though streamlined and standardized, it does not apply in all states. [www.americanbar.org/content/dam/aba/administrative/law\\_aging/2011\\_aging\\_hcdec\\_univhcpaform.pdf](http://www.americanbar.org/content/dam/aba/administrative/law_aging/2011_aging_hcdec_univhcpaform.pdf)

<sup>4</sup> See, for example, New York Governor Cuomo’s Executive Order [www.dos.ny.gov/licensing/notary/DOS\\_COVID19\\_RemoteNotaryGuidance.pdf](http://www.dos.ny.gov/licensing/notary/DOS_COVID19_RemoteNotaryGuidance.pdf) and Oregon’s recent law that allows remote notary until July 2021 only. <https://rb.gy/m5dwj6>.

Ensure patients and their loved ones have the opportunity to discuss advance care plans with providers. Authorize coverage of discussion and review of advance care planning decisions with individuals identified by the patients and at their discretion and clinicians including social workers. In order to avoid conflict and confusion concerning the advance care plans of an individual, Medicare should provide coverage for a follow-up discussion with individuals identified by the patient to review the advance directives with their provider, at the discretion and election of the patient.

Increase access to advance care planning for Medicare beneficiaries in skilled nursing facilities, Medicare-Medicaid dual-eligible beneficiaries, and individuals with multiple comorbidities. Provide incentives to skilled nursing facilities, healthcare providers serving beneficiaries who are dual eligible or who have multiple comorbidities to aid in meeting the requirements of advance directives including appointment of a designated power of attorney for healthcare consistent with state laws. This policy will support patient completion of advance directives. Due to antiquated state law requirements providers must expend additional resources to ensure the proper implementation and integration of legally effectuated advance directives, as well as portability through, for example, registries and provider electronic health records.

Safeguard patient notice of and use of advance directives in federal healthcare programs. Remove the U.S. Department of Health & Human Services' authority to waive the requirements of sections 1902(a)(58) and 1902(w)(1)(A) of the Act (for Medicaid); 1852(i) of the Act (for Medicare Advantage); and 1866(f) of the Act and 42 CFR section 489.102 (for Medicare). Collectively, these sections require hospitals and Critical Access Hospitals to provide information about their advance directive policies to patients.

Increase portability of individuals' advance directives. Increase portability of advance directive by establishing electronic standards for advance directives facilitated by the U.S. Department of Health & Human Services (Office of the National Coordinator, the Office of Civil Rights), U.S. Department of Commerce (National Institute on Standards and Technology), and external stakeholders.

Streamline process to finalize advance directives. Remove impediments to completing advance directives by facilitating the electronic completion and implementation of advance directives through remote and electronic notarization.

Ease barriers to consent for care authorizations by patient's power of attorney for healthcare decision-making and healthcare proxies. Remove impediments to electronic consent to care authorizations by requiring all healthcare providers and suppliers in federal health programs to offer e-signature.

Ensure patients receive equitable, quality end-of-life care through transparent reporting. Require the U.S. Department of Health and Human Services (HHS) to facilitate reporting on patient access to advanced illness and end-of-life care through quality measures. They include metrics such as pain levels, symptom distress, and intensive care unit admission in 30 days before death for patients who elect palliative care that includes reporting of quality measures by race and ethnicity.

Enforce compliance with patient advance directives. Require all Medicare providers and suppliers to agree as a condition of enrollment that failure to follow the documented advance care planning directives of Medicare beneficiaries constitutes medical error. Prohibit billing when patient-documented advance directives are not met, including those directives expressed by persons with a durable power of attorney.

## CONCLUSION

Finally, it is prudent to leverage investments already made by healthcare providers and other payers to support rapid scaling of virtual services during this public health emergency and to implement additional measures to modernize end of life care. Ten thousand individuals are turning 65 every day and healthcare professional shortages are projected to worsen. Further, we do not know the long-term impact of the trauma experienced by health-care professionals as a result of the coronavirus conditions, which may drive higher than projected attrition rates and resultant shortages. The threat of another major public health emergency remains ongoing. We urge you to take steps now to ensure that healthcare information, planning resources, and a full range of end-of-life care options are readily accessible to seriously or terminally ill individuals to improve their experience of care, as the nation's population ages. If you have any questions, please contact Sylvia Trujillo, Policy Director / Senior Legislative Counsel, [strujillo@compassionandchoices.org](mailto:strujillo@compassionandchoices.org).

Sincerely,



Kim Callinan  
President & CEO  
Compassion & Choices