

April 28, 2020

Honorable Alex M. Azar II  
Secretary  
Health and Human Services Department  
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Re: COVID-19 Hospital and Critical Access Hospital Notice of Advance Directive Policy Waiver

Dear Secretary Azar:

On behalf of Compassion & Choices, the nation's oldest, largest, and most active nonprofit working to improve care and expand health care options for the end of life, we applaud the U.S. Department of Health & Human Services' (HHS) response to the COVID-19 health crisis. By expanding access to health care through telehealth and virtual services in Medicare and other federally-funded programs, you have eased the burden of seeking care for some terminally ill and other vulnerable patients. However, we are concerned that the Centers for Medicare and Medicaid Services' (CMS) recent waiver of the regulation that requires hospitals, including critical access hospitals, to inform patients about their advance directive policies<sup>1</sup> will negatively impact patient-directed care. While we recognize the need to address the shortage of healthcare resources, we can do it in a far more advisable, humane and politically palpable manner: by educating and empowering patients to make their own end-of-life care decisions.

#### SUMMARY

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 achieve that goal is by helping individuals initiate open, honest conversations with their health care providers, memorialize their wishes in advance directives, and become strong advocates for themselves and their loved ones. Now, more than ever, individuals need to engage in informed discussions about what end-of-life care they want or don't want if they get seriously ill and who will make health care decisions on their behalf if they are unable. Only approximately one in three of the nation's adults are

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<sup>1</sup> CMS, COVID-19 Emergency Declaration Blanket Waivers for Health Care Providers, April 21, 2020, [www.cms.gov/files/document/summary-covid-19-emergency-declaration-waivers.pdf](http://www.cms.gov/files/document/summary-covid-19-emergency-declaration-waivers.pdf).

documented to have completed an advance directive,<sup>2</sup> leaving too many physicians and family members in the midst of this pandemic to make last minute, agonizing, life-and-death decisions for an individual.<sup>3</sup> If hospitals are not required to inform patients of their advance directive policies, who knows whether these advance directives will even surface or be honored.

Furthermore, research studies and clinical practice demonstrate when patients have open and honest conversations with their healthcare providers about available treatment options, the vast majority will choose to forgo invasive end-of-life treatments. When asked, many patients will self-select out of invasive and futile care, rather than hospitals and doctors having to ration it. Given this, rather than waiving requirements that hospitals inform patients of their advanced directive policies, we urge that you support widespread adoption of advance care planning.

CMS is able to take four immediate actions that support patient-directed care while relieving clinicians of moral injury that they are experiencing when making difficult decisions about patient care without patient input:

- Reinstatement of the requirements under the Patient Self-Determination Act for hospitals to inform patients about their advance directive policies.
- Issue guidance to urge physicians to engage in advance care planning visits available via telehealth through Medicare.
- Allow electronic authentication of advance directives for certifying patient wishes.
- Urge clinicians to utilize advanced care planning tools that address COVID-19 realities.

## DISCUSSION

The CMS waiver undermines the Administration's modernization efforts that are designed to enable patient active participation in their healthcare.<sup>4</sup> The waiver during the pandemic is subjecting both patients and clinicians to moral injury when it removes notice requirements and care is then delivered inconsistent with patient wishes (particularly when this occurs in the context of rationing).

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<sup>2</sup> Yadav, Kuldeep N. et al., *Approximately One in Three US Adults Completes and Type of Advance Directive for End-Of-Life Care*, Health Affairs, July 2017, [www.healthaffairs.org/doi/10.1377/hlthaff.2017.0175](http://www.healthaffairs.org/doi/10.1377/hlthaff.2017.0175)

<sup>3</sup> *Doctors Worry They Will Be Forced Into Life-Or-Death Decisions Amid Virus Pandemic: "I'm Not God,"* CBS NEWS, April 8, 2020, [www.cbsnews.com/news/coronavirus-doctors-hospitals-life-or-death-decisions-pandemic/](http://www.cbsnews.com/news/coronavirus-doctors-hospitals-life-or-death-decisions-pandemic/).

<sup>4</sup> For example, the Administration's historic efforts to reduce data blocking so that patients will have increased access to their health information in order to improve patient involvement in care delivery.

### *Takes away patients' legal rights*

Over the past three decades, patients have successfully advocated for a greater voice in their end-of-life care, starting with the adoption of the Patient Self Determination Act in 1990. This law recognizes and establishes the importance of patients being able to determine if they want or do not want aggressive end-of-life treatments. In the absence of an advance directive or a designated health care proxy, treatment typically defaults to aggressive and invasive life-sustaining procedures, including intubation. This may also violate the wishes and values of the patient and are frequently futile.<sup>5</sup> By the time a patient is on a ventilator, it is too late: providers and clinicians need to reach out to their patients as soon as possible about advance directives to document their end-of-life care wishes.

### *Places undue stress on physicians*

There have been an increasing number of stories in the media about the extreme stress the COVID-19 pandemic is placing on front line workers including physicians.<sup>6</sup> Being put in the untenable position of having to make end-of-life care decisions for patients -- without clear direction from them -- only increases the stress. The default mode in medicine is to do "everything possible;" however, the physicians are seeing first hand that "everything possible" in this case may mean subjecting a patient to futile treatments, yet they feel obliged to do that when resources are available. In other instances, resources will not be available, and they are then forced to implement a hospital policy to ration care, which is equally unconscionable for a physician who has gone to medical school to treat and cure.<sup>7</sup> Physicians themselves have been authoring op-eds calling on their patients to fill out advanced directives in order to ease this burden. In addition, extreme life-sustaining measures place a tremendous burden on an already over-taxed healthcare system and risk endangering the safety of health care workers.<sup>8</sup>

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<sup>5</sup> John Bacon, *A Bridge Between Life and Death: Most COVID-19 Patients Put on Ventilators Will Not Survive*, USA TODAY, April 10, 2020, [www.usatoday.com/story/news/health/2020/04/08/coronavirus-cases-ventilators-covid-19/2950167001/](https://www.usatoday.com/story/news/health/2020/04/08/coronavirus-cases-ventilators-covid-19/2950167001/).

<sup>6</sup> Father of ER doctor says her suicide makes her 'casualty' of coronavirus, The Hill, April 27, 2020, [www.thehill.com/policy/healthcare/494877-father-of-er-doctor-says-her-suicide-was-casualty-of-coronavirus](https://www.thehill.com/policy/healthcare/494877-father-of-er-doctor-says-her-suicide-was-casualty-of-coronavirus)

<sup>7</sup> *Ventilator Triage Policies During the COVID-19 Pandemic at U.S. Hospitals Associated With Members of the Association of Bioethics Program Directors*, Annals of Internal Medicine, April 24, 2020, <https://annals.org/aim/fullarticle/2765364/ventilator-triage-policies-during-covid-19-pandemic-u-s-hospitals>

<sup>8</sup> "Many [patients] have been intubated and may remain to be intubated. The problem is that the viral load in the airway is probably very high and is very contagious. This poses significant risks for those who are performing intubation." Mengqiang Luo, M.D. et. al., *Precautions for Intubating Patients with COVID-19*, Anesthesiology, March 26, 2020, <https://anesthesiology.pubs.asahq.org/article.aspx?articleid=2763451>.

*Exacerbates healthcare disparities for all underserved communities*

The media has been filled with stories about the impact that COVID-19 has had on communities of color. Advance directives reduce the possibility that care for incapacitated patients is influenced by implicit bias or based on overtly discriminatory grounds. In short, at a time of immense stress and medical resource shortages in some parts of the country, advance directives better enable clinicians to decide who should, and should not, receive intensive care. Increasing the use of advance directives is one step, though others will be needed, to address the disparate impact of COVID-19.

*Increases health systems' need to ration care*

Studies find that seriously ill patients who have conversations with their doctors about their end-of-life care goals were far less likely to receive cardiopulmonary resuscitation (CPR), be put on a ventilator, or be admitted to an intensive care unit (ICU).<sup>9</sup> As an example, a [study from the New England Journal of Medicine](#) this month found that 80 percent of seriously ill patients would choose to die one year sooner if that meant avoiding invasive treatments in intensive care units (ICUs) like ventilators and resuscitation in the final weeks of their life.

*Subjects surviving family members to increased trauma*

Family members also have a difficult time making care decisions for their loved ones absent end-of-life planning conversations. If the dying person has decided in advance that they do not want invasive treatments and it has been clearly communicated to their loved ones, there will be less upset among family members. If family members believe that their loved ones are being denied treatment that would have saved their love, the upset will be tremendous. And nobody should be making life and death decisions, uninformed, uneducated and spur of the moment. Not surprisingly, studies confirm that families are much less likely to experience major depression after their deaths if their loved ones have had advanced care planning conversations.<sup>10</sup>

## REQUESTED ACTION

In addition to reinstating the requirements under the Patient Self-Determination Act to require hospitals to inform patients of their advance directive policies, Compassion & Choices also asks CMS to take three additional actions:

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<sup>9</sup> Atul Gawande, *Letting Go: What Should Medicine Do When it Can't Save Your Life*, The New Yorker, July 26, 2010, [www.newyorker.com/magazine/2010/08/02/letting-go-2](http://www.newyorker.com/magazine/2010/08/02/letting-go-2).

<sup>10</sup> Id.

*Issue Guidance that Encourages the Widespread Adoption of Advanced Directives and Medical Orders of Life Sustaining Treatment (MOLST)*

Rather than removing requirements to inform patients about advanced directives policies, we should be expanding their adoption. This includes issuing guidance that health care providers, with the exception of hospitals, and clinicians in federally-funded health care programs schedule appointments to initiate or update advance care plans and encourage more widespread adoption of Medical Orders for Life Sustaining Treatment. Particular emphasis should be placed on skilled nursing facilities, home health agencies, and other community-based providers. This policy is beneficial for several reasons:

- Encouraging providers to initiate conversations with their patients about advance care planning would increase the number of advance directives and MOLSTs, relieving clinicians in emergency settings from having to guess about the patient's wishes concerning care.
- Medicare reimburses providers and clinicians for counseling beneficiaries on advance directives, including via telehealth.<sup>11</sup> This both recognizes the value of advance care planning and encourages more physicians to engage in these kinds of conversations which can be done safely without subjecting patients or clinicians to risk of exposure to the coronavirus.
- At a time when physicians are seeing a decrease in patient visits that impacts the sustainability of their practices, encouraging telehealth counseling about advance directives would promote patient-directed care, financially benefit practitioners, and lower overall health care costs by potentially reducing emergency department visits.
- By utilizing 21st Century technology, providers can safely sustain their practices while giving agency and decision-making authority to individuals at the end of life.

*Allow electronic authentication of advance directives for certifying patient wishes*

Given the pandemic, people don't have access to notary publics. This requirement is an impediment to the widespread adoption of advance directives. We urge you to work with Congress and state officials to facilitate either interactive video notarization of documents or permitting witness attestations using interactive video where there are state impediments.<sup>12</sup>

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<sup>11</sup> CMS, Medicare Learning Network Booklet, *Telehealth Services*, March 2020, [www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/TelehealthSrvcsfctshst.pdf](http://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/TelehealthSrvcsfctshst.pdf).

<sup>12</sup> For example, the New York Governor issued Executive Order 202.14 authorizing the act of witnessing to be performed utilizing audio-video technology, provided a number of procedural conditions are met. This important directive allows families to continue formalizing significant end-of-life decisions that cannot be put on hold during the pandemic. However, the witnessing provision of Executive Order 202.14 is currently set to expire after May 15.

*Urge clinicians to use advance care planning tools that address COVID-19 realities*

The COVID-19 pandemic has resulted in a unique set of end-of-life care decisions -- such as whether a person would prefer to be treated with home care and without invasive procedures or whether a person would prefer to go to the ICU and wants a ventilator. Current advance directives do not address these unique issues; although they could be documented as a part of a MOLST.

To facilitate more patients to understand their options, so that they can document them, we have developed a free online 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](#). We encourage you to disseminate these materials as well as materials developed by others as a part of your advance care planning guidance, so that doctors will have specific tools they can use with their patients to address the unique COVID-19 realities.

## CONCLUSION

We applaud your swift action and leadership in promoting accessibility of care through telehealth and other virtual services for patients with serious and terminal conditions. We urge you to rescind the waiver of the regulation requiring providers to inform patients about advance directives, and instead issue a guidance that all providers and clinicians in federally-funded programs, with the exception of hospitals, use telehealth technology to initiate conversations with their patients about advance directives. If you have questions, please contact me at (202) 441-0089 or [kcallinan@compassionandchoices.org](mailto:kcallinan@compassionandchoices.org).

Sincerely,



Kim Callinan  
President & CEO  
Compassion & Choices

cc: Honorable Seema Verma  
Administrator  
Centers for Medicare & Medicaid Services