

# End-of-life care challenges during COVID-19: What doctors must know

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Advance directives play a crucial role in ensuring patients get the care they want—and don't get the care they don't want—at the end of life. Everyone should have one, but the COVID-19 pandemic has caught many patients by surprise, leaving physicians grasping to understand their patients' values and preferences.

A [videocast](#) from the *AMA Journal of Ethics*<sup>®</sup> ([@JournalofEthics](#)) features an interview with Helen Stanton Chapple, PhD, RN, a professor of nursing and interdisciplinary studies at Creighton University and an expert in end-of-life issues. In her conversation with the journal's editor-in-chief, Audiey Kao, MD, PhD, Chapple notes how documented advance directives can help to make certain that patients' wishes are respected at the end of life.

More broadly, the AMA and the Centers for Disease Control and Prevention are closely monitoring the COVID-19 pandemic. Learn more at the [AMA COVID-19 resource center](#). Also check out pandemic resources available from the [AMA Code of Medical Ethics](#), [JAMA Network™](#) and [AMA Journal of Ethics](#), and consult the [AMA's physician guide to COVID-19](#).

## Advance directives are more important than ever

About two-thirds of deaths attributed to COVID-19 are taking place in inpatient care settings, and almost all of these are absent of family members who are typically called upon to make health care decisions when patients can't speak for themselves, giving new urgency to talking about matters of life and death with our loved ones in advance.

"We think about the living will perhaps most personally, because that's the part of the advance directive in which we specify what our preferences might be," Chapple said. "But another part of the advance directive, which may be even more important, is the designation of a decision-maker, a

medical proxy. There are many words for this, [such as] surrogate decision-maker—the person who will be designated to make those decisions if you are unable to speak for yourself and you are terminally ill.”

## Contact with COVID-19 patients’ families is critical

Many patients with COVID-19 present without an advance directive, though, and are often not in a position to create one if they are severely ill and hospitalized.

“If these patients are on a ventilator, they are not going to be able to talk. They will be sedated. They may be paralyzed, chemically paralyzed,” Chapple said, calling out the need for physicians to understand who the patients were in the fullness of their lives.

“The most important thing to be doing is to communicate with families,” she said, and “it has to be at least daily so that families are feeling like they are part of the team in taking care of these patients.”

## How loved ones can connect with COVID-19 patients

Most people see a good death as one that happens at home, surrounded by family members and friends, but with most COVID-19 patients’ dying in hospitals, physicians might wonder how they can strive to approximate that experience.

“It’s very, very challenging, because ... [physicians and the health care team] have to be the stand-ins for the family, and so communication is key,” Chapple said, noting that physicians can utilize our cellular devices, through audio and video exchanges, to bring patients together with loved ones when death is imminent. “And perhaps they can assure the family that they are in the room when the patient is passing on. That can be very, very comforting to the family if they cannot be there—that they know the person, their loved one, did not die alone.”

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