Hope Is Fine, but Reality Is Best in End-of-Life Care

Hi. I'm Art Caplan, director of the Division of Medical Ethics at the NYU Grossman School of Medicine in New York City.

A colleague of mine at the University of Pennsylvania, Ezekiel "Zeke" Emanuel, wrote a very interesting essay in *The Atlantic* about the death of his 92-year-old father in a large, high-quality, academic-affiliated hospital. Zeke said it wasn't the death that his dad would have wanted, nor was it the death he wanted his dad to have.

After being admitted with suspected pneumonia, his father was diagnosed with a large brain tumor, which nobody could do anything about. This led to an unfolding of many different interventions, none of which were going to save Zeke's dad but all of which seemed intrusive, unnecessary, and in some ways, burdensome.

This is a story we still hear too often today. We have hospice and palliative care, but I fear that they are not offered soon enough. We continue to have an attitude for very old and very sick individuals that, in this example, we still should try to treat the pneumonia and still order CAT scans to determine how big that brain tumor is, even when we know that the person has an underlying terminal disease.

I even get upset when I see people who we know are going to die yet are still getting woken up in the middle of the night to have their vital signs taken. We know these signs are going to be bad because we're supposed to be allowing these people to die. Nonetheless, we're still taking these measurements or tests in a way that's not comfort care.

In my own experience, I've seen too many examples where hospice gets there, but at too late a point, 3-4 days before the person is going to die. They're only called then because people are reluctant to give up hope for the patient. And in some instances, palliative care doesn't get there on time either. And when they do, the opioid epidemic is making practitioners unnecessarily conservative about giving people adequate pain control.

None of this should be going on. We have the tools and the knowledge to allow people a good death. We know that what they want is comfort, access to friends, and to have a good quality of life, as best they can, while they die. Occasionally, they want to go home. And that's okay too, as long as the family understands the management challenge that this sometimes can pose, but the option should always be laid out.

The notion that we have to pound on people with all the technology we've got, because that represents our not giving up hope, flies in the face of the fact that sometimes we know that hope is gone. It's hard to admit it. It's hard to say. But I think we have to at least get prepared, even in talking to patients and their families when they come in to the hospital, that this may not end well, and here's what we will try to do if that occurs.

I think planning ahead with seriously ill, very old patients makes sense in terms of weighing out how they're going to be managed, what will happen to them to provide them comfort when they need it, and what will happen to the family to provide them support when they need it.

I think Zeke's story was moving, telling, and disturbing. If he, as a major professor and a major voice in health policy in the United States, couldn't get the death that he thought his dad would have wanted, that bodes ill for the rest of us. We've got to fix it.