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While social distancing, do your other patriotic duty: have The Conversation about serious illness care

By Angelo Volandes, Aretha Delight Davis, and Ira Byock April 7, 2020



At no time since World War II has there been a clarion call for the entire nation to do its patriotic duty: in this case, physically distance ourselves from others, often including close family members; avoid leaving home; and even make face masks to protect medical professionals from Covid-19. Another personal step that could help us deal with this catastrophe is for every adult to have what we call The Conversation.

The Conversation is a "goals-of-care conversation," an honest talk with your family and your health care team. It is a frank conversation about what would be medically achievable for you, physically and functionally, during a health crisis. Let them know if you would want — or want to avoid — treatments like CPR if your heart stops or a ventilator if you can't breathe for yourself. Tell them what brings you joy, and what brings you comfort during difficult times. Share your hopes. And tell them how you'd like to be cared for when you are dying.

These conversations are best done in advance, not when someone is in the midst of a medical emergency.

Despite efforts within health care to make these conversations routine, most adults have not discussed or expressed their personal priorities for care during serious illness with their physician or other care providers. These conversations are now critically important for all adults, but especially for those who would most likely need intensive medical interventions if they fall ill with Covid-19. That includes older individuals, those living in nursing homes and assisted living communities, and people with common chronic conditions including heart disease, COPD, asthma, diabetes, and kidney disease.

Although the trajectory of this unfolding public health crisis is still uncertain, we know that the major medical complication of Covid-19 is respiratory failure, often requiring prolonged ventilatory support. In normal times, doctors assume that all patients desire to be placed on a ventilator if their breathing fails, and so routinely intubate them and start mechanical ventilation. But these are not normal times.

In the near future, there may not be enough ventilators for every patient with respiratory failure. More sobering still, when an older person or someone with a chronic medical condition develops respiratory failure due to Covid-19, even mechanical ventilation often fails to rescue them.

Collectively, the three of us have had thousands of goals-of-care conversations with patients and know that people who are frail, older, or living with serious illness often do not want to be intubated and have their breathing maintained by machines. Many people who are ill and facing the waning days of their lives want to avoid invasive life-prolonging treatments, preferring a comfort-oriented approach to care — at home if possible, in a familiar setting and surrounded by the people they know and love.

In the new reality of Covid-19, when invasive treatments may lead to more distress and physical separation from friends and family, often without changing the course of illness, having The Conversation is urgently important.

If all Americans, especially older adults and people with chronic medical conditions, talk with their families, their doctors, and other caregivers and make their wishes known, our health systems will be better able to provide personalized care during dire situations. If all adults expressed their priorities for care during serious illness, we could better align patients' care with their personal values and priorities.

With the looming surge of patients with respiratory compromise and predictions of severe shortages of ventilators and ICU beds, we can imagine no greater waste of limited vital resources than imposing aggressive treatments on people who would not have wanted them.

It's time to think outside of the box. Clinicians can safely have these conversations by phone, FaceTime, Zoom, or other modes of communication with patients. One of us (I.B) is affiliated with the Providence health system, which has adopted a way for patients without advance directives to verbally designate a Trusted Decision Maker during a face-to-face or telehealth visit with a doctor or nurse practitioner. If they wish, patients can also indicate general preferences for treatments during life-threatening conditions by choosing one of the following statements:

- I want to continue living even if my quality of life seems low to others and I am unable to communicate with people. In general, I would accept support of my breathing, heart, and kidney function by machines that require me to be in a hospital or special care unit.
- Life is precious, but I understand that we all die sometime. I want to live as long as I can interact with others and
 can enjoy some quality of life. I would accept intensive treatments only if I had a reasonable chance of getting
 better. I would refuse long-term support by intensive medications or machines if my quality of life was poor and I
 was not able to communicate with people.
- It is most important to me to avoid suffering. I do not want extraordinary medical treatments, such as breathing machines or cardiopulmonary resuscitation (CPR). If my natural body functions fail, I would refuse treatments and choose to die naturally.

Although lacking the legal standing of a formal advance directive, a patient's Trusted Decision Maker designation form in their electronic health record conveys information that may be crucial for clinicians and family members to consider in the future.

The Covid-19 crisis must be addressed with all available strategies. We commend leaders in government and health care who are building makeshift hospitals and scouring the globe for ventilators and medical staff, as well as those adapting ventilators to serve two (or more) patients simultaneously. Health systems must also take emergency steps to support those providing palliative and hospice care, who are caring for people through the end of life. They, too, deserve to be seen as part of our national guard.

Among the essential strategies for fighting Covid-19 is making sure that individuals who are most at risk of developing severe complications from it are properly informed about the potential benefits, expected burdens and limitations of available therapies, and that those who undergo intensive care and mechanical ventilation actually want these invasive interventions.

In addition to avoiding crowds and staying home, talk with your family and call or email your primary medical professional. Consider it your duty to have The Conversation.

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