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We Need to Talk About Death in 2022

By Dan Morhaim, M.D.

“In this world nothing can be said to be certain, except death and taxes,” Benjamin Franklin once said. On Tax Day, you have dealt with your finances, so now it’s time to recognize National Healthcare Decisions Day and pay attention to our end of life care.

In 2012, Bucilla Stephenson, 91 years old, checked into Doctors Hospital of Augusta Georgia with a chronic cough. She wanted care, but she made it clear that she did not want heroic medical efforts to save her life as outlined in her “[advance directive](#),” a plan for hospitals to follow in case one needs serious medical treatment, and she requested that her daughter be contacted before any major procedures were done.

Although her wishes were well documented in her directive, she was intubated and moved to the ICU where she spent the last two weeks of her life in a coma. Her daughter sued the hospital for disregarding her mother’s clearly and legally expressed instructions. Ultimately, the case was settled for one million dollars before trial. According to the family’s attorney Harry Revell, the family would not agree to an undisclosed settlement, saying “We feel it’s important for the public to be informed about this issue, and for healthcare providers to be mindful of this. The amount will hopefully get everybody’s attention.” Thus began a new chapter of American medical-legal history: the legality surrounding a wrongful death.

Typically, we hear of wrongful death suits when there is negligence that led to a premature loss of life. However, these “wrongful life” suits also hold hospitals and health care workers accountable when they ignore a patient’s documented wishes. Cases like Mrs. Stephenson’s are making a significant contribution to the growing awareness of the importance and legal force of an advance directive as well as the need for healthcare institutions to be sure their workforce understands this.

While death is inevitable, we are the first generation in human history that has a say about when, how, and where we die. This is about promoting empowerment and respect for personal values. That’s why it’s particularly appalling when these wishes are not honored.

As advance directives become a more common practice in the medical world, it becomes even more important that every adult has one. Even younger people should complete advance directives. While their deaths are less likely, when catastrophes occur, the decisions become even harder for them. In fact, the three most famous legal cases in this field all concerned women under 30: Karen Ann Quinlan in 1976, Nancy Cruzan in 1990, and Terry Schiavo in 2005.

Here's what advance directives accomplish. They are straightforward legal forms available in every state to help manage end-of-life care. Advance Directive forms are available for free from many sources including your state or local health department, hospitals, AARP, faith-based groups, and online (of these, my personal favorite is mydirectives.com).

If you are awake, alert, and competent, you have the power to make your own medical decisions about what care to get and what to forgo. But what happens when you can't speak for yourself due to an accident, illness, or dementia? Who speaks for you? That's when an advance directive comes into play. In that document, you can select others who would make those decisions for you, and you can specify the level and kind of care you want.

Ask yourself this question, and take 10 seconds to answer it: When death comes, where would you like to be, who is around you, and what's going on? I've asked that to thousands of people in presentations around the country, and the answer is always much the same: at home, with loved ones around, pain free. No one wants to be languishing for weeks in an intensive care unit long past any hope of recovery, on a ventilator, tied to tubes and monitors and IVs, minimally aware or comatose.

Don't get me wrong. In my own advance directive, I specify that I want the best that modern medicine has to offer, but when the end is inevitable, I want only those treatments that are supportive for me and my family. My own directive also specifies other personal choices. For example: I want to be taken outdoors as much as possible, and if that can't be done, put me where I can see outside. I want vodka and medical cannabis. I want control of the remote and a bite of chocolate every day. I have a list of music I'd like to hear and a list of people I'd like to see – and maybe a few I can do without.

As an Emergency Medicine physician for over 40 years, I've seen the benefits of advance care planning. It allows families to come together, to get helpful services like palliative care and hospice care, and to complete the circle of life in a calm and meaningful way. Likewise, I've seen what happens when it's not known what a patient wants. Family members get into conflict, and clinicians don't know how to treat the patient. Chaos ensues, and decisions often are made by others – a hospital committee or a government agency – who don't know the person involved.

Our culture celebrates personal freedom and autonomy. Yet, in this one area, we collectively abdicate those values. Only about 40% of Americans overall – and about 20% in communities of color – take advantage of this tool for empowerment, control, and respect for individual values.

As a Maryland state legislator for 24 years, I brought attention to this issue. In community meetings I would be asked what issues I was working on, and there were many. Then, I'd bring up advanced medical care planning, asking "Have you completed your advance directive? It will help you when death is near. Also, don't forget to vote for me in the next election."

Politicians like celebratory events such as ribbon cuttings and graduations, but I was talking about dying and death. While some advised me that doing this was politically dumb, I found that constituents appreciated that I was bringing up an experience that they had gone through or were facing. They thanked me for breaking the silence on this universal topic in a helpful and practical

way. That's why I've admired people like Betty Ford, who broke down barriers and talked about breast cancer, and others who can bring up personal issues like a family member with addiction or one with a birth defect.

Everyone agrees that US healthcare costs are too high. We've created a system that defies understanding and is bureaucratically complex. While incredible care does happen, too many of us don't have adequate coverage or are one illness from medical bankruptcy. Preventative medicine does not get the attention and funding it deserves. Meanwhile, CEOs of insurance companies, hospitals, and healthcare systems are making millions.

And how are "savings" achieved? It's done by shifting costs among taxpayers, employers, and employees who face rising premiums, with more co-pays, less coverage, and higher deductibles. The Baby Boom generation is living longer (a good thing) but caring for them will become more expensive along the way. Medicare expenditures are almost \$900 billion/year. Of that, it's estimated that 20%-25% is spent on the last months of life.

When people make personal choices, most of us don't choose the "full court press" for everything. Thereby fewer "expensive" deaths occur in hospitals. More are dying at home or in hospice settings, both of which are less costly and more personal. In other words, healthcare costs can be significantly reduced by respecting the values and choices individual citizens make.

Here's what needs to happen. Individuals need to complete their advance directives (remember: only you can complete yours); these must be available (not hidden in a file cabinet) to key family members and clinicians; and clinicians must learn to honor these forms as legal documents.

We've got a long way to go to normalize a natural and unavoidable event. The tools are there. National Healthcare Decisions Day reminds us to take that first step. You'll find that it only takes a few minutes, and by doing so, you've taken control of your health and your life.

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