## "Wrongful life and advance care directives"

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## by Dan Morhaim, MD

Failing to observe or ignoring a patient's planning wishes could lead to lawsuits.



Wrongful death lawsuits occur when alleged negligence has led to a premature loss of life. Those are well known. But now there's a surge in a new type of litigation: "wrongful life" lawsuits. While not yet grabbing headlines, these lawsuits emerge when hospitals and clinicians don't bother to obtain – or choose to ignore – a patient's documented care planning wishes. These lawsuits not only cost the healthcare system substantially but call attention to the growing demand of today's consumers wanting to have their voices heard in end-of-life decisions.

Advances in diagnoses, treatments, and medications are allowing people to live longer and more productive lives than ever before, making end-of-life care issues of growing significance. But is this an issue strictly of personal values, or is it also an issue of economics, public policy, as well as a looming public health crisis? Actually, it is all of these.

End-of-life care is a subject that Americans avoid, but we should no longer. Instead, we should embrace the fact that we are the first generation in human history that has some say about how, when, and where we die. In this regard, we are empowered as never before and can avoid (or greatly reduce) what we fear the most – pain, isolation, and dependency – through taking one simple step: completing an advance care directive.

Advance care directives provide the opportunity to clearly articulate who can make medical decisions for us when we can't, whether we want or don't want heroic measures, where we want to receive treatment, and what is important to us as we weigh days of life vs. quality of life. As Thaddeus Mason Pope, JD, PhD, professor of law at Mitchell Hamline School of Law in Minnesota says: "it's a medical error to provide too much treatment, just as it is to provide too little treatment."

It is ironic that in our culture that celebrates personal freedom, autonomy, and equity, only about 40% of Americans have completed these forms, and the rate is about 20% in minority groups. That makes this an issue to which attention must be paid. "From an ethical point of view, a patient has the right to decide their end-of-life treatment," says Samuel D. Hodge, Jr., JD, a professor of legal studies at Temple University. "And that decision must be respected."

Having an advance care planning document in place and easily accessible makes it possible for the patient's voice to be considered in clinical decision-making and increases the likelihood that the care delivered will align with their values and priorities. This is especially important when the patient, for whatever reason, is unable to make decisions for themselves. As a career Emergency Medicine doctor, I've seen the positive outcomes when patients have committed those decisions to paper (or video) and have designated a trusted person to help assure that their wishes are respected. In those cases, care is personalized, and families are not as distressed. Sadly, I have also seen what happens when an advance care plan is not made (or not readily available in time of need): stress, chaos, conflict, and heartache ensue.

While the primary reasons to complete advance directives are for individualized care and respect for values and wishes, every healthcare policy action has financial implications. Completion of advance directives will reduce health care costs by respecting people's choices. For most Americans, it is estimated that 25% or more of all the health care dollars spent in their entire lives are spent in the last months of life. Money is often expended to keep people alive far past any reasonable hope of recovery, money that could be spent earlier, when the impact would be much greater in terms of quality and length of life. Not only should individuals complete advance directive forms, but clinicians must learn to honor them. That will require training and a change in medical culture.

Advance directives are not just for old people. The three most famous medical-legal cases in this field all concerned women under 30: Karen Ann Quinlan in 1976, Nancy Cruzan in 1990, and Terry Schiavo in 2005. When medical catastrophes occur in younger people, the decisions become even harder. That's why every American over the age of 18 should complete an advance directive and why we should update them routinely as our life circumstances change. There are many sources of advance directive forms. One of the easiest and most user-friendly (and free) is <a href="mydirectives.com">mydirectives.com</a>. It guides consumers through the process of creating an advance care plan or uploading an advance care planning document they already have. Then MyDirectives safely stores these documents along with portable medical orders like DNR orders and POLST forms and makes them available to healthcare providers 24/7/365 nationwide with secure access.

The inevitable cannot be avoided, but how we get there can be a supported, manageable, family-centered experience that respects individual values. Having an advance directive on file should be as routine as getting a driver's license or a Social Security number. The cost is negligible, and the payoff is substantial.

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