



Having Your Say: What if Advance Directives Are Ignored?

By Professor Kim Dayton

Making medical and financial choices for an aging parent or other adult with special needs can be stressful. Health care directives and financial powers of attorney are meant to establish an agent's decision-making authority, but in practice, it doesn't always work that way. Time and again, health care professionals ignore medical preferences and financial institutions challenge an adult child who's simply trying to pay Mom's bills. It can be infuriating. But there are steps you can take to minimize the likelihood that bureaucracy and miscommunication will thwart efforts to assist.

Health Care Directives

A health care directive combines instructions regarding an individual's preferences for treatment with the appointment of someone (the "agent" or "surrogate") to act on the person's behalf. It may state that extreme life-sustaining measures should be avoided or, to the contrary, that all possible medical treatments and measures should be undertaken.

Frankly, the conversations an individual has with the agent, other family members and health care professionals are as significant as the document itself. While the agent and others close to the individual should have copies, it's just as important for them to understand the values and rationale underlying the preferences described. It should also be explained to other relatives why the agent was chosen. Warring family members can cause chaos. (For tips on having this discussion, check out [The Conversation Project](#).)

Advocates stress that people with intellectual disabilities should be as actively involved as possible in making their own medical choices, and with the growing focus on supported decision-making, [it's increasingly common for them to have health care directives](#). Even though it can be difficult to determine whether these individuals fully understand their options, and discerning their wishes can be challenging, it's essential that such documents accurately reflect any health care and related preferences that they may have regarding treatment. (Information regarding health care directives for persons with intellectual disabilities and a workbook for writing an advanced directive are available from [Caring Community](#)).

Healthcare directives should be reviewed periodically, because people's opinions may vary as they get older. They may also wish to change agents, switching from a spouse or parent to an adult child or sibling.

Talk to the Doc

Before creating the directive, discuss medical options candidly with a trusted physician. An article published by Annals of Internal Medicine reports that “only 12 percent of patients with an advance directive had received input from their physician in its development, and physicians were accurate only about 65 percent of the time when predicting patient preferences; they tended to assume that patients would want less life-prolonging treatment than they actually desired, even after reviewing the patient’s advance directive.” ¹

Be sure that medical records indicate that a directive is in place and where a copy can be found. Share this information with all new medical professionals.

At the Hospital

Take the directive with you whenever visiting a hospital or nursing facility. Hospitals are required by law to ask if an incoming patient has a health directive and to include details in the person’s medical chart. But that doesn’t ensure that doctors and nurses will actually read the directive. Furthermore, if a doctor issues a “Physician Order for Life-Sustaining Treatment” (POLST) that conflicts with the directive—even if the agent is actively objecting to a particular regimen—health professionals tend to follow the doctor’s instructions. In some states, the POLST protocol was developed by medical professionals without input from patient advocates, and a POLST can generate serious potential conflicts if it is inconsistent with the patient’s health care directive.

The potential for controversy over medical treatment for a person unable to make his or her own decisions underscores the importance of choosing an agent who will not be intimidated by medical professionals and will boldly represent the patient’s wishes. The law clearly bars doctors from giving unwanted treatments. Even when the written directive is unclear, if a physician ignores an agent’s attempts to enforce the patient’s preferences, there are grounds for a lawsuit.

On the other hand, if doctors believe that a requested procedure would be futile, they can refuse treatment, although they may be required to refer families to other medical professionals. It should be noted, also, that if parents refuse care that physicians are convinced would prolong the life of a minor child, different rules may apply and, in extreme cases, the state may intervene.

Financial Power of Attorney

A financial power of attorney (POA) grants an agent the authority to make property- and money-related decisions on someone else’s behalf. Those rights may be narrowly

defined—such as paying bills—or wide-ranging. Most states don't require financial institutions to recognize POAs, and many banks have developed their own forms. They sometimes refuse to respect an "old" POA. This is, at least partly, a reaction to the widespread financial abuse of seniors, but in many cases, it simply creates obstacles for family members who are trying to help out.

Be Proactive

To avoid a crisis, contact organizations where the individual maintains accounts or conducts other financial transactions ahead of time. Give them copies of the POA, answer any questions they may have and—although there is no law requiring it—get signed any forms they require.

On the other hand, if you're face-to-face with an uncooperative bank teller, ask to speak with the branch manager. If necessary, ask that the bank's legal department be contacted. You may also want to ask the attorney who drafted the POA to make some phone calls.

Dual Residence

If the individual divides his/her time between two states, you need to account for the possibility that state laws differ. That means either drafting the POA and health care directive with both jurisdictions in mind, or having two versions of each document. (See <https://fivewishes.org/shop/order/product/five-wishes-advance-directive> for suggestions on writing a healthcare directive that meets most states' technical requirements.)

My basic message is that you shouldn't wait for an emergency before pulling directives from the safety deposit box. In fact, don't keep them in a safety deposit box at all! Lay the groundwork for smooth acceptance of your documents when they're needed most. With a little upfront planning, potentially tense situations can be a lot more manageable.

¹ Mary Butler, Edward Ratner, Ellen McCreedy, Nathan Shippee, Robert L. Kane, "Decision Aids for Advance Care Planning: An Overview of the State of the Science," *Annals of Internal Medicine* (November 25, 2014).

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