

Avoiding Confusion

Pay attention to the donation language in an advance directive

Editor's note: Attention should be paid to the possible confusion between a person's documented desire to be a donor and also, as written in his or her advance directive, to be removed from ventilator support at end of life.

As you begin to make your plans for recognition of National Donate Life Month, you may also want to consider that National Healthcare Decision Day is April 16. The auspicious overlap provides a good opportunity to educate professionals and the public on advance directives and how to avoid inadvertent confusion between the donation decision and end-of-life care.

BY CHRISTINA WOODWARD STRONG, ESQ

Properly documenting the decision to be an organ donor is an important part of end-of-life planning, as important as planning for the disposition of property (having a will) and documenting one's health-care treatment wishes (having an advance directive). Studies show that people expect to have their documented wishes followed.

Unfortunately, however, the attorneys and social workers most often involved in helping people with advance directives don't always have the knowledge to ask the right questions about donation or the tools at hand to document the donation decision properly within an advance directive.

In addition, hospitals' advance-directive forms—even those used by donor and transplant hospitals—may add to the confusion. The wording on those forms frequently fails to reflect the relationship between what kind of end-of-life care a patient wants and the patient's desire to be a donor.

Under the Revised UAGA* and some states' laws, a person may include his or her decision on organ donation within an advance directive. In other words, if an individual wants to be a donor, his/her advance directive can be considered a properly documented donation decision. The individual also can specify in the advance directive what organs and tissues are to be donated and may authorize research and/or educational use of the gift.

AVOIDING CONFUSION

If a person is documenting a donation decision in an advance directive, the directive should specify the understanding that donating organs may involve delaying the withdrawal of ventilator support, for example, in order to facilitate donation.

Without that clarifying language, hospital counsel and families may be confused when an advance directive requests removal of treatment at end of life—and also states that the person wants to be an organ donor. Being a donor, as most in the transplant community know, may require temporary treatment measures (i.e., ventilator support).

Although the Revised UAGA specifies that a patient be kept on "life-sustaining treatment" until his/her wishes are known, a clear advance directive is the simplest way to make sure that events proceed in keeping with the patient's documented wishes.

It is also important to note that the donation decision in the United States is not a matter of a simple yes or no. Many people knowingly opt to leave the decision to their survivors rather than acting upon the issue themselves.

Leaving the decision to others is similar to allowing the survivors to make other body disposition decisions, such as whether and where to cremate or bury.

ANOTHER OPTION


Most advance directive forms—even those that hospitals distribute—offer a "no" or refusal option as the sole alternative to making a gift. Clearly, a third choice is also available: "I delegate this decision to my health-care agent or others, under the Revised Uniform Anatomical Gift Act."

When patients approaching end of life have both an advance directive specifying withdrawal of treatment and a document directing donation, such as a donor registry designation, it may appear that the documents conflict. Undoubtedly, that conflict was not the patient's intent.

As an attorney who addresses those issues with my clients, it's become clear to me that they intended that their desire to save lives through donation would dictate procedures for withdrawal of treatment, rather than the other way around.

In the face of conflicting documents, however, the law of most states directs that there be a "huddle." Composed of hospital staff and the patient's family and/or advocates, the huddle meets to determine the patient's most-likely intent in light of the available information and clinical reality.

A possible result of a huddle, though, can be that the patient's desire to donate is thwarted by hospital exigencies or the family's grief and confusion.

That regrettable result can be prevented only by clear expressions of the patient's intent in his/her advance directive that take donation into account—and by patient advocates willing to support those wishes. 

*The Revised Uniform Anatomical Gift Act of 2006 has been adopted by 45 jurisdictions and is pending in many others.



For more about National Healthcare Decisions Day and advanced directives, visit nationalhealthcaredecisionsday.org.

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