

Never too early to consider end-of-life wishes

February 18 2015, by Chris Defrancesco



Most cases of disagreements over patients' wishes for end-of-life care that have made national headlines have typically involved previously healthy people who didn't think the conversation was relevant to them. Dr. Susan Levine, medical director of UConn Health's general medicine practice, says it's never too early to plan for end-of-life decisions in the event you become unable to speak for yourself.

Levine is ambulatory site director of the UConn School of Medicine's internal medicine residency program and is a member of UConn's Health ethics committee. In those roles she has developed an expertise in [advance directives](#).

How should patients go about making their end-of-

life wishes clear?

It is most important that you have a meaningful conversation with your loved ones, and then share the outcome of that conversation with your [primary care physician](#). Physicians are often busy, and they may have a different agenda in mind for your follow-up appointment, such as making sure your blood pressure or diabetes are well controlled. So remind your physician to address and review your advance directives—a legal document in which you provide directions about your [health care](#) and ideally appoint someone to act on your behalf. In Connecticut, advance directives include a living will, health care instructions, and the appointment of a health care representative.

Review of your advance directives should be a regular part of your annual wellness exam or be something that is discussed any time there are major changes in your health.

When should the conversation about advance directives take place and how often?

Ideally, it is not a conversation to have for the first time just prior to major surgery; but certainly if it hasn't happened yet, it would be appropriate. The ideal time to think these things through is when you are well and not dealing with a medical crisis. Most of the landmark cases in which disagreements about patients' interests around [end-of-life care](#) have made national headlines – Karen Ann Quinlan, Nancy Cruzan, for example – have typically involved previously healthy young women who didn't think the conversation was relevant to them. There is no way to predict, unfortunately, when any of our lives might take a sudden turn and we might find ourselves in a similar situation.

Why is it important to appoint a health care

representative?

A health care representative is a person you authorize in writing to make decisions on your behalf. This person can decide on your behalf to accept or refuse any treatment, service, or procedure used to diagnose or treat any physical or mental condition. A health care representative can also make the decision to withhold or withdraw life support.

This is critically important, because not only is it the best way to assure that your wishes are clearly communicated, but it also alleviates the stress and uncertainty that I see all too often when family members assemble after a medical tragedy and try to piece together what their loved one would have wanted. Legally, the system typically turns to a living spouse first, a parent second, and children last. It is my experience that children often disagree with each other about what Mom or Dad would have wanted, and so great conflict among family members can arise that might be avoided with a previously identified representative. Sometimes when there is no legal representative and [family members](#) disagree, the court is petitioned to appoint the appropriate guardian, and in those instances the individual appointed may have no connection whatsoever to the family.

Note that a health care representative does not act unless you are unable to make or communicate your own medical decisions.

What's the best way to prepare your family for a meaningful conversation about advance directives?

The nonprofit organization Aging with Dignity has produced a simple document titled [Five Wishes](#) that I find a very useful starting point. It poses the following five simple questions:

1. Who do I want to make decisions for me when I can't? This has to do with assigning a health care representative.
2. What kind of medical treatment do I want or don't want? This refers to the living will.
3. How comfortable do I want to be? This section addresses matters of comfort care, such as what type of pain medication you would like, and whether you would like to know about hospice care.
4. How do I want people to treat me? This section speaks to personal matters, such as whether you would like to be at home, whether you would like someone to pray at your bedside, and so on.
5. What do I want my loved ones to know? This section deals with matters of forgiveness and how you wish to be remembered, as well as final wishes regarding funeral or memorial plans.

How are patients' end-of-life wishes properly recorded or documented?

That's where the advance directive comes in. All the information you need to complete a legally binding advance directive can be found on the Connecticut Department of Social Services website. Type "advance directives" in the search bar and then select "aging services:legal services development" for a link to a printable English or Spanish file of the advance directive documentation. You can find a very similar document through the Connecticut Department of Public Health.

I encourage you to discuss the Five Wishes with your family first. In doing so, you will likely discover things about yourself you had not thought about previously. In the state of Connecticut, the Five Wishes document or the state Department of Public Health document serve as legal advance directives. Bring a copy of your advance directive to your primary care doctor, and be sure that he or she reviews it with you

periodically.

Provided by University of Connecticut

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