



Tough Conversations

Talking to your patients, residents and families about advance directives.

By Monica Chadwick

Most people don't want to think about the end of life, much less talk about it. With advancing medical technologies, however, the end of life can often be a conscious decision as opposed to a predestined moment in time. Not talking about that decision before it arrives can cause unbearable distress—distress we can mitigate by discussing advance directives.

Shawn McGarry, a Utah defense attorney, has been through conversations about advance directives with clients and with his own family. "The fact that people create a will without advance directives is shocking to me," he says. He observes that people often seem to care more about how their belongings are distributed than alleviating the burden of end-of-life decisions on their loved ones.

George Schoephoerster, MD, a family practitioner and geriatrician, engages in end-of-life discussions on a daily basis in nursing homes across central Minnesota. Dr. Schoephoerster describes an advance directive as a conversation about what a person values and feels was the meaning of their life. This leads to decisions about when life is worth living and when to let go.

Advance directive

An advance directive or health care directive is a document expressing a person's wishes concerning life-sustaining care if they become unable to make decisions. Any competent adult can and should complete a directive, not just those facing a terminal illness. A directive is where a person expresses—while still able to think clearly—two important issues: first, what life-saving treatment they would choose (also covered by a living will); and second, who can make decisions on their behalf (also covered by a power of attorney or proxy). Those involved can address either of these separately, but the advance directive usually encompasses both.

Anyone can complete an advance directive on their own, with or without help from a provider or an attorney. McGarry agrees that an attorney is usually not necessary. The critical issue is that “there has to be communication between and among family members.” In addition, Dr. Schoephoerster feels that as the end of life draws nearer, the provider should be involved so the directive can be more specific to the medical realities.

Living will

In a living will, a person specifies what life-sustaining interventions they want or don't want if certain events become a reality. This may include wishes about care, resuscitation, hospitalization and under what circumstances they want to live or to let go.

McGarry describes how his father's living will came from jokes about whether he wanted to live if he could only eat tofu. Funny scenarios led to serious scenarios and then to a written document. When his father's health deteriorated, “it alleviated the burden of having to face those questions,” both for the family and for the providers involved. Knowing his father's wishes preempted any disagreement between family members and gave them peace.

Without a living will, McGarry believes the burden on his mother to make decisions would have been too much to bear. To illustrate, the living will directed that his father wanted extubation when it was clear he would not recover. When the tube was removed, however, his father seemed to struggle. “If my mom had been saddled with the decision to let him die, then for her to see him struggling to breathe... It would have been horrific for her. But we had a directive in place that said, ‘If these certain things are present, then I don't want to live.’”

Power of attorney or proxy

A power of attorney, also called a proxy or health care agent, designates a loved one to manage a medical crisis, to communicate with providers and to speak on a patient's behalf should they become incompetent.

Dr. Schoephoerster feels that a proxy is the most critical piece of any advance directive. He explains that living wills can be too vague to cover a specific, real-life scenario. A living will requesting “no heroic measures” leaves too much room for interpretation. As scenarios change, a proxy can look at

the situation day to day and say, “Now this is what I think the person would want.”

Dr. Schoephoerster explains that a proxy can also take the provider out of the middle of feuding family members. The patient already selected one representative to speak on his or her behalf, and that person speaks for the whole family.

Physician order for life-sustaining treatment

The physician order for life-sustaining treatment (POLST) is a standing and transferrable medical order completed by a physician that directs treatment in specific scenarios. The POLST functions as a do not resuscitate (DNR) order that can transfer between facilities, sometimes even between states.

Unlike other directives, the POLST becomes appropriate at the end of life because it is effective immediately, not when some hypothetical circumstance arrives. It is used for those with mental capacity, but who face life-threatening illnesses; those with very specific, perhaps religious, preferences about end-of-life; and those who want a DNR order outside of a health facility.

Dr. Schoephoerster explains that the POLST form has two advantages over other advance directives. First, it is an order from a physician. The physician is involved with providing care and is involved in the decision-making. Second, it is specific. The POLST is completed when medical realities are present, not hypothetical, and it addresses specifics of chronic disease management, resuscitation, hospitalization and other real scenarios.

The National POLST Paradigm, an organization promoting POLST usage, estimates that 45 out of 50 states have existing or at least developing POLST programs.¹ Of Constellation's 21 states, 13 have POLST programs in place or in the works.

Start the conversation

Providers hold enormous power to break down intimidation and start the conversation. Sharing talking points about options can lead families to face the harder part—talking about values in life, spiritual beliefs and their feelings about their humanity that will lead to decisions about end-of-life care.

References

1. National POLST Paradigm Program Destinations. bit.ly/38yFy0v. Accessed February 27, 2020.

Resources

Utah Guide to End-of-Life Care www.leaving-well.org

Minnesota Department of Health—Questions and Answers about Health Care Directives bit.ly/331BFjr

CaringInfo—National Hospice and Palliative Care Organization caringinfo.org

The National POLST Paradigm polst.org



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