



Advance Care Planning: When Law and Medicine Intersect

Planning for disability and end-of-life decisions is getting more media attention than ever before. I have asked my friend, Dr. Greg Phelps, the hospice medical director for the University of Tennessee Medical Center, if he would write an article about developments in advance care planning, and the intersection between law and medicine. What obstacles do doctors encounter and how can we help our clients and

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their families plan and avoid drama when there should be peace and understanding as our loved ones enter that final slope of life? He is a doctor who still makes house calls and truly listens to his patients and their families. Many thanks to Dr. Phelps for sharing his knowledge and experience with us in this article and as a speaker at the 2015 Tennessee Bar Association Elder Law Forum.

The Ethos of Palliative Care

It was a bit of a surprise to me after 27 years as a family practitioner to discover the ethos of palliative care. In conventional, curative medicine such as I had practiced, the object of treatment was “the disease.” The patient was a collection of parts with a specialist for each. We placed our faith in tests, medications and procedures with little thought to the patient and their context. Comfort was secondary. The goal was to keep the patient alive longer. Death was the ultimate failure.

In palliative care and hospice the “object of treatment” is the patient and his family. Comfort and quality of life are our primary concerns. We treat the patient as a complex, integrated, bio-psycho-social spiritual person. We practice medicine within the context that life is finite for all. It’s not a matter of “there is nothing else to do.” Instead, what we, as health care providers, choose to do turns on the patients’ choices about how they want to live out their lives.

Tennesseans are fortunate to be the beneficiaries of the Healthcare Decisions Act,¹ which became law in 2004 and was amended in 2013. The resulting Tennessee End-of-Life Partnership² has been a driving force in the effort to make Advance Care Planning an accessible and straightforward process for all Tennesseans. Many of our fellow southern states have little or nothing to compare.

Advance care planning is not about the piece of paper. Instead, it is about the conversation with loved ones. To that end, several national initiatives to promote conversations about end-of-life care have been launched. These include *Talk Turkey*,³ which brings the discussion of goals of care to the family Thanksgiving meal. Another is *National Healthcare Decisions Day* on April 16. (Get it? Death and taxes.)

The Knoxville Academy of Medicine has been among 23 pilot project sites around the nation to focus on improving the conversation about care and treatment choices in the final period of life. Sponsored by the Institute for Healthcare Improvement, the project incorporates the work of Pulitzer Prize-winning columnist and bestselling author Ellen Goodman, who founded The Conversation Project in 2012. This public health campaign aims to change the way people talk about, and prepare for, death — across the nation and beyond⁴ — by

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improving the frequency and quality of conversations around patients' end-of-life wishes.

Why would we need to pursue such a goal? In America, it seems that death is often viewed as somewhat negotiable. Joanne Lynn MD, director of the Altarum Institute's Center for Elder Care and Advanced Illness, admonishes: "Let's stop telling the public that exercising and eating blueberries will avoid the problem."

Consider these statistics from the American Society of Geriatrics:

- The average person who makes it past the age of 65 will endure three years of needing assistance with activities of daily living (bathing, toileting, eating, dressing, etc.) before dying from a chronic illness.
- Additionally, 68 percent of adults over age 65 will have greater than four chronic conditions that will account for 80 percent of Medicare spending.
- Finally, fully 25 to 30 percent of the Medicare budget is spent on the 5 percent of patients in the final year of life (often with little to show for it).

Despite the movement toward substantive advance care planning, doctors remain notoriously loath to talk with patients about end-of-life care. In an article published in the *Journal of the American Medical Association*, a study of terminally ill cancer patients revealed that only 37 percent had taken part in a

conversation with their doctors about the care they would want if they were terminally ill. Cancer is not the only condition with an often-terminal course. Chronic obstructive pulmonary disease (COPD), congestive heart failure and end-stage renal disease carry 50 percent mortality at five years. Yet, discussions about mortality are not typically a part of the plan of care.⁵

Rather than a single act, *advance care planning* is a process consisting of multiple conversations occurring over a period of time. The importance of form and structure to prepare and guide physicians and to empower patients is undeniable, and the creation of best practice guidelines is a work in progress. One of the most successful programs is the Gundersen⁶ model, which originated in La Crosse, Wisconsin. Their *Respecting Choices* program outlines a minimum of three conversations.

The Tennessee advance care planning forms address decisions regarding overall quality of life and list the conditions that would create an unacceptable quality of life for the patient, such as "permanent confusion" and "permanently unconscious condition." Specific medical interventions to keep people alive such as tracheostomy, ventilation and cardiopulmonary resuscitation are listed for consideration. In practice we physicians generally prefer more narrative *about what people want to be able to do going forward*. I have entered into many a conversation with a patient's family where they want "everything" done. As we talk about the

actual impact of the life-ending condition, and the inevitable functional losses and limitations for the patient, the conversation often turns to comfort care.

For the effective implementation of an Advance Care Plan, a crucial consideration is the patient's choice of a surrogate or health care agent. The "palliative care nightmare" is the family member from the other side of the country who hasn't seen dad in 20 years and is now pounding the table and saying, "I want everything." My response is to say, "I know you love your dad, but if he was standing beside you now, what would he say?"

Often chronically and terminally ill patients are sick and tired of being sick and tired. When informed of the terminal nature of their illnesses, they often choose a much less aggressive course of treatment than their families would choose for them. In fact one of the most common reasons patients do select aggressive care is "to not disappoint the family."⁷ A health care surrogate should have good knowledge of the patient and their wishes, be available, be willing to make hard choices and *be willing to follow the patient's desires*.

It is often difficult for physicians to turn their attention and efforts to this final slope. In some states, including New York and California, legislators have passed laws requiring physicians to begin the conversation about palliative care when they determine the patient likely has less than a year to live. At the intersection of law and medicine, such legislation has profound social and economic implications.

In her November 2013 JAMA article,⁸ Dr. Lynn identifies four core elements necessary to assure that Americans are able to live comfortably and meaningfully, at a sustainable cost, through the period of frailty associated with late life:

- 1. Honest discussion:** We should stop deluding the public with the message that late life frailty is a preventable problem. Of course good health habits should be encouraged. But most who do all the right things will still have a period of disability when they reach advanced age. Let's

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The Law at Work

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to meet for many plaintiffs, this does not always ensure summary dismissal for defendants. And finally, *Williams* provides perhaps the most valuable guidance of all: just because your step-father is the chief of police, doesn't mean you can avoid a citation for speeding in Burns, Tennessee. ⚖️

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Notes

1. *Tenn. Code Ann.* § 50-1-304.
2. *Sykes v. Chattanooga Hous. Auth.*, 343 S.W.2d 18, 26-27 (Tenn. 2012).
3. No. 2014-00271-COA-R3-CV, 2014 Tenn. App. LEXIS 789 (Tenn. Ct. App. Dec. 1, 2014), perm. app. denied at 2015 Tenn.

- LEXIS 297 (Apr. 10, 2015).
4. 2014 Tenn. App. LEXIS 789, at *22.
 5. *Id.* at *3.
 6. *Id.* at *5.
 7. *Id.* at *22.
 8. *Id.* at **16-17
 9. *Id.* at *31.
 10. No. E2014-02213-COA-R3-CV, 2015 Tenn. App. LEXIS 839 (Tenn. Ct. App. Oct. 15, 2015).
 11. *Id.* at *21.
 12. *Id.*
 13. *Id.* at *22.
 14. *Id.*
 15. 465 S.W.3d 96 (Tenn. May 4, 2015).
 16. *Id.* at 121.
 17. *Id.* at 122.

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instead talk about how to maintain good quality of life in elders with late life disability.

2. Better advance care planning, based on each elder's goals, that targets care and services based upon each elder's individual needs. (Perhaps we could call these "life panels?")

3. Care delivery in the elder's home. For disabled elders, just making it to a doctor's office can be an insurmountable hurdle.

4. A care system that embraces long-term supportive services and medical care as equal partners: "food, transportation and direct personal services are often more important than diabetes management."

The importance of having these crucial conversations while they're still possible is aptly expressed in one of The Conversation Project's central mottos: "It's always too soon until it's too late."

So now I ask: Do YOU have an advance care plan? ⚖️

Notes

1. *Tenn. Code Ann.* § Section 68-11-1801, et seq.
2. Tennessee End of Life Partnership, <http://endoflifecaretn.org>.
3. "Talking Turkey over Turkey," Nov. 6, 2013, *Compassion & Choices*, <https://www.compassionandchoices.org/2013/11/06/talking-turkey-over-turkey/>
4. The Conversation Project, www.theconversationproject.org.
5. Wright, A.A., Zhang, B., Ray, A., Mack, J.W., Trice, E., Balboni, T., Mitchell, Jackson, V.A., Maciejewski, P.K., Prigerson, H.G., "Associations Between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death and Caregiver Bereavement Adjustment," *JAMA*, 2008; 300(14):1665-1673, doi: 10.1001/jama.300.14.1665.
6. "Respecting Choices® Advance Care Planning," Gundersen Health System, <http://www.gundersenhealth.org/respecting-choices>.
7. Jackson, K., "Transitions to Hospice Care — Social Workers Foster Meaningful Conversations about Dying," *Social Work Today*, July/August 2013, Vol. 13 No. 4 P. 22.

8. Lynn, J., "Reliable and Sustainable Comprehensive Care for Frail Elderly People," *JAMA*, 2013; 310(18): 1935-1936. doi: 10.1001/jama.2013.281923.

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