

***"End-of-Life Decisions and the Law: The biggest life-and-death decision of your life....will be made by someone else"***

**Susan Shapiro**

*Research Professor, American Bar Foundation*

*Moderated by Hon. Elizabeth S. Stong*

*U.S. Bankruptcy Court, Eastern District of New York*

Thursday, January 25, 2018

Offices of Wachtell, Lipton, Rosen & Katz

51 West 52<sup>nd</sup> Street, New York, NY

# The Living Will as Improvisation

by Susan P. Shapiro



Six years after controversy over “death panels”<sup>1</sup> scuttled efforts to compensate health professionals for advance care planning, the Centers for Medicare and Medicaid Services will begin doing just that in January 2016, including for explanation and completion of advance directive forms with patients and their families. As hundreds of thousands of practitioners stand poised to counsel tens of millions of Americans under Medicare, it is appropriate to reflect on the legacy of advance directives and ask how physicians might best serve their patients as they anticipate life’s end.

Ironically, this long-awaited Medicare change comes as support for these advance directive forms has reached its nadir.<sup>2</sup> Although the value of proxy directives, which designate a medical decision maker in the event that a person loses capacity in the future, has been repeatedly demonstrated, that of instructional directives or so-called living wills, which state treatment preferences, has not. A new report by the Institute of Medicine concludes that legal approaches embodied in living wills have “been disappointingly ineffective in improving the care people nearing the end of life receive and in ensuring that this care accords with their informed preferences.”<sup>3</sup>

But some recent studies offer a more hopeful prognosis. Drawing on medical records, death certificates, or retrospective surveys, several find a correlation between treatment preferences expressed in directives and outcomes such as final treatment

or place of death.<sup>4</sup> Of course, correlation is not necessarily cause. As these investigators concede, they have no way of knowing whether the living wills were even consulted or instead serve as a marker for something else.

It is not surprising that data on whether and how instructional directives are actually used are in short supply, since they require prospectively observing decision making as it unfolds. Research in two intensive care units (ICUs) in a large urban teaching hospital with a diverse population of patients has done just that.<sup>5</sup> For three years, a medical social worker and I observed medical decision making on behalf of patients without decision-making capacity, day after day, from admission to discharge. Daily observations over the course of each patient’s ICU stay tracked when anyone asked about or referred to an advance directive, how the directive was used, and the correspondence between the patient’s treatment preferences articulated in the directive and the host of decisions made on their behalf. Both qualitative and quantitative analyses of these data cast further doubt on the efficacy of these documents.

About half of these ICU patients reportedly had advance directives. Yet, in more than 1,000 encounters and family meetings between almost 300 health care providers and more than 600 patient friends and

<sup>1</sup> Nyhan, Brendan. “Why the ‘Death Panel’ Myth Wouldn’t Die: Misinformation in the Health Care Reform Debate.” *The Forum* 8, no. 1 (2010): Article 5.

<sup>2</sup> Gillick, Muriel R. “Reversing the Code Status of Advance Directives?” *New England Journal of Medicine* 362, no. 13 (2010): 1239-240; Sabatino, Charles P. “The Evolution of Health Care Advance Planning Law and Policy.” *Milbank Quarterly* 88, no. 2 (2010): 211-39; Fagerlin, Angela, and Carl E. Schneider. “Enough: The Failure of the Living Will.” *The Hastings Center Report* 34, no. 2 (2004): 30-42.

<sup>3</sup> IOM (Institute of Medicine). *Dying in America: Improving Quality and Honoring Individual Preferences near the End of Life*. National Academies Press, 2015.

<sup>4</sup> Degenholtz, Howard B., YongJoo Rhee, and Robert M. Arnold. “Brief Communication: The Relationship between Having a Living Will and Dying in Place.” *Annals of Internal Medicine* 141, no. 2 (2004): 113-17; Hammes, Bernard J., Brenda L. Rooney, and Jacob D. Gundrum. “A Comparative, Retrospective, Observational Study of the Prevalence, Availability, and Specificity of Advance Care Plans in a County That Implemented an Advance Care Planning Microsystem.” *Journal of the American Geriatrics Society* 58, no. 7 (2010): 1249-255; Silveira, Maria J., Scott Y.H. Kim, and Kenneth M. Langa. “Advance Directives and Outcomes of Surrogate Decision Making Before Death.” *New England Journal of Medicine* 362, no. 13 (2010): 1211-218.

<sup>5</sup> Shapiro, Susan P. “Advance Directives: The Elusive Goal of Having the Last Word.” *NAELA Journal* 8, no. 2 (2012): 205-32; Shapiro, Susan P. “Do Advance Directives Direct?” *Journal of Health Politics, Policy and Law* 40, no. 3 (2015): 487-530.

family, for only a quarter of patients with directives did anyone ever ask about treatment preferences expressed in the document, let alone describe them. And for every directive that helped honor patient wishes—providing clarification, corroboration, or closure, fostering consensus, or assuaging guilt—another failed to do so—its instructions flouted, ignored, misunderstood, providing insufficient guidance or directions no longer consistent with patient preferences.<sup>6</sup>

Of course, directives do not have to be invoked, described, or even mentioned to affect medical decisions. If living wills, or the conversations their completion occasions, provide information, guidance, authority, reassurance, or absolution to decision makers or health care providers, one would expect them to play a role in the decision-making process. Yet the study found little difference (controlling for demographics and severity of illness) in how decision makers armed with instructional directives and those without them proceed. Across almost three dozen aspects of the decision-making process, outcomes, or impact—from whether and how participants reprised patient wishes, to the decision criteria considered, how quickly decisions were reached, conflict, the emotional burden on family members, responses of health care providers, even the decisions themselves (from refusing an intervention to withdrawing life support)—only one significant difference could be found. Discussion of goals of care was more often initiated by family members of patients with directives. Though aggressive treatment is the default when patients have no advance directive, treatment decisions were not different; they were made no faster; they weighed similar criteria; and they appeared to be no less burdensome for families.<sup>7</sup>

These findings are limited to only two ICUs in a single hospital and do not reflect other settings in which end-of-life medical decisions are negotiated. Nonetheless, they raise questions about the mechanism by which living wills have the effects reported in the correlational studies. Perhaps instructional directives play a more important role outside of ICUs, for example, keeping patients out of hospitals altogether.

<sup>6</sup> Shapiro, Susan P. “Advance Directives: The Elusive Goal of Having the Last Word.” *NAELA Journal* 8, no. 2 (2012): 205-32.

<sup>7</sup> Shapiro, Susan P. “Do Advance Directives Direct?” *Journal of Health Politics, Policy and Law* 40, no. 3 (2015): 487-530.

Still, more than two-thirds of Medicare recipients visit a hospital (42% an ICU) in the last six months of life.<sup>8</sup> There, loved ones face a torrent of complex decisions, nested in often uncertain, equivocal information, which could hardly be anticipated in a menu of checkboxes or scripted instructions written in better times when healthy patients could not envision the excruciating choices their loved ones might someday face.

Do we really want to squander Medicare dollars compensating health professionals to complete the instructional directive forms that failed, betrayed, or proved irrelevant for so many of the patients in the ICU study? Even worse, do we want to send the message to healthy patients that writing scripts with the blessing of their physician is all they need do to ensure fidelity to their wishes and protect their loved ones at life’s end?

Scripted instructions can play an important role when patients face a known imminent terminal illness.<sup>9</sup> But advance care planning for the rest of us must eschew writing scripts and reflect on process:<sup>10</sup> How to choose the most effective proxies and prepare them for what many characterize as the most difficult role of their life? What decision criteria are most important; how should they be weighed and tradeoffs balanced? How to evaluate probability, risk, or prognostic uncertainty? How long to pursue aggressive interventions before changing the goals of care from cure to comfort? How much suffering along the way is acceptable? What constitutes an acceptable quality of life? What fates are worse than death? How much weight to give to the needs of the family?

<sup>8</sup> Percent of Medicare Decedents Hospitalized At Least Once During the Last Six Months of Life, by Gender and Level of Care Intensity. Dartmouth Atlas of Health Care Web Site. Accessed December 1, 2015. <http://www.dartmouthatlas.org/data/distribution.aspx?ind=133&loc=&loct=2&tf=34&fmt=158&ch=9,32&oloc=2,3,4,5,6,7,8,9,10,11,12,13,14,15,16,17,18,19,20,21>.

<sup>9</sup> Hickman, Susan E., Christine A. Nelson, Alvin H. Moss, Susan W. Tolle, Nancy A. Perrin, and Bernard J. Hammes. “The Consistency Between Treatments Provided to Nursing Facility Residents and Orders on the Physician Orders for Life-Sustaining Treatment Form.” *Journal of the American Geriatrics Society* 59, no. 11 (2011): 2091-099.

<sup>10</sup> McMahan, Ryan D., Sara J. Knight, Terri R. Fried, and Rebecca L. Sudore. “Advance Care Planning Beyond Advance Directives: Perspectives From Patients and Surrogates.” *Journal of Pain and Symptom Management* 46, no. 3 (2013): 355-65.

A wealth of stimulus material—questionnaires, videos, online exercises, facilitated dinner conversations, even card games—already exist to assist individuals and their loved ones in exploring these abstract questions. These exercises do not help formulate better scripts for unforeseen medical crises, but provide insight into how to improvise when the unthinkable occurs, especially when loved ones interact with clinicians who never knew us or our wishes.

What then should we ask of or expect from our health care providers? They ought to encourage us to undertake the advance care planning process and share the relevant stimulus materials. But their contributions are necessarily limited by the time required for these complex ongoing conversations, lack of access in an office visit to all the participants who may one day try to speak for us, and lack of training to facilitate these difficult conversations,<sup>11</sup> which have more to do with family dynamics and personal values than medical expertise or judgment. Still, physicians should help us identify the most effective proxy decision maker, insure that we

---

<sup>11</sup> Halpern, Scott D., and Ezekiel J. Emanuel. “Can the United States Buy Better Advance Care Planning?” *Annals of Internal Medicine* 162, no. 3 (2015): 224-25.

understand the choices we face, discourage us from writing scripts prematurely, pose the hard questions appropriate to our medical status, prod us to reflect on these questions with our loved ones, and remind us to reexamine our responses, priorities, and choice of decision maker as life circumstances change. But we need directors inspiring and guiding improvisation, not scriveners checking boxes on boilerplate forms.

A truly directive living will is not a script, but rather an evolving, ongoing dialogue throughout the life course with those who may someday be called to improvise on our behalf. Let’s hope that Medicare dollars are used to help enrich the conversation.

---

*Susan P. Shapiro is a sociologist and research professor at the American Bar Foundation in Chicago. She works at the intersection of fiduciary relationships and trust, on the one hand, and law and regulation, on the other. Her most recent research, conducted in two intensive care units, examines how families and others make medical—often end-of-life—decisions for patients who are unable to speak for themselves. She is also a Commissioner of the ABA Commission on Law and Aging. ■*

## Health Decisions Resources

March 2017

### A. THINKING ABOUT AND DISCUSSING YOUR GOALS AND VALUES

**Consumer's Tool Kit for Health Care Advance Planning**, by the ABA Commission on Law and Aging is available for free download at: <http://ambar.org/agingtoolkit>.

**The Conversation Project**, an initiative begun in 2010 by noted columnist Ellen Goodman and a group of her colleagues, concerned media, clergy, and medical professionals, all dedicated to helping people talk about their wishes for end-of-life care. Resources include the Conversation Starter Kit at: [www.theconversationproject.org/](http://www.theconversationproject.org/).

**The Go Wish Game**, a card game for sorting out values related to end-of-life decision-making, created by the Coda Alliance, a community organization in Santa Clara County, California. An easy, entertaining way to think and talk about what's important to you if you become seriously ill. Available for purchase at: [www.codaalliance.org](http://www.codaalliance.org).

**PREPARE web site**. This free web site is designed to help people and their loved ones prepare for medical decision making by guiding the user through five easily understandable steps of preparation for decision-making with the help of multiple video aids. The result is a printable action plan. Available at: [www.prepareforyourcare.org](http://www.prepareforyourcare.org).

**Advance Care Planning: Tips from the National Institute on Aging**. This tip sheet describes advance care planning and offers some questions to get the process going. It also describes ways to share your wishes with others. Available at: <http://www.nia.nih.gov/health/publication/advance-care-planning>.

### B. HELPING YOU DRAFT AN ADVANCE DIRECTIVE

**Five Wishes**. Published by Aging with Dignity. This nationally used, popular advance directive and guide lets your family and doctors know:

- Who you want to make health care decisions for you when you can't make them.
- The kind of medical treatment you want or don't want.
- How comfortable you want to be.
- How you want people to treat you.

- What you want your loved ones to know.

Available for purchase/download at: [www.agingwithdignity.org](http://www.agingwithdignity.org).

**Caring Conversations Workbook**, published by the Center for Practical Bioethics, is both a workbook and advance directive. It can be downloaded for free from their web site: <http://practicalbioethics.org/files/caring-conversations/Caring-Conversations.pdf>.

**Thinking Ahead: My Way, My Choice, My Life at the End.** This workbook and video were created by California advocates with developmental disabilities. However, it is a good tool for anyone who wants a simple, easy-to-follow workbook. Available for free at: <http://coalitionccc.org/tools-resources/people-with-developmental-disabilities>.

**A Guide to Living Wills and Health Care Proxies**, by Harvard Medical School (for purchase): [www.health.harvard.edu/special\\_health\\_reports/the-health-care-power-of-attorney-and-living-will](http://www.health.harvard.edu/special_health_reports/the-health-care-power-of-attorney-and-living-will).

**MyDirectives.com.** MyDirectives is a free web-based service that walks you through the process of creating an “advance digital directive” which can be electronically signed. The directive is encrypted and stored in their secure database, available to you and your medical treatment providers 24/7. Available at: <https://mydirectives.com/>

## C. HELPING HEALTH CARE AGENTS DO THEIR JOB WELL

**Making Decisions for Someone Else: A How-To Guide**, published by the ABA Commission on Law and Aging, this guide is for anyone serving in the role of health care decision maker for someone else: <http://ambar.org/agingproxyguide>.

## D. ADVANCE DIRECTIVE FORMS

***Giving Someone a Power of Attorney for Your Health Care:  
A Guide with an Easy-to-Use, Multi-State Form for All Adults***

Prepared by the ABA Commission on Law and Aging (2011), available at:

<http://ambar.org/HealthCarePOA>. This form works in all but the five states listed below. The link next to each state takes you to a form acceptable in those states:

- Indiana: [www.in.gov/isdh/files/advanceddirectives.pdf](http://www.in.gov/isdh/files/advanceddirectives.pdf)
- New Hampshire: [www.healthynh.com/advance-directives-healthcare-decision-coalition-home.html](http://www.healthynh.com/advance-directives-healthcare-decision-coalition-home.html)
- Ohio: <http://ohiohospitals.org/advance-directives>
- Texas: <http://www.caringinfo.org/files/public/ad/Texas.pdf>
- Wisconsin: <https://www.dhs.wisconsin.gov/forms/advdirectives/index.htm>

## Links to state-specific Advance Directive forms for all states:

- National Hospice and Palliative Care Association at:  
<http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289>

## E. ADVANCE DIRECTIVE REGISTRIES

### Online or Cloud-based registries

Your state may sponsor a registry to enable providers to have access to your advance directive 24/7. Plus, there are several national registries such as the following:

- America Living Will Registry: [www.alwr.com](http://www.alwr.com)
- U.S. Living Will Registry: [www.uslwr.com](http://www.uslwr.com)
- MedicAlert Foundation: [www.medicalert.org/join/advance-directives.htm](http://www.medicalert.org/join/advance-directives.htm)
- MyDirectives: [www.mydirectives.com/](http://www.mydirectives.com/) A website that enables you to digitally create an advance directive and register it in a database accessible to providers.

## F. GENERAL END-OF-LIFE CARE RESOURCES

### Handbook for Mortals: Guidance for People Facing Serious Illness

(2<sup>nd</sup> Ed., Oxford Univ. Press, 2011) by Joanne Lynn, Joan Harrold, and Janice Lynch Schuster. A comprehensive and readable 320-page guide to dealing with serious, eventually fatal illness. Find on Amazon, Barnes & Noble, or in book stores.

### Hard Choices for Loving People: CPR, Artificial Feeding, Comfort Measures Only and the Elderly Patient

by Hank Dunn. A&A Publishers, Inc. Web site: [www.hankdunn.com](http://www.hankdunn.com). A concise and helpful 80-page booklet on end-of-life decisions concerning resuscitation, food and fluids, hospitalization, and cure versus comfort care.

### National Health Decisions Day

Held April 16 of each year, you can learn more about NHDD at: <http://www.nhdd.org>