

## *Respecting Choices: A Case Study for Incorporating Advance Care Planning into Person and Family-Centered Health Care Delivery*

By Janet H. Forlini and Lee Goldberg

There has been a paradigm shift in the relationship between the health care system and consumers. The Institute of Medicine (IOM), in its 2001 report *Crossing the Quality Chasm*,<sup>1</sup> highlighted the importance of patient-centered care, defining it as “care that is respectful of and responsive to individual patient preferences, needs, and values” and care that ensures “that patient values guide all clinical decisions.”<sup>2</sup> Similar to patient-centered care is the concept of person-centered care that focuses on accumulated knowledge of individuals’ health problems and needs over time;<sup>3</sup> it is a viewpoint that can be traced back to the independent living movement in the early 1970s.<sup>4</sup> Person and family-centered care, which has also gained attention in recent years, is an orientation to the delivery of health care and supportive services that addresses an individual’s needs, goals, preferences, cultural traditions, family situation and values.<sup>5</sup>

The person-centered approach inherent in advance care planning reflects this evolution. Advance care planning is a process of planning for future medical decisions. But in order to be effective, it must meet a higher standard of involvement than the process of informed consent: individuals need to consider how their health may change; reflect on how treatment may impact their life goals, values and preferences; and over a period of time discuss their choices and plans with those who might be responsible for implementing them.<sup>6</sup> This policy brief, the second in a series that highlights issues raised by the Campaign to End Unwanted Medical Treatment, makes

the case that advance care planning can play a crucial role in ensuring that people receive the care they want throughout various stages of their lives.

Implemented in 1991 by the Gundersen Lutheran Health System in LaCrosse, Wisconsin, *Respecting Choices* is a comprehensive program that aims to engage patients and families in informed conversations about end-of-life decision-making. The program provides standardized materials to patients across all health settings in the community; trains non-physician facilitators to guide patients and families in advance care planning; and implements common policies and practices for collecting, maintaining, retrieving and utilizing advance care planning documents across settings. According to Bernard “Bud” Hammes, PhD,<sup>7</sup> Director of Medical Humanities for Gundersen, one of the greatest misconceptions about advance care planning is that it is a static process — a one-time event. Attempting to plan for all possibilities in a single document or at a single point in time is both impossible and unnecessary, according to Hammes. In the *Respecting Choices* model, advance care planning is an ongoing process of communication, integrated into the person-centered care routine and appropriately staged to the individual’s state of health.

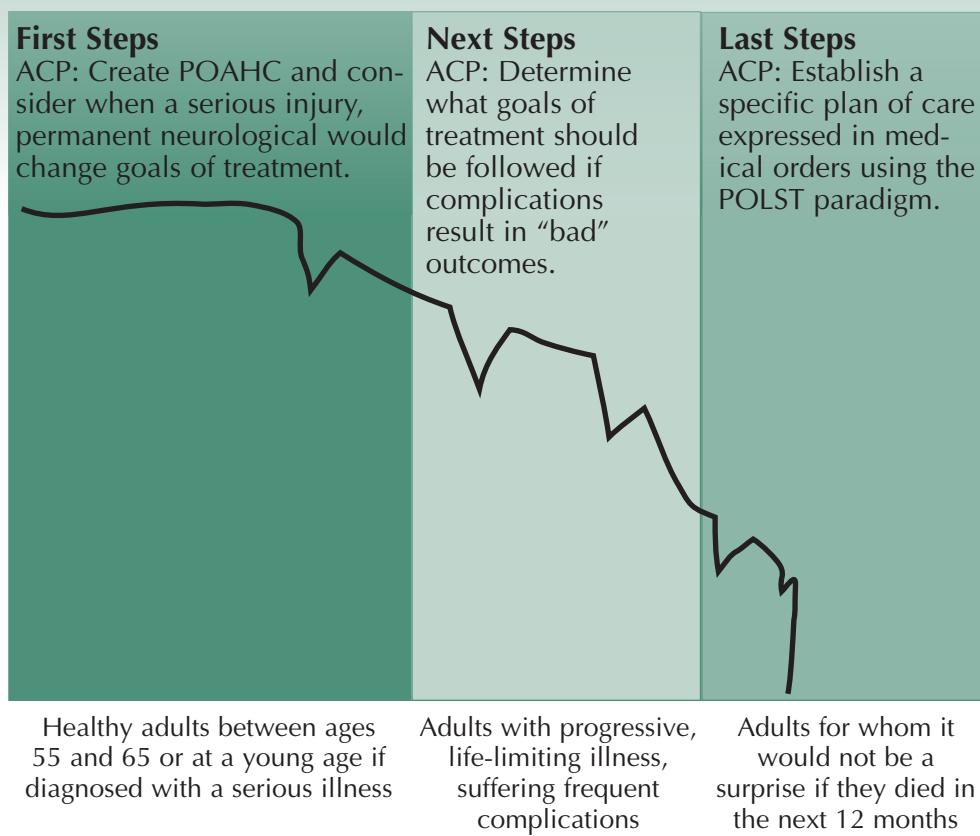
*Respecting Choices* is only one model that addresses advance care planning. From a public policy perspective, fairly extensive peer-reviewed research of the model offers instructive lessons for improving outcomes not only for individuals but also for families. Having been

successfully replicated in communities across the U.S. as well as internationally, the model appears to have also addressed the issue of scalability that has been a challenge for other programs aimed at meeting the needs of people with chronic care conditions. Most importantly, the *Respecting Choices* model allows for advance care planning over the course of a person's life – not just when an individual is approaching the last phase of life – and adapts as individuals move through various stages of health.

This ongoing process allows for the possibility that individual preferences might change over time as health status worsens due to chronic illness or an acute episode

(see Figure 1). *Respecting Choices* breaks the stages of planning into three possible categories that reflect a person's stage in life. The first category is for healthy adults between 55-65 or a young person diagnosed with a serious illness. These individuals would create a power of attorney for health care decisions and would begin to consider whether a significant change in health status might change their goals for treatment. The second category in the diagram captures adults with progressive, life-limiting illness who are suffering frequent complications. These individuals may want to begin considering how treatment should be adjusted if complications result in undesired outcomes. The third and final category includes adults for whom it would not be sur-

**Figure 1: Stages of Advance Care Planning over the Lifetime of Adults from the *Respecting Choices* Model**



Source: Hammes, Bernard. "How Can A 'Care Planning System' Improve Care?" Campaign to End Unwanted Medical Treatment Series presentation on December 3, 2013.

#### Acronyms:

ACP = Advance Care Planning

POAHC = Power of Attorney for Health Care

POLST = Physician orders for Life-Sustaining Treatment

prising if they died within a year. These individuals should establish a plan of care expressed in medical orders.

Advance care planning is not part of the average person's current experience in the health care system in this country. Instead, much more common is a one-time utilization of statutory documents — generally living wills and durable powers of attorney for health care — that allow individuals to indicate preferences and name a proxy in the event they become unable to make decisions for themselves. Advance directives, however, can be provided orally or in writing. They can even be in the form of a patient's letter to a loved one. Many options exist.

Commonly-used legal documents may address the disposition of property and the transfer of decision-making power, but research has shown that such documents may not serve the purpose of accurately identifying a patient's wishes and values. A preferable approach to advance care planning may be one that relies not on forms but on carefully structured conversations that explore patients' values. The process of advance care planning, with its inclusion of meaningful discussion and reflection, does not have the same risk.

Research also shows that the *Respecting Choices* model improves outcomes not only for the patients involved but also for the family members. A 2010 study<sup>8</sup> looked primarily at the proportion of patients whose end-of-life wishes were known and respected by the physician. The secondary measure assessed the impact of the patient's death on relatives. Results found that end-of-life wishes were known and respected for 86 percent of the patients in the intervention group who died compared to only 30 percent of those in the control group. Similarly, 76 percent of the deaths in the intervention group were associated with positive comments from family members compared to only 19 percent of the control group. The researchers concluded that advance care planning improves end-of-life care for the patient and reduces stress, anxiety and depression in surviving relatives.<sup>9</sup>

Gundersen is also part of an ongoing Medicare Health Care Quality Demonstration,<sup>10</sup> the goal of which is to examine health delivery factors that lead to improved

quality of care. The demonstration project, which began in 2010 and is scheduled to end in 2014, will allow the Gundersen Lutheran staff to share strategies and potentially operationalize the program on a broader scale. While the demonstration project is still underway and results are not yet known, the hope is that Gundersen's approach may be able to improve quality of care for Medicare beneficiaries in a more sustainable way.

Under current law, institutions participating in Medicare and Medicaid must inform patients of their rights to accept or refuse treatment and to execute an advance directive. But neither Medicare nor Medicaid provides reimbursement to health care professionals engaging in voluntary advance care planning discussions with patients. Two legislative proposals—*The Care Planning Act of 2013* (S. 1439) and the *Personalize Your Care Act* (H.R. 1173)—are efforts to change that.

In the meantime, the *Respecting Choices* model is being implemented by other health care systems in the U.S. and abroad. *Honoring Choices Wisconsin* is a state-wide initiative to build system change, advocacy and education around advance care planning. As part of *Honoring Choices Wisconsin*, the state medical society serves as a convener, coordinator and catalyst to build clinical improvements combined with outreach in communities across the state. Participating health care organizations systems have agreed to embrace a common emphasis on improving the conversation across health systems; use patient-tested forms and informational materials; share lessons learned formally and informally; and support community outreach.<sup>11</sup> Australia and Singapore have also successfully piloted efforts to incorporate advance care planning based on the *Respecting Choices* model.

Health reform has changed the way policymakers, providers and the public view health care delivery for individuals. Significant progress has been made with regard to an individual's right to make informed, person-centered decisions about their health care options and to refuse unwanted medical treatments. Increased use of advance care planning is needed to ensure the evolution of our nation's health care system in a manner that promotes person-centered choices in all stages of life.

## ENDNOTES

- 1 Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Century. Vol. 6. Washington, DC: National Academy Press; 2001.
- 2 *Id.*
- 3 “Is Patient-Centered Care the Same as Person-Focused Care?” *Perm. J.* 2011 Spring; 15(2) 63-69.
- 4 Feinberg, Lynn. “Moving Toward Person and Family-Centered Care,” *AARP Public Policy Institute*, March 2012.
- 5 *Id.*
- 6 Hammes, Bernard. “How Can a ‘Care Planning System’ Improve Care?” Campaign to End Unwanted Medical Treatment Series Presentation on December 3, 2013.
- 7 *Id.*
- 8 Detering, Karen M., Andrew D. Hancock, and William Silvester. “The Impact of Advance Care Planning on End-of-Life Care in Elderly Patients: Randomised Controlled Trial,” *BMJ* 2010; 340; c1345.
- 9 *Id.*
- 10 Section 1866C of the Social Security Act, as amended by Section 646 of the *Medicare Prescription Drug, Improvement, and Modernization Act of 2003*, P.L. 108-173, Section 1866C(b).
- 11 Wisconsin Medical Society: <https://www.wisconsinmedicalsociety.org/professional/hcw/>. Accessed December 5, 2013.

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