What we talk about when we talk about dying: Case managers and end-of-life conversations

We need to talk.

That’s the message Patrice Sminkey, CEO of the Commission for Case Manager Certification, is delivering—not only to professional case managers, but to everyone. “We need to talk about end-of-life care.”

It’s a conversation many case managers are already having with clients and families, but it’s not happening often enough, she says. For example, while most people say they would prefer to die at home, only about a third of adults actually have completed an advance directive—a document expressing end-of-life wishes.¹ That’s especially true for

“A lack of understanding around the patient’s desires can greatly increase the risk that making end-of-life care decisions will be overlooked.”

— PATRICE SMINKEY, CHIEF EXECUTIVE OFFICER, COMMISSION FOR CASE MANAGER CERTIFICATION

those receiving care at home. Only 28 percent of home health care patients, 65 percent of nursing home residents and 88 percent of hospice care patients have an advance directive on record.²

Often, it comes back to having—or not having—those difficult conversations, Sminkey says. “The barriers to having ‘the talk’ are many. But a lack of understanding around the patient’s desires can greatly increase the risk that making end-of-life care decisions will be overlooked.”

Case managers have the skills and training to elicit a client’s preferences and to make sure they are understood. “Case managers are highly skilled communicators, well-suited to help guide these conversations. Conversations about the patient’s personal preferences for end-of-life care—often considered in the wake of a life-changing diagnosis or traumatic health event—should be broached with delicacy and empathy. Professional case managers can do that.”

Harriet Warshaw, director of The Conversation Project (TCP), has been promoting such conversations for years. It’s not just an abstract concept for her: She saw the benefit before her parents died; she saw the harm of failing to have them when her brother died.

The Conversation Project, launched in collaboration with the Institute for Healthcare Improvement, is dedicated to helping people talk about their wishes for end-of-life care, and its mission is to make sure that everyone’s wishes are both expressed and respected. TCP provides tools and support to make sure these conversations happen. (See sidebar for more on The Conversation Project.)

TCP takes a two-pronged approach to breaking the “conspiracy of silence,” Warshaw explains. The first is creating public awareness around the need for these conversations. This includes a national media campaign with readily accessible tools, including a Conversation Starter Kit that offers questions and prompts to facilitate discussions about end-of-life preferences. The questions are neutral as to decision, outcomes, etc. “People bring their own values,” she says.

In its five years of existence, The Conversation Project has engendered thousands of important discussions with friends and family about end-of-life-care wishes. When families can have frank conversations, the grieving process becomes less painful, Warshaw says.

But just talking isn’t enough: If the wishes aren’t documented, they

---

can’t be honored. “We know 70 percent of people want to die at home, but 70 percent die in institutions,” says Warshaw. Those wishes must be documented and shared with health care professionals, which leads to the second prong—and the one most important to case managers: health system transformation.

As important as allergies

The first element of health system transformation is to make end-of-life conversations an institutional priority. Some hospitals and health systems have formalized it as a standard of care. She likens it to asking a patient about allergies. The question “Do you have any allergies?” does not stop with a “yes” answer. People have to be assured they aren’t going to get the penicillin to which they are allergic. That means the allergy information needs to follow them to every health care setting. The same should happen with end-of-life wishes. They need to be articulated, documented and acted upon.

The professional case manager can play a key role.

Physicians are trained to ward off death, she explains. There is beginning to be a cultural shift, but it will take a while for many of them to accept that accompanying people on their end-of-life journey is as least as important as the latest technology. Moreover, patients often have difficulty confiding in physicians. As a result, there’s a disconnect between what patients say they know and what they really know. They aren’t always willing to ask their physician about things such as “how long do I have to live” and “what are the risks of treatment,” but they are willing to talk to someone with whom they have a trusting relationship.

That, says Sminkey, creates an important opening for the professional case manager. “We as case managers are highly skilled communicators who are aware of our patients’ needs and wishes. We are clearly in a unique position not only to start the conversation, but to reframe the way we talk about dying,” she says.

Becoming conversation ready

It’s a delicate path to walk, even for professional case managers, says Warshaw.

“That’s no magic bullet, but at The Conversation Project, we have come up with five guiding principles to help make organizations conversation ready,” Warshaw says: Engage, steward, respect, exemplify and connect.

These five principles reflect an expanded and more active role for health care providers, require
providers to engage in their own personal conversations about their wishes regarding end-of-life care, and call for heightened sensitivity to diverse cultural contexts that may influence end-of-life-care preferences. They emerged out of the recognition that, as individuals and families begin to have these conversations, health care organizations would need to be “conversation ready”—to have systems in place to receive, record and respect patients’ wishes.

Engage with patients and their families to understand what matters most to them at the end of life. Ideally, the conversation takes place in advance of a medical crisis.

Steward information about each patient’s end-of-life-care wishes. She returns to the allergy analogy: Knowing, confirming and documenting patients’ end-of-life-care wishes are as important as knowing, confirming and documenting their allergies. Such information should be readily accessible in patients’ health records—and it needs to be more than a yes/no response to a question about an advance directive. Even when wishes are expressed, if they aren’t adequately documented, it’s hard to honor them. Between 65 and 76 percent of physicians whose patients had an advance directive were not aware it existed.

Respect people’s wishes for care at the end of life by partnering to

---


## Changing payment to support the conversation

The need for and importance of end-of-life conversations is increasingly being recognized—and soon, those conversations will be reimbursable. The Center for Medicare & Medicaid Services announced Oct. 30, 2015, that Medicare will pay doctors to talk to patients about the care they want at the end of life. The rule takes effect Jan. 1, 2016. The counseling is entirely voluntary and could take place during seniors’ annual wellness visits or during regular office visits.

“This represents an important change, not just in how we pay for health care, but in how we think about it,” Sminkey says. “Six years ago, at the height of the Affordable Care Act debate, this sort of reimbursement idea touched off a political uproar about ‘death panels,’ she notes. Many health care organizations and providers have been asking for this sort of policy change, and the idea is gaining traction in the marketplace. Some private insurers already reimburse for it, and this new policy could make these discussions more common among about 55 million Medicare beneficiaries.

It’s already making a big difference, says Warshaw. The Conversation Project is collaborating with physician groups, especially now that CMS is paying for end-of-life conversations. It’s also working with health plans. Some are already taking a “quiet” role in this, she says. Among them are Cambia Health Solutions and Aetna, which has placed TCP tools on its website. “Now that CMS has made their decision to pay for these conversations, you are going to see this become ubiquitous,” she says.
considering the ways religious, ethnic, socioeconomic, educational and geographic factors affect how a patient approaches end-of-life care. History and culture can have a profound influence. She points out that many Hispanic patients, because of religious convictions and a belief in miracles, want as much care as possible. She also cites another, very different, cultural issue: African-American patients are less likely to have documented advance care plans because of the historical denial of care. Henry Ford Health System in Michigan conducts two-way training between clergy and clinicians to learn about faith traditions and medical care at the end of life. It also tailors advance care planning outreach to underserved and underrepresented populations.

Changing the culture

Case management, as defined by the Commission, is a collaborative process that assesses, plans, implements, coordinates, monitors and evaluates the options and services required to meet the client’s health and human service needs. Facilitating end-of-life discussions aligns with this process, says Smink. Moreover, with each conversation—including the ones with their own families—case managers can begin to break the “conspiracy of silence” Warshaw speaks of. “TCP offers a blueprint for changing the cultural mindset from one of avoidance to one of permission to choose one’s own path,” Smink adds.

Warshaw agrees. “What an extraordinary privilege it is to honor someone’s wishes.”

---

5 “Conversation Ready,” op. cit.
6 “Conversation Ready,” op. cit.
7 “Conversation Ready,” op. cit.
About the Experts

Patrice Sminkey, Chief Executive Officer, Commission for Case Manager Certification

Sminkey comes to the Commission from URAC, where she most recently served as senior director of sales. Prior to that, she was senior vice president, operations and client management, Patient Infosystems in Rochester, N.Y. She brings a proven track record in operations management in small and large operations, multilevel services and cross-functional teams. She has extensive experience in client management and coordination, including marked improvement in client retention, timely and fiscally sound program implementation and an expanding book of business.

As chief executive officer, Sminkey oversees the management of all activities related to the Commission’s operations, including all programs, products and services; and the provision of quality services to and by the Commission. She is a direct liaison to the Commission’s Executive Committee. She works with CCMC’s volunteer leadership to evaluate and develop potential new products for implementation by CCMC, and she establishes and maintains communication and working relationships with other organizations, agencies, groups, corporations and individuals.

She holds a diploma of nursing from the Chester County School of Nursing.

Harriet Warshaw, Executive Director, The Conversation Project

Warshaw brings more than 35 years of management experience in both the public and private sectors. As vice president at the Boston Hospital for Women, she oversaw the development of the first NICU and the first midwifery program in Boston, as well as the integration of the Boston Hospital for Women into the Brigham and Women’s Hospital. She has also held elected office in the Town of Wellesley, Massachusetts, serving 10 years on the Wellesley Board of Health and nine years as a member of the Wellesley Board of Selectmen.

Join our community of professional case managers!