



## IssueBrief

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A photograph of an older couple seen from behind, embracing in a park. The man is wearing a grey sweater and a dark scarf, and the woman is wearing a white sweater and a grey scarf. They are standing on a grassy path with trees in the background.

# 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.<sup>1</sup> That's especially true for

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

<sup>1</sup> Pew Research Center for the People & the Press. "Strong Public Support for Right to Die: More Americans Discussing—and Planning—End-of-Life Treatment." Telephone survey of 1,500 older adults under the direction of Princeton Survey Research Associates International. January 2006.

***"We've been wrong about what our job is in medicine. We think our job is to ensure health and survival. But really it is larger than that. It is to enable well-being...Whenever serious sickness or injury strikes and your body or mind breaks down, the vital questions are the same: What are your fears and what are your hopes? What are the trade-offs you are willing to make and not willing to make? And what is the course of action that best serves this understanding?"***

—ATUL GAWANDE, BEING MORTAL

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.<sup>2</sup>

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.)

***There's a disconnect between what patients say they know and what they really know.***

She emphasizes the conversation itself is what's important. "The Conversation Project does not take a position on what type of care someone gets. We really have no

preference for whether people want more or less care as long as they talk about it." She encourages everyone, including case managers, to have those conversations around the kitchen table early and often—before there is a crisis.

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

<sup>2</sup> Jones AL et al. "Use of Advance Directives in Long-Term Care Populations." *NCHS Data Brief*, No 54. National Center for Health Statistics. 2011.

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.

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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.

## About the Conversation Project



The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care. It began in 2010, when Pulitzer Prize winning journalist Ellen Goodman and a group of colleagues and concerned media, clergy and medical professionals gathered to share stories of "good deaths" and "hard deaths" within their own circle of loved ones. Over several months, a vision emerged for a grassroots public campaign spanning both traditional and new media that would change our culture. The goal: to make it easier to initiate conversations about dying, and to encourage people to talk now and as often as necessary so their wishes are known when the time comes. To make this vision a reality, The Conversation Project began its collaboration with the Institute for Healthcare Improvement. ■

## Becoming conversation ready

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

"There'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

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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.<sup>3</sup>

**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.<sup>4</sup>

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

<sup>3</sup> McCutcheon Adams K, Kabcenell A, Little K, Sokol-Hessner L. “*Conversation Ready*”: A Framework for Improving End-of-Life Care. Institute for Healthcare Improvement; 2015.

<sup>4</sup> Kass-Bartelmes BL. U.S. Agency for Healthcare Research and Quality. “Advance Care Planning: Preferences for Care at the End of Life.” *Research in Action* Issue 12. 2003.

## 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. ■

develop a patient-centered care plan. That means not only documenting those wishes, but turning them into a plan that's accessible across the continuum of care—and that can be updated as wishes change. At Virginia Mason Medical Center in Seattle, a section of the EHR is designated for preferences regarding end-of-life care.<sup>5</sup> This is quickly becoming part of the care plan, Warshaw adds. Epic is reformatting the advance care planning section of the EHR, and other vendors are following suit.

**Exemplify** this work in our own lives, so that we fully understand the benefits and challenges. “Until clinicians have had the conversation with their own family and clinicians, it’s hard to ask others to do this,” she says, adding that it’s surprising how few have. “Go home and do this. It’s important for you as an individual and as a professional case manager.” It can help uncover issues that might interfere with encouraging your patients to talk about dying. To foster this, UPMC (formerly called University of Pittsburgh Medical Center) holds an annual Day of Conversation to encourage discussions about end-of-life care throughout the health care system and the community.<sup>6</sup>

**Connect** in a manner that is both culturally and individually respectful of each patient. This fifth principle may be the most important, because it encompasses the other four; all four need to be viewed through this lens, she says. Patient-centered end-of-life care requires

<sup>5</sup> “Conversation Ready,” op. cit.

<sup>6</sup> “Conversation Ready,” op. cit.

## Tools for case managers



The Commission for Case Manager Certification has added The Conversation Project’s tools to its website to support case managers in end-of-life conversations with their clients. Resources, including videos, articles and the Conversation Starter Kit can be found at [ccmcertification.org/webinar-library](http://ccmcertification.org/webinar-library). They are also available as a learning module and free toolkit through the Commission’s Case Management Body of Knowledge®: [cmbodyofknowledge.com/content/conversation-project-toolkit](http://cmbodyofknowledge.com/content/conversation-project-toolkit). ■

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.<sup>7</sup>

## 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 Sminkey. 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,” Sminkey adds.

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

<sup>7</sup> “Conversation Ready,” op. cit.

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— HARRIET WARSHAW,  
EXECUTIVE DIRECTOR,  
THE CONVERSATION PROJECT

## 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.



### **Commission for Case Manager Certification**

1120 Route 73, Suite 200 • Mount Laurel, NJ 08054  
(856) 380-6836 • [ccmchq@ccmcertification.org](mailto:ccmchq@ccmcertification.org)  
[www.ccmcertification.org](http://www.ccmcertification.org)

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