Institute *for* Healthcare Improvement

# Respecting End-of-Life Care Wishes

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*Developing reliable systems for what matters most to patients.*

The convergence of shifting payment models, an aging population and the moral imperative to determine what matters most to patients at the end of life is effecting a sea change among healthcare providers accustomed to practicing curative medicine. Medical technology, which has pushed the boundaries of what can be done to treat illness, turns out not to be the best guide because, given a choice, many patients don't want aggressive intervention. Healthcare leaders are being called on to guide their organizations in developing reliable systems to receive, record and ultimately respect patients' wishes for end-of-life care.

For the past five years, The Conversation Project and the Institute for Healthcare Improvement have worked together to help people express their end-of-life care wishes to loved ones. In 2012, as the many free tools from TCP were being developed alongside community resources to engage the public in end-of-life conversations, IHI began to work with 10 healthcare organizations that wanted to improve their ability to support and respond to a more activated public—to be "Conversation Ready." This work expanded to engaging with 60 teams in three separate improvement collaboratives and

involved many others through seminars and virtual programs.

Through these efforts, five principles emerged, as described in detail in IHI's 2015 white paper *"Conversation Ready": A Framework for Improving End-of-Life Care*. These principles can help healthcare leaders guide their staffs in developing "Conversation Ready" organizations:

- *Engage with our patients and families to understand what matters most to them at the end of life.* This principle focuses on proactively engaging patients in discussing what matters most to them at the end of life; it is intended to mirror the ways in which healthcare providers talk with patients about other health issues (e.g., smoking cessation, blood pressure, colon cancer screening). Approaching end-of-life care preferences as equal to other health issues helps normalize the discussion and moves the provider culture toward becoming one in which raising the topic of death doesn't only occur when it is imminent. "Conversation Ready" healthcare systems intentionally build clinician encounters to include end-of-life care wishes as a valuable part of

establishing patients' overall goals for care. For example, Care New England in Rhode Island created the Conversation Nurse program to initiate values-based conversations with palliative care patients about their wishes.

- *Steward this information as reliably as you would allergy information.* When "Conversation Ready" organizations begin focusing on this work, they often learn that the extent of their knowledge about patients' end-of-life care wishes begins and ends with selecting "yes" or "no" fields in the medical record to note whether a healthcare agent has been designated and an advance directive submitted. Imagine if allergy information was tracked in this way: Does this patient have an allergy? A simple "Yes" would fail to include critical information about that patient's allergy. This principle focuses on building information technology systems that can store documentation of end-of-life care wishes accessibly in two different formats: documents that the patient has completed (e.g., do-not-resuscitate form, advance directive, healthcare proxy information) and narrative clinician notes that detail

important conversations that have taken place throughout a patient's life. Virginia Mason Medical Center in Seattle built the Advance Directive Note Type field into its EHR, which captures both scanned documents and narrative clinician notes.

- **Respect** *people's wishes for care at the end of life by partnering to develop a patient-centered plan of care.* Engaging patients in talking about their wishes and then stewarding this information are for naught if the expressed wishes aren't used to build an appropriate care plan when the end of life approaches. The principle of respect doesn't presume a particular care plan path, but rather a partnership to ascertain the best actions available given the patient's articulated wishes about his or her preferences. Acting on this information gets to the heart of being "Conversation Ready." In that vein, Beth Israel Deaconess Medical Center in Boston expanded the definition of "preventable harm" to include issues such as disrespect and failure to communicate, especially at the very moment patients and family members assume healthcare providers have clarity about their priorities for end-of-life care.

- **Exemplify** *this work in our own lives so that we fully understand the benefits and challenges.* This principle encourages healthcare staff who will be engaging patients in end-of-life care conversations to find out what it feels like first. When staff reflect on their own end-of-life care wishes and talk with their families, it removes any hypocrisy of encouraging patients to do the same. Staff are positioned to say, "I did this myself, and although I encountered some challenges, it was worth it." Elder Services of Merrimack Valley in Massachusetts began its "Conversation Ready" work by training staff to have their own conversations before engaging clients to do so.

- **Connect** *with patients and families in a culturally and individually respectful manner.* Recognizing the degree to which cultural values shape one's thinking about death and dying is essential. Clinicians need to remind themselves that patients draw from myriad identities, influences and experiences (e.g., ethnic, religious, geographic, gender, sexual orientation, profession, socioeconomic status) to form an outlook about death. Starting from a place of curiosity to better understand the cultural signals that might affect a patient can go a long way toward respecting what matters most to him or her at the end of life. Here, too, looking at one's own beliefs is a key tactic for authentic engagement. Henry Ford Medical Center in Detroit has led an impressive series of symposia between faith leaders and physicians to share professional and personal knowledge across their respective fields.

These five principles provide a holistic approach for healthcare organizations to begin tackling the complex issue of end-of-life care in a way that is more reliably respectful of what matters most to patients—with the goal of doing so for every patient, every time.

Whether people have their values respected at the end of life should not depend on which healthcare system cares for them, which service they receive or unit they are on, their cultural background, or if they have an advocate who can act on their behalf and give voice to their wishes, if necessary.

However, healthcare does not have to do this work alone. Community partnerships with civic organizations, faith communities, employers and others are facilitating the engagement of people in end-of-life care conversations well before an imminent health crisis may occur. For example, TCP works with more than 400 communities across the United States to bring together a broad array of stakeholders with the express purpose of normalizing end-of-life care conversations, supported by a host of free TCP Conversation Starter Kit (theconversationproject.org) tools and other resources.

Changing a culture is a complex process. Just as U.S. smoking rates were not reduced as the result of one action or one organization, creating a culture in which people, in concert with their loved ones and providers, feel comfortable talking about what matters most to them at the end of life requires the work of many. We all have a role to play—in our families, in our own patient-physician relationships and in the healthcare organizations we lead. Is your organization "Conversation Ready"? ▲

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**Editor's note**: The IHI white paper can be accessed at www.ihi.org/ resources/Pages/IHIWhitePapers/ ConversationReadyEndofLifeCare.aspx.