It’s the difficult conversation many of us want to avoid, but all of us will have to face at some point: end-of-life care decisions and choices. Even as health care professionals, advocating for and educating individuals across the health care spectrum, we may feel uncomfortable around having that conversation. These awkward and unsettling feelings, however, can be looked at as a gift. By acknowledging them, we are able to put ourselves in the shoes of the individuals for whom case managers advocate: the individuals (“clients” of case management) and their families/support systems. So often, these individuals and those who love them avoid having difficult conversations, especially around end of life, because death is rarely an easy topic to discuss.

By putting ourselves in the position of the person and his/her family, even drawing from our own personal experiences, we become more empathic in our listening and communication. We transition from giving information dispassionately to truly listening and connecting with the individuals. In end-of-life and other difficult conversations, empathy is crucial.

As difficult as these conversations may be, they are ultimately empowering for all involved, especially the individual—the person at the heart of patient-centered care. When end-of-life discussions are initiated well in advance of those critical or even crisis moments when decisions are imperative, the choices can be easier to make. They flow as part of a natural outcome of quality care at every phase of life.

As advocates and as role models, professional case managers need to learn how to support others in these discussions. Case managers, particularly those who are board certified, may find themselves in a unique position to initiate the conversation and help reframe the way we talk about dying, by focusing on making careful choices for how we want to live at the end of our lives.

The Commission for Case Manager Certification (CCMC) encountered this need when we received feedback from case managers about the topics they wanted to address. Across the board, case managers provided feedback that they are encountering people who are dying in many different care settings; many of these professionals feel unprepared to have end-of-life discussions. More specifically, they are not prepared from a patient-centered standpoint to optimize the conversation with individuals and their families/support systems about choices and decisions around end-of-life care.

To support case managers, CCMC is making available a resource toolkit to help case managers and other health care professionals learn how to talk about end-of-life wishes and engage in other “difficult conversations.” The End of Life Conversation Project Toolkit is available at no cost, via the CCMC Case Management Body of Knowledge (CMBOK), at www.cmbodyofknowledge.com. It is a collection of resources from the Commission and from The Conversation Project, a collaboration with the Institute for Healthcare Improvement.

Attitudes toward death and dying start with one’s own self-awareness. No matter our age or stage of life, we need to examine our thoughts and attitudes about death and dying. In our own lives and interactions, how comfortable are we with having end-of-life conversations with our families and support systems? To be clear, this conversation is not limited to a discussion that occurs when someone is at the end stage of life, when choices can feel binary about whether or not to continue a course of care. Having the conversation can and should happen now about our end-of-life wishes. Over time and with changes of circumstances, our attitudes might become
more refined and decisions about end of life may change. But initiating the conversation early, instead of avoiding it, is a gift to ourselves and to those who love us.

From this personal self-awareness, case managers can become more honest about their ability to initiate difficult conversations such as end-of-life care discussions with individuals and their family. Case managers may find that, with additional education and support, such as the End of Life Conversation Project Toolkit, they can increase their comfort and knowledge about engaging in these discussions. For some, however, their discomfort may be so great that they recognize that they can best serve the needs of the individual and the family/support system by bringing in someone who has the experience and sensitivity to engage in end-of-life conversations.

Although greater self-awareness helps case managers see where they are in their knowledge and comfort around end of life, professionals never impose their choices, opinions, or values on others. Every individual has the right to make choices that impact his/her quality of life and quantity of life. As with any other life choice, the professional case manager adheres to underlying values and ethical principles of case management. As the Code of Professional Conduct for Professional Case Managers states, board-certified case managers “understand that case management is guided by the ethical principles of autonomy, beneficence, nonmaleficence, justice, and fidelity” (CCMC, 2009).

For case managers from varied disciplines—whether nursing, social work, rehabilitation, mental health counseling, pharmacy, or others—and in work settings across the spectrum of health and human services, the End of Life Conversation Project Toolkit will be a valuable resource. The toolkit includes a step-by-step conversation starter kit and a topical brochure and access to videos and white papers.

With greater understanding of end-of-life care, case managers are better prepared to navigate what are sometimes difficult dynamics among individuals and their families/support systems. As a certified case manager with an experience in hospice observed, based on her professional experience, when families/support systems have not engaged in end-of-life conversations until a critical moment, decision making around end-of-life choices is often emotionally charged. A particularly difficult scenario is when a loved one is no longer able to communicate his/her end-of-life wishes, and the family/support system is making decisions on behalf of that person.

Even when someone has power of attorney and the authority to make decisions, making those choices can be extremely stressful and potentially divide families. Advocacy and education by a professional case manager can help defuse these challenging dynamics.

As discussed in a CCMC-developed issue brief, “What we talk about when we talk about dying: Case managers and end-of-life conversations,” adherence to five principles can help case managers facilitate end-of-life discussions (CCMC, 2015):

- Engage with individual and families/support systems to understand what matters most to them at end of life.
- Steward information about each person’s end-of-life-care wishes, confirming and documenting information.
- Respect people’s wishes for care at end of life.
- Exemplify this work so that we fully understand the benefits and challenges.
- Connect in a culturally and individually respectful manner with each individual.

End-of-life conversations need not be difficult if we focus on the key word: life. Normalizing the conversation to uncover people’s wishes and choices around quality and quantity of life helps neutralize stressful and crisis moments. For professional case managers, this is the heart of advocacy and the pathway to good consumer care across the health and human services spectrum, including and especially at end of life.

**References**


Patrice V. Sminkey, RN, is the Chief Executive Officer of the Commission for Case Manager Certification (CCMC), the first and largest nationally accredited organization that board-certifies case managers. To date, more than 35,000 professionals have been awarded the Certified Case Manager certification. For more information, please see www.ccmcertification.org.