

# **The Conversation Project: How to Talk About End of Life, Now**

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***By Patty Webster, MPH***



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# The Conversation Project: How to Talk About End of Life, Now

I never fully understood why talking about end-of-life care was so important until we experienced it with my mom. At age seventy-three and in good health, my mom suffered her first stroke a few years into her retirement. With her stroke, she literally lost her voice. The stroke left her with aphasia (the loss of ability to speak or understand speech), so she could no longer fully communicate with us. When the second, more devastating stroke came three weeks later (while she was rehabbing from the first), my sisters and I were faced with many complex decisions to make on her behalf that her advance directive alone could not guide us through. Although my mom was no longer able to communicate her wishes, she had already given us the incredible gift of sharing with us, many times previously, how she wanted to live her life through the very end and what “quality of life” meant to her. As surreal and devastating as the situation was for us, we were able to draw on those conversations and respect

her end-of-life wishes. My mom didn’t wait until it was too late; she made it okay to have these conversations anytime, anyplace, and often. Her conversations with us were grounded in her values, exactly what The Conversation Project is all about.

## Origins of The Conversation Project

The Conversation Project (TCP) was launched in 2012 to encourage and enable more people to sit down in the comfort of their own home with family members and friends and talk about what matters most to them when it comes to care through the end of life. Pulitzer Prize-winning columnist Ellen Goodman founded the project after caring for her mother, who was unable to speak for herself at the end of her life. All decisions fell on Ellen, without her knowing what her mother would have wanted. After her mother’s death, Ellen got together with peers, her colleagues in the media, and health-care and religious

leaders. She learned that, unfortunately, her experience was not unique. In her conversations, she noted the differences between what people called a “good” death and a “hard” death: having conversations about end-of-life care was a common characteristic of the good deaths. Through a public engagement campaign, a website, story sharing, and practical guides, TCP encourages people to have these discussions long before a serious illness or health crisis. Rather than talking about medical and legal questions, TCP tools focus on values-based conversations around what matters to an individual, grounded in that person’s beliefs. The millions of conversations prompted and aided by TCP over the past eight years have reinforced an essential truth: the decisions that emerge from these discussions have profoundly important ramifications for everyone involved. There are multiple beneficiaries from these talks, not just the older person who reveals personal end-of-life wishes. Family and friends who join the discussion experience relief knowing they can make the same decisions the dying person would choose, and they have often been spurred to address the elephant in the room — discussions around death and dying — with their own family.

### Jump-Starting Conversations

We know these conversations don’t come easily. One top reason people avoid talking about their wishes near the end of life is that they simply don’t know how or where to start. The Conversation Project has several online and downloadable Conversation Starter Guides that help individuals get their thoughts together, record them, and then have the conversation with those that matter: a loved one, family, friends, or health-care professional. The guides can be used by people getting ready to tell someone else what they want, or by those seeking to help others share their wishes. In a simple, four-step progression, the guides provide open-ended prompts to help unpack an individual’s values and beliefs, asking, “What matters most to you?” Prompts help make a plan for who to talk to, when, where, and what to say.

Several guides are available, including one on how to choose a healthcare proxy, another on how to be that proxy, one for those affected by Alzheimer’s disease or other forms of dementia, a pediatric guide for families with seriously ill children, one on how to talk with a healthcare professional, and a two-page guide on being prepared in the time of COVID-19. All guides are free and available in multiple languages on the website or by ordering in bulk (there is a shipping fee). The main Conversation Starter Guide can also be accessed in audio version (English only).

### Championing Conversations in the Community

As part of TCP’s mission, the organization provides resources and support to thousands of community groups, including individuals in professional service organizations and those who are in the business of working with aging clients to help them navigate their needs — financial, legal, and social — as they age. These professionals share the Conversation Starter Guides with clients and provide workshops, virtually and in person, to help individuals understand the importance of planning ahead.

Beginning in 2014, Fidelity investment company has integrated end-of-life care into conversations about financial and estate planning for its 32 million clients. The firm’s leadership knew this was a natural fit, given the myriad financial decisions that relate to a person’s longevity. They also recognized that a financial advisor may be one of the first to notice a family member’s decline in health. The question wasn’t “Why should we?” but rather became “Why *wouldn’t* we incorporate end-of-life discussions as a crucial additional planning step to support our clients and families?”

Argent Wealth Management has taken a similar tack. Beth Gamel, Argent’s former managing director, knew from a death in her own family that the starter guides would be a great tool for her clients and colleagues. She familiarized herself with the content by using it in her own family, sharing her and her husband’s wishes with their adult daughter. Next, Gamel brought materials from The Conversation Project into two financial spheres, integrating it into both her wealth management firm work with clients and also into a cross-state professional development networking group of which she is a member. When reviewing client documents, she simply asks if they become sick, do they have strong feelings about what type of care they may want or may not want? Gamel shares TCP’s website and Conversation Starter Guide as tools to consider, in addition to any other paperwork clients need to update or review. She also shares her own story with clients about how she and her family have had the conversation together.

### Professionals Can Lead

Professional service groups, senior centers, health care, or other community organizations recognize that integrating TCP’s Conversation Starter Guide and other resources into their practice is one way to support and build deeper relationships with their community. Patients, clients, and families (including the next generation) decrease potential conflict and ultimately are



➤ **This list doesn't cover everything, but here are some things you can say to start talking.**

- "I need your help with something."
- "Can you and I have a conversation about \_\_\_\_\_?"
- "I was thinking about what happened to \_\_\_\_\_, and it made me realize \_\_\_\_\_."
- "Even though I'm OK right now, I'm worried that \_\_\_\_\_, and I want to be prepared. Can we talk about some things that matter to me?"
- "Will you help me think about my future?"
- "I heard about the Conversation Project and answered some of their questions about things that matter to me when it comes to my care through the end of life. I'd like to talk to you about it."
- "When \_\_\_\_\_ died, do you think their wishes and priorities were respected toward the end of their life?"

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able to live their best life all the way up until it ends.

Professionals who work with older adults are in prime position to help the public understand why it's important to do this early and often before a medical crisis hits: in the comfort of one's own home, not in the intensive care unit. Yet people in health care or providing services to older adults, despite a greater exposure to, and familiarity with, death and dying, also find it hard to engage in these conversations (Heath, 2020). Exposure to death, it turns out, doesn't create an immunity to reluctance and anxiety when it comes to talking about death. In order to truly support others and create more comfort in engaging with them, advisors can "walk the talk" and exemplify this in their own life. The Conversation Starter Guide can help. The first step is to think about what matters most. Then, talk to someone who may enact decisions on your behalf if you are not able to at some future point and tell them your care wishes, rooted in your own values and beliefs (TCP's proxy guide is an excellent resource). Going through this personally will help you relate to, and be better prepared to advise, others. This is the one condition, the human condition, that everyone will experience.

Pairing the Starter Guide with other resources available to discuss and document wishes — such as PREPARE™ for your care (for advance directives and other tools), 5 Wishes® (to discuss and document care and comfort choices), and state-specific advance directives — will help people think, talk, decide, document, and be prepared with a plan.

## No Better Time than the Present

We are in the midst of a major cultural shift regarding talking about death. A national survey commissioned and released by The Conversation Project in 2018 showed real progress. In 2013, only 27 percent of Americans reported having had the conversation about their end-of-life care wishes, despite 90 percent of those same people agreeing it was important. Five years later, 32 percent of Americans reported having had the conversation. What is holding more people back from discussing these wishes? The No.1 concern is fear of upsetting a loved one, family, or friends. However, in that same survey, 53 percent of respondents stated they'd actually be relieved if a loved one initiated the conversation, and a full 95 percent want to, or are willing, to have these conversations (The Conversation Project, 2018). Having prior planning conversations reduced depression in grieving relatives after the loss of a loved one (Detering, Hancock, Reade & Silvester, 2010). What's more, the number of people actually having the conversation about end-of-life care is likely a lagging indicator of larger cultural changes. As Goodman notes, books about death and dying regularly top bestseller lists, death is more accurately and realistically portrayed on television and in the movies, and health reform legislation finally allows clinicians to be reimbursed for time spent talking to their patients about end-of-life care (Zeitoun, 2015).

In the current COVID-19 climate, policymakers have taken further steps to make these conversations

more accessible, removing billing barriers around the use of telehealth (Zeitoun, 2015). The annual Medicare exam has a question about advance directives and provides an excellent opportunity to have this discussion with a personal physician, nurse practitioner, or health-care team member, even if that professional does not bring it up. Involving family caregivers, as appropriate, to help initiate these conversations with a health-care professional is crucial.

Additionally, “A number of states have issued executive orders that waive or modify regulations and guidance around the requirements that certain legal documents, including advance directives, that must be witnessed and/or notarized in person. Given how COVID restrictions have made in-person interaction much more difficult, most of these orders now allow for digital witnessing and remote notarization using technology to meet these legal requirements” (Rosenthal, S. & Nintean, K. 2020, pg. 1).

### Urgency and Need in the Community

The emergence of COVID-19 in early 2020 placed our mortality right out in front of us, especially for Black, Indigenous, and other people of color in our communities. The sheer number of articles in mainstream media on the importance of discussing wishes for care and making plans should someone fall ill with COVID-19 provide further evidence of the growing recognition that proactive planning and discussion is needed for everyone, and should be happening now. Documents in absence of conversations can sometimes be detrimental and/or don't do any good if they are locked away in a safe deposit box. However, the realities of limited family presence at the bedside continue to play out in front of us in the media. Now more than ever, our communities need connections and support to help access needed services for life as well as death, especially for economically disadvantaged individuals, those in remote and underserved areas, and racial and ethnic minority groups (CDC, 2020).

### Five Steps to Getting Started

The role professionals play in encouraging community members to talk about what matters most when it comes to living and dying has become indispensable. Advisors to older adults are prime to champion this cause, ensuring a good life through the end.

1. Start by learning more about The Conversation Project, including guides, videos, and other free resources.
2. Reflect on personal values and what matters most by having these conversations with friends, family,

and other trusted professionals to put in practice that which you'll be asking others to do.

3. Lead conversations with clients and community members by sharing personal experiences; talk about how you have had the conversation and make it real.
4. Listen to others' experiences and initiate conversations about transition planning right from the start, helping clients/community members think about it, pick their trusted person, talk about what matters most, and make a plan. “What if something happens to you? Who will be your person to make decisions on your behalf? Let's bring this person/family into the conversation to get everyone on the same page with planning.”
5. Make this part of daily workflow by adding a prompt for end-of-life planning into existing advisor checklists or planning documents/tools; integrate and include steps, in writing, into existing processes.

Professionals can bring this to their personal or social circles first to test the waters, such as by hosting a virtual coffee hour or bringing the Conversation Starter Guide to a book club. Then they can branch out to share it with those they support by telling their own story and providing the guide as a handout with other materials. Another possibility is to host a virtual workshop, walking individuals through the Conversation Starter Guide. The word can be spread in newsletters, email, or on blogs or other social media platforms. Links to TCP guides can accompany a story in the news that will serve as a jumping-off point.

Professionals are encouraged to think bigger and share these concepts in a wider community. Consider pairing with another group, such as a service organization. The following ten questions are prompts for reaching a broader audience. Further description and examples of these questions can be found in the free Getting Started Guide for Communities on TCP's website.

1. Who do you want to reach? How many? By when?
2. What actions do you want people to take?
3. How and where do you want to reach them?
4. How will your target audience respond to the topic of end-of-life care? Whose guidance might you seek to find this out?
5. Who else is already doing work on this topic in your community? Who else could you be working with?
6. Who are respected leaders or organizations that could help you advocate for the importance of this work?

7. Who will be responsible for actually doing this work in your community?
8. What do you need to get started?
9. What can you measure to track your goal?
10. How will you capture and learn from successes and challenges?

## Network and Support

Professionals working to spread the message can take advantage of the support system and network offered by The Conversation Project as part of its mission, which is to help others talk about these conversations where people live, work, pray, and learn. Trusted professionals working with older adults are in a unique position to encourage them to have meaningful conversations about the end-of-life experience. By reaching out within their community, these professionals can extend their impact on individuals and families that may find themselves making crucial decisions on behalf of those that matter most to them. While the conversation may be hard to start, the rewards are worth it. •CSA



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## RESOURCES

**The Conversation Project®:** <https://theconversationproject.org/>  
 Conversation Starter Guides: <https://theconversationproject.org/starter-kits/>  
 Community Resources: <https://theconversationproject.org/resources/community>  
 6 Fun Games to Help You Talk about End-of-Life Care (blog): <https://theconversationproject.org/tcp-blog/death-is-not-a-game-well-sometimes-it-is/>  
 The Other Conversation (blog) and Sampling of Resources to Address Racial Inequities: <https://theconversationproject.org/tcp-blog/the-other-conversation/>  
 Thoughtful Icebreakers that Lead to Meaningful Conversations: <https://theconversationproject.org/tcp-blog/thoughtful-icebreakers-that-lead-to-meaningful-conversations/>  
 Further resources available include lessons learned, case studies,

agendas, slide decks, promotional materials, and more from hundreds of individuals and organizations. Also available are a discussion group, newsletters, and hosted monthly networking community calls.

**PREPARE™ for your care:** Prepare provides easy-to-read advance directives and others tools as part of a step-by-step program to help individuals fill out an advance directive. <https://prepareforyourcare.org/welcome>

**5 Wishes®:** Five Wishes is an approach to discussing and documenting care and comfort choices. It includes an easy-to-use legal advance directive document written in everyday language. It helps all adults, regardless of age or health, to consider and document how they want to be cared for at the end of life. <https://fivewishes.org/>

**Death over Dinner:** Death over Dinner provides an uplifting interactive adventure that transforms the seemingly difficult conversation about end of life into one of deep engagement, insight and empowerment. The organization provides a simple set of tools to host a gathering of friends and family to talk about our mortality over a meal. <https://deathoverdinner.org/>

**Cake:** Cake is an online repository providing guidance on death, grief, and mortality. Cake invites users to explore thousands of articles and tools designed to help individuals learn about and prepare for end of life. <https://www.joincake.com/>

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