



The Conversation Project

Tips for Facilitating and Teaching about The Conversation Project

A companion to *Getting Started Guide for Communities*.

the **conversation** project



Overview

Organizing an event, in-person or virtual, about The Conversation Project (TCP) is one of the best ways to gain interest and help spread the mission of TCP. There's no right or wrong audience for these kinds of presentations — we've seen successful events of every size and scope.

TCP was created to assist people in gaining knowledge and a level of comfort to talk about their wishes for care through the end of life, so those wishes can be understood and respected.

Sample Event Types

Below are just a few of the formats we know to be successful.

1. **Overview of The Conversation Project:** This is a general session where the presenter has the opportunity to give background information on TCP, strategy, and exciting news highlights. These can range from 15 minutes to an hour.
2. **Conversation Starter Guide Workshop:** In these sessions, participants take a deep dive into TCP's flagship resource, the [Conversation Starter Guide](#). They are given time to reflect, fill out the guide, and share in groups. Sharing can be done at their tables during in-person events or in virtual breakouts or via chat during virtual events. This activity is a starting point intended to prompt post-workshop action to have the conversation with those who matter most (family members, a friend, faith leader, health care team member, etc.). These workshops are often offered in two sessions. The second session is a debrief of how the real-life conversation went.
3. **Train the Trainer:** These half-day to day long sessions give participants the tools they need to bring The Conversation Project back to their home organization or community.

What's in This Guide

We've gathered the following tips from years of experience in the field – from our TCP team members and from hundreds of champions around the globe who have hosted events both virtually and in-person across their communities.

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10 Things to Think About When Hosting an Event

1 Before you teach, talk.

- Have you used the Conversation Starter Guide yourself and talked to people who are important to you? Have your co-facilitators done the same? Try this yourself before helping others.
- Going through this process can help you understand, firsthand, that these conversations aren't always easy. It also gives you an opener to share your experience.

2 The messenger matters.

- Who will resonate with the intended audience? For example: a faith leader, fellow caregiver, person of the same race or ethnicity, etc.
- If you have multiple people co-facilitating, think about your order. Who will connect first to spark interest and bring the content to life?

FOR EXAMPLE

- Don't put dry legal language at the beginning unless the audience has a legal background or gets excited about this!

3 The message matters.*

- **Talk up the benefits.** Share how conversations about what matters most to someone you care for can strengthen relationships.
- **Don't lead with death and dying,** or the negative impact/gloom and doom of not having conversations. This is about living well until the end. A positive vision of what is possible is proven to be more powerful than frightening people.
- **Use stories.** Open with your story. Keep it personal and positive, not fearful. Invite others to share their stories to offer various perspectives.
- **Speak from 'we'.** If your messages have the tone of telling others that you know better, you risk being perceived as paternalistic or condescending. Speak inclusively. Recognize that we all will be affected by death. Focus on our human connectedness.
- **Emphasize caring.** Messages about love, caring, and connection motivate individuals to engage.
- **Invite dialogue — and not just once.** Above all, the call to action is to encourage conversations: Getting individuals to talk with people who matter most to them about what's important and the care that follows their wishes.

**adapted from research conducted by The John A. Hartford Foundation*

This is about living well all the way up until death. These conversations make supporting each other possible. No one gets outta this alive, the mortality rate is still at 100%. These conversations don't have to be so scary when folks understand the importance. It's how we care well for each other—knowing what matters most.

~Hope Ililaniokakahiaka Young,
Kokua Mau, HI

Facilitators may need to have several stories they can use or choose from depending on the group. The same stories may not be right for every group. And, "love and care" also comes through wrestling with some difficult thoughts, discussions, and decisions.

~Rev. Sabrina Gray, Bethel AME Church, MA

4 Make sessions interactive and conversational.

- **Engage your audience** by creating time for dialogue, small group or pair sharing, and authentic listening to each other.
- **Bringing your funny bone** and humor to the work is ok and recommended!



Framing Tip:

Emphasize that you have no preference for the choices someone makes. It's the talking that matters.

FOR EXAMPLE

- We show our short funny videos during workshops to bring some laughter. We note that we don't make light of death but we bring lightheartedness to the work through stories and humor to make this more accessible and approachable to people.

5 Support your audience to feel comfortable.

- **Set up ground rules** at the beginning with your audience so they can be comfortable sharing. Note that nothing personal shared will leave the event and all perspectives matter. Create a safe space.
- **Think about who might be in your audience** and what you can do to relieve potential stressors.

FOR EXAMPLE

- If you have couples or family members attending an interactive session where participants will talk about their own wishes, suggest they might split up and mix with those they don't know. The goal of our sessions is to practice, and it can often be easier to talk with strangers first before trying this out with each other.
- Some couples or family members may want to stick together — let them! It's their choice.
- Recognize people may bring their tears. Support them, bring tissues, and give space for emotions.
- Note at the beginning and throughout that if someone opts out of sharing, that is ok.
- Notice non-talkers without putting them on the spot. Make eye contact. Read body language. Look out for discomfort.
- Do not be afraid of silence.
- Take breaks.

- **Recognize the lack of trust in health care across all demographics**, which is all the more reason to have conversations. In particular, Black communities have an ongoing history of adverse treatment and racism by the medical system. Talk up the importance of a trusted decision maker who can help speak for you if you are unable to speak for yourself. Help your audience understand that conversations clarify and can give individuals a sense of control.

6 Manage your time.

- **Most of the work of a facilitator happens before an event.** Plan your time, so you don't run out of time at the end.

FOR EXAMPLE

- If you have 60 minutes and 4 different themes to cover, block off 20 minutes per topic or give additional time to an area that may need more emphasis with your particular audience.

- **Expect the unexpected!** Be flexible and build in spare time. Don't cram too much into one session.
- **Adapt.** Sometimes the audience really wants to go in another direction. Adjust as you go to meet group needs. Sometimes one participant takes over the conversation. Recognize them, listen to them, and then gently steer them back. Talk with them during a break to show you care.
- **Create a "parking lot"** for topics that may discourage your group (e.g. frustrating topic of interest to one person but not many). Recognize their importance, and suggest this topic be discussed at the next gathering (or with other appropriate people). Suggest that the host (if not you) make note of this important discussion for later.

7 Tap the existing assets in your community.

- **Think ahead about who you can invite** to share resources your audience may find helpful.

FOR EXAMPLE

- If you are hosting a workshop for families or groups of individuals in the community, invite a notary to provide any services needed, ask an attorney to join to be part of a Q&A on legal issues, or invite a local care advocate/navigator/coach or someone who can help individuals navigate social services within the community.

8 Word choice matters.

- **The language we use (e.g., "loved one," "family," "good death") is not universal** and may be off-putting to others.

FOR EXAMPLE

- Not everyone has a **loved one** and using this phrase may isolate those that don't (solo agers). Alternates: "those that matter most," "those important to you," "those that may need to care for you at some point" (family, friends, faith leader, health care member)
- Not everyone's **family** looks or acts the same. Consider using "your chosen family" or ask "Who do you identify as your support system?" Families of origin may not always be a support system for a person. This is one reason to emphasize the importance of planning ahead to document who you want to speak (or not speak) on your behalf.
- Most people do not connect with the phrase "**good death**," according to the latest messaging research.

FOR EXAMPLE

- The Conversation Project used to teach about having a "good death." We now recognize the privilege inherent in this messaging. For many Black, Indigenous and Persons of Color, the more urgent focus may be having the tools and support for a good life, given racial injustice and raging health inequities.
- For many in the LGBTQ+ community, distrust in a system that hasn't recognized their rights may contribute to reluctance around care planning or choices made for end-of-life care options.

- **For many, what matters most is being respected, valued, and getting the care they deserve.** They seek to be able to live in peace, not just rest in peace.



Address the Elephants in the Room: Many lack trust in the healthcare system. Acknowledge it out loud and unpack it together. Make a commitment to talking about these issues in the context of your community.

9

If something is not resonating, STOP and find out why.

- **Ask and listen to those in the room.** It's not about what we want to share, it's about what those in the room need and how they may best receive the message. Build in time to see what's resonating, or not, and adjust as you go.

FOR EXAMPLE

- Michael Hebb, founder of Death Over Dinner, noticed one of the groups he was leading a Death Over Dinner with just wasn't connecting to his content, at all. He stopped and asked the group why it seemed to be falling flat. The community he was working with said they didn't use the word or talk about "death" but instead, they talked about "going home." He adjusted accordingly.
- Pastor Corey Kennard of Amplify Christian Church in Detroit, shares his story of facilitating a discussion on dying with a group of African Americans. One of the participants noted his frustration, saying, "You're now telling me I'm supposed to talk and think about dying?" Pastor Kennard learned that the message resonated better if he talked instead about establishing a legacy.

10

Leaving in action.

- **What do you want participants to do when the session ends?** Will you give them something, in addition to the Conversation Starter Guide, to take home? Think about what you want them to walk away doing. If possible, at the end of the session, provide them with time and resources to start planning how they may do this (e.g., an Advance Directive document so they can name their health care proxy).

Stories We Use and Share

Below are stories we share to illustrate key points in our Conversation Starter Guide:

- **Make the role you want to play known.** Whether you want someone else to decide what's best or you want your wishes to be followed exactly, make sure this is known to those who may have to make decisions on your behalf.
 - One woman noted she really wanted her adult kids to decide what kind of care she would receive and make decisions that brought them peace. This is the conversation she needs to have with them – to tell them this wish so they aren't left wondering what their mom would have wanted.
 - [Katy Butler](#), an author, wrote a letter to her family laying out specifically what she would want (and not want) should she be diagnosed with dementia and unable to make her own care decisions later. She knew what she would want given the experiences she went through with her own father at the end of his life.
- **Give current answers.** Encourage people to share what they would want right now.
 - One of our TCP leaders and her husband went through the Conversation Starter Guide and shared their answers. Her husband started sharing what he would want in the future, as if he were over 80 with a diagnosis of Alzheimer's. She stopped him and said: "What if something should happen to you now. What is most important to you at this age and in your current health, body, and mind?"
- **Home is not always feasible. Probe for what's important.** We hear from many people, "*My grandma said the only thing she wanted was to die at home and we just weren't able to do that.*" Help people recognize that home isn't always medically, financially, or physically feasible. Instead, unpack what "home" represents. What is it about home the individual may want? Does your important person have a pet they want to see? Are they afraid no one will visit them? What are the values or feelings behind "home" that are most important to incorporate if the physical space isn't an option?
- **Be wary of "the whole enchilada" and "plug pulling."** There are plenty of folks who think they've had "the conversation." Statements like: "*If I ever get like that, pull the plug*" or "*make sure when they ask what treatment that you give me the whole enchilada,*" come up a lot.
 - Encourage people to unpack what they mean by this: "*It sounds like you're worried about receiving [too little OR too much] care, is that right? Tell me more.*"
- **Tell more than one person.**
 - We hope to avoid the "seagull effect": when the out-of-town child (who doesn't understand their parent's wishes) swoops in and tramples over the carefully made plans of those who are right by the parent's side and know what the parent wants.
 - Be sure to tell all who may have a stake in your well-being who your health care proxy is and that they will make decisions on your behalf. For example, one could say "Timmy, I've told Carol what I want please listen to her. That will be the greatest support to me when my time comes."
- **Beware of family or caregiver pressure or bullying.**
 - A family member at a workshop realized she and her siblings had been imposing their wants and needs on their dying father instead of really listening and following what he wanted. He had a recent health episode that they thought would be best dealt with at the emergency room (ER). They made him go to the ER, even though he repeatedly said he did not want to go back to the hospital. While they did this out of a place of love, it was against their father's wishes.
- **Offer up your own thoughts if someone isn't ready to share their wishes with you.**
 - A woman nicknamed her husband "Eeyore," as he was always gloomy and pessimistic and refused to talk about his own wishes. So, she sat down with him and said, "*Here is what I think you might want if I had to make decisions on your behalf... Does this sound right? What did I get wrong?*"
- **Decisions and wishes can change.**
 - A man changed his plans when a great-grandchild was due in 3 weeks. He asked his caregivers to temporarily do all they could to help him be around to meet his great-grandchild just once.



This is not about medical scenario planning. This is about learning what matters to you. Talking about the values you have in life now will help inform the medical decisions that may come up later.

Common Discussion Topics

Below are some frequent topics of discussion and ways you might tackle them.

- **Legal confusion:** Because rules and regulations may differ from place to place, it's helpful to get familiar with the medical and legal requirements for end-of-life planning in your area. Those you connect with may have state-specific questions and understanding your state's regulations can help you clarify which documentation or resources will be medically or legally binding. You could work with or invite someone with this background to your session (perhaps at a second, follow-up session).
- **POLST/MOLST questions:** We recommend staying away from POLST/MOLST discussions in initial sessions, as these focus on medical issues and is only applicable for those toward the very end of life. The focus of TCP's conversations about what matters most are intentionally geared toward values, which are an easier entry point. Medical discussions can quickly turn into scenario planning, and we emphasize we cannot plan for every scenario. Understanding what matters to you – based on faith, spirituality, culture, family background – will inform the clinical discussions that individuals can have with clinicians later. If people have more questions about this, encourage them to speak with their physician.
- **Using other tools:** People usually ask how to know which tool to use – Five Wishes®, PREPARE™ for your care, the *Hello* game, the Go Wish™ game, Heart to Heart® cards, and many more are available. We encourage you to use any and every material that will resonate with the diversity of people you are reaching. Test them all out as you never know what will stick. Many groups pair multiple tools together.

FOR EXAMPLE

- Many have hosted the Hello game to jump start discussion and then offer a Conversation Starter Guide as their “leaving in action” tool to complete at home.
- Bethel AME Church in Boston, MA, hosts multiple “Planning Ahead” sessions for small cohorts of congregants. Participants walk through the Conversation Starter Guide during session one. They then watch and discuss a movie together (e.g. *Extremis* or *End Game*) and walk through the Five Wishes® document during session two.
- The Chinese American Coalition for Compassionate Care hosts “Heart to Heart®” cafes, using playing cards in Chinese and English to help spark conversations. They pair this with the Chinese version of the Conversation Starter Guide for people to fill out at home.

- **“Dysfunctional” family situations:** What we share is all well and good, but not all families or individuals can talk easily due to underlying tension. When conversations just cannot materialize, you can recommend the following:
 - Make sure your wishes are in writing and send this to whoever may have a stake in your care with a note.
 - Write a letter expressing how you feel and send it to all who may need to hear what you are feeling.

- Tap the support of someone who may serve as a bridge to those who need help talking: a faith leader, a social worker, a financial advisor, a professional service agency. You can also advise people to contact your local area on aging for potential support.
- **These are ongoing conversations:** We joke that we could have been named The Conversation[s] Project as it is rarely a one and done conversation. Encourage individuals to start talking and keep talking!

I think of one gentleman I've met with three different times. It's not just a one-and-done thing... get in front of someone more than once.

~Ashley Areyan, Institute for Human Caring, Providence St. Joseph Health, CA

Additional Resources:

Looking for...	Look to...
A Guide to engaging your community in end-of-life care conversations, and how to think about engaging other community partners in this work. Includes easy links to additional resources.	Getting Started Guide for Communities
Additional ready-made, free resources to bring conversations to your community, including event agendas, standard slide deck, and checklists for hosting.	The Conversation Project Website, Get Involved Tab: https://theconversationproject.org/resources/community
A compilation of lessons learned, ideas and tips from communities on promoting, spreading, and sustaining momentum as well as reaching unique audiences.	The Conversation Project Website, Get Involved Tab (under Promote Your Message) https://theconversationproject.org/resources/community#promote
Resources on tailoring your approach, including messaging ideas for various segments of the population.	Communicating with the Public About COVID-19 and Advance Care Planning http://maseriouscare.org/covidresources
Ways to engage, get involved and network with others.	The Conversation Project Website, Get Involved Tab https://theconversationproject.org/get-involved <ul style="list-style-type: none"> • Community calls and recordings, Champions map, Facebook discussion group, newsletters, and more

The Conversation Project is an initiative of the Institute for Healthcare Improvement, a not-for-profit organization that is a leader in health and health care improvement worldwide.

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This document does not seek to provide legal advice.

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Dedicated to Improving the Care of Older Adults



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