

Coaching the Conversation

A Guide to Facilitating Conversation Groups

The Conversation Project is a national campaign dedicated to helping people talk about their wishes for end-of-life care. Our goal is that everyone's wishes for end-of-life care will be expressed and respected.



Created by The Conversation Project and the Institute for Healthcare Improvement

We believe that the most important first step is having the conversation with your loved ones around the kitchen table, before a medical crisis happens. Talking openly and honestly about what matters most to you at the end of life gives everyone a shared understanding for making decisions about care when the time comes. We developed the Conversation Starter Kit to help people take that first step. (It's available for free at theconversationproject.org.)

Many people find it helpful to get started by participating in a "Conversation Group"—a small group of people who share a desire to try to have the conversation, and who welcome the support of others who want to try it as well.

A Conversation Group can take place anywhere—in your workplace, in your place of worship, in your book group, or just with a group of friends. **This guide will provide you with the information and tools you need to facilitate a Conversation Group—to “coach the conversation.”**

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Conversation Group Overview

What is a Conversation Group?

We've found that a simple, effective Conversation Group consists of two sessions (60-90 minutes each), with an action period (a few weeks) between the two sessions.

- **Session One: Making a plan to have the conversation**

Everyone in the group learns together how to have the conversation, supported by the coach and by the Conversation Starter Kit. Each person leaves with a plan to have the conversation.

- **Action period: Trying out the plan**

Everyone goes their separate ways and tries to put their plan into action.

- **Session Two: Reporting back on how things went**

A few weeks later, everyone comes back to the group and talks to one another about how it went—whether they “had the conversation” or not.

Note: The Conversation Project does not recommend particular choices for end-of-life care. We simply want to help people talk about what matters most to them.

We invite you to help us make this guide better. Please let us know what works well, what doesn't work well, and what else you need. You can email us at ConversationProject@IHI.org.

Who should attend a Conversation Group?

Conversation Groups work best with about 10 to 15 people.

Large enough to have a variety of experiences and points of view, but small enough to allow everyone to be comfortable talking and sharing.

Conversation Groups work best with willing volunteers.

Requiring people to participate doesn't work. The only requirement of Group members is a desire to try having the conversation—and a commitment to attend two sessions (60-90 minutes each).

Conversation Groups are not just for older adults facing their own death or the death of a loved one.

People of all ages can benefit—whether it's younger adults who want to encourage their parents to have the conversation, couples who want to have the conversation with one another, or older adults who want to talk to their adult children, relatives, or friends. The more perspectives represented in a group, the better.

If the Conversation Group is taking place at your workplace, it works well if the group includes people from all levels of the organization.

No matter what their role or job title in this group, it's really important to remember that people attend a Conversation Group as people—not in their role in the organization.

Note that a Conversation Group is probably not the best forum for someone who is dealing with a medical crisis. (See the FAQ in the Resources section, for suggestions about what to do if a group member is a little closer to crisis than anticipated.)

Who should coach a Conversation Group?

Coaching a Conversation Group doesn't require any special clinical or human resources training, but it does require that you've "had the conversation" yourself—or that you will do so before you lead a group.

A good coach should be:

- **A good listener:** someone people can trust, who is at ease with differing opinions and sensitive to people's personal experiences.
- **A good facilitator:** someone who can create a comfortable atmosphere for learning and sharing.
- **A good coordinator:** someone who can take the lead to initiate a group, get a room and times set, send emails, and follow up with those who want to be part of the group.

Before the first session, the coach should:

- ...be familiar with the Conversation Starter Kit.
- ...have had the conversation—either telling a friend or loved one what you want, or listening to a friend or loved one tell you what they want... or both!
- ...be willing to share your own story about what it was like to have the conversation.

Evaluation Forms (optional)

We have provided two sample evaluation forms to use with your group—one to hand out after the first session, and one to hand out after the second session. (See Resources section.) The evaluations provide useful information about two things: 1) whether participants had the conversation, and 2) whether the sessions were helpful and how they might be improved.

Participants can fill out their evaluations immediately after the session, or they can take them home and return them to you at a later date.

Session One: Making a plan to have the conversation

Inviting people to join a Conversation Group

We've found that it works well to speak to a group of people in person to explain the purpose of a Conversation Group and invite them to participate. If it's not possible to invite people in person, email is fine. In either case, you'll want to:

- Explain the purpose of the group.** A small group of people who share a desire to try to have the conversation, and who welcome the support of others who want to try it as well.
- Explain the structure of the group.** Two sessions (60-90 minutes each) with an action period in between.
- Explain what's asked of group members.** A commitment to attend both sessions, and to try having the conversation during the action period.
- Briefly tell a personal story about why you had the conversation, how it went, and how you felt about it afterward.**
- Follow up with an email invitation.** See the sample email invitation in the Resources section.

Preparing for Session One

- Reserve a **quiet, private room**—a safe space—with chairs set up in a circle.
- Bring enough **Conversation Starter Kits** to hand out to each person attending the session. (You might want to give a copy of the Conversation Starter Kit to attendees in advance, and ask that they read through it before the first session.)
- You might want to bring some simple **name tags** (white stickers) and a marker.
- Bring enough **evaluation forms** to hand out to each person attending the session.

Meeting Agenda for Session One

In this session, participants will talk with one another about how they feel about “having the conversation.” They’ll begin to think about **what** matters most to them, **who** they want to talk to, **when** they might have the conversation, and **where**. They’ll work through exercises in the Conversation Starter Kit, and they’ll leave with an action plan.

We’ve found that Session One usually takes the full 90 minutes. Note that the times listed below are approximate; coaches should feel free to adjust the timing and choice of items (for example, whether to screen the ABC News video clip).

- **Introduce yourself.** Briefly explain The Conversation Project and the purpose of Conversation Groups, and review the goals and general framework of the session. *(5 minutes)*

- **It may be helpful to set the scene by screening a video clip about The Conversation Project on a laptop.** ABC News created a 4-minute video of a family actually having the conversation live. Additionally, you could share a recording of WBUR’s Carey Goldman having the conversation with her father. See the Resources section for links. *(5 minutes)*

- **As a group, agree on some simple ground rules.** Using a big piece of paper/marker may be helpful—then you can bring it back for the second meeting. *(5 minutes)*

Example Ground Rules

- Privacy. Please do not share others’ personal stories.
- Listen quietly. This is not a time to offer advice or solve problems.
- Turn off cell phones.
- Everyone is here as a person, not a “role” or “title.”
- What else is important to people in the group?

- **Share the story of your conversation. (5 minutes)**
- **Going around the circle, ask participants to introduce themselves** by first name and briefly say why they decided to participate OR state their role in an important relationship, perhaps the relationship in which they'd like to explore the conversation—for example, "I am a daughter." **(10 minutes)**
- **Hand out the Conversation Starter Kit to anyone who doesn't have one.** Explain that we're all here because we've decided to try having the conversation—Step 1 of the Kit. Then ask participants to review the Starter Kit's Step 2: Get Set, and to consider what matters most to them. Ask them to note any questions, concerns, or surprises. Tell them they will have 5 minutes to think quietly. **(5 minutes)**
- **Ask people to work in groups of two or three to reflect about their experience with Starter Kit's Step 2.** Tell them that they will have up to 10 minutes to discuss. **(10 minutes)**
- **Ask the small groups to report back to the larger group.** What did they learn? Share questions, concerns, and surprises. **(10 minutes)**
- **Ask participants to review and think quietly for a few minutes about the Starter Kit's Step 3: Go.** (Who do you want to talk to? When? Where? What do you want to say?) Work in groups of two or three to talk through each person's responses. Ask them to note any questions, concerns, or surprises. Tell them they will have 10 minutes. **(10 minutes)**
- **Ask the small groups to report back to the larger group.** What plans did people make? Share questions, concerns, and surprises. **(10 minutes)**

- **Wrap up.** Explain what happens next: Everyone will have two to five (depending on what you've chosen) weeks to try out their plan. Then they'll come back together to share how it went. They're welcome to contact you, or a fellow group member, if they have questions or need help during the action period. Hand out and explain evaluation forms. *(5 minutes)*

It's important to emphasize that it's okay to come to Session Two even if you haven't had the conversation. The important thing is to think about it and to try, and if it doesn't happen for any reason, to think about and report back why.

During the action period...

- Send an email to everyone in the group, restating what will happen during the action period and at the second meeting. Also, remind people that they can talk to you or a fellow group member during the action period.
- Halfway through the action period, email participants to remind them to try having the conversation, and to remind them that the second session is coming up.
- Email participants just prior to the second session. (See sample emails in the Resources section.)

Session Two: Reporting back on how things went

Preparing for Session Two

- Reserve a **quiet, private room**—a safe space—with chairs set up in a circle.
- You might want to bring **name tags** (white stickers) and a marker.
- Bring enough **evaluation forms** to hand out to each person attending the meeting.
- Just before the meeting, **write the following questions** on a blackboard or flip chart.
 - Did you have the conversation? If not, why?
 - Who did you talk to and where?
 - What happened?
 - Were there any surprises?
 - How did it compare to what you expected?
- Or you might want to **write three simple questions**.
 - How did you feel before you had the conversation?
 - During the conversation?
 - After you had the conversation?

Meeting Agenda for Session Two

- **Reintroduce yourself by first name, and ask others to do the same.**
Remind participants of the goal of this session—to share stories about their conversations. And those who did not have a conversation still have a story to share! Just thinking about the conversation should be considered a success. Everyone will have up to 5 minutes to share their story. *(5 minutes)*

- **Review the ground rules.** You can post the piece of paper you used to list the ground rules during the first session. *(5 minutes)*

- **In addition, you might want to emphasize that nobody can be interrupted, and there should be no feedback after the sharing—just generous presence.** Also, acknowledging that people may become emotional could be helpful (as well as having some boxes of tissues handy).

- **How did it go?** Go around in a circle and ask people to take a few minutes to share their experiences. Ask for a volunteer to start, and then go in a circle. It's okay for someone to pass, and either wait until their turn comes around again or opt not to speak. *(40 minutes)*

- **Wrap up.** Thank everyone for participating in the group, for their willingness to try having the conversation, and for sharing at today's session. Encourage participants to share their stories on The Conversation Project's website. Hand out and explain evaluation forms. *(5 minutes)*

Note: Because Session Two builds on Session One, we recommend that only those who attended the first session should attend the second session (no new participants, no guests).

Follow-up after Session Two

Send an email thanking group members. (See sample email in the Resources section.)

- Encourage participants to share their stories on The Conversation Project's website.
- Ask if anyone is interested in being a coach for another Conversation Group. If so, invite them to send an email through "Contact Us" at theconversationproject.org.

Additional Resources

Frequently Asked Questions (FAQ)

What if someone is very, very emotional?

It's a great idea to have a box of tissues on hand. It might help to remind your group that people will become emotional. These are emotional conversations. Tears are natural. In advance of the meeting, get a sense of available support networks. Is there an Employee Assistance Program, for example, that you could connect someone to? You could also consider having a helper or co-facilitator provide some one-on-one support.

What if someone feels like a failure?

The fact that someone comes and participates in a Conversation Group is proof that they are successfully engaging. Just thinking about having the conversation is a success! Even if someone isn't able to have their conversation during the action period, they will have learned something important. And if a conversation is challenging or doesn't go well, it's important to remind people that this is a work in progress. We are all meant to have many conversations—it's not a one-chance thing.

What if someone interjects strong political or religious opinions about particular end-of-life wishes?

This may be something to tackle when you set ground rules. Remind participants that the group is about sharing stories—not giving/getting advice or airing opinions. If someone isn't able to stick to the ground rules, they may need a gentle reminder. You could say something like, "We all have different opinions about the options that are available to us. But this isn't the place to talk about it. Remember, we are just exploring and expressing our wishes, no matter what they are."

What if a participant asks for specific advice? E.g., "My sister is my mother's health care proxy, but I know that she won't do what my mother has requested. What do I do?"

The facilitator should not give any legal or clinical advice. Again, remind participants that this group is about sharing stories—not giving/getting advice, or airing opinions. You could refer someone to an Employee Assistance Program. You can suggest that they connect with their health care provider. You can always refer people to The Conversation Project and we can try to connect them with appropriate resources.

Resources for Conversation Group Coaches: Links, Videos, and Starter Kit

■ **Conversation Group Preparation Checklist**

An easy, step-by-step checklist to help you organize and moderate a Conversation Group.

■ **“Six Voices” video**

A powerful and sometimes humorous series of reflections by individuals who describe their first experience with “having the conversation.” vimeo.com/31457267

■ **ABC News video**

ABC created a 4-minute video of a family actually having the conversation live. A link to the video is available on our website. theconversationproject.org

■ **A conversation between a daughter and her father**

Carey Goldberg and her father use the Conversation Starter Kit to guide them through their first conversation, excerpts of which were broadcast on WBUR (Boston NPR affiliate) just after The Conversation Project’s launch in summer 2012. theconversationproject.org/lets-discuss-dying-the-conversation-about-how-my-dad-wants-to-go

■ **Evaluation Forms (Optional)**

Two sample evaluation forms to use with your group—one to hand out after the first session, and one to hand out after the second session. Participants can fill out their evaluations immediately after the session; they can take them home and return them to you at a later date.

■ **Sample Emails**

- Invitation to join the Conversation Group
- Follow-up email after Session One
- Follow-up email after Session Two

■ **Conversation Starter Kit**

Download from our website. theconversationproject.org

Conversation Group Preparation Checklist

- One month prior to Session One**
 - Publicize the Conversation Group and invite 10-15 people to attend (staff meetings, newsletters, community bulletins, organizational listservs, etc.)
 - Schedule two meetings, about 2-5 weeks apart
 - Reserve rooms for meetings

- Two weeks prior to Session One**

Send email invitation (see sample)

- Two weeks after Session One**

Email participants to remind them about the action period (see sample)

- One week prior to Session Two**

Email participants with a reminder of the time, place, and agenda for the second session (see sample)

- The day after Session Two**

Email participants, thanking them and inviting them to submit their stories (see sample)



Conversation Group: Evaluation after Session One

Your Group Name _____

Date _____ Identification Number _____

Note: The evaluation is anonymous. The identification number allows us to compare your responses after Session One and Session Two.

1. Prior to today's session, have you had the conversation?

- No.
- No, but I have thought about it.
- Yes, but at a very general level.
- Yes. The conversations have included enough detail that I feel confident my loved ones know my wishes.

2. Do you plan to have the conversation during the action period?

- No. This is not a priority for me at this time.
- No. I know what I want, but do not feel comfortable talking with others at this time.
- Yes, but at a very general level.
- Yes. I plan to have a conversation with others so that loved ones feel confident they know my wishes.
- Yes. I've already had these conversations, but plan to revisit the conversation with my loved ones.
- N/A. I've had detailed conversations prior to today.

3. If you plan to have the conversation, do you feel prepared?

- Yes.
- Unsure.
- No.

4. What did you find most useful about Session One?

5. What suggestions do you have for improving Session One?



Conversation Group: Evaluation after Session Two

Your Group Name _____

Date _____ Identification Number _____

Note: The evaluation is anonymous. The identification number allows us to compare your responses after Session One and Session Two.

1. Did you have the conversation?

- No.
- No, but I have thought about it.
- Yes, but at a very general level.
- Yes. The conversations have included enough detail that I feel confident my loved ones know my wishes.

2. Were you comfortable having the conversation?

- No.
- Slightly.
- Yes.

3. If you had the conversation, did you feel prepared?

- No.
- Slightly.
- Yes.

4. Did Session One help prepare you for the conversation?

5. What did you find most useful about Session Two?

6. What suggestions do you have for improving Session Two?

7. What suggestions do you have for improving the Conversation Starter Kit?

8. What additional tools, resources, or discussions would be helpful?

Sample Emails

Email invitation to join the Conversation Group

From: The Conversation Project
To: Recipient
Subject: Join the Conversation Group!

The logo for The Conversation Project, featuring the words "the conversation project" in a lowercase, sans-serif font. A thin, curved line arches over the word "conversation".

the conversation project

Hello everyone,

You may have heard about The Conversation Project—a public campaign designed to help everyone talk about their end-of-life wishes. You can learn more at www.theconversationproject.org. In an effort to further The Conversation Project’s goal that everyone’s end-of-life wishes are expressed and respected, I am hosting a Conversation Group gathering. This group is for anyone who’s interested in trying to have the conversation, and welcome the support of being in a group with others who want to try it as well.

The Conversation Group consists of two 60- to 90-minute sessions, with an action period in between. At the first session, we’ll meet in a small group and talk together about “having the conversation” and we’ll all develop a plan to have the conversation. Then during the action period, we’ll go our separate ways and try putting our plans into action. A few weeks later, we’ll meet again to report back and share our experiences.

I will do my best to schedule the sessions for days and times that work for people who express interest. I have also attached a copy of the Conversation Starter Kit, in case you’d like to look it over before the first session.

If you’re interested in participating in the Conversation Group, please RSVP to me by _____.
If you have any questions about the group or about The Conversation Project, please don’t hesitate to contact me. Thank you!

Email after Session One

From: The Conversation Project
To: Recipient
Subject: Thank you for your participation!

the conversation project

Hello to all Conversation Group participants,

Thank you for your participation in Session One. This is just a friendly reminder about our collective action plan—having conversations with friends/family about end-of-life wishes—yours or theirs. Please let me know if you have any concerns or questions. Our next session is scheduled on _____.

I look forward to hearing your reflections.

Email after Session Two

From: The Conversation Project
To: Recipient
Subject: Thank you for your time!

the conversation project

Dear Conversation Group participants,

Thank you for devoting your time to this important issue. I hope that you found our Conversation Group useful.

I encourage you to share your own stories and experiences on The Conversation Project's website at www.theconversationproject.org.

If you or anyone you know is interested in leading a Conversation Group, please let me know.