



The Conversation Project

# Getting Started Guide for Congregations



Institute for  
Healthcare  
Improvement

the conversation project

CREATED BY THE CONVERSATION PROJECT AND THE INSTITUTE FOR HEALTHCARE IMPROVEMENT

The Conversation Project is a national initiative to ensure that everyone’s end-of-life care wishes are both expressed and respected. Since 2012, we have worked to raise the profile of this issue by increasing awareness with the public and by creating free tools, like our **Conversation Starter Kits**, to help individuals “have the conversation” with others in their circle of care, especially family, friends, and health care providers.

The Conversation Project aims to reach people where they live, work, and pray to encourage more people to start talking about their wishes for end-of-life care — sooner rather than later — in the comfort of familiar places like their congregations and homes, not waiting until there is a medical crisis.

This guide is designed to help congregational leaders introduce The Conversation Project’s mission and free resources in the communities they know and serve. It is filled with examples of how diverse faith communities are encouraging their congregants to engage in thoughtful reflection and have conversations about their end-of-life care wishes with loved ones and health care providers.

You know your community better than we ever could, so you may want to adapt the ideas outlined in this guide for sermons, programming, and pastoral care. When you have questions or suggestions about how we can improve this guide, please be in touch: [info@theconversationproject.org](mailto:info@theconversationproject.org). Thank you for taking the first step toward helping more people give their loved ones the gift of having the conversation.

**Watch our short video about how The Conversation Project is working with faith communities: [“Talking Matters in Faith Communities”](#)**

## RESOURCES

You can find more resources and tools in our online [Resource Center](#), including sample sermons, videos, newsletter articles, and program suggestions, as well as our free [Conversation Starter Kits](#), which are available in several languages.

.....

## TABLE OF CONTENTS

**Step 1: Get Ready ..... 3**

**Step 2: Get Set ..... 7**

**Step 3: Go ..... 11**

**Step 4: Keep Going ..... 15**



# There is often a wide gap between what we hope will happen surrounding the end of our lives and what actually happens.

## STATISTICS ILLUSTRATE THE GAP:

**70%** of Americans indicate that they would prefer to die at home

———— yet ————

**70%** die in hospitals, nursing homes, and other locations outside the home

Source: *Final Chapter: Californians' Attitudes and Experiences with Death and Dying*. Feb 9, 2012

**90%** of Americans say that it is important to talk about their end-of-life care wishes

———— yet fewer than ————

**30%** have had those conversations

Source: *The Conversation Project National Survey 2013*

Consequently, people who may have to make health care decisions for us in the event that we cannot speak for ourselves are uncertain about our wishes.

Faith communities have an important role in helping shift our culture from one that doesn't talk about end-of-life care wishes to one in which having the conversation is normalized. We have learned that through hearing sermons and attending programs on end-of-life themes, congregants are better prepared to have conversations about what matters most to them about living. Receiving faith-based teaching and pastoral support helps people become stronger, compassionate advocates for themselves and their loved ones when it comes to the kind of care they want to receive — and don't want to receive — especially at the end of life.

## SIX REASONS WHY CONGREGATIONS ARE IDEAL SETTINGS FOR SHARING THE CONVERSATION PROJECT:

- 1 Congregations are existing communities of people of all ages that are committed to living according to shared values.
- 2 Congregations encourage living with more compassion and less fear — things we all need if we are going to engage in these kinds of tender conversations.
- 3 Congregations are story-telling communities — and much of this work is about sharing our stories: what happened when someone died; what works and what doesn't; what we hope and what we fear.
- 4 The seeds of cultural change are often planted in congregations, and we need culture change to normalize "having the conversation."
- 5 Faith communities seem to like to eat together. We are seeing wonderful success with programs like *Death Over Dinner*, where people gather to talk about end-of-life wishes in comfortable settings over comfort food.
- 6 Congregations are positioned to support people with serious illnesses and their families, as well as clinicians who care for the seriously ill.

# Step 1 Get Ready

**First things first.** We get excited about bringing new ideas or programming to our congregations. And we want to change the world — right now! However, we have learned that sometimes it's best to go slow to go fast. So before announcing a new, congregation-wide initiative, we encourage you to gather a team; pause to reflect; engage your clergy leaders and allies; assess the needs, desires, and resources of the community; and then try something on a smaller-than-you-first-imagined scale.

---

## Gather your team.

While one person can bring inspiration, time, and leadership to a project, you are more likely to succeed when a team is engaged to support a shared vision.

Find at least one other person who loves the idea of bringing advance care planning activities to your community as much as you do, then aim to double that number.

### Your team could include:

- People who work professionally in this area:
  - Nurses
  - Chaplains
  - Social workers
  - Doctors
  - Therapists
  - Teachers
- People who have cared for loved ones who have died
- Congregants who have had good experiences with end-of-life matters
- Congregants who have had bad experiences with end-of-life matters

**Remember:** Pay attention to socio-demographic diversity when building your team, including diversity of race, gender, class, and age. (Advance care planning is for anyone over 18!)

# Pause, assess, reflect.

## Review your theological framework.

With your team members, lay some theological groundwork. Look to your sacred texts and traditions for teachings and practices that support infusing end-of-life conversations into the full cycle of life and work of your spiritual community. Beliefs and needs around the topics of death and dying are deeply personal and are connected to cultural backgrounds as well as to individual life experiences. There are few places outside of congregations where people can explore and connect their spiritual beliefs and practices to this sensitive topic. Take advantage of the opportunity to have these conversations in your special setting and frame the conversation within your faith tradition and ethics.

## Be sure to use the Conversation Starter Kit yourself first. This is an essential preparatory step.

As people of faith, we lead by example. Work through the exercises in the Starter Kit to reflect on and articulate what matters most to you when it comes to end-of-life care. By having the conversation yourself, you will gain a better understanding of the process, the challenges and the benefits, as well as the emotions and fears that can arise. Modeling the mature spiritual practice of embracing the reality of your mortality and having the conversation about your wishes first is a way to exemplify your openness and commitment. Share your thoughts and questions with your team, and support each other in having the conversation with loved ones. Later on, when it comes time for your next health appointment, aim to share your wishes with your health care provider, too. By “walking the walk and talking the talk,” you will emerge as an authentic leader of this work.

## Assess the interest and resources in your community.

There is one more step before jumping in: Interview your clergy leaders, pastoral care team, health care ministry team, deacons or elders to learn what has been done — or is underway now — to support people who are seriously ill, their caregivers, and the wider community on end-of-life matters. It’s helpful to know what has been tried and what has, or has not, worked in your community.

With support from their rabbi, volunteers at **Temple Beth Hatfiloh in Olympia, Washington**, placed a survey in their monthly newsletter and weekly e-news to solicit input on what end-of-life topics people were most interested in. This communication confirmed that there was strong interest and helped them recruit several new team members.

# Engage your clergy leaders and allies.

In our experience, the congregations that have had the most success infusing and sustaining The Conversation Project and advance care planning activities have had the full support of their clergy leaders and key allies.

Early on, set up meetings for one-to-one conversations with them to share your vision, commitment, and readiness to take responsibility for this work. Listen to their questions, concerns, and, possibly, resistance to bringing these important conversations into the community. Offer to walk them through the Conversation Starter Kit, and invite them to have the conversation with a friend or loved one.

**Clergy may take on different roles in this enterprise. Before proceeding, have a sense of:**

- Will the senior clergy leader be actively involved?
- Will the clergy leader delegate the work to another clergy member?
- Will the clergy leader observe your work, but not get involved?
- If the clergy leader's level of involvement is uncertain, what can you do to increase buy-in (e.g., direct them to [sample sermons on The Conversation Project's website](#))?

**In addition, ask yourself who in your community...**

- ...will oppose your work?
- ...will let your work happen?
- ...will help your work happen?
- ...will make sure this work gets done?

**Asking these questions at the outset may help you identify more team members as well as prepare your team to address concerns in a positive frame.**

**Remember:** Your clergy leader can support this work by offering sermons and pastoral care, writing in their congregation's newsletter or blog, making announcements during services, or simply approving use of building space for programs. While some clergy leaders may not want to take an active role, their endorsement in some visible way will have a positive impact on the success of your efforts.

## Start small.

We understand: You want everyone to have the conversation right now! That's great. For starters, however, we urge you to start small with a receptive group to work out the kinks and revise your content, format, and communications as needed for a successful wider roll-out.

---

### 10 STEPS TO HELP YOUR CONGREGATION INTEGRATE, SUSTAIN, AND RENEW CONVERSATIONS ABOUT END-OF-LIFE CARE WISHES:

- 1 Build a team.
- 2 Understand what your community already does (or has tried to do in the past).
- 3 Engage senior clergy support.
- 4 Inform and engage your board and other key lay leaders who might feel ownership of this work.
- 5 Study your faith's traditions, practices, texts, and ethics regarding end of life.
- 6 Engage your congregation in having the conversation. Help interpret your tradition's principles and practices to understand what matters most to your congregants at the end of life.
- 7 Infuse this information through all aspects of congregational life, paying particular attention to those who are isolated, vulnerable, or marginalized.
- 8 Guide individuals and families as they have the conversation and make decisions.
- 9 Test your ideas for programs with targeted groups.
- 10 Revise your activities as you gather feedback.

# Step 2 Get Set

**Set a goal.** Congregations of various denominations from across the country have implemented successful, sustainable, and measurable activities that are supporting their members to engage in meaningful, values-centered conversations about their wishes for end-of-life care. These activities emerged out of the answers to three assessment questions that helped them set a goal:

? **Who is the audience you're trying to reach?**

? **How is it best to reach them?**

? **What actions do you want them to take?**

---

## GOAL

Let's say that you want to set a goal for your team to:

**Engage 50 members of the congregation to have the conversation with a loved one.**

? **Who is the audience you're trying to reach?**

That's great! Now, ask yourself: Who are these 50 people? Look to where people are already gathering in shared interest groups such as:

- Your staff or pastoral care team
- Everyone over age 65 in your community
- Graduating high school seniors
- Members of the board, committees
- Men's club, Sisterhood, bowling league, book club, knitters, social justice team

Existing groups or committees are pre-formed audiences that are already meeting on a regular basis. It can be easier to make inroads when you have a relationship with group leaders or members. In short, go where there is good will, receptivity, and a captive audience.

## GOAL

Once you've chosen a target audience, you might refine your goal to be more specific. For example:

**Engage 50 members of the congregation who are 65+ to have the conversation with a loved one.**

? **How is it best to reach them?**

Now go deeper. Given your target audience, ask yourself: How will you try to reach them? Some outreach channels include:

- Sermons
- Website and social media (Be mindful of the digital divide, ensuring that communications include non-digital channels for those who do not regularly use the Internet or social media.)
- Weekly bulletins, newsletters, and worship service announcements
- One-to-one pastoral visits
- Workshops
- Guest speakers
- An all-congregation book reading or movie night



## GOAL

Once you've chosen an activity to reach your audience, you can refine your goal further to state:

**Via three Conversation Starter Kit sessions, we will engage 50 members of the congregation who are 65+ to have the conversation with a loved one.**

### ? What actions do you want them to take?

Finally, understand what actions you want your audience to take. Being clear about what you want people ultimately to do can make the “offer” and the “ask” clear and concise. For example, do you want people to:

- Have the conversation with a loved one to explore their end-of-life care wishes?
- Have the conversation with a member of the clergy or pastoral associate to explore a wide range of wishes and decisions?
- Have the conversation AND talk to their doctor AND designate a health care proxy AND prepare an advance directive?
- All of the above.

Clarifying the desired actions will help frame your content and communications. By narrowing the scope of your work at the outset, you can be more creative as you learn what works in your setting. When all options are on the table, it can be confusing to know where to start.

**Ideally, all goal statements will include “how much” and “by when” elements.**

A goal statement that does NOT include “how much” and “by when”:

*We're going to promote advance care planning conversations in our congregation.*

**A clearer goal statement:**

*Via three Conversation Starter Kit sessions, we will engage 50 members of the congregation who are 65+ to have the conversation with a loved one by April (one year from now).*

# A few words about measurement.

We establish goals so we can aim to reach them. Measuring helps you assess your progress and your success.

## KEEP IT SIMPLE

**Use a simple process for tracking progress toward your goal and start counting:**

- How many people attended a sermon about the importance of having the conversation?
- How many people registered to attend a Conversation Starter Kit Workshop?
- How many people attended the Conversation Starter Kit Workshop?

You might try tracking results in the moment on a simple form with check marks or colorful sticky dots on a flip chart to tally later.

## CONSIDER STARTING WITH A SIMPLE SURVEY

**A congregation-wide survey, conducted before implementing any programming, will give you a baseline for understanding how your activities make a difference. You could ask:**

- Have you had a conversation with a loved one about your wishes for care at the end of life?
- Do you have a health care proxy/agent/durable medical power of attorney (a person who can make decisions about your care in the event that you cannot speak for yourself)?
- Are you interested in learning more about advance directives? Or how to start having these conversations?
- Are you interested in joining a team to support our congregation in having more open conversations about these matters?

Doing the same survey after six months or a year of activities will give you information about the impact your work has had.

**Note:** It can be difficult to measure how many conversations are happening at home. That's why measuring something else — like how many signed advance care directives, health care proxy forms, or power of attorney for health care forms — can be a useful indicator of the effectiveness of your activities.

## Three congregations that have brought The Conversation Project to their communities:

### **St. John the Evangelist RC Church, Howard County, Maryland**

They established a new ministry for their 3,000-member congregation, called “Your Gift of Peace.”

- Priests preached at three Masses (two in English, one in Spanish) about the importance of having the conversation.
- They hold Conversation Starter Kit Workshops three times a year.
- They trained lay Pastoral Associates to share the Conversation Starter Kit with other congregants.
- They developed a library of materials pertaining to end-of-life decision making, spirituality, and care.
- They held panels featuring health care providers on topics such as hospice, palliative care, and what happens in the ICU.

---

### **Bethel AME Church, Boston, Massachusetts**

Their “Planning Ahead” ministry infuses the conversation about end-of-life wishes throughout the congregation with preaching and multimedia messaging.

They regularly offer a three-part program to small cohorts to:

- Lead people through the Conversation Starter Kit.
- Review advance care planning documents.
- Celebrate congregants who complete documents and have the conversation with their doctor.

---

### **First Church Bedford, Massachusetts, Unitarian Universalist**

They offered a variety of programs to meet people at their interest level.

- They preached on the importance of having crucial, intimate conversations sooner rather than later.
- They hosted Death Over Dinner events.
- They held Conversation Starter Kit Workshops.
- They used the improv “True Story Theater” company to dramatically interpret people’s stories and feelings about a “good death” or a “hard death” — having or not having had the conversation.
- They convened panels on legal and medical implications, home funerals, and green burials.

# Step 3 Go

Activities for implementing The Conversation Project in congregations fall into three categories:

- **Sermons and Worship**
- **Pastoral Care**
- **Programming**

***Note:** You and your congregation are not expected to implement every idea outlined in this guide. Nor are you limited by the examples offered. As you implement or innovate ideas and activities, we would love to hear about what works in your setting so we can share your successes with other congregations. Please share what you learn: [info@theconversationproject.org](mailto:info@theconversationproject.org).*

*While we have aimed to include activities implemented in congregations of various denominations from around the United States, this is not an exhaustive list, nor are all denominations represented. We apologize for any errors or terminology that may not resonate with your faith tradition or culture. Please help us improve this guide by offering constructive feedback and information, including sample sermons, texts, and practices.*

## SERMONS AND WORSHIP

- Write and deliver a sermon on why “talking matters” during The Conversation Project’s national Conversation Sabbath, with a call to action to have “the conversation.”
- Choose a text that illustrates a revered leader having important conversations with followers to lay the groundwork for congregational discussions (e.g., Jacob blessing his children, death of Moses or Sarah, death of the Prophet, Jesus at the Last Supper).
- Identify other themes and supporting texts to ground and guide a sermon on topics that touch so many (e.g., aging wisely, caregiving, caregivers, ethics, suffering).
- Deliver a sermon on the importance of being present for one another in times of need and suffering, using excerpts from appropriate texts or teachers.
- Consider which religious seasons lend themselves to reflection on end-of-life matters, and tie the holy day or season to talking with one another openly. Examples we have heard include: Yom Kippur, when the largest number of congregants are present and when Jews say Yizkor (remembrance of relatives who died); Advent, when themes of preparing and gift giving (including the gift of having the conversation) can emerge; Lent, when Christians follow Jesus as he prepares for death; and All Saints and All Souls Days.



- Consider secular seasons as times to connect to the importance of having the conversation: Thanksgiving, when families and friends gather and celebrate gratitude; Fall, the turn of seasons and nature's preparation for change; Winter Solstice, the dying of the year; New Year's Day, which could include making resolutions to have the conversation; Graduations, Mother's and Father's Days, Valentine's Day, when giving the gift of the conversation is an act of love.
- Plan and implement a thematically integrated, intergenerational worship service that addresses the importance of having the conversation at many points along the life spectrum.
- Use ordinary times (non-High Holy days) to structure a service with a "conversation" or "death and dying" theme.
- Prepare a list of texts, readings, poems, and hymns that could be used in a service during the Conversation Sabbath, recognizing there are elements of celebration to be incorporated (e.g., celebrate our courage to embrace the reality of our mortality, celebrate the beauty and power of being alive today with time to plan and make our wishes known).
- Identify members of the congregation who would be prepared to recount their story during a service about the challenge or blessing of having the conversation and the difference it made.
- Write and share your own story about an experience of a "hard" or a "good" death and what you learned.

## PASTORAL CARE

### **Offer or seek professional and volunteer training to develop capacity for discussing end-of-life wishes among clergy, staff, lay leaders, and congregants.**

- Attend a clergy retreat or seminar on end-of-life care issues and conversations.
- Offer a workshop for pastoral care associates or health care committee on how to facilitate introducing or having the conversation with congregants they visit.
- Work with the Cantor or Music Director to recruit and train choir members to give comfort to the sick and dying with chanting or other music (e.g., Threshold Choir).
- Learn about palliative and hospice care and state-specific advance care planning (ACP) documents.
- Learn about special considerations for discussing end-of-life wishes with people with Alzheimer's disease or dementia, and parents of seriously ill children.
- Collate pertinent texts on: care of the stranger, the widow, and the orphan; who is one's neighbor; or other related themes. Convene a group to study and inquire: how might these sacred texts inform our practices of caring for the elderly, isolated, seriously ill, and mentally ill? Are there community pastoral practices we wish to institute or revise in response?

### **Develop or update a library of documents pertaining to end-of-life care and wishes.**

- Collect, display, and update accurate printed and digital information on advance care planning documents for your region, hospice and palliative care, as well as funeral and burial practices and resources.
- Have website links and/or printed copies of the Conversation Starter Kit available to share with congregants as appropriate.
- Review or build and maintain a system for recording and retrieving individual wishes and/or documents related to funeral/memorial services and burials. Convene clergy, staff, and lay leaders to discuss the role of the congregation in maintaining these records. What kinds of processes would need to be established and maintained if we were to adopt the role of stewarding these records?

## PROGRAMMING

**Offer programs that train and encourage people to reflect on and share “what matters most” at the end of life.**

- Plan, promote, and implement a Conversation Starter Kit Workshop for your board and committee chairs.
- Schedule a Conversation Starter Kit Workshop and promote it to members of your congregation after a sermon on a topic related to end-of-life decisions or why talking matters.
- Plan a program on spiritual and religious considerations in making end-of-life care decisions.
- Host a “Take Your Agent to Dinner” event near Valentine’s Day: Bring your designated (or proposed) health care agent to dinner at your congregation for a focused conversation with others on “what matters most.”
- Host a small group discussion on Atul Gawande’s best-selling book, *Being Mortal*, or other thematically related book.
- Screen the Frontline program “Being Mortal” or the film “Extremis” for interested adults, followed by a facilitated discussion.

**Offer programs on medical and legal considerations in making end-of-life care decisions.**

- Present a program on secular and theological legal issues led by an attorney and a religious leader or scholar.
- Host a panel with an estate attorney, financial planner, and funeral director on making plans before a crisis.
- Invite palliative and hospice care professionals to offer a program on care options and facilities in your community.
- Convene congregants who have engaged with hospice as professionals, volunteers, patients, and/or loved ones to share their perspectives and experiences with one another and pastoral leaders.

**Boulder Valley Unitarian  
Universalist Fellowship in Colorado**  
co-hosted “The End: Movies and  
Mortality,” a five-week film series at  
the Lafayette Public Library and The  
Conversation Project in Boulder County.

### **Connect with health care providers who serve your community.**

- Set up one-to-one meetings with area Visiting Nurse Association and hospice leaders, perhaps offering to be a resource on your faith tradition's rituals and requirements for after-death care of the body.
- Build relationships with community palliative and hospice care providers through one-to-one meetings, perhaps sharing your congregation's efforts and readiness to have conversations about what matters most at the end of life.
- Partner with community health care providers to host a "Community Conversation" forum in your setting, during [National Healthcare Decisions Day](#).
- Partner with local health care systems to convene a symposium with faith leaders for a two-way training between clergy and clinicians to learn about faith and cultural traditions and medical care at the end of life.

### **Share your knowledge and experience with other faith communities.**

- Invite interfaith clergy colleagues to a lunch discussion to share texts and teachings that ground values-based decision making on end-of-life care.
- Gather with interfaith clergy to share the Conversation Starter Kit as a way to reflect on our own wishes for end-of-life care and what matters most, and build capacity for talking with loved ones and congregants.
- Convene an interfaith panel to meet with community health care leaders to share what matters most from our various faith traditions.
- Offer to lead a Conversation Starter Kit Workshop at your denomination's annual regional and national gatherings for clergy and lay leaders.
- Share your learning and experience at a meeting of your clergy colleagues.
- Invite clergy colleagues to gather for breakfast or lunch in a private setting to share personal and professional experiences about "hard" and "good" deaths.

# Step 4 Keep Going

## What can you do by next Tuesday?

There will always be more planning or research you can do. Avoid getting too bogged down: get started. What is a small “test” you could do in the next week? Who are one or two people you can connect with to introduce the Conversation Starter Kit?

*“Our ultimate goal, after all, is not a good death, but a good life to the very end.”*

ATUL GAWANDE

### “IT’S A LONG RUNWAY!”

This is something we hear from many congregational leaders who work to implement The Conversation Project in their faith communities. Not everyone is as ready as you are to champion talking about end-of-life wishes or advance care planning. You may get frustrated by the amount of time it takes to set up meetings, do an interest survey, practice leading a Conversation Starter Kit Workshop, get on the events calendar, etc. You are not alone. Be patient. Be persistent. We also hear: “It took some time to get this important and healing work off the ground, but it was worth it. People are giving their loved ones the gift of knowing what matters most.”

## With Gratitude

It has been an honor to work with so many clergy and congregants to test and refine ideas for bringing The Conversation Project to faith communities.

We are grateful to the hundreds of leaders across the country and from various denominations who have participated in Conversation Sabbath, held Conversation Starter Kit Workshops, and innovated programming for their communities.

## CONTACT US


### VISIT US


[theconversationproject.org](http://theconversationproject.org)

### E-MAIL US

[conversationproject@ihi.org](mailto:conversationproject@ihi.org)

### FOLLOW US

 @convoproject

 TheConversationProject



the conversation project