



The Conversation Project

Getting Started Guide for Communities

the **conversation** project



The Conversation Project wants to help everyone talk about their wishes for care through the end of life, so those wishes can be understood and respected. Since 2012, we've worked to increase awareness of this issue with the public and to create tools, like our Conversation Starter Guide, to help individuals have conversations with those who matter most.

Bringing The Conversation Project to Your Community

Mission/Purpose

To bring about national change, we need to reach people where they live, work, pray, and learn. Many individuals and community leaders like you have asked us for help with introducing The Conversation Project in their communities.

This **Getting Started Guide** is intended to help you do just that. This guide can help you talk with community members about the importance of conversations, whether you are looking to reach five, 25, 100, or 1,000 people. You know your community better than we ever could, and we hope this Guide will provide a helpful framework for you.

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How to use this guide

Use this guide as a workbook to help you or your team:

- **Review, reflect, and write it down:** We kick off each section with what we've learned, sharing examples and questions to help you formulate your own thoughts. Then it's your turn to use the blank space provided to capture your thoughts and adapt based on the assets already in your community.
- **Learn from others:** Insights from people like you, with years' of experience in bringing this to their communities, are sprinkled throughout.
- **Engage community partners**
- **Pace yourself:** Work at your own pace and with an eye toward the resources and time you have to start something – in your social circles and the community at large. You don't have to take on all of this work at once.
- **Skip what doesn't feel useful for you and take breaks.** If you are looking to reach a small number of people in your immediate community or social circles, some of the later questions and examples may not be for you.
- **Track your accomplishments:** Make note when you finish a question or section. Reward yourself or your team for moving forward!

For those **looking to reach a larger scale audience** over a longer period of time, Step 2 Question 7 may be of particular interest to help think about how to work collaboratively and expand your reach.



This guide is not meant to be prescriptive. Use the prompts, adapt ideas that resonate, and do what's right for your community!

Step 1: Think about it

Why does this work matter to you?

Before jumping in to support others, it helps first to think about why you want to bring this to others in your community. What drives your passion? What do you bring to the table that people may relate to and connect with? This work is rooted in stories. Stories shared can reveal our human connection and help to invite others to join your cause.

Why does this work matter to you? Share what makes you passionate about this work.

How might you approach this work?

If you're reading this, you are probably ready to jump in and connect with as many people as possible. It's helpful to remember that not everyone comes to this from the same place that we do. Many are hesitant to have these conversations for various reasons. For example, individuals may have other pressing issues that need to be attended to first (e.g., the need for survival, food security, job security, equity in health care, etc.).

Some things to keep in mind:

- **Start from a place of humility:** Individual needs will vary tremendously. Be curious and *listen* to what those you are trying to reach are going through. Don't push your agenda or your own biases. Meet people where they are.
- **Connection before content:** Listen and learn more about the person or people in front of you first before diving into these conversations. What are their struggles? What are their priorities?
- **Practice cultural curiosity and humility:** How might an individual's culture, faith, and background influence their values around the end of life? How might yours differ? The lifelong process of personal reflection and examination of our biases can be powerful ways to develop cultural curiosity and humility. Learn and adapt as you go.
- **Appreciate the context of individuals' lives:** Recognize that socioeconomic status, race, religion, ethnicity, educational history, language, cultural background, sexual orientation, gender identity, family structure, and many other factors shape perspectives and interactions.
- **Hold space for individuals to lead their own journey:** Let go of the notion that everyone should have "the conversation." Create space. Telling people what to do can be more harmful than helpful.
- **Do with, not for:** Learn from and co-design this work with those you are hoping to reach. Don't assume you have something for people with your agenda in mind.
 - Seek out existing leaders in your community of those you seek to reach (e.g., faith leaders, cultural group leaders, neighborhood leaders, social services leaders, etc.) to build relationships from the very beginning. Meet them where they are, listen and learn about the assets within your/their community as well as the needs and concerns of various groups. Ask multicultural community members to lead. Have them on your staff/volunteer list.



Conversations are made up of two parts: talking and listening.

- **Use a strengths-based approach:** We strongly encourage you to focus on the assets you already have available in your community just waiting to be tapped, rather than thinking about the things or resources you don't have. WHO and WHAT makes your community great?
- **Many hands make light work:** You are not alone! There are many passionate individuals and groups doing this work across the country and most likely in your own community. Seek out other like-minded champions to work together. The Conversation Project has [an entire network of support](#) for you!
- **This is a marathon, not a sprint:** Change takes time, but we promise it's rewarding.
- **Seek to understand:** Listen carefully to the stories of those most seemingly stubborn naysayers – those who seem unwilling to change. These individuals may become your most vocal champions.
- **Think big and start small:** Try out your message with a handful of friends. See how it goes and how they react – and then adapt and adjust before taking it to a larger group.



There is no one way to do this work. Different people are at different points in their planning, have different resources available to them, and have different levels of acceptance of the idea of end-of-life planning in their communities.

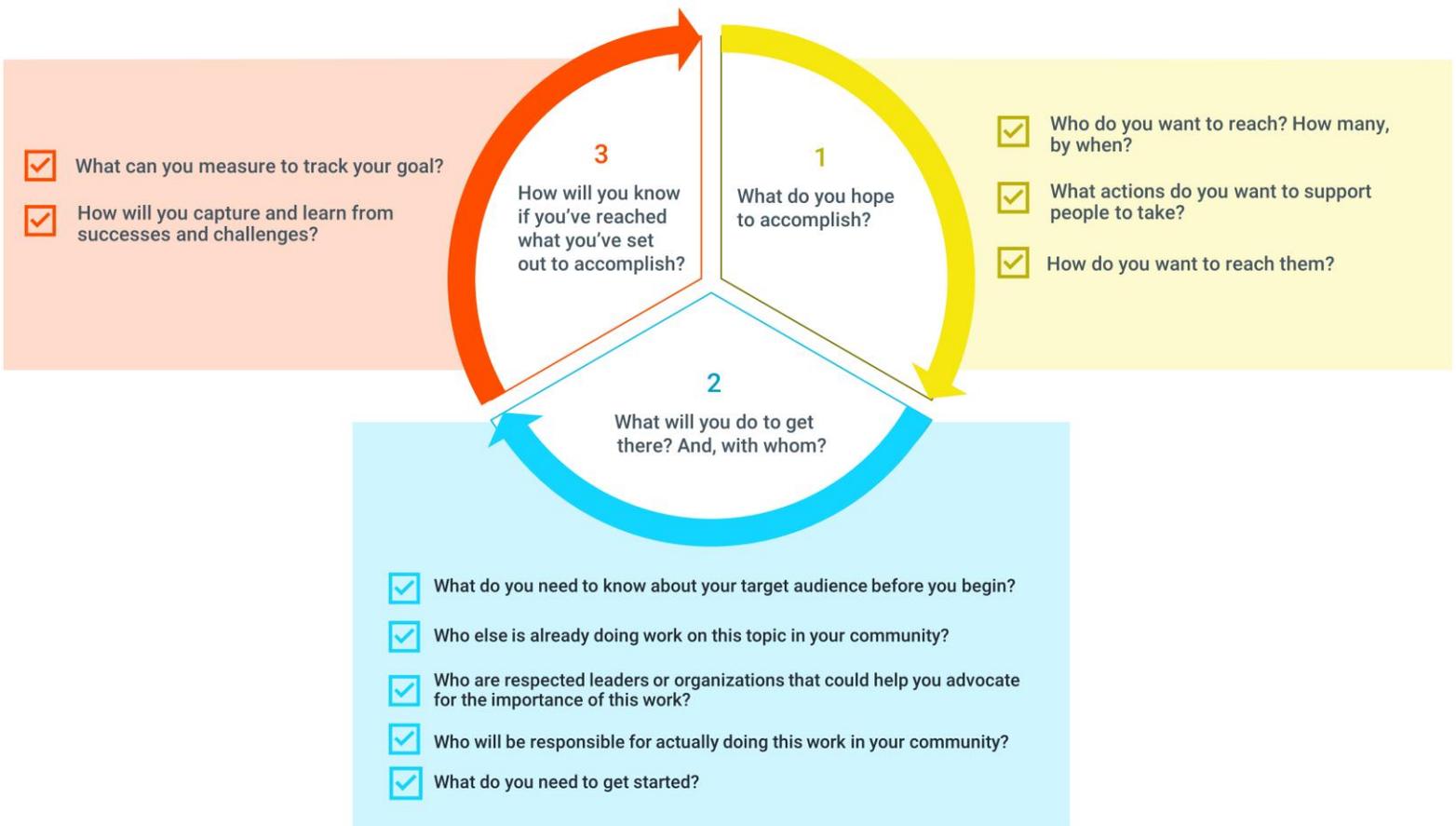
How might you approach this work? What key things do you want to keep in mind?

I realized that there is no perfect time, place, or way to start these discussions. But at the end of the day, this imperfect time may just be the right time. The right time for self-reflection, the right time to ask those uncomfortable questions around death. By leaning into those questions and staying curious, we open ourselves to deeper relationships with not only our loved ones but ourselves. And I, for one, am glad to walk alongside my community as we embark on our journeys of life, and death, together.

Naomi Edmondson, Death Doula

Step 2: Plan Your Strategy

Many have found it helpful to start with the following framework and questions. We'll walk through each question with ideas and examples to guide your thinking. Once you complete each question, check it off the list!



If you have a team tackling this together: you may want to answer these questions as an individual exercise first and then come together to talk through your thoughts as a group, so everyone's voice is heard.

Ten Questions to Get You Started

#1 Who do you want to reach? How many, by when?

The audience you want to reach can, and likely will, grow over time. It's helpful to set a goal early on. Who do you want to reach, and by when? Being clear about your plans will help you pace your work, clarify next steps and focus on outcomes.



- **Who are you interested in engaging in your community?** Is this because of a noted need? Because you have connections with this group?

FOR EXAMPLE, ARE YOU TRYING TO REACH...

- Your book club members? A study group within your faith community?
- Support group attendees?
- Staff working in local retirement communities?
- Your employees? (e.g., hospital staff, professional service organization staff, etc.)
- Everyone over age 75 in your community?
- Everyone over age 18 in your county?

- **Think about who is most affected by inequities in care through the end of life.** What would it take for that to change? How might you engage those being left out?

- **How might you test the waters?** We recommend first focusing your efforts on willing participants – those eager to start the conversation about their care wishes through the end of life. Sometimes it's better to start with this group than to spend time and energy trying to convince those who aren't yet ready. You'll work out some of the kinks in your process with a friendly audience.

Think big but start small...let it organically build momentum with those that are interested as it can't be forced. Also, collaborate, be creative & customize the programming to the audience.

Tracy O'Donnell Grafton

Expand and adapt: If you've reached one person, you are a champion! If and when you're ready, you can expand the focus to a larger group — those who might have been resistant early on. Again, pay attention to those who might be left behind.

- **For those looking to reach a wider swath of their community, how do you plan to reach diverse groups of people?** Consider the diversity of your community (language, age, race, religion, culture, sexual orientation, gender identity, socioeconomic status, abilities...). Learn more about the demographics in your area. How might you ensure this diversity is well represented among those you plan to reach?

FOR EXAMPLE

- Many groups, including TCP, realized that our willing participants were middle-aged, White, English-speaking, formally educated women. While it is ok to start with the willing, careful attention is needed to not further exacerbate inequities in care through the end of life by limiting your support to one segment of the population.

Here are a few examples of target audiences some of The Conversation Project's community partners identified after reevaluating the demographics of their regions:

- Black, Indigenous, People of Color (BIPOC)
- LGBTQ+ population
- Non-English-speaking populations
- People with mental health problems
- Younger adults and new parents
- High schoolers and older children
- Solo agers
- People with memory conditions
- Incarcerated people and returning citizens
- Homeless population

FOR EXAMPLE

- *Your Decisions Matter*, a community-based initiative to engage the public in conversations about end-of-life care and decision making in New Jersey, wanted to diversify their outreach and programming. They reached out to local faith leaders as a first step. Then, they approached the advocacy organization Garden State Equality to collaborate on joint programming for the LGBTQ+ population. Finally, they reached out to organizations working with those experiencing homelessness in their town to brainstorm ways to reach them that would be sensitive and helpful.
- *Brockton Visiting Nurses Association, Inc.* in Massachusetts invited a guest speaker to help inform staff and facilitate discussions around how different cultures may identify a surrogate decision maker.

- **For those thinking about large-scale reach:** We recommend starting with a smaller sub-group (for example, your congregation instead of the whole network of churches, or a city or county instead of an entire state) while you get your bearings and learn about others who might already be working on this topic in your region.
- **Once you've got your "who," create a goal for "how many" and "by when":** Do a back-of-the-envelope calculation to determine the number of people you'd like to reach in order to start making an impact in your community. It's good to have an idea of what you think success will look like.

FOR EXAMPLE

- There are 60 members of your rotary club, and an average of 15 consistently attend monthly meetings. Your goal may be to reach 15 members of your rotary club by the end of next month.
- There are 30 health care facilities in your county, each with 3-5 social workers. Your goal may be to reach the social workers at 12 healthcare facilities over the next year: 3 each quarter.
- There are 5,000 people over 75 years of age in your town. Your goal might be to reach 10% of them (500) over the next year — and an additional 10% the year after that.

Who do you want to reach? How many, and by when?



How might you adapt the concepts above to your plans?

#2 What actions do you hope people take?

There are a lot of possible areas to cover in Advance Care Planning (ACP). Talking about specific steps will make it easier for people to take action when they are ready.



- **What are you hoping people will do?** Knowing this early on helps you to be clear, concise and targeted with your support to help them.

FOR EXAMPLE

Do you want to support them to...

- Understand why conversations about what matters most are helpful?
- Have a conversation with a family member or friend?
- Have a conversation with a family member or friend AND talk to their doctor?
- Have a conversation with a family member or friend, talk to their doctor AND prepare an advance directive that includes designating a health care proxy?
- Have a conversation with a family member or friend, talk to their doctor, prepare an advance directive AND share copies with their health care proxy, or others who may have a say in care including their doctor?

If you're going to work on "all of the above," be sure to share the steps in a clear, organized way.

- **Be patient and supportive.** Understand there may be many paths people take toward action (e.g., having conversations about what matters most).
- **What can you achieve realistically with the time and resources you have?** Who you want to reach and what actions you hope they take will depend on the time and resources you have (including other partners).

FOR EXAMPLE

- A group in Hawaii wanted to go deep and support their community to take all the above actions, so they focused their efforts on a smaller group so they could better support them and track progress along the way.
- A group in Nevada wanted to reach over 100,000 community members in their catchment area and they knew they wouldn't be able to support each person individually. They chose to focus on raising awareness - spreading information to increase knowledge of the importance of conversations.

- **What tools will you use? How can you help make sense of the many resources available?**

Some community groups choose to focus on encouraging their target audience to have the conversation (the primary goal of The Conversation Project), while others focus on making sure people have medical or legal documentation (e.g., health care proxy/advance directive) on file. You can decide what is best for you.

EXAMPLES INCLUDE: The Conversation Project's Conversation Starter Guides * Five Wishes * Honoring Choices * Respecting Choices * Prepare for Your Care * State-specific ACP tools

FOR EXAMPLE

- A group in Denver, Colorado, found that many people they spoke with had conversations about care wishes through the end of life with important people in their life. But they had not yet talked with their clinicians about end-of-life care. So, this group chose to focus on engaging health care providers.

- **Before you start, do a quick, informal assessment to see what community members have already done.**

FOR EXAMPLE

- Ask 20 seniors at the community center whether they've had a conversation about their care wishes through the end of life or have completed an advance directive.
- Use one of the measurement tools in our [Community Resource Page](#) to poll attendees after an awareness-building event to learn more about whether they had a conversation with someone important to them or a clinician.
- If you are in health care and have access to patient medical charts, pull the charts of 20 patients in your target audience to see if they have a health care proxy or advance directive on file. Better yet, see if conversations about what matters most to them or their goals of care have been documented.

What actions do you hope people will take?



How might you adapt the concepts above to your plans?

#3 How and where do you want to reach them?

Think about what motivates different groups of people. What is unique or special about the group you're trying to engage? Learn from those you want to reach by co-designing activities together.



- **Imagine a person you might try to engage:**

- What is their day-to-day life like?
- What do they care about?
- How can you design your outreach to meet the needs and current activities of your target population?

- **How can you reach your target audience where they:**

- Live?
- Work?
- Pray?
- Learn?

- **What activities might help you engage your target population? What do you think will attract your target audience and encourage them to take action?**

FOR EXAMPLE

Publicity:

- Write op-eds for the local newspaper, social media, newsletters, flyers, or advertisements
- Create a media and Public Service Announcement (PSA) campaign to raise awareness
- Share information via podcast or on local radio programs (targeting various languages)

Events (virtual or in-person):

- Speak at conferences or educational events
- Host a conversation session that is open to the general public
- Host a brown bag lunch or pop-up booth with information to share
- Train many champions to spread the word
- Host many training events in the community over the course of the year
- Host virtual roundtable discussions or Q&A panels through Webinars, video chat, live social media broadcasts, etc.

Repository of resources:

- Set up a website, a blog, or social media page
- Create your own vlog and YouTube channel

- Your target audience may not require any in-person events at all (and/or circumstances don't allow for in-person events). If not, how will you reach them?
- **What do you need to reach your audience?** Who are the advocates you may need to partner with first in order to be successful?

FOR EXAMPLE

- Contra Costa Regional Medical Center in California recognized that their Spanish language interpreters hadn't been taught about end-of-life conversations first, before translating this information for Spanish-speaking patients. They now train interpreters to be prepared for advance care planning conversations with patients.
- A group in Hawaii is reaching the Deaf community through work and presentations with interpreters first, working through local resource centers designed to help the Deaf navigate a hearing world. The interpreters were a crucial bridge and were thankful to learn this together to better support each other.

- **Reflect and take action toward reaching underserved or marginalized members of your communities:** Think through partners you could engage to join you or your steering committee, or help you think through how to introduce this topic to a more representative audience. This may not happen seamlessly but planning for equity from the start is crucial. Consider one step at a time. Who is the best messenger for this audience? Remember to be humble.



COMMIT TO DIVERSIFY: Show your commitment by diversifying your team – have diversity at the table to show you value all voices and perspectives.

- **Use stories:** When creating your portfolio of activities, use personal profiles, case studies, and testimonials to engage people's hearts and minds. See our [Tips for Facilitating and Teaching about The Conversation Project Guide](#) for more.
- **Will you offer up activities free of charge or will there be a cost?** Think about ways to get in-kind support. Some individuals/small business owners (a doula, coach, therapist, financial advisor, etc.) offer activities for free to help share work about their business or help promote education about their services (e.g., a hospice provider seeking to dispel myths about hospice care). Some groups might be able to offer their space free of charge (e.g., a library), or be willing to sponsor coffee and muffins (e.g., a local coffee shop).

How and where do you want to reach them?

How might you adapt the concepts above to your plans?

Putting it all together:

Take a look at your answers to the first three questions.

- **Put together a short goal statement:** Include all the components you just brainstormed to help in the next phase of your work. This goal statement can serve as a nice starting point when describing the work to others. Or, if you are seeking to go larger, it can serve as your elevator pitch for potential partners or funders. It can also help you pay attention to whether you're achieving what you set out to accomplish and whether you need to adapt.



FOR EXAMPLE

At first, you may have said: “We’re going to promote advance care planning conversations in our community.”

Create a goal statement that is much more specific:

- Via three workshops, we will engage 100 members of the congregation (over age 65) to have a conversation with key people (family, friends, others) in their lives by December of this year.
- We will share resources and information about the importance of care conversations through the end of life with 10% of all Spanish-speaking adults in our town by October of this year and 50% by October of next year. We plan to translate all materials into Spanish, train two local community groups that support Spanish-speaking populations to use TCP resources, and host one targeted event.
- Through a targeted media campaign, we will share information about the importance of having planning ahead conversations now to 50,000 young adults (ages 18-25 years) in our state by January of next year.

What is your goal statement?

How might you adapt the concepts above to your plans?

#4 What do you need to know about your target audience before you begin? Whose guidance might you seek?

Depending on the audience or region you've selected, there may be different ways to reach different people.



- **How are you taking into consideration the local environment?**
 - A state policy conversation, such as consideration of adopting the POLST Paradigm (Physician Orders for Life-Sustaining Treatment), may provide an opening to introduce the topic or cause some resistance, depending on the audience.
 - What works in one setting will not always work in another. When you read an exciting idea, consider your local context (religious beliefs, urban/rural differences, the number and type of health care institutions, etc.) before trying to adopt it.
- **Tap the assets you already have to understand your community better.** Someone in your target audience may know what reactions to expect. Think about groups or individuals who have already been supporting these community members.
 - How might you enlist and learn from someone in your target audience?
 - Who has been running social services or outreach to your target audience?
 - Respect that these leaders have a lot on their plate. While you are passionate about this topic, approach them with curiosity and deference to their priorities. Compensate them for their time, if possible.

FOR EXAMPLE

- A community member from Cape Cod noted they hadn't run any programs for the Spanish-speaking community because of language barriers. She stopped to think about past programs in her community for this audience and identified the leader of those programs as someone to contact.
 - Peaceful Presence End-of-Life Doulas in Oregon knew how important it was to connect with the diverse members of their community. They organized a virtual Fall event with leaders of the Black Leaders Assembly, Latinx Community Association, Confederated Tribes of Warm Springs, and OUT Central Oregon.
 - Boston Senior Home Care engaged the Chinese American Coalition for Compassionate Care to teach and train their staff culturally appropriate ways to engage with their local Chinese community.
- **Understand past and current realities that may influence your audience's response:**
 - Some groups or individuals have deeply rooted mistrust (from past or current harm) in the health care system. They may fear their wishes won't be honored, or their partner won't be recognized as their health care proxy, for example. Make sure to take this into account.
 - Religious beliefs often play a major role in medical decisions made. How might you explore the various beliefs across your community and factor those into your outreach?

FOR EXAMPLE

- Henry Ford Health System in Detroit recognized communication and collaboration with faith leaders was needed to truly understand and support the needs of their common community. They held an educational panel where various clergy taught clinicians how they provided support to their community members, and clinicians taught clergy what they needed in order to better support end-of-life discussions.
- A home health and hospice organization in Ohio invited both community members (caregivers) and health care staff for a two-day long, educational workshop on end-of-life planning and hospice care. During a session on respecting wishes, a Black community member shared her personal story of how her father's wishes were not honored and how she was there to help bring about change. This highlighted the importance of listening and understanding past harm.
- The American Muslim Senior Society (AMSS) in Maryland notes that within their community, the younger generation is expected to shoulder the responsibility of caring for their elders as a way to pay homage to all they have received from their elders. Some in their community don't ask for outside help, even when struggling, as they consider this taboo. AMSS developed a program to support family caregivers with this in mind, equipping local care Ambassadors (serving as advocates and navigators) to bring resources to families, meeting them where they are.

- **Think about how your target audience usually receives information.** Use ways of communication that are familiar to your audience.

FOR EXAMPLE

- Does your target audience use social media and email? Or do they like receiving hard copies in the mail?
- Do they prefer podcasts vs. newspaper and public broadcasting channels?
- When inviting undergraduates on a college campus to an in-person event, you would probably use different recruitment strategies than you would to connect with residents of assisted-living facilities.

- **Accept different approaches to sharing this message, depending on the host organization. Think about the choice of messenger.**
 - The person introducing the topic at an employee event may take a very different approach than a faith leader with their congregation.
 - Consider language translations or other settings that may help convey the message.
- **Think through political, ethnic, or cultural systems at play in your community. Have you accounted for cultural diversity in the population you are trying to reach?**

FOR EXAMPLE

- Leaders in New Mexico learned that the topic of end-of-life conversations was better received in the local Latinx community when introduced to entire families at once and not only to individuals.
- An Indigenous Deathworker working on tribal lands noted the Conversation Starter Guide could be useful to help educate the younger generation, who would be critical to helping navigate the way through the health care system for their elders – but the format and how to begin the conversation should be adapted depending on the nation (tribe) being supported. Is it patriarchal or matriarchal? Do they have their own medical health system in their community, or do they need to travel off their land to get medical care? She plans to share these Guides during workshops and retreats to train caregivers how to approach the questions with less linear thinking patterns to match local customs.

- **Match your messaging and approach to your community.** Some simply think they don't need a plan for care through the end of life or this isn't for them. Listen to what they are saying and adapt your approach.

FOR EXAMPLE

- Leaders of the Speakeasy Howard initiative in Howard County, Maryland learned the importance of offering different options and adapting the message to reach different people. There are some people who won't be turned off by the phrase 'end-of-life.' But to reach others, the messaging may need to be less confronting, like: "Have you thought about the future?" or "Who's going to speak for you if you can't speak for yourself?"
- Many leaders paused their work during initial months when the COVID crisis hit the US. Residents weren't able to focus on conversations when their needs centered on personal and financial safety first. Groups shifted to support their residents through public safety messaging, outreach to combat isolation and food insecurity, and alleviating fears. Leaders then adapted messaging and re-focused conversations as a way to be prepared.

How will your target audience respond to the topic of care through the end of life? Whose guidance might you seek to find this out?



How might you adapt the concepts above to your plans?

#5 Who else is already doing work on this topic in your community? Who else could you be working with?

Do a quick review of other organizations or informal groups in your community or region to see what work is already underway. Rather than adding more “noise” to a crowded field of helpful initiatives, see if there are ways you could assist those already in existence or select a theme of your work that’s a bit different or in support of their work.



FOR EXAMPLE

- There may be a group in your community particularly focused on education around the state’s MOLST/ POLST project or legal documentation (e.g., advance directives). You could connect with them to learn more about how to help promote the idea of having the conversation in addition to their goal of completing the legal paperwork. Or perhaps both groups will agree that you’re targeting different audiences but will establish monthly connections to bring each other up to speed on current work and areas of overlap.

- **When resources are limited, it’s important to leverage partnerships with existing groups. Don’t operate in isolation.** Look for partners and cooperate to advance this important work. Be respectful of the hard work others have done before you.
- **In addition, you can approach and partner with new groups and audiences.** Below is a collection of possible partners to consider for outreach. Check off the groups that might be a good fit for your initiative.

<input type="checkbox"/> Advocacy and civil rights organizations (e.g. NAACP)	<input type="checkbox"/> Faith-based organizations, clergy, chaplains, ministerial associations	<input type="checkbox"/> Local community resources (e.g., libraries, book clubs, Chamber of Commerce, Lion/Rotary/ Elks Club)
<input type="checkbox"/> Assisted living facilities	<input type="checkbox"/> Family counselors and therapists	<input type="checkbox"/> Multi-cultural organizations
<input type="checkbox"/> Businesses and local employers	<input type="checkbox"/> Financial community (e.g., banks, CPA firms, financial advisors)	<input type="checkbox"/> Media channels (local, state, regional)
<input type="checkbox"/> City employee retirement system	<input type="checkbox"/> Foundations	<input type="checkbox"/> Nursing homes, rehab facilities, long-term care
<input type="checkbox"/> Death Doulas	<input type="checkbox"/> Fraternities/Sororities	<input type="checkbox"/> Notary professionals
<input type="checkbox"/> Department of Public Health, Mental Health, Behavioral Health	<input type="checkbox"/> Funeral care	<input type="checkbox"/> Physician office practices/primary care/ community health centers
<input type="checkbox"/> Educational institutions (students, families, alumni, and faculty)	<input type="checkbox"/> Health plans/insurers Home care/VNA	<input type="checkbox"/> Prisons/jails
<input type="checkbox"/> Elected officials	<input type="checkbox"/> Homeless shelter/ services	<input type="checkbox"/> Retirement communities and home owners’ associations
<input type="checkbox"/> EMT providers	<input type="checkbox"/> Hospice	<input type="checkbox"/> School District (employee benefits, Parent/Teacher Organizations)
<input type="checkbox"/> End-of-life coalitions in your community or state (e.g., Honoring Choices)	<input type="checkbox"/> Hospitals/health systems	<input type="checkbox"/> Senior Advocacy Organizations/Elder Services (Area Agency on Aging, senior centers, transportation services, meals on wheels)
<input type="checkbox"/> Estate/legal entities (e.g., elder law, legal aid offices, local bar association)	<input type="checkbox"/> Insurance plans	<input type="checkbox"/> State hospital/medical/ nursing/social work associations
		<input type="checkbox"/> Veterans Services

- **Consider the diversity of your community.** Think about the demographics in your community. What partners can you engage to learn about existing work with those residents who may be most likely to face inequities in care through end of life? How might you work together?

FOR EXAMPLE

- Emily Vass, an Indigenous Deathworker and advocate, notes the importance of involving Indigenous end-of-life and medical workers to lead these conversations in their own community in order to create a safe space. She emphasizes how critical it is to understand and respect community sensitivities to an outsider coming in with their own agenda to educate. Having a member of the community lead helps create instant rapport and easier access and eliminates the need for training on local customs. Without understanding the history (past and current harm, as well as lack of support this community receives), sending someone to have these conversations without local knowledge and skills could cause irreparable harm.

Who else is already doing this work in your community?
Who else could you be working with?



How might you adapt the concepts above to your plans?

A stakeholder assessment can be a helpful tool for identifying partners. See the Appendix for this tool.

#6 Who are respected leaders or organizations that could help you advocate for the importance of this work?

Who in your community is well respected by your target audience and could help promote your initiative? Think about groups and individual leaders — for example, a local political figure, employer, news anchor, or religious leader?



BEFORE CONNECTING WITH THEM, THINK THROUGH “WHAT’S IN IT FOR THEM?”:

How does your initiative align with the work a person or an organization is already doing?

- What is their day like? How much time can they offer?
- Why is working with you in their best interest?
- What do they care about?

FOR EXAMPLE

Perhaps

...you could suggest the topic of planning for care through the end of life to local media outlets (TV, radio, newspaper) and offer to help pull together a panel of experts and speakers.

... a large local church may need topics for congregant educational programming, and you can offer to present in a few weeks, encouraging their faith leader to attend or say a few words.

... an influential individual has had this on their personal “to-do” list for a long time and wouldn’t mind being filmed or giving a quote after having their own conversation with someone who matters to them.

- **Think about what you want to ask, specifically.** Remember not to request too much from any one person or group. A letter of support? Space to host an event? Sponsorship for refreshments? Photocopied materials? Telling their story publicly?
- **Don’t make this an unpleasant obligation.** Make saying “yes” an easy decision that could lead to additional fruitful interactions or connections. Identify some simple opportunities for engagement. Many community partners have local leaders...
 - ... kick off the agenda for public events with a personal story.
 - ... share photos on social media for National Healthcare Decisions Day (NHDD) with a copy of their Conversation Starter Guide or advance directive.
 - ... provide a quote for a blog post or media opportunity.



Partnerships can extend your community reach and help share limited resources, connections, and needed knowledge.

A small request can go a long way toward reaching and engaging your target audience.

Which respected leaders or organizations could help you advocate for the importance of this work?

How might you adapt the concepts above to your plans?

For those seeking to go bigger...

#7 Who will be responsible for actually doing this work in your community?

If you are expanding and working with others, is there an individual or organization who can “own” this initiative in your community? Will everyone share the same responsibilities? Will there be a single leader or leadership group?



- **If you'd like to be the lead individual or organization, think through what you want your role to be and how much time you have to dedicate to this work.**

A FEW QUESTIONS TO HELP YOU THINK THROUGH PLANNING AND EXECUTION ACTIVITIES:

- Reflect back on your original goal
- What can you do or plan for today that will advance this work?
 - If you have four hours per week to dedicate to this project, how do you want to spend them to have the biggest impact in your community?
 - Speaking at events?
 - Training additional presenters?
 - Connecting with more partners to take on additional pieces of work?
- What feedback or data are you getting about your efforts?
 - What can you stop doing that would be time better spent elsewhere?
 - What are some low-risk things you could try (with minimal resources) to learn what works best in your community?
- How can you create pace in your work?
 - What are some themes or core goals you could organize around each quarter?
 - How can you identify and link the work to key milestones?
- **There are many models of partnerships that could work.**
- **Depending on the model you select, it can be helpful to develop a steering committee of interested partners who can help you with planning, execution, and dissemination.**

FOR EXAMPLE

- Many retirees with a background in end-of-life work start their “encore career” volunteering to lead The Conversation Project work in their community.
- Some groups collaborate loosely for a one-time or annual event (around NHDD, for example). At an event in Arizona, a hospice took responsibility for leading the presentation/activities, two notaries provided free services for participants, and one attorney provided pro bono support for legal issues.
- SAGE Eldercare in Summit, NJ was awarded a 3-year grant from two local medical centers' Community Advisory Boards to develop a community outreach program to engage the public in conversations about end-of-life care and decision making while helping to normalize the topic.
- Healthy Aging Martha's Vineyard has created an advocacy coalition of over 70 leaders, representing 37 nonprofit and municipal organizations serving Martha's Vineyard elders and their families. Advance care planning is one of their funded programs, with its own small, dedicated team.
- The South Carolina Coalition for the Care of the Seriously Ill engages many groups within the state. These groups all provide staff time and resources to keep the work moving forward.

- **Areas that will need to be addressed and owned:**
 - Relationship with high-level champions (governors, for example)
 - Relationship with interfaith community
 - Measurement
 - Media placement for PSA ads and social media
 - Ties to health care institutions
 - Training coaches/speakers and managing events
 - Funding

For additional resources on building coalitions from the Coalition to Transform Advance Care (C-TAC), see Step 4: Keep Going in this guide.

● **As your work continues, how will you plan for growth?**

As some community initiatives have matured, they've garnered so much interest from the public that the demand for presentations and the interest from community members to volunteer have grown. Many of these groups have now developed trainings for "conversation champions" and "conversation coaches."

Conversation Champions/Speakers are volunteers trained to educate and engage the general public and community stakeholders regarding the benefits of having conversations about care through the end of life. They are available to make presentations to community organizations, community groups, or any other interested groups and individuals. The Conversation Project team has a recorded training for those interested in becoming speakers. Visit the "[Community Calls/Connections](#)" section of the Get Involved Tab on TCP's website and click on "Training."

Conversation Coaches are volunteers trained to work with individuals and families who request support with ACP and care conversations through the end of life. This can be a great role for people who are more comfortable with one-on-one interactions than with public speaking, or who have a professional background in this topic, such as death doulas.

Many community leaders have invested in developing or providing these trainings.



As your work grows and you engage various types of partners: think through ways you can help them share with each other. Perhaps host an interfaith meeting for religious leaders in the community to share questions and best practices. Or host a neighborhood event at which different local organizations share what they've been doing to advance this work in the same specific geographic area in your region.

Who will be responsible for actually doing this work in your community?



#8 What do you need to get started?

Now that you've strategized, don't forget to sketch out some logistics to help you operationalize your plan.



FOR EXAMPLE

- What budget do you have?
- What space might you use?
- How much time do you have to dedicate?
- Who else may agree to help you? And, how much time do they have?
- What else might you need?

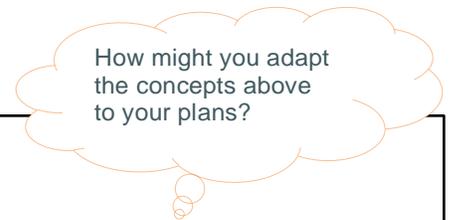
Thinking about and anticipating potential challenges in the above areas is a helpful exercise to help you plan ahead. See the Appendix for a helpful tool.

You can create a simple checklist. If working with other partners, try a spreadsheet to help you keep track of your work plan, what you need to get there, roles, responsibilities, and anything else that will help you get organized.

Category	Specific Needs Identified	Assets to Tap
Funding		
Space		
Materials		
People		
Time		

You don't need big funding to get started. Many people get started with no additional funding or minimal supplies.

What do you need to get started?



9 What can you measure to track your goal?

Think back on the goal you have set – your outcome. Break that down into something you can track (a measure) to see if you are nearing your goal.



FOR EXAMPLE

High-level outcomes you are trying to achieve:

- # people who complete the Conversation Starter Guide (or % of total target)
- # people who discuss wishes for end-of-life care with health care provider
- # people who complete an advance directive

Next, break it down further to measure the steps you take to reach your goal.

This is called a process measure. Tracking these can help you see if you are making progress.

FOR EXAMPLE

Specific steps in a process that lead to your goal:

- # individuals who attend a Conversation Starter workshop (or % of total target)
- # media placements about The Conversation Project in local newspapers or magazines
- # presentations to community partners about The Conversation Project
- # individuals who receive a Conversation Starter Guide

Some things are very hard to measure. For instance, we (and many others) find measuring the number of conversations or number of people completing a Conversation Starter Guide is very hard to track across a large-scale effort. Consider either adjusting your goal, or setting up a proxy measure – the next best thing that can be tracked and measured to understand your progress.

FOR EXAMPLE

- The Conversation Project measures monthly “episodes of engagement” among the general public. Primary episodes of engagement are defined as any direct exposure to TCP messages and/or resources via a TCP staff member, social media, newsletter, or website. We combine this with secondary episodes of engagement, defined as any exposure to TCP via our community champions through their own events, media, newsletter, or other reach. We gather secondary estimates quarterly via a survey sent out to community champions.
- Both primary and secondary are weighted – some count more than others, according to the power of the engagement. For example, attendance at an event (virtual or in-person) would count fully, while the others are counted partially, as exposure via social media, newsletter, email, etc. isn’t as engaging as an in-person event.
- Episodes of engagement is our proxy measure – the next best thing to tracking the number of people who have had a conversation about what matters most when it comes to their care through the end of life. It is for our learning purposes, and our best attempt to measure steps taken that can lead to conversations.

- Don't collect data just for the sake of collecting it. If you don't have plans to use a particular measure to improve your work, don't capture it!
- If a particular method of data collection is too burdensome and the information could be captured in a different way, take the less resource-intensive route.
- Measurement and evaluation should always be in service to your work — something you look forward to capturing and analyzing, not something you dread.

What can you measure to track your goal?



#10 How will you capture and learn from successes and challenges?

It is always helpful to think about how you will capture learning to identify successes or areas for improvement.

FOR EXAMPLE

- Create a process to track all contacts made and lessons learned.
- Develop a process for synthesizing this learning on a regular basis.



Qualitative data (words and stories that appeal to the heart), is just as important (if not more) as quantitative data (numbers and charts that appeal to the head) to learn about impact. How might you collect stories about impact in the community? For example, you can do a community-wide call for stories via blog post, capture stories through short video testimony, or regularly survey your community and include open-ended questions to capture the heart of what you want to learn.

This will allow you to notice variation or identify trends in which types of events or engagements have been more or less successful.

FOR EXAMPLE

- Are you receiving the same questions from congregants and need to adjust your approach or materials?
- Is there a message that really resonates with senior housing communities that you should incorporate the next time or share with others who are reaching out to this group?
- Are you seeing a big increase in the number of 18- to 24-year-olds visiting your website? What content is suddenly of particular interest?

Data can show potential partners and the media what you've accomplished. It also helps funders.

- **It is far easier to ask for additional resources** when you can show what you've been able to accomplish. By getting started, you'll identify what works for you and what has been a struggle and can then address these challenges with potential partners or funders — many of whom will be pleased to see what you've already started.
- **Additionally, many funders are interested in evaluation**, and it can make for a stronger funding proposal if you can show the impact of the work and how you plan to evaluate your work going forward.

How will you capture and learn from successes and challenges?

How might you adapt the concepts above to your plans?

Step 3: Take Action

Well done! You've done some thinking and are ready to jump in. There will always be more planning or research you could do. Instead, we invite you to get started and try out your "pitch"!

What is something small you could try by next week? Who are one or two people you can connect with or introduce the Conversation Starter Guide to? What can you start right away, say by next Tuesday?



"Don't let the perfect be the enemy of the good!"

What can you do by next Tuesday?

Remember, you will adapt this as you go. You know your community best. **Go for it!**

We hope that, with the assistance of this Getting Started Guide, you will think through the individuals, associations, institutions, physical assets, and connections you can access as you plan your next steps. You are not in this alone. TCP and many other champions are here to support you as you go! [Check out our Conversations Champions Map](#) for connections.

Step 4: Keep going!

To dive in deeper, you can find a host of free resources related to each of the previous sections [on our Get Involved page on our website](#) that can help to spread The Conversation Project throughout your community. Some examples of the resources we have include:

- [Tips for Facilitating and Teaching about The Conversation Project: A Companion to Getting Started Guide for Communities.](#)
- [Getting Started Guide for Congregations](#)
- [A compilation of lessons learned, tips and tools from communities on getting started, promoting your message, hosting an event, and spreading and sustaining momentum.](#)
- [Ways to engage, get involved and network with others.](#)

In addition, a sampling of outside resources from other organizations is listed below. We know there are MANY more out there. We hope this sampling, along with the resources on our website, keeps you going strong.

Looking for...	Check out...
Additional guidance and tools to support ACP in your community	Five Wishes® Advocate Toolkit (from Aging with Dignity)
Comprehensive guidance to developing and strengthening partnerships on the state and local level	Community Engagement Toolkit Companion Guide (from C-TAC)
Guidance specifically for African-American communities	The African-American Spiritual and Ethical Guide to End-of-Life Care – Special 2020 Advance Care Planning Edition (from Heart Tones™)
Comprehensive resources to develop effective, sustainable programs for ACP that support person-centered decision making	Resources for Convenors (from Respecting Choices®)
Ways to engage people from different backgrounds, perspectives, and experience into your work	Engaging People with Lived Experience Toolkit (from 100 Million Healthier Lives and The Institute for Healthcare Improvement)

We can't wait to hear what you design for your community. We hope you'll keep us posted as you embark upon this work. Email us at conversationproject@ihi.org

Stay engaged with The Conversation Project:

- [Join our webinars for community leaders](#) to hear updates from The Conversation Project team and presentations from others. Listen to past webinar recordings and slides to learn how to:
 - Get started
 - Speak on this topic
 - Expand outreach
 - Reach solo agers
 - Build coalitions
 - Message your audiences
 - Sustain this work
 - And more....
- [Sign up for The Conversation Project newsletter](#)
- Check out [our Conversation Champions Map](#) to connect with others doing work in your area and join our [Community Champions Discussion group on Facebook](#) to learn and connect with others.

The Conversation Project can offer in-person and virtual trainings or community planning sessions for a fee.

Appendix: Planning tools and templates

Bringing The Conversation Project to Your Community

Ten Questions to Get You Started

Who do you want to reach? How many, by when?

What actions do you hope people take?

How do you want to reach them?

What do you need to know about your target audience before you begin? Whose guidance might you seek?

Who else is already doing work on this topic in your community? Who else could you be working with?

Who are respected leaders or organizations that could help you advocate for the importance of this work?

Who will be responsible for actually doing this work in your community?

What tools, resources, workforce do you need to get started?

What can you measure that will tell you you've reached your goal?

How will you capture and learn from successes and challenges?

Anticipating and Overcoming Challenges Worksheet

Thinking about and anticipating potential challenges – time, resources, budget, space, how this is received by community –helps you plan ahead. Not everything can be anticipated. Expect plenty of surprises! But taking time to brainstorm now could help alleviate some headaches. If you are doing this on your own, ask a friend to help you think.

Potential challenges (what, who, where, when)	Ways to tackle (who, what, where, when, how)
1.	
2.	
3.	
4.	
5.	
6.	
7.	

Stakeholder Assessment

A stakeholder assessment can be a helpful tool for identifying partners. Think about the groups or individuals you want to engage (or that you think might hold back your efforts) and consider the larger context of this work.

Ask yourself:

- Are these stakeholders going to: stop, let, help, or make this happen?
 - **Make this happen:** Who will make sure this work gets done?
 - **Help:** Who is likely to help you with this work?
 - **Let:** Who may let the work happen, but won't be particularly helpful to the initiative?
 - **Stop:** Who will work to actively stop you? And why?

Group Name	Make It Happen	Help You	Let You	Stop You	What Matters to Them?

To begin, you may want to focus on what you can do to introduce your plan to the “make it happen” and “help you” partners and work with the “stop you” groups to shift them to “let you” partners. (They don't have to become your biggest champions, but see if you can work to transfer their energy away from blocking your efforts.)

Pay attention to the balance of community partners you work with and how your collective message will resonate with your target audience. For example, if you're working to engage young adults in your region, be sure to connect with the local universities and employers and not just home care and senior services.

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.

Created by the Conversation Project, an initiative of the Institute for Healthcare Improvement.



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the **conversation** project