

the conversation project



Kate DeBartolo, Senior Director
Patty Webster, Improvement Advisor
April 8, 2026

the **conversation** project



Helping people share their wishes for care through the end of life

Why talking matters

We can't plan for everything. But we *can* share what matters to us with the people who matter most to us.

Talking creates the foundation of a care plan built on our values—a plan that will be available when the need arises.

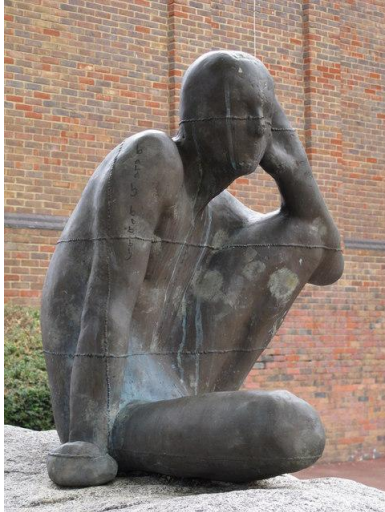


All in the approach

Shifting from	...to
Death and dying	Life and living
What's the matter <u>with</u> you	What matters <u>to</u> you
Clinical model	Values-based model
Telling	Listening



Listening matters too



This Photo by Unknown Author is licensed under [CC BY-SA](#)

“It is often **through the quality of our listening** and not the wisdom of **our words** that we are able to effect the most profound changes in the people around us. When we **listen**, we offer with our attention an opportunity for wholeness”

– Rachel Naomi Remen, MD

Our website

the **conversation** project

Institute for Healthcare Improvement

donate »

Home Get Started About Us What's New Blog Videos Get Involved NHDD



Helping people share their wishes for care through the end of life.

Free Guides

What's New

Get Involved



Personal stories

Blog

With Dementia, More is Needed than a Boilerplate Advance Directive

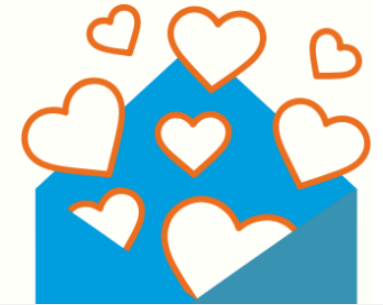
By Katy Butler, 02/25/2019



Blog

Dear Loved Ones: Trim My Chin and Upper Lip Hairs!

By Anna Waclawiczek, 06/07/2019



Blog

Breaking Down the Barriers Between Medicine and Spirituality

Posted on 05/30/2017



Blog

A Matter of Heart: A Father's Reflections on Advance Care Planning

By Ira Byock, MD, 06/10/2019



Free tools (in multiple languages and audio)

Starting a Conversation

Choosing a Health Care Proxy

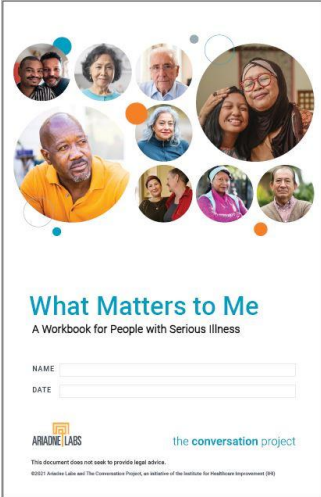
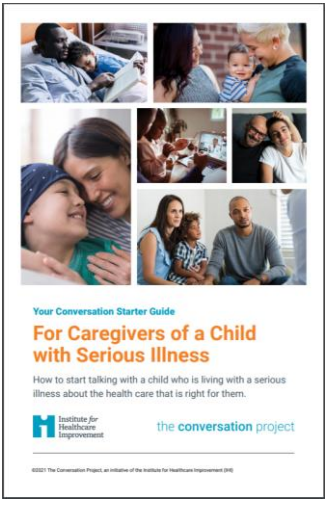
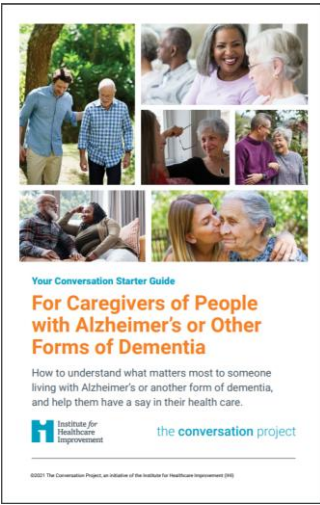
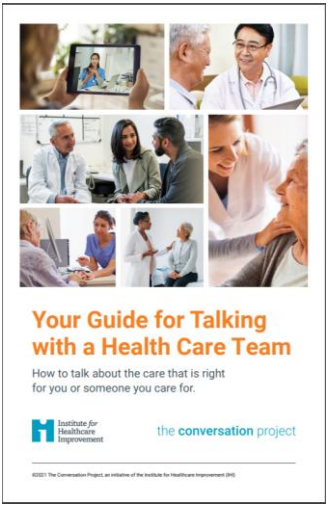
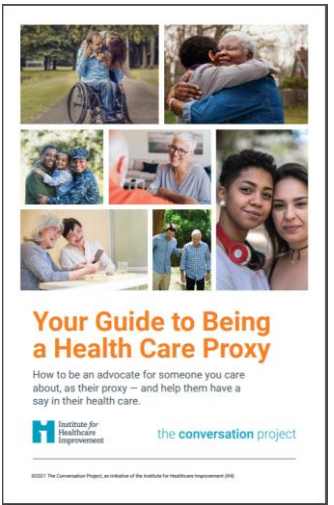
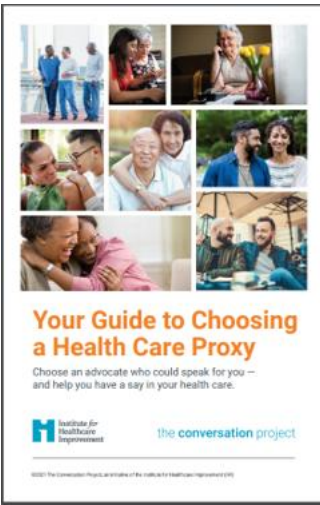
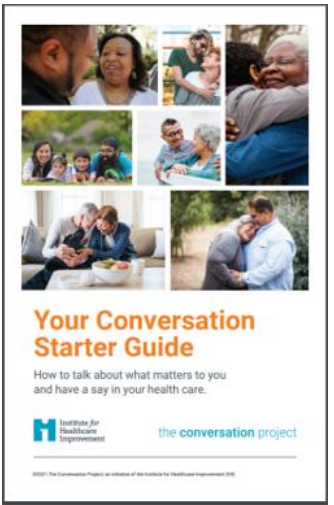
Being a Health Care Proxy

Talking with a Health Care Team

Caregivers of People with Alzheimer's or Other Forms of Dementia

Caregivers of a Child with Serious Illness

People with a Serious Illness



My Health Checklist



My Health Checklist

A guide to help you prepare for your medical appointment

Name

Date

Age-Friendly Health Systems
An initiative of The John A. Hartford Foundation and the Institute for Healthcare Improvement (IHI) in partnership with the American Hospital Association (AHA) and the Catholic Health Association of the United States (CHCA).

This work was made possible by The John A. Hartford Foundation.
© 2024 Institute for Healthcare Improvement. All rights reserved. Individuals may photocopy these materials for educational, not-for-profit uses, provided that the contents are not altered in any way and that proper attribution is given to IHI as the source of the content. These materials may not be reproduced for commercial, for-profit use in any form or by any means, or republished under any circumstances, without the written permission of the Institute for Healthcare Improvement.





This guide is designed to help you get ready for your medical appointment.

It's meant especially for older adults.

First, it will help you think about different aspects of your health and living well. Then it will help you identify the most important questions or concerns you want to talk about with your provider. A provider is a doctor, nurse practitioner, primary care practitioner (PCP), etc.

Being prepared for your appointment can help you get the care that's right for you. You are part of the team. You can have a say in your care.

This guide focuses on four areas that can help you think about your health.



What **Matters** to you in your life Medication you may take Your **Mind** and sense of well-being Your **Mobility**

The 4Ms

For each of the 4Ms, we'll ask you about your situation now, what's going well, and what could be better. Then you can write down any questions you have or things you want to share with your provider.

2 Age-Friendly Health Systems



Exemplify - taking this to your community

Live

- Local leaders promoting TCP (retirees!)
- Presentations (invited and hosted)
- Train the trainer

Work

- Health care organizations
- General employers – mailings, brown bag lunches, HR process

Pray

- Shared sermons and materials – guest preaching
- Hosted events at houses of worship
- Integration of TCP into pastoral care and seminary education
- Collaboration with regional interfaith organizations

Learn

- Medical and nursing school courses
- Undergraduate courses/lectures in ethics, bioethics, and humanities
- Faith-based educational institutions
- Health care systems partnering with local university/high schools
- OLLI courses

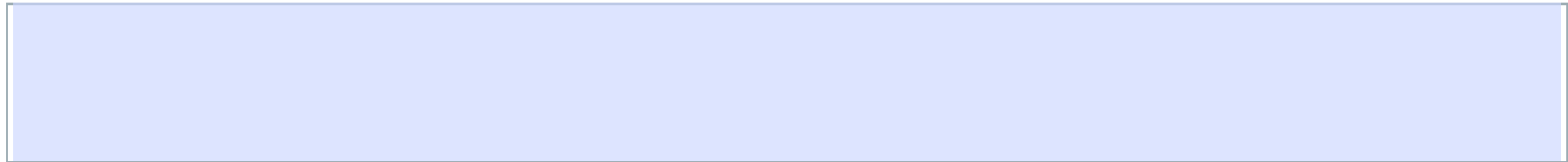


The Starter Guide: Preparation

STEP 1

Think About What Matters to You

- › Try finishing this sentence:
What matters to me through the end of my life is...



SOME IDEAS Being able to recognize my children; being independent;
being able to spend time with the ones I love

That's your "what matters to me" statement.

What matters to me...

“I want to say goodbye to everyone I love, have one last look at the ocean, listen to some 90’s music, and go.”

“Having my sheets untucked around my feet!”

“Peaceful, pain-free, with nothing left unsaid.”

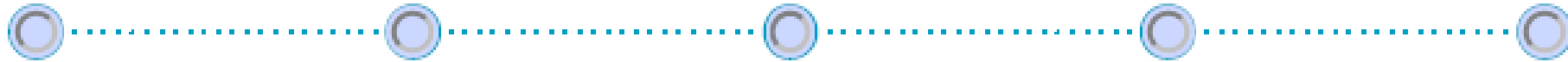
“In the hospital, with excellent nursing care.”



STEP 2

Plan Your Talk

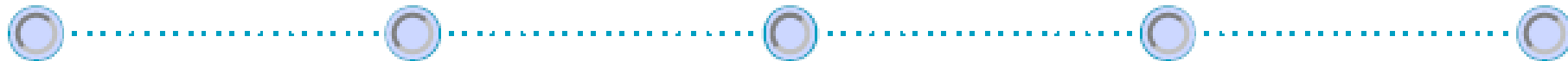
▶ **When there is a medical decision to be made, I would like...**



My health care team to do what they think is best

To have a say in every health care decision

▶ **What are your concerns about medical treatments?**



I worry that I won't get enough care

I worry that I'll get too much care



› **Who needs to know what matters to you in your health care?**

Check all that apply:

- | | |
|---|--|
| <input type="checkbox"/> Parent(s) | <input type="checkbox"/> Trusted friend(s) |
| <input type="checkbox"/> Spouse/partner(s) | <input type="checkbox"/> Doctor(s) |
| <input type="checkbox"/> Chosen family member(s) | <input type="checkbox"/> Nurse practitioner/nurse(s) |
| <input type="checkbox"/> Adult child/children | <input type="checkbox"/> Social worker |
| <input type="checkbox"/> Faith leader (minister, priest, rabbi, imam, etc.) | <input type="checkbox"/> Other: <input type="text"/> |

› **Where would you feel comfortable talking?**

- | | |
|---|--|
| <input type="checkbox"/> At the kitchen table | <input type="checkbox"/> Video chat or phone call |
| <input type="checkbox"/> At a favorite restaurant | <input type="checkbox"/> At my place of worship |
| <input type="checkbox"/> In the car | <input type="checkbox"/> Other: <input type="text"/> |
| <input type="checkbox"/> On a walk | |

› The Conversation Project uses the saying, “It always seems too soon, until it’s too late.”

When will you start this conversation?

When to have a conversation

Early

Coming of age – 18 & 21

Often

Before a medical crisis – 30, 40, 50, 60, 70

Major life event

College, marriage, children, divorce, Medicare, death in the family

Major trip

Newly diagnosed with a serious illness



How to start

“I need your help with something”

“Will you help me think about my future?”

“I was thinking about what happened to _____ and it made me realize _____.”

“Even though I’m OK right now, I’m worried that _____ and I want to be prepared.

Can we talk about some things that matter to me?”

“I heard about the Conversation Project and answered some of their questions about things that matter to me when it comes to my care through the end of life. I’d like to talk to you about it.”



Areas to watch for

The role someone wants to have

Autonomy

Type of care

Current answers

Home

“Whole enchiladas” and “plug pulling”

“If I can parent our children...”



The role others will play

Finding a proxy who will/can honor wishes

Solo agers

Telling more than one person

Avoiding family or caregiver “bullying”

How to bring it up

Ways that make someone comfortable –
pumpkin pie

Emails/family gatherings

Who brings it up

Where – park bench



How to help someone who may be uncomfortable

Help the person feel comfortable, both physically and emotionally

Focus on what is most important (in life) right now, not on future medical scenarios

Pick one question from our guides

Use current events or TV shows

Bring up stories from the past

Make it simple – Eeyore

Confirm who will make decisions

Keep an open mind

Offer to talk more than once

Walk the walk

the **conversation** project

“Sounds like you don’t want to talk about this right now. I’m going to respect that.”

“Most of all, I want you to know that I’m here for you and want to be sure your wishes are honored. If you’re up for it another time, I am really eager to understand your wishes. For example, you could send an email to me later, pick someone else to talk to, or bring a note to talk about with your doctor.”



Who benefits?

Clinicians

Patients and Caregivers

99% of adults 50+ say that in the event of a serious illness, it's important that **What Matters** be the primary consideration for their care. The John A. Hartford Foundation, November 2023

Clergy

the **conversation** project



Hope and miracles

“There's always hope...[T]he question is what we are hoping for?”

“Early on, we hope for a cure...[A]nd when that is impossible, we hope for as much good time as possible. And then, at a later point, we hope for relief from suffering. And then, in everyone's life, we reach a time when we are hoping for a death with dignity.”



Hope and miracles

“Part of doing everything for you is knowing what you’d want if there’s a time you can’t communicate with me – would you be willing to talk about that?”

- What are you fighting for?
- What does “doing everything” mean?
- What does a miracle look like to you?

“Tell me what this experience has been like for you? What was surgery like for you?”

Giving up → Letting go “Your father is a strong man. His body is struggling”



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

~ Dr. Atul Gawande



Messaging to remember

Talk up the benefits These services and care improve peoples' lives. Don't lead with dying

Present choices for every step At every stage of an illness, we have choices

Use stories Use positive and aspirational stories and don't bombard with statistics

Invite dialogue—and not just once The call to action is to talk with someone

Invoke a new team Patients, people who matter to them, health care providers, & community all have a role

Imagery matters Use positive and aspirational images without looking too “cheesy”
“We'll figure this out together”

Conversations clarify

Sent: Monday, March 29, 2021 9:39 AM

To: Info <info@IHI.org>

Subject: Thank you so much

I have elderly grandparents who live alone in another state, with nobody nearby to take care of them. I have suggested assisted living or having an aide come to their home for years but they always refuse. They have dementia and other health problems but have always been fiercely independent and mistrustful of others. I viewed your Conversation Project guides on my flight to Colorado and when I got here, I decided to change my usual approach to the issue. **I started asking questions instead of telling them how worried I was.** The questions I asked came straight out of your materials. Your guide was very helpful to start a 2 way conversation and I am so grateful for your initiative. Not only are they open to me being their healthcare proxy, they also have agreed to move to assisted living. I am so relieved, and so grateful for the information you made available at no cost to people. Thank you!



“The new hope is that we can change the culture to treat the patients as they wish to be treated rather than treating them because we can.”

-Billie Kester, Reid Hospital, Indiana, Conversation Ready Health Care Community Member



Leaving in action



Complete the Conversation Starter Guide

Pick your person, start the conversation with someone who may speak on your behalf

Document your proxy and wishes

Bring **What Matters to Me** concept back to your organization / community

Send a text to someone right now

Don't Panic – It's OK: A letter to my family

If you are faced with a decision that you're not ready for,

It's ok

I'll try to let you know what I would want for various circumstances,

But if you come to something we haven't anticipated,

It's ok

And if you come to a decision point and what you decide results in my death,

It's ok.

You don't need to worry that you've caused my death – you haven't –

I will die because of my illness or my body failing or whatever.

You don't need to feel responsible.

Forgiveness is not required,

But if you feel bad / responsible / guilty,

First of all don't and second of all,

You are loved and forgiven.

If you're faced with a snap decision, don't panic --

Choose comfort,

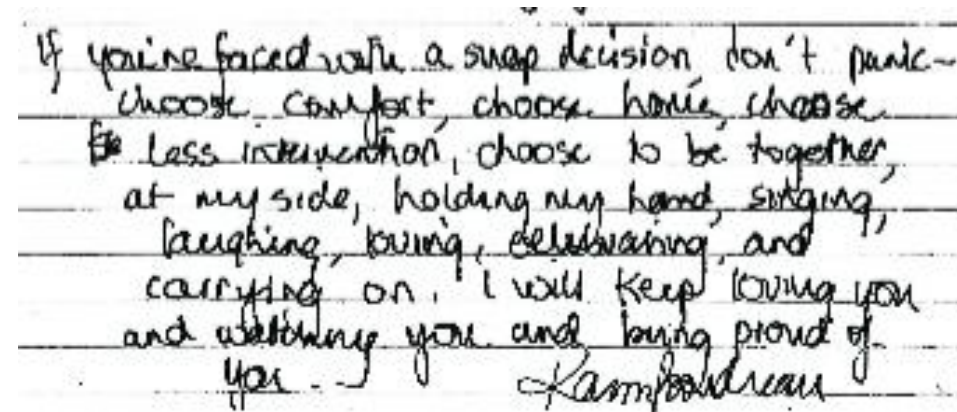
Choose home,

Choose less intervention,

Choose to be together, at my side, holding my hand,

Singing, laughing, loving, celebrating, and carrying on.

I will keep loving you and watching you and being proud of you.

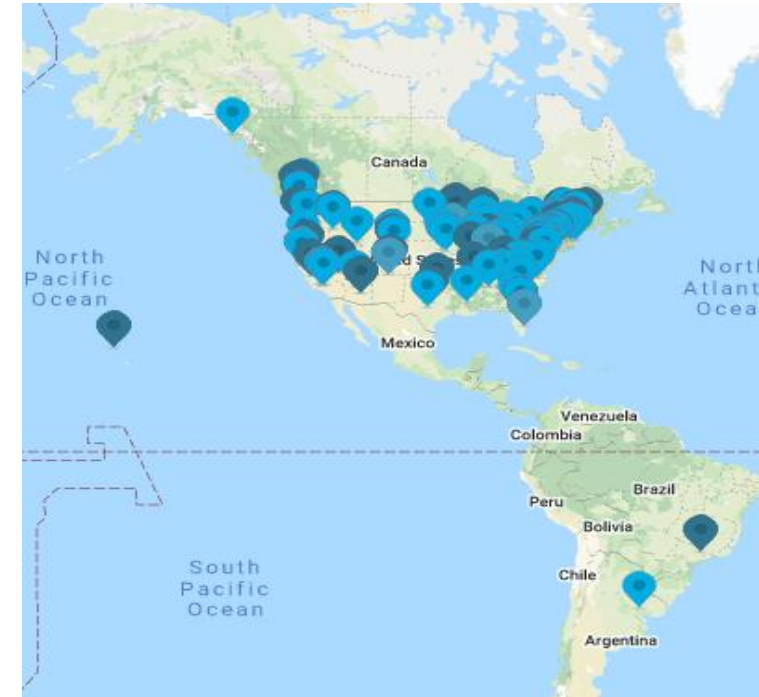


If you're faced with a snap decision don't panic -
choose comfort, choose home, choose
less intervention, choose to be together,
at my side, holding my hand, singing,
laughing, loving, celebrating, and
carrying on. I will keep loving you
and watching you and being proud of
you. - Kamryn

Ways to engage with TCP's network

Share and connect with each other
Community Champions Facebook
discussion group
Champions Map

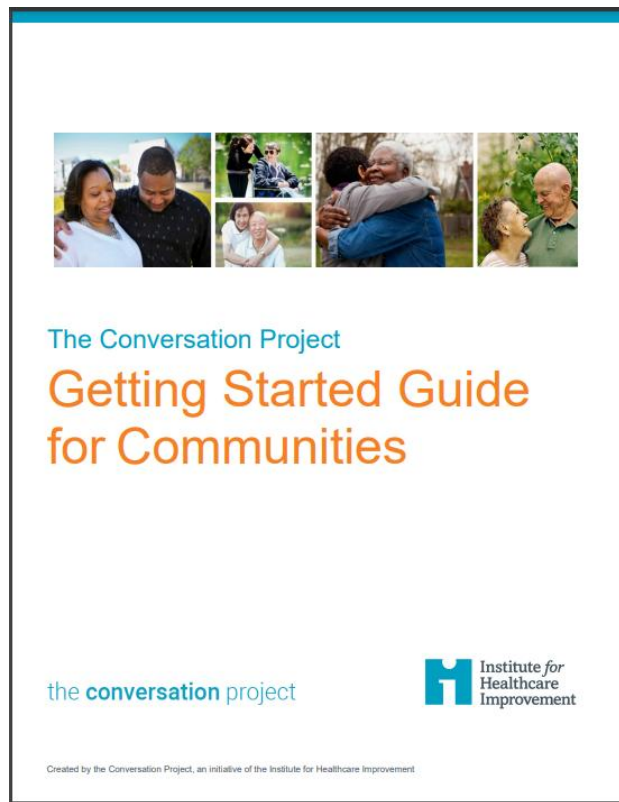
Tweet us, tag us on social media
Facebook: @TheConversationProject
Instagram: @convoproject



theconversationproject.org/get-involved



Ways we support improvement/spread



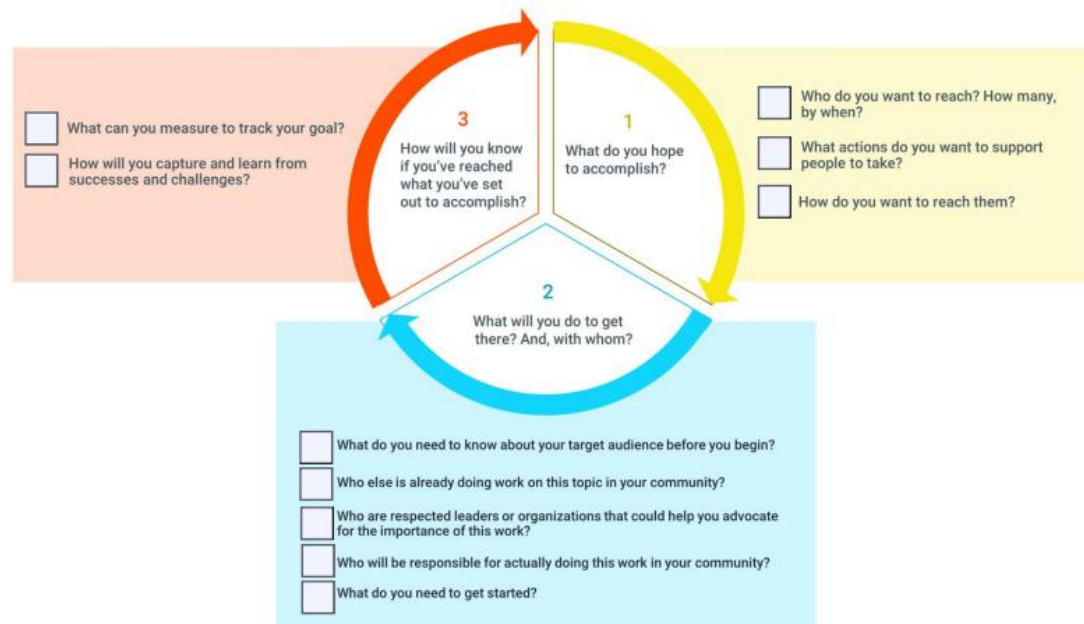
In this guide

Step 1: Think About It	2
Step 2: Plan Your Strategy	4
Step 3: Start/Take Action	24
Step 4: Keep Going	25
Appendix: Planning Tools and Templates	26

the **conversation** project

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!



<https://theconversationproject.org/wp-content/uploads/2021/02/StarterGuideforCommunities.pdf>



Questions?

Kate DeBartolo

kdebartolo@ihi.org

Patty Webster

pwebster@ihi.org

theconversationproject.org

the **conversation** project

