The Conversation Project: Virtual Speaker Training

September 18, 2019

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Zoom Quick Reference

- Welcome to today’s session!
- Click the *Participants* and *Chat* buttons
- Please Chat to “Everyone” for questions
- For technology issues only, please Chat to “Host”
- *Raise hand* if you would like to speak your question
Ice Breaker Question

Type into the chat box your response to the following question:

How did you learn about this call?
(TCP newsletter, web site, word of mouth, etc.)

Make sure you send your message to “Everyone.”
In chat: Where are you located on the map?
Speaker Training Agenda

- Introduce you to resources
- Run through slides
- Get your feedback and questions
- What else?
What We’re Seeing

- **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
What We’re Seeing

From January – December 2018:

• >3,800 events in almost all 50 states and globally
• > 85,000 people reached in-person

Events: BIG and small (no one size fits all!)
• ~80% of above events had less than 25 people

* From TCP’s quarterly community activity survey
Planning for Your Event

- Community Getting Started Guide
  - Audience + community partners
- Coaching the Conversation Guide
- Presentation Checklist
- Setting up the space
  - Printed materials and presentation
  - AV and evaluation
- Have the conversation yourself!
- What are we missing?

the conversation project
Timelines

- 15-30 minutes – introduce TCP and resources available

- 60 - 90 minutes – walk people through the Conversation Starter Kit

- 90+ minutes – training for others, give examples and time for planning
Tips for Hosting Conversation Groups

- Do this yourself ahead of time. Share your story
- Reserve a quiet, private room
  - Groups work best at round tables of 6-8
  - Willing volunteers
  - Separate family members!
  - Group patient visits are a possibility
- Remember your ground rules
  - No strong political or religious views in groups
- Before you start, ask “what do you hope to learn?”
- Decide whether to address state-specific questions
- Consider a second session for review or deeper dive
Standard Presentation
My Story

Feel free to share your organization’s or your personal story surrounding end-of-life care and why you are leading today’s session.

Add a photo for visual interest
Introductions & Stories

- Your Preferred Name
- Your Organization
- Share a time when you experienced a “good” or “hard” death - either personally or professionally

X minutes
A public engagement campaign dedicated to assure that everyone’s wishes for end-of-life care are expressed and respected.
Diane Sawyer Video

https://youtu.be/J1r0Xbh0UVo

*Found on TCP website: Home page, Top Tools & Get Involved: Community Resources page*
70% WANT TO DIE AT HOME.
70% ACTUALLY DIE IN A HEALTHCARE FACILITY
80% WANT TO TALK TO THEIR DOCTORS
18% have had a conversation with their doctors.
HAVE HAD A CONVERSATION WITH THEIR DOCTORS
HAVE HAD A CONVERSATION WITH THEIR DOCTORS
THINK IT’S IMPORTANT TO HAVE END-OF-LIFE CONVERSATIONS
32%

HAVE ACTUALLY DONE SO
FEEL RELIEF FROM HAVING THE CONVERSATION
“Our ultimate goal, after all, is not a good death but a good life to the very end.”

~ Atul Gawande
What Matters TO Me?

As Well As

What’s the Matter with Me?

Public Awareness
Community Engagement

Health Systems Transformation
The Conversation Continuum

End of Life Wishes

Healthy

Living with Chronic Illness

Approaching End of Life

Expressed

Spoken

Documented

Respected

Accessed

Implemented
Our Website

The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care.

Start your conversation today.

Free Conversation Starter Kit »
Our Tools

- Conversation Starter Kit (translations, audio version)
- Starter Kit for Families and Loved Ones of People with Alzheimer’s Disease or Other Forms of Dementia
- Who will speak for you? How to choose and be a health care proxy/agent
- How to Talk to Your Doctor Starter Kit
- Pediatric Starter Kit for Parents of Seriously Ill Children
Pause

- Any questions?
The Conversation Starts with You
Setting the Table

- **How it works**
  - Give current answers!
  - Personal, table, report out

- **Ground rules**

  **Example Ground Rules**
  - Privacy. Please do not share others’ personal stories.
  - Listen quietly. This is not a time to offer advice or solve problems.
  - Turn off cell phones.
  - Everyone is here as a person, not a “role” or “title.”
  - What else is important to people in the group?
Step 2  Get Set

What’s most important to you as you think about how you want to live at the end of your life? What do you value most? Thinking about this will help you get ready to have the conversation.

❓ Now finish this sentence: What matters to me at the end of life is...
(For example, being able to recognize my children; being in the hospital with excellent nursing care; being able to say goodbye to the ones I love.)
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.”
peaceful

with God

joyful

quick

calm

quiet

tranquil

natural

with family and friends

surrounded by friends and family

dignified

celebrated

loving

musical

no regrets

supported

uncomplicated

meaningful

fulfilling

memories

happy

laughter

easy

graceful

filled with music

celebration

at home

celebrated

full of love

a good story

easy for my family

comfortable

painless
How long do you want to receive medical care?

- 1
- 2
- 3
- 4
- 5

Indefinitely, no matter how uncomfortable treatments are

Quality of life is more important to me than quantity

What are your concerns about treatment?

- 1
- 2
- 3
- 4
- 5

I’m worried that I won’t get enough care

I’m worried that I’ll get overly aggressive care
MARK ALL THAT APPLY:

WHO do you want to talk to?

☐ Mom
☐ Dad
☐ Child/Children
☐ Partner/Spouse
☐ Sister/Brother
☐ Faith leader (Minister, Priest, Rabbi, Imam, etc.)
☐ Friend
☐ Doctor
☐ Caregiver
☐ Other: 

WHEN would be a good time to talk?

☐ The next holiday
☐ Before my child goes to college
☐ Before my next trip
☐ Before I get sick again
☐ Before the baby arrives
☐ The next time I visit my parents/adult children
☐ At the next family gathering
☐ Other: 

WHERE would you feel comfortable talking?

☐ At the kitchen table
☐ At a favorite restaurant
☐ In the car
☐ On a walk
☐ Sitting in a park
☐ At my place of worship
☐ Other: 
When to Have “The 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**
What Did You Learn?

- What plans did you make?
- Questions
- Concerns
- Surprises
- Trends
How to Start

Here are some ways you could break the ice:

“I need your help with something.”

“Remember how someone in the family died—was it a ‘good’ death or a ‘hard’ death? How will yours be different?”

“I was thinking about what happened to [insert person], and it made me realize...”

“Even though I’m okay right now, I’m worried that [fill in concern], and I want to be prepared.”

“I need to think about the future. Will you help me?”

“I just answered some questions about how I want the end of my life to be. I want you to see my answers. And I’m wondering what your answers would be.”
Practice Makes Perfect Video

https://youtu.be/pyMXtVprN74
Who will speak for you? Proxy Video

https://www.youtube.com/watch?v=iTxv-20ULwQ&t=2s
Optional: Additional Topics

- Advance Care Planning (ACP)
- Advance Directive (AD)
- Health Care Proxy/Agent/Durable Power of Attorney
- Living Will
- MOLST/POLST
Tips from the Field

- Give current answers
- Home is not always feasible. Probe for what’s important.
- Ask if this person will/can honor your wishes
- Tell more than one person
- Invite others to share their wishes with you
- Be wary of “whole enchiladas” and “plug pulling”
- Beware of family or caregiver “bullying”
- The opportunity to strengthen relationships – these are very loving conversations and don’t have to be serious
Leaving in Action

- Complete the Starter Kit
- Have the Conversation with those that matter most to you – those that may speak on your behalf if you cannot
- Appoint a Healthcare Proxy/Agent
- Bring **What Matters to Me** concept back to your organization / community
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.
Questions?

<Your name and organization>
<Your email address/phone number>

www.theconversationproject.org
A Soul Doctor and a Jazz Singer

Lachlan Forrow M.D.
Director of Palliative Care Programs at Beth Deaconess Medical Center
Additional Thoughts
Organizing Tips

- Support (space/materials/promotion/catering)
- Recruitment (email, social media, flyers)
- Understand your audience
  - Are they expecting this topic or not? How will that affect your agenda?
- Medical and legal expertise
- Cultural considerations
- Test with a small group first
Set an Aim

- A general statement — something like, “We will increase the number of people having The Conversation” — isn’t good enough.

- The **aim statement** should be time-specific and measurable, stating exactly: “How good?” “By when?” and “For whom?”
Who do you want to reach? And by when?

- Who are you interested in engaging in your community?
- For example, are you trying to reach:
  - Your employees?
  - Everyone over age 75 in your community?
  - Staff working in the local retirement communities?
  - Everyone over age 18 in your county?
  - A study group within your faith community?
What actions do you want to support people to take?

- What do you want to support people to ultimately do? Know this early on so you can make the “ask” clear and concise.

- For example, do you want people to:
  - Have the conversation with a loved one?
  - Have the conversation AND talk to their doctor?
  - Have the conversation AND talk to their doctor AND designate a health care proxy AND prepare an advance directive?
Establish Measures

- You need feedback to know if a specific change actually leads to an improvement, and quantitative measures can often provide the best feedback.

Example Measures

- Number of people who attend a workshop on The Conversation Project
- Number of people who receive the Conversation Starter Kit
Evaluations

- End-of-event forms (rapid feedback)
- Commitment cards (collecting info)
- Follow up survey
  - Capture email addresses, follow-up at next event

Available on our Get Involved Page: Community Resources
  - [https://theconversationproject.org/resources/community](https://theconversationproject.org/resources/community)
  - “Evaluate” Category
TCP Get Involved Page: (Free!) Community Engagement Resources

Get started
- Community organizing guide and resources
- Case studies
- Template for tracking progress, suggested metrics

Promote your message
- Sample promotional materials (PSAs, ads)
- Social media toolkit

Host an event (planning, publicizing, facilitating, evaluating)
- Invitations and agendas for events
- Press release and flyer templates
- Slide deck, videos, materials to bring
- Movie screening guides

https://theconversationproject.org/get-involved
Other resources / news

- Community Champions Map!
  https://theconversationproject.org/get-involved

- NHDD – April 16th
  - www.nhdd.org

- Conversation Sabbath
Upcoming Community Calls

The next Conversation Project Community Call will take place on:

**Wednesday, October 16th, 3:00-4:00 PM EDT**

<table>
<thead>
<tr>
<th>Date and Time</th>
<th>Topic</th>
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<tbody>
<tr>
<td>Wednesday, October 16th, 3:00 – 4:00 pm ET</td>
<td>Community 201: Designing for Sustainability</td>
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<tr>
<td>Wednesday, November 20th, 3:00 – 4:00 pm ET</td>
<td>Special Interest: Solo Agers/Elder Orphans</td>
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Stay Connected!

- Twitter: @convoproject
- Facebook: The Conversation Project
- Instagram: convoproject
- Newsletter:
  - General Newsletter
  - Community Engagement Newsletter
We want your feedback!

After this call you will be redirected to a Survey Monkey form

Please take a few moments to answer the following questions:

- How useful was this session on a scale from 1-5?
- Given today’s topic, what would you like to learn more about?
- Any other comments on today's session?
Questions?
Thanks and appreciation

The John A. Hartford Foundation
Dedicated to Improving the Care of Older Adults