The Conversation Project: Virtual Speaker Training

September 19, 2018

Patty Webster
Naomi Fedna
Welcome to today’s session!

Please use Chat to “All Participants” for questions.

For technology issues only, please Chat to “Host”

WebEx Technical Support: 866-569-3239

Dial-in Info: Audio / Audio Conference (in menu)
Ice Breaker Question

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

*How did you learn about this call?*

Make sure you send your message to “All Participants.”
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 – June 2018:

• >1,900 events in almost all 50 states and globally
• > 50,000 people reached in-person

Events: BIG and small (no one size fits all!)

• ~75% 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?
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 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
70% WANT TO DIE AT HOME.
70% ACTUALLY DIE IN A HEALTHCARE FACILITY
WANT TO TALK TO THEIR DOCTORS
HAVE HAD A CONVERSATION WITH THEIR DOCTORS
HAVE HAD A CONVERSATION WITH THEIR DOCTORS
92%

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 available)
- Starter Kit for Families and Loved Ones of People with Alzheimer’s Disease or Other Forms of Dementia
- How to Choose/Be a Health Care Proxy
- How to Talk to Your Doctor
- 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.”
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 [ ], and it made me realize…”

“Even though I’m okay right now, I’m worried that [ ], 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
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 a Loved One
- Appoint a Healthcare Proxy/Agent
- Bring **What Matters to Me** concept back to your organization / community
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
- “Evaluate” Category
Get Involved Page: Community Resources

- Get started
  - Community organizing guide and resources (identifying partners and sample work plans)
  - 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
  - Evaluation forms

- Bonus content
Other resources

- Community Champions Map!
- Blogs/stories:
  - e.g. Tips from the Field: Outreach tactic blog
# Upcoming Community Calls

The next Conversation Project Community Call will take place on:

**Wednesday, Oct 17\textsuperscript{th}, 3:00-4:00 pm ET**

<table>
<thead>
<tr>
<th>Date and Time</th>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wednesday, Oct 17\textsuperscript{th}, 3:00 – 4:00 pm ET</td>
<td>Seasoned: Including Alzheimer’s-specific Programming Into Your Work</td>
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<tr>
<td>Wednesday, Nov 14\textsuperscript{th}, 3:00 – 4:30 pm ET</td>
<td>Special interest: Ensuring equity, reaching diverse communities</td>
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<tr>
<td>Wednesday, Dec 19\textsuperscript{th}, 3:00 – 4:00 pm ET</td>
<td>Community Planning 101</td>
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[Image]
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?