

The Conversation Project: Virtual Speaker Training

September 18, 2019



**Patty Webster
Karen Barnett**

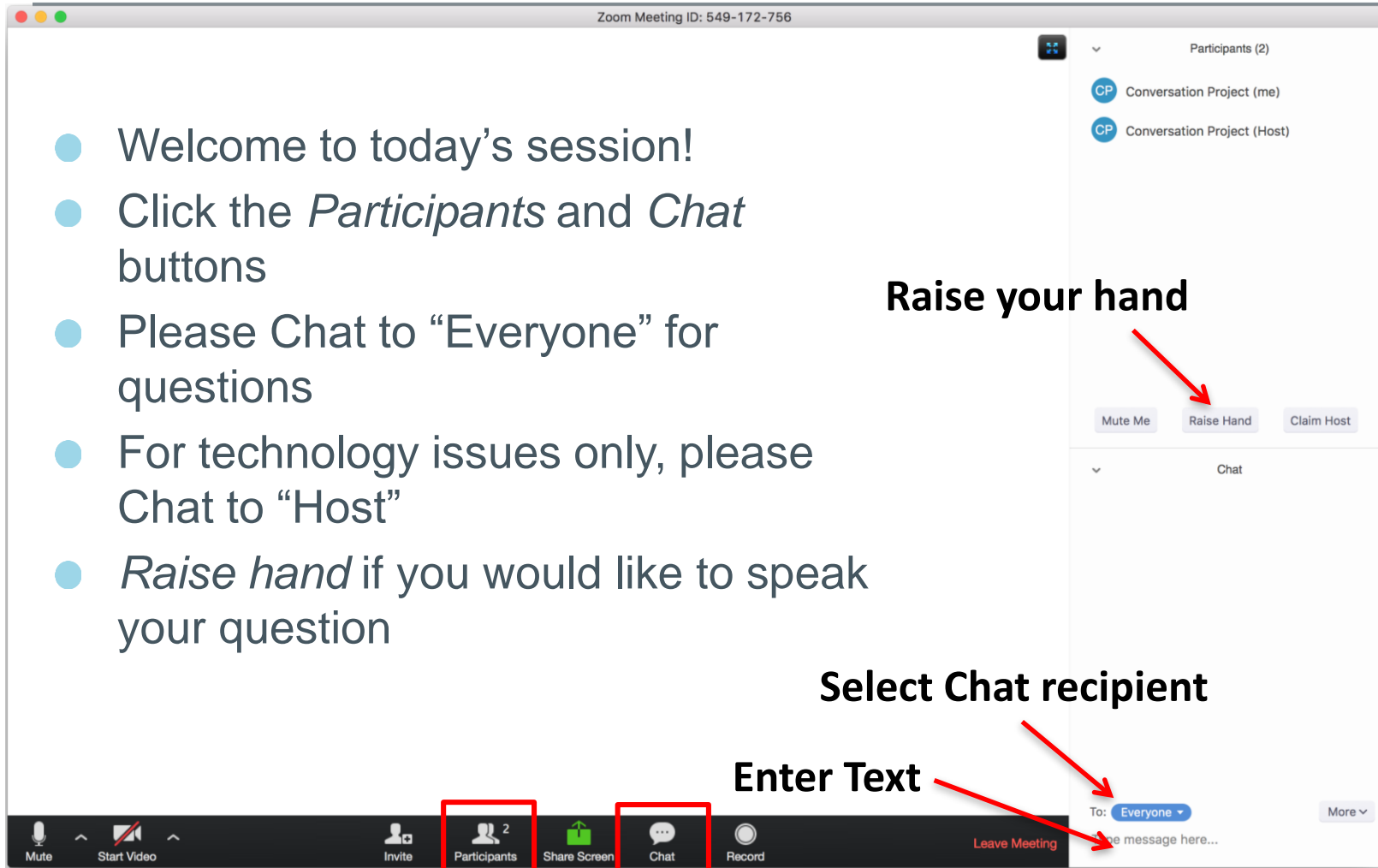
Zoom Quick Reference

- 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

Raise your hand

Select Chat recipient

Enter Text



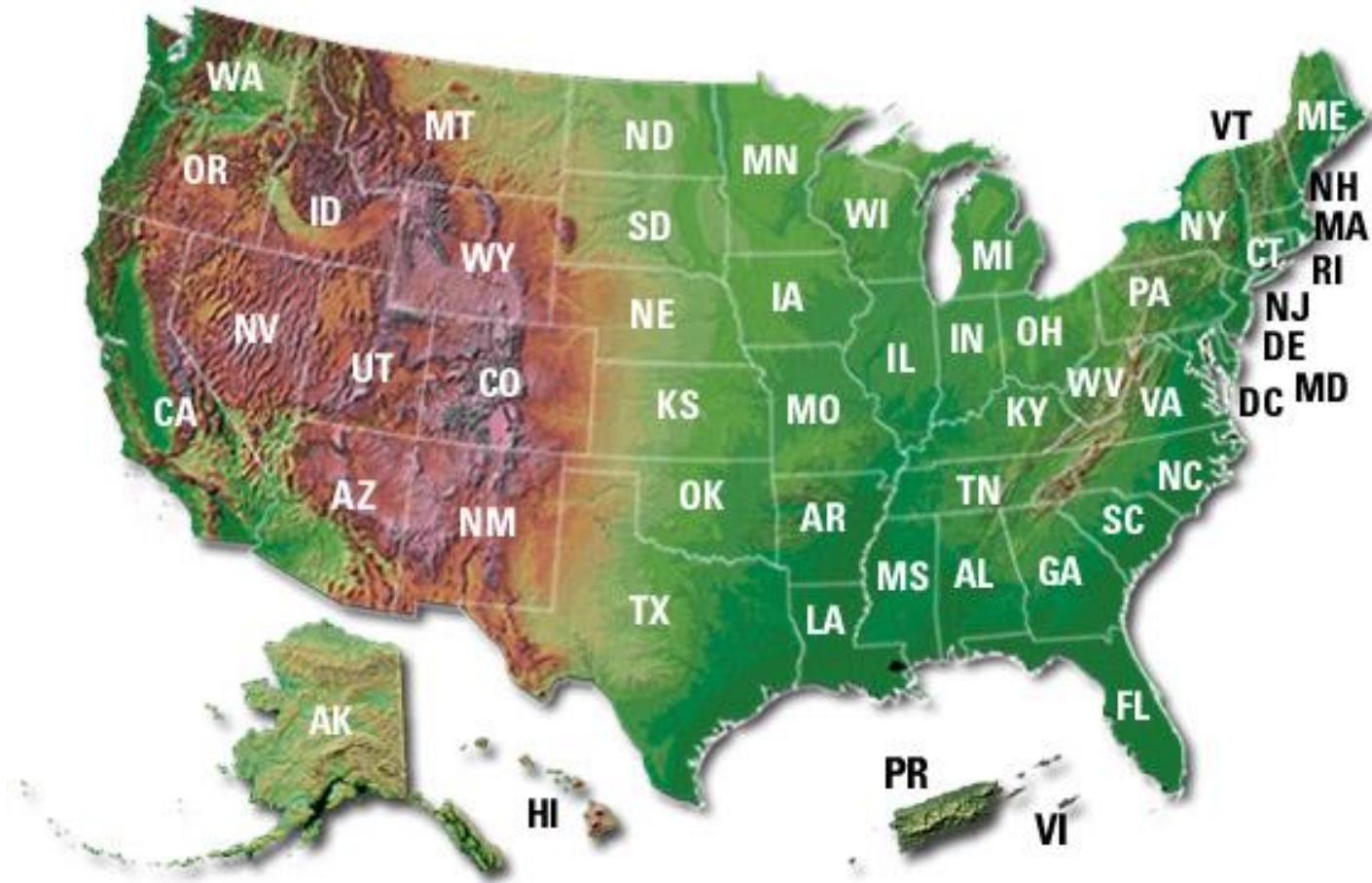
Ice Breaker Question

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

7

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?

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.

the conversation project

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**



17%



**HAVE HAD A CONVERSATION WITH
THEIR DOCTORS**



7%



**HAVE HAD A CONVERSATION WITH
THEIR DOCTORS**

92%

**THINK IT'S IMPORTANT
TO HAVE END-OF-LIFE
CONVERSATIONS**

3 2 %

HAVE ACTUALLY DONE SO

5 3 %

**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?

Public Awareness
Community Engagement

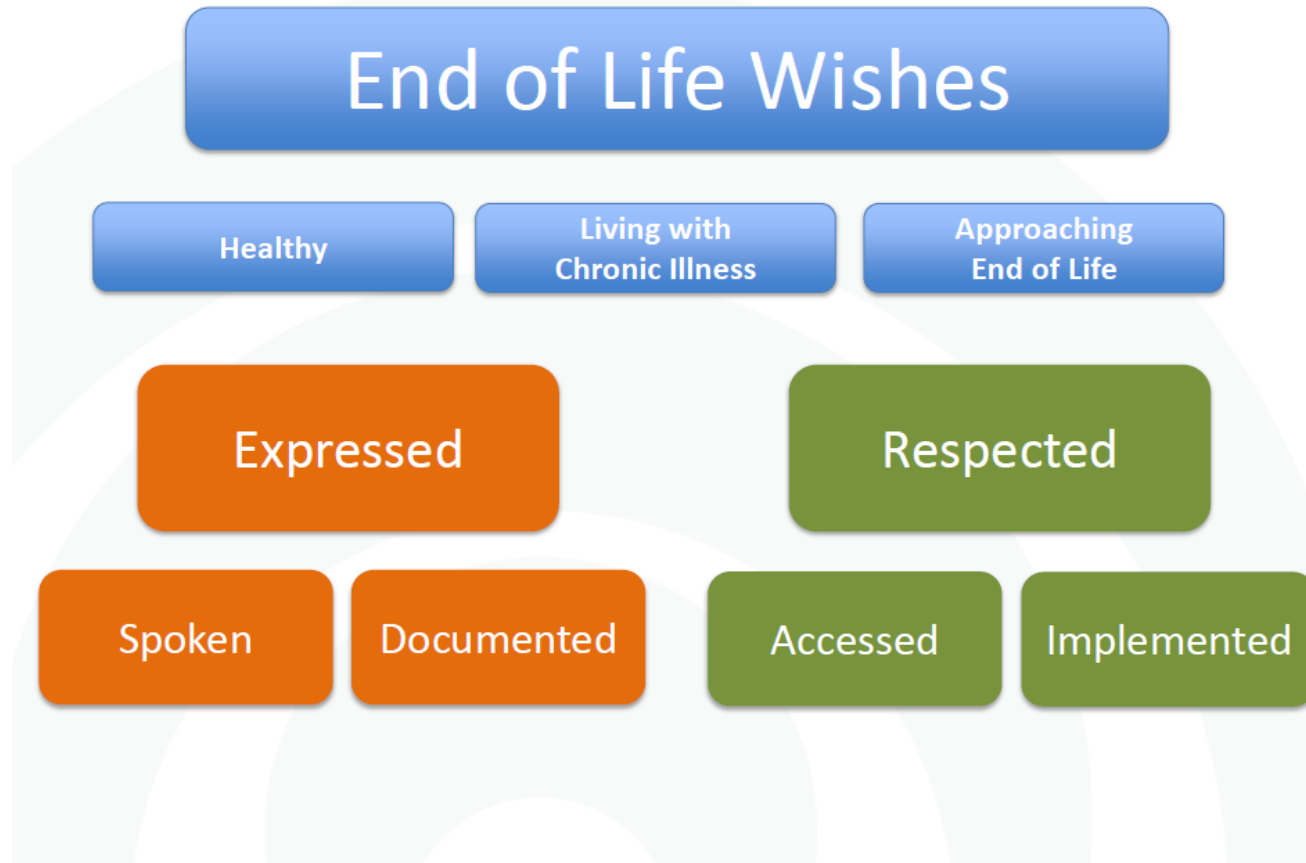
As Well As

Health Systems
Transformation

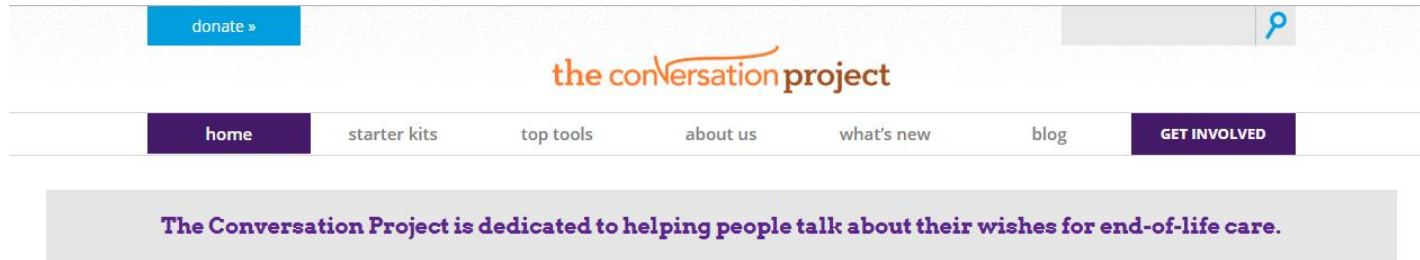
What's the
Matter
with Me?



The Conversation Continuum



Our Website

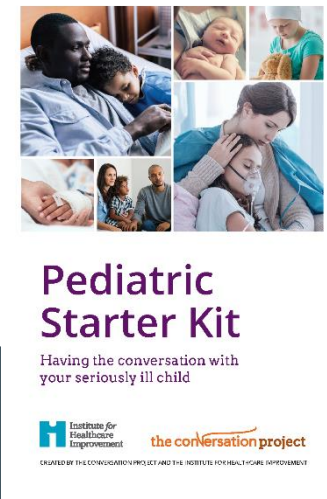
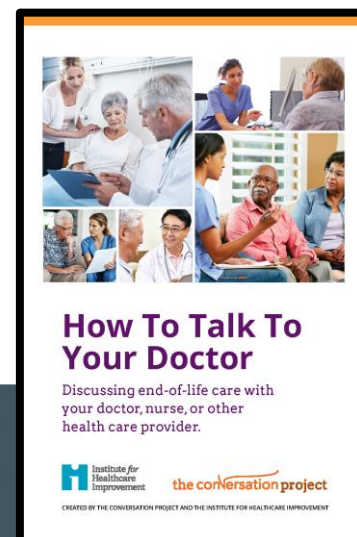
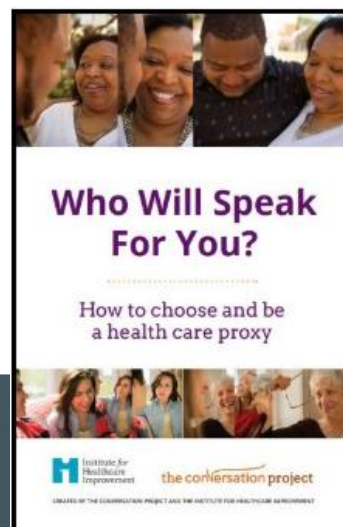
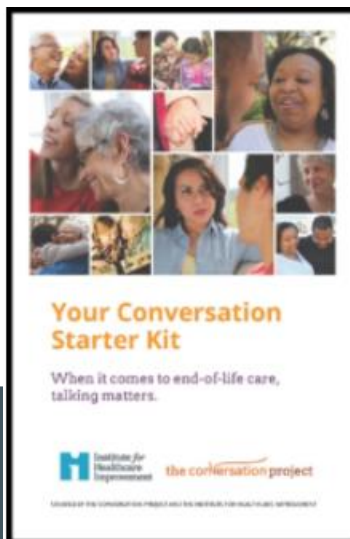


Start your conversation today.

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.”*



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?

- | | |
|---|---|
| <input type="checkbox"/> Mom | <input type="checkbox"/> Faith leader (Minister, Priest, Rabbi, Imam, etc.) |
| <input type="checkbox"/> Dad | <input type="checkbox"/> Friend |
| <input type="checkbox"/> Child/Children | <input type="checkbox"/> Doctor |
| <input type="checkbox"/> Partner/Spouse | <input type="checkbox"/> Caregiver |
| <input type="checkbox"/> Sister/Brother | <input type="checkbox"/> Other: <input type="text"/> |

? WHEN would be a good time to talk?

- | | |
|--|---|
| <input type="checkbox"/> The next holiday | <input type="checkbox"/> Before the baby arrives |
| <input type="checkbox"/> Before my child goes to college | <input type="checkbox"/> The next time I visit my parents/ adult children |
| <input type="checkbox"/> Before my next trip | <input type="checkbox"/> At the next family gathering |
| <input type="checkbox"/> Before I get sick again | <input type="checkbox"/> Other: <input type="text"/> |

? WHERE would you feel comfortable talking?

- | | |
|---|--|
| <input type="checkbox"/> At the kitchen table | <input type="checkbox"/> Sitting in a park |
| <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 | |



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>



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,

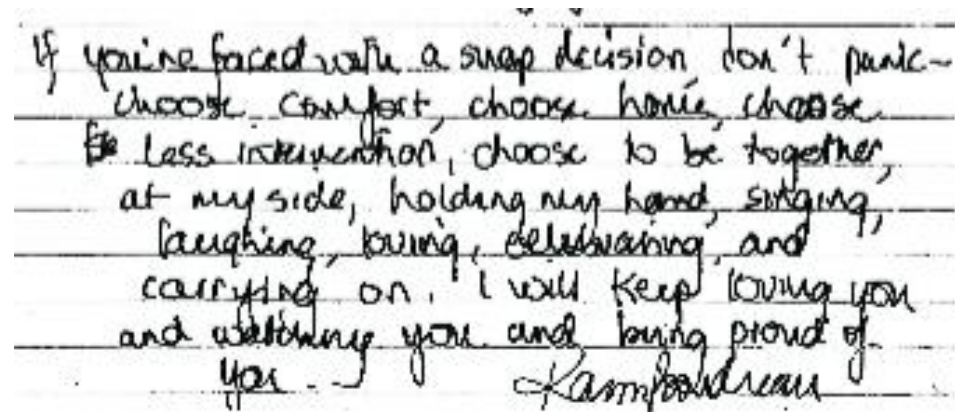
Choose home,

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.



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

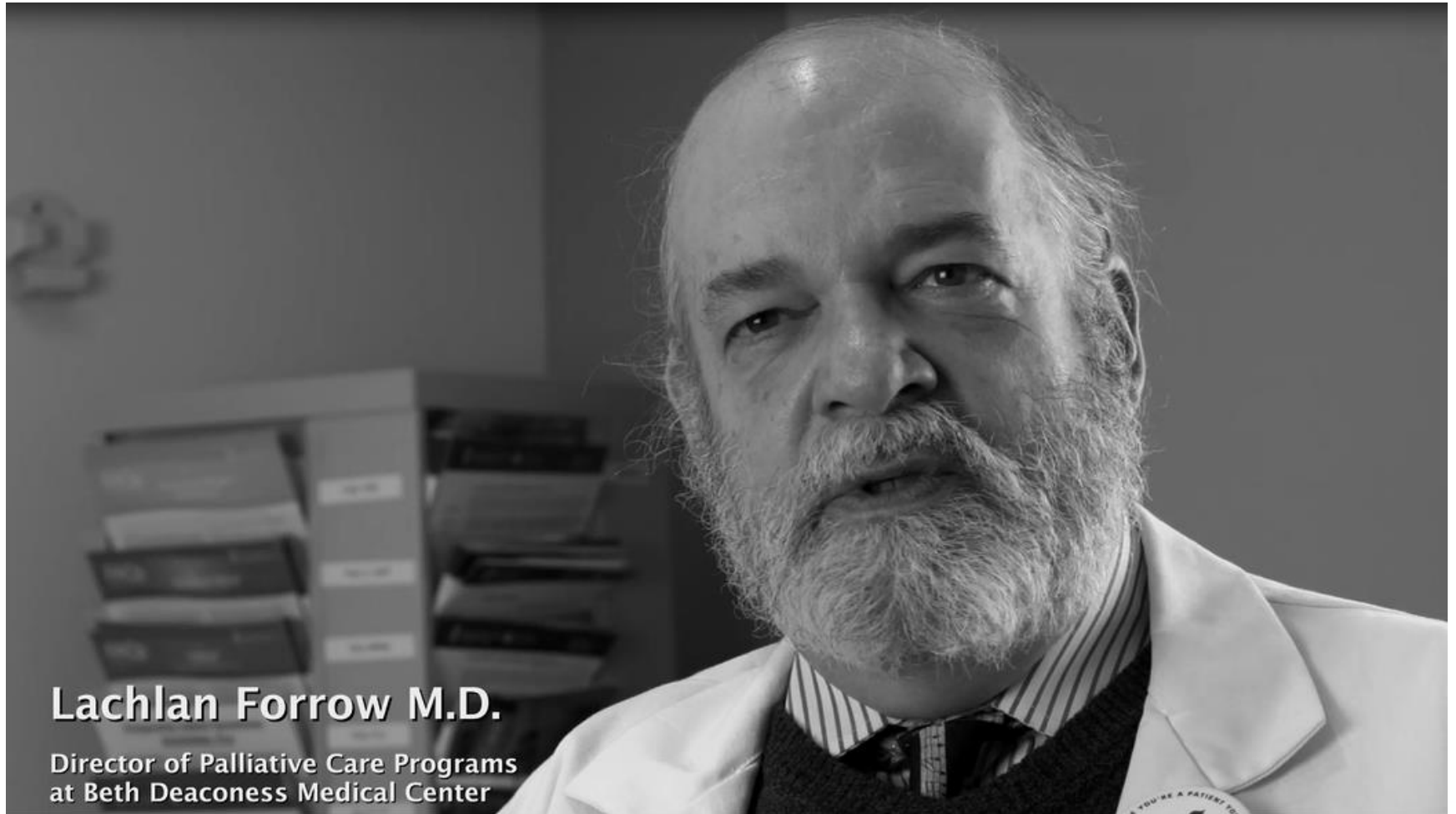
Questions?

<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?

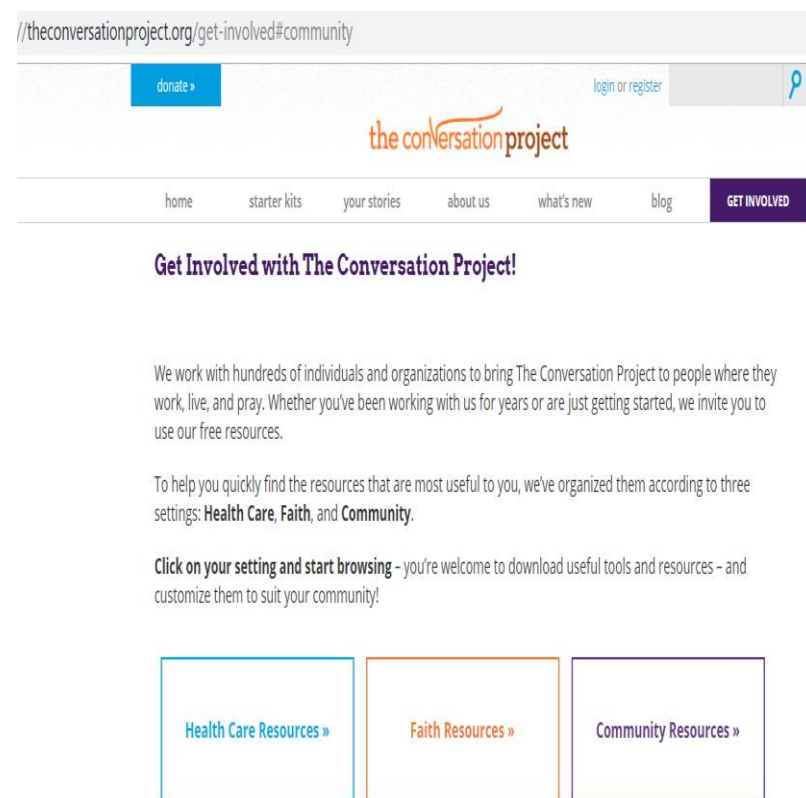
Establish Measures

- 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

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

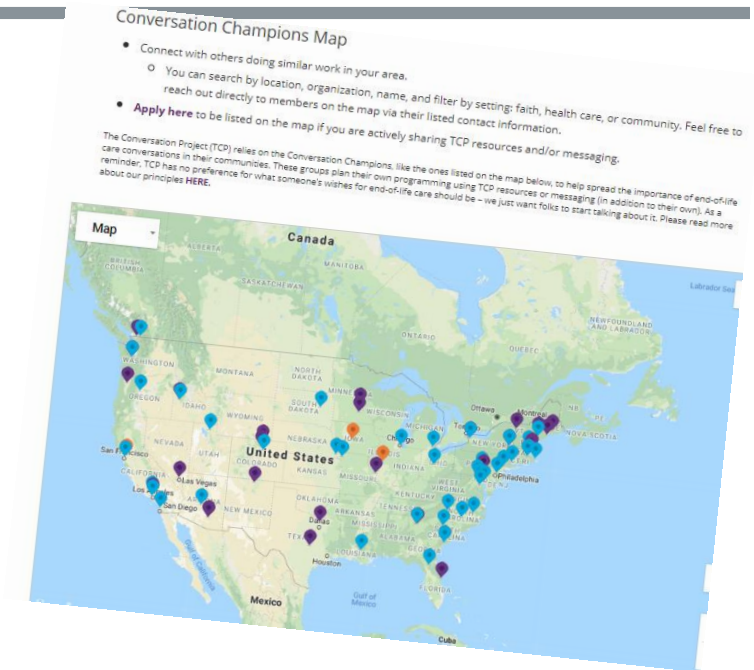
– www.nhdd.org

- Conversation Sabbath

conversation sabbath

Oct. 25 – Nov. 3 | #ConvoSabbath

the conversation project



Upcoming Community Calls

The next Conversation Project Community Call will take place on:

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

Date and Time	Topic
Wednesday, October 16 th , 3:00 – 4:00 pm ET	Community 201: Designing for Sustainability
Wednesday, November 20 th , 3:00 – 4:00 pm ET	Special Interest: Solo Agers/Elder Orphans

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

