

The Conversation Project: Virtual Speaker Training

September 19, 2018



**Patty Webster
Naomi Fedna**

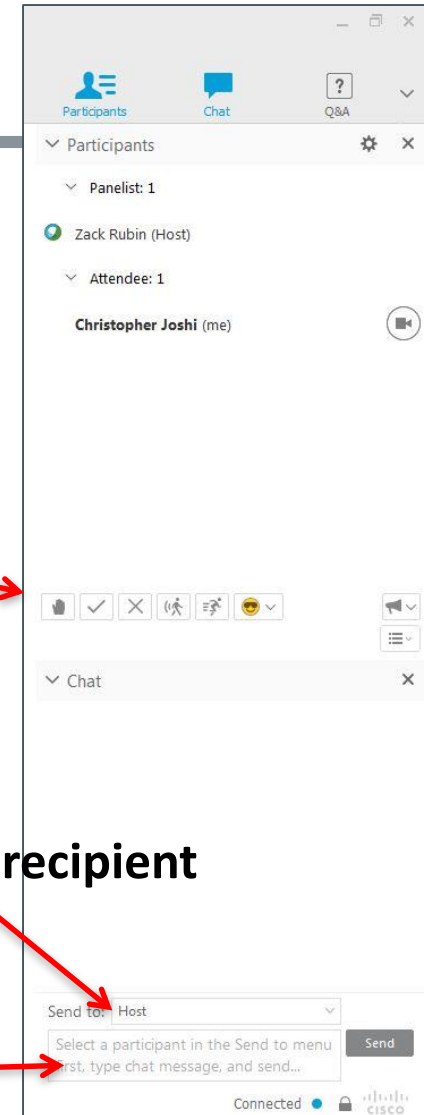
WebEx Quick Reference

- 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)

Raise your hand

Select Chat recipient

Enter Text



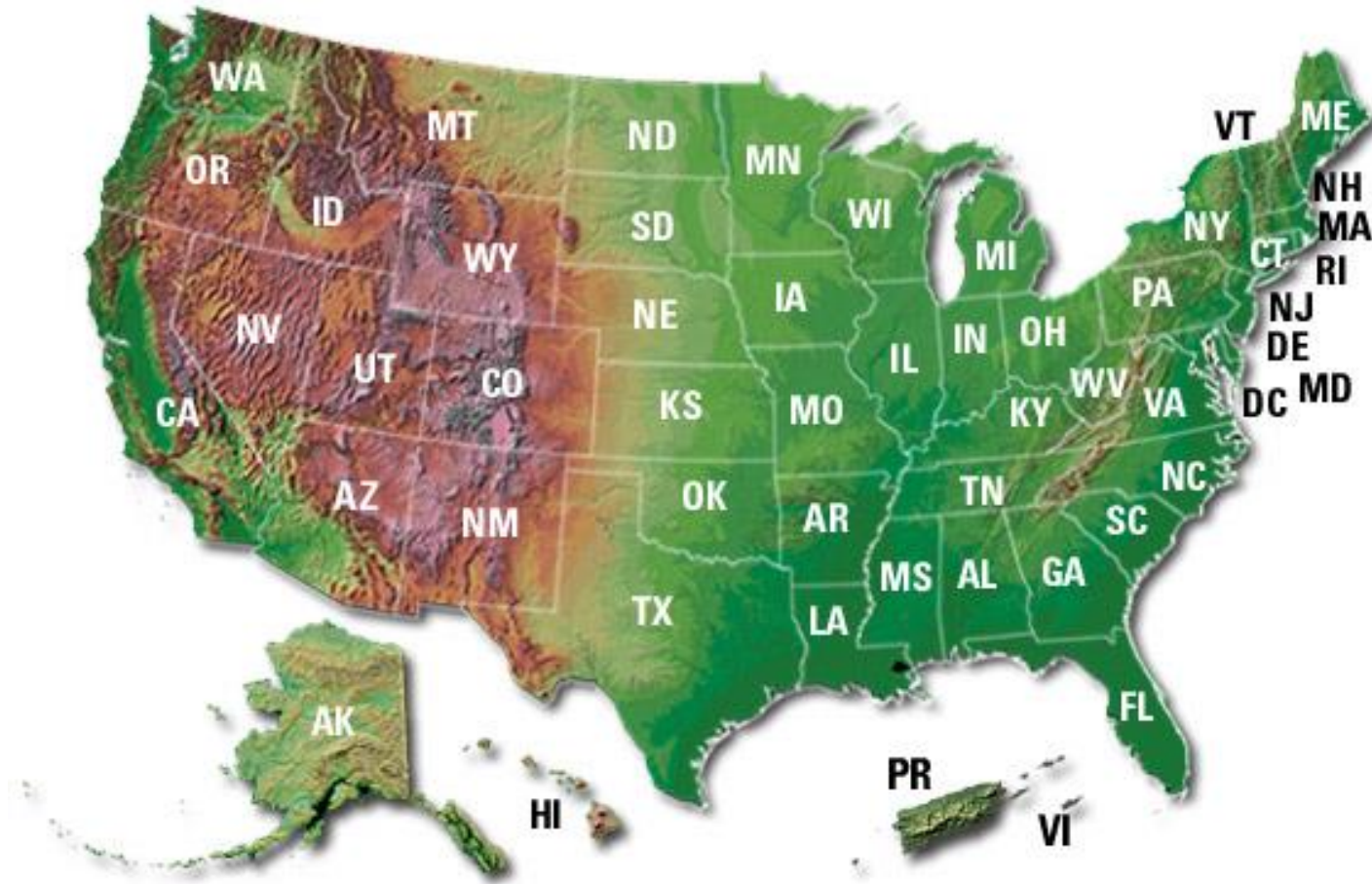
Ice Breaker Question

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

How did you learn about this call?

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

7

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.

the conversation project

Diane Sawyer Video

- <https://youtu.be/J1r0Xbh0UVo>

70%



WANT TO DIE AT HOME.

70%



**ACTUALLY DIE IN A
HEALTHCARE FACILITY**

80%



WANT TO TALK TO THEIR DOCTORS



17%



**HAVE HAD A CONVERSATION WITH
THEIR DOCTORS**



7%



**HAVE HAD A CONVERSATION WITH
THEIR DOCTORS**

9 2 %

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

3 2 %

HAVE ACTUALLY DONE SO

53%

**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

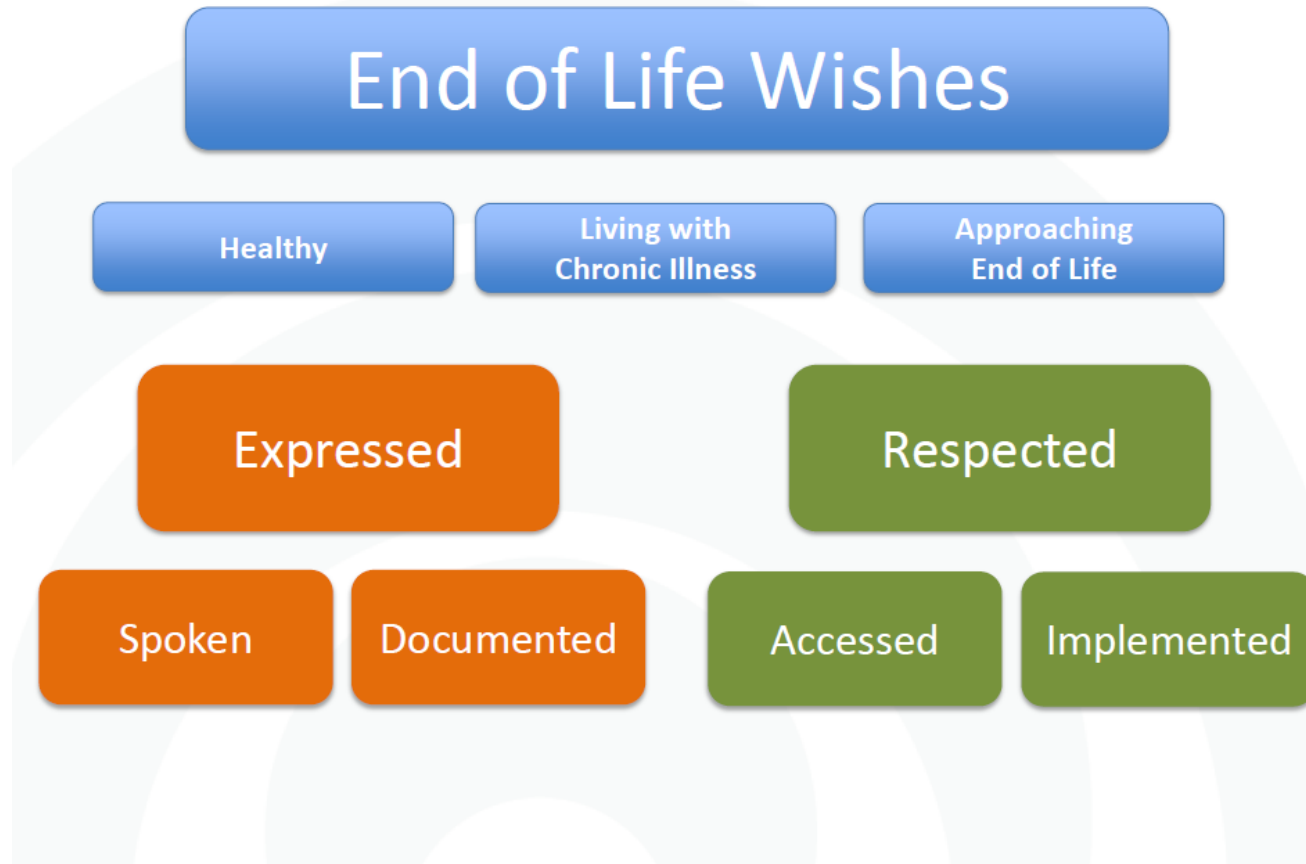
What's the
Matter
with Me?

Public Awareness
Community Engagement

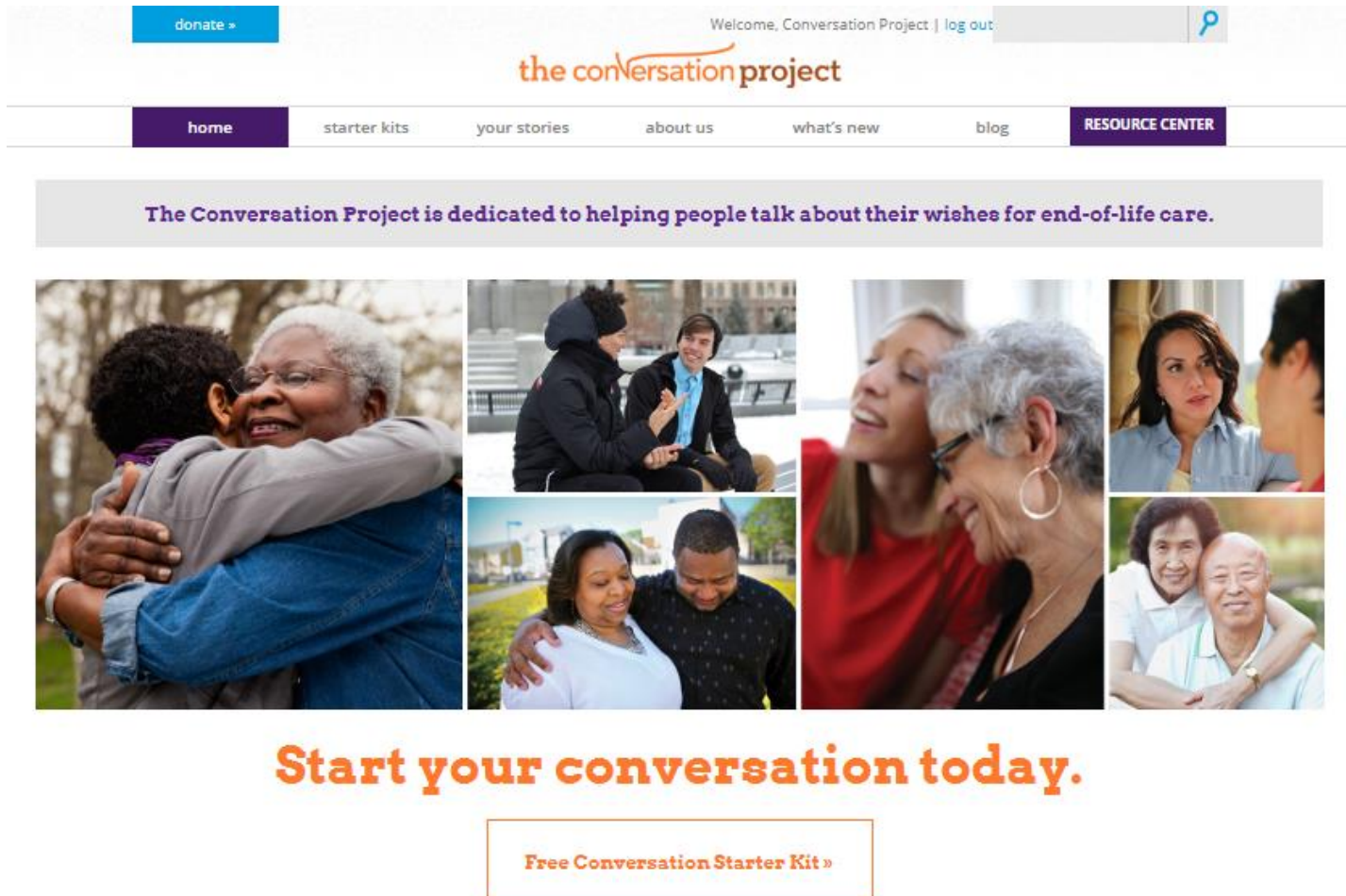
Health Systems
Transformation



The Conversation Continuum

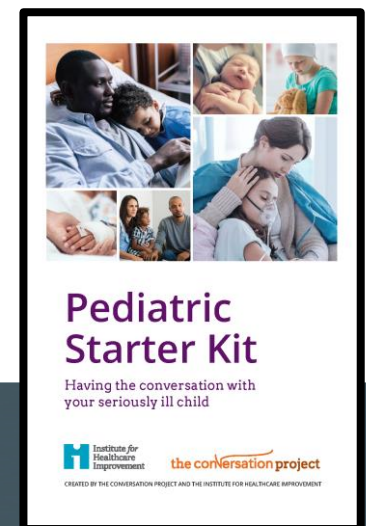
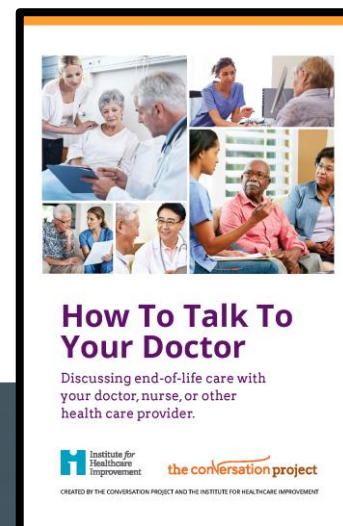
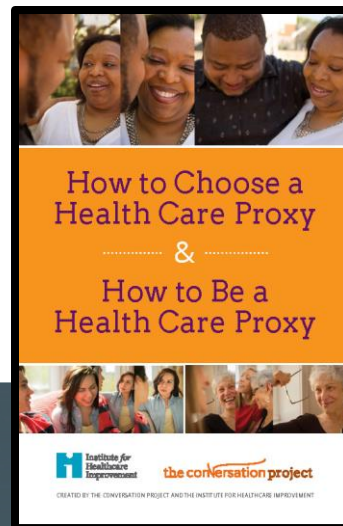
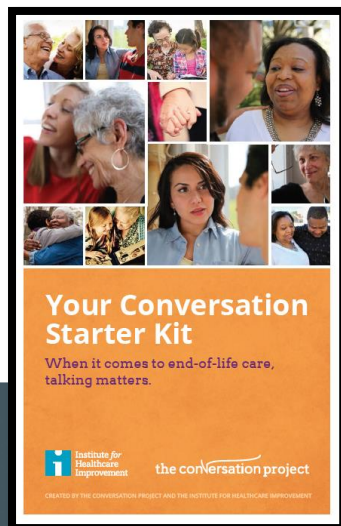


Our Website



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?

- | | |
|---|---|
| <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>

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

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,

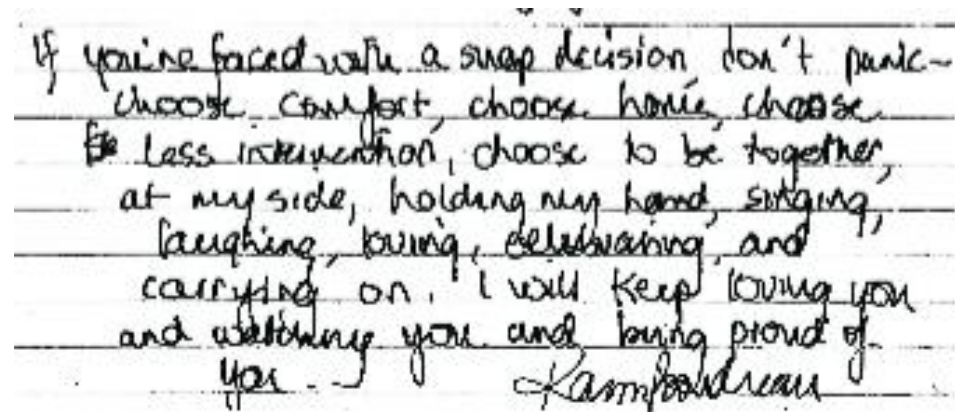
Choose home,

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

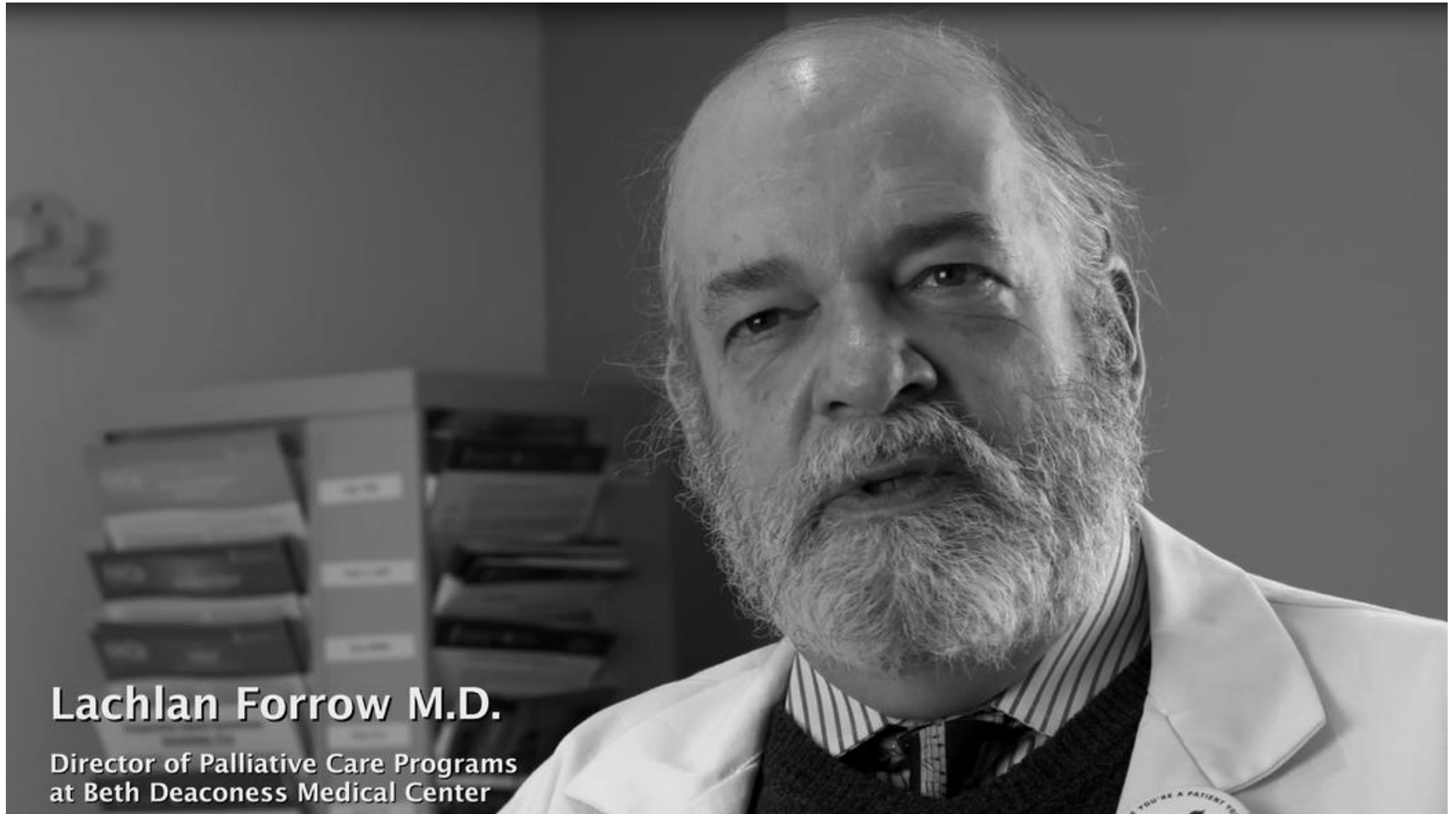
Questions?

<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

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 17th, 3:00-4:00 pm ET

Date and Time	Topic
Wednesday, Oct 17 th , 3:00 – 4:00 pm ET	Seasoned: Including Alzheimer's-specific Programming Into Your Work
Wednesday, Nov 14 th , 3:00 – 4:30 pm ET	Special interest: Ensuring equity, reaching diverse communities
Wednesday, Dec 19 th , 3:00 – 4:00 pm ET	Community Planning 101

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?

