

The Conversation Project: Virtual Speaker Training

April 18, 2018



**Kate DeBartolo
Naomi Fedna**

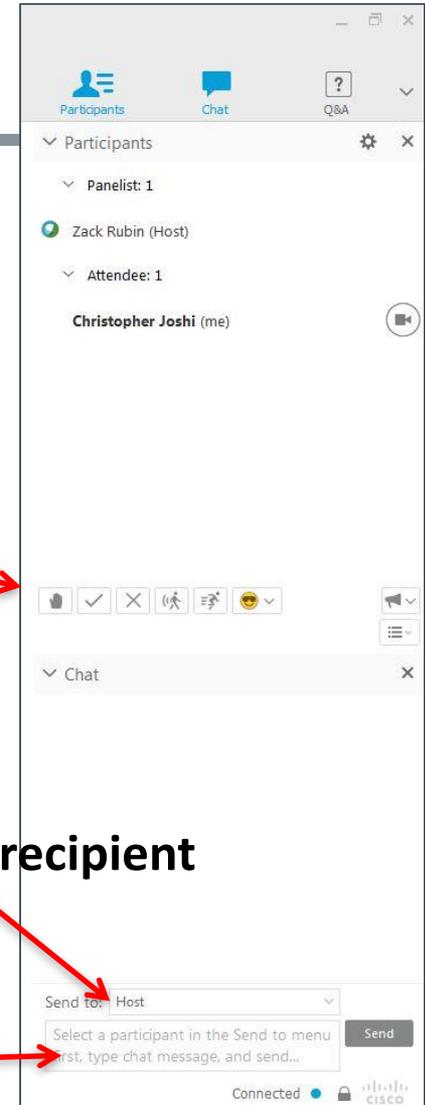
WebEx Quick Reference

- 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.”

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

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 couples!
 - Group patient visits are a possibility
- Remember your ground rules
 - No strong political or religious views in groups
- Decide whether to address state-specific questions
- Consider a second session for review or deeper dive

Standard Presentation



Introductions

- Name
- Organization (if applicable)
- What brought you to this session?
 - Share a time when you experienced a “good” or “hard” death - either personally or professionally

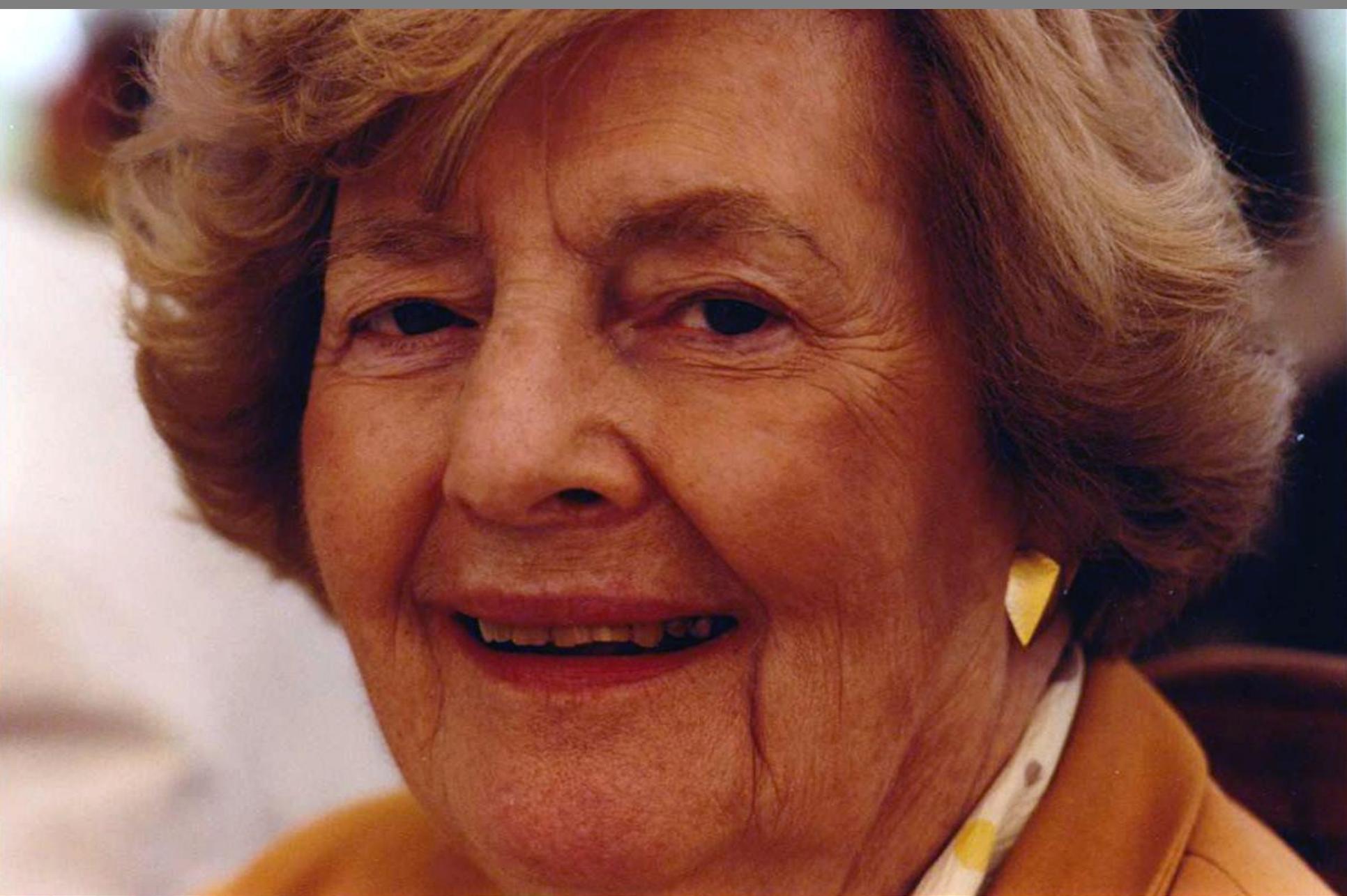
5 -10 minutes

A public engagement campaign dedicated to assure
that everyone's wishes for end-of-life care are
expressed and respected.

the conversation project

TCP Founder Ellen Goodman



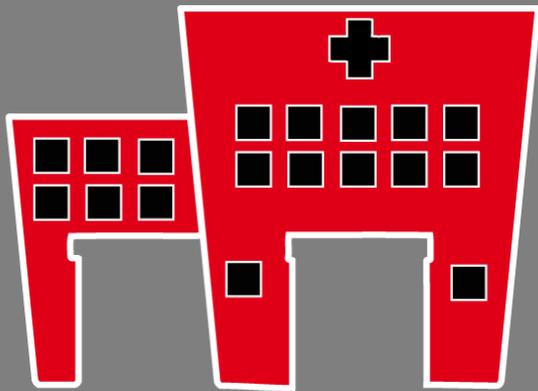


70%



WANT TO DIE AT HOME.

70%



**ACTUALLY DIE IN A
HOSPITAL**

80%



WANT TO TALK WITH THEIR DOCTORS.



17%



HAVE HAD A CONVERSATION WITH THEIR DOCTORS

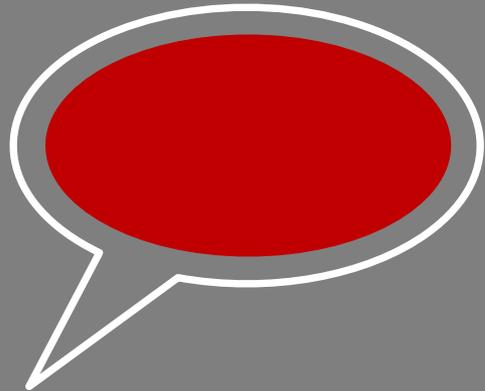


7%



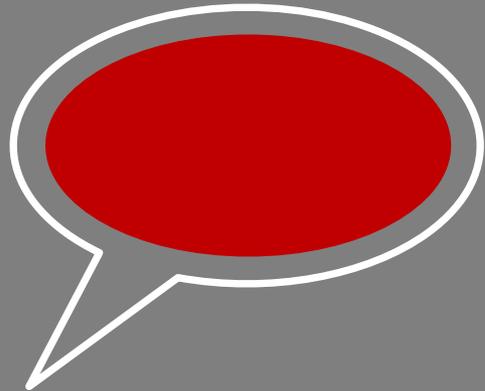
HAVE HAD A CONVERSATION WITH THEIR DOCTORS

90%



**THINK IT'S IMPORTANT
TO HAVE THESE CONVERSATIONS.**

30%



HAVE ACTUALLY DONE SO

“Maybe stories are just
data with a soul.”

— Brené Brown

Signs of Cultural Change

● Mainstream

- Dr. Atul Gawande’s book “Being Mortal” hits the best seller list
- Opening weekend success of “The Fault in Our Stars”
- The Writers Guilds East and West
- Brittany Maynard’s illness and death provokes national debate

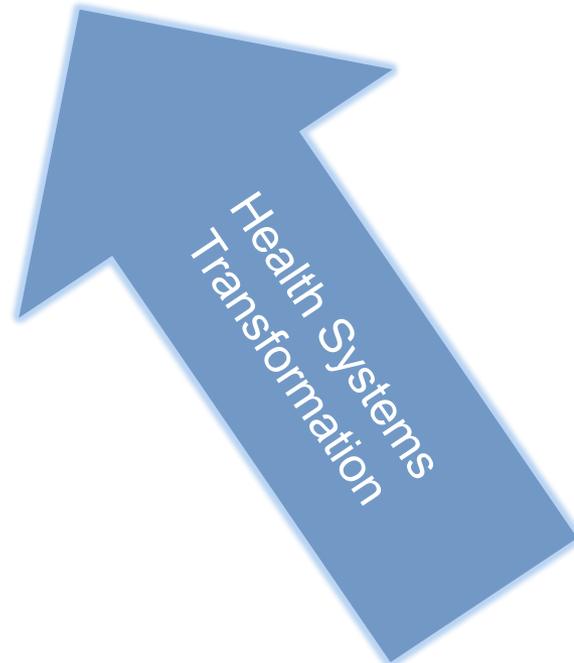
● Medicine

- The Institute of Medicine releases its report, “Dying in America”
- Massachusetts rules that doctors must have a conversation about advance planning with terminally ill patients
- CMS now reimburses for End-of-Life Care Conversations

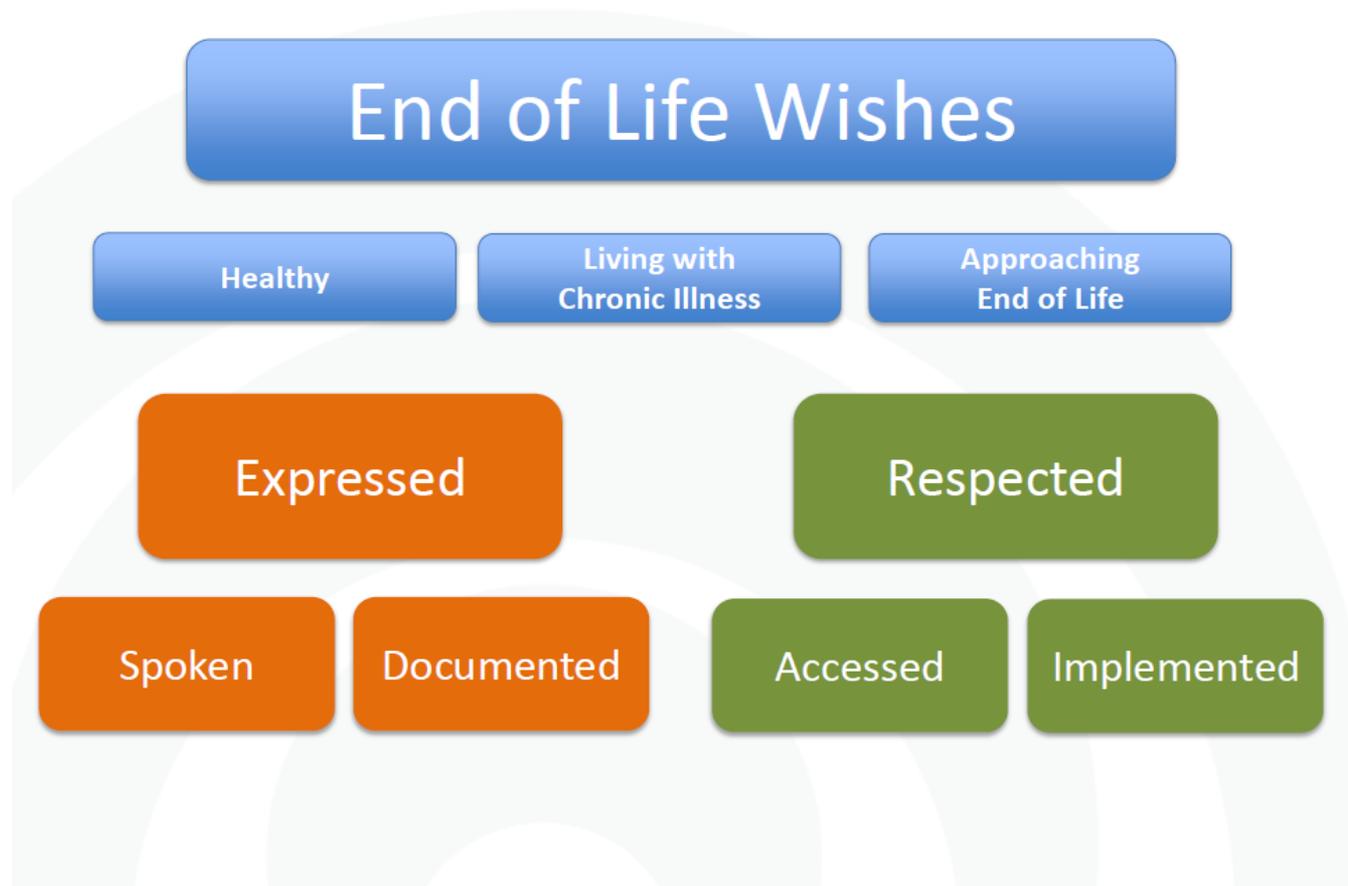
**What Matters to
Me**

AS WELL AS

**What's the Matter
with Me**



The Conversation Continuum



Strategy for Creating Cultural Change

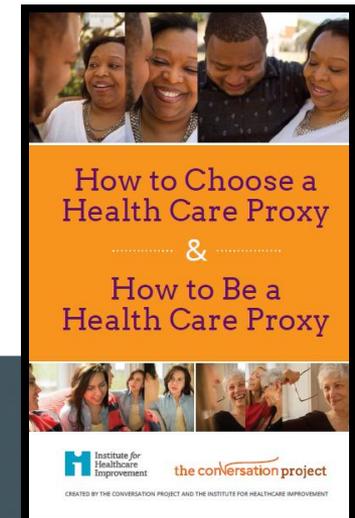
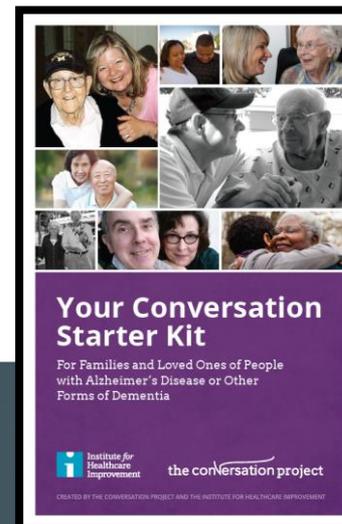
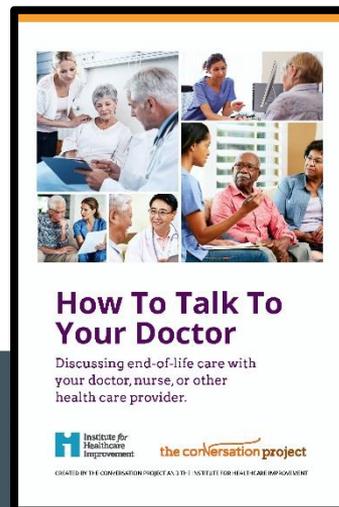
- **Awareness:** National media campaign and community engagement events
- **Accessible:** Tools to help people get started
- **Available:** Bringing TCP to people where they work, where they live, and where they pray

Awareness: Media Engagement



Accessible: Our Tools

- Conversation Starter Kit (translations)
- How to Talk to Your Doctor Starter Kit
- Starter Kit for Parents of Seriously Ill Children
- Starter Kit for Families and Loved Ones of People with Alzheimer's Disease or Other Forms of Dementia
- How to Choose a Health Care Proxy



Available: Where People Live, Work, and Pray

- Conversation Ready Communities: 2500+ contacts in over 40 states
- Conversation Ready Companies: Tufts Health Plan, Goodyear Tire and Rubber Company, Fidelity and Dow Chemical bringing TCP to their employees
- Conversation Ready Health Systems: 60+ systems
- Conversation Sabbath: an interfaith initiative started in Boston - engaging many faiths in November

Community Efforts



Pause

- Any questions?

The Conversation Starts with You



Setting the Table

- Literally – please set your table! Tablecloths out!
- 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?

The Starter Kit

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.”*
- *“A tingling sensation of sadness combined with gratitude and overflowing love for what I leave behind.”*
- *“Paced (and with enough space and comfort so that I can make it a ‘quality chapter’ in my life.) I want time and help to finish things.”*
- *“Having my sheets untucked around my feet!”*
- *“Peaceful, pain-free, with nothing left unsaid.”*
- *“In the hospital, with excellent nursing care.”*

The Starter Kit: Get Set

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

The Starter Kit: Go

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:

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

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."

What Did You Learn?

- What plans did you make?
- Questions
- Concerns
- Surprises
- Trends

The Starter Kit: Go

- Health Care Planning (HCP)
- Advance Directive (AD)
- Health Care Proxy
- MOLST/POLST

Leaving in Action

- Complete the Conversation Starter Kit
- Have the conversation
- Share the Conversation Starter Kit and other tools with friends and family
- Appoint a proxy, talk to your doctor, complete and Advance Directive
- Share your stories on our website
- Team up with local efforts in your region
- Join our monthly webinar for those interested in community efforts



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,

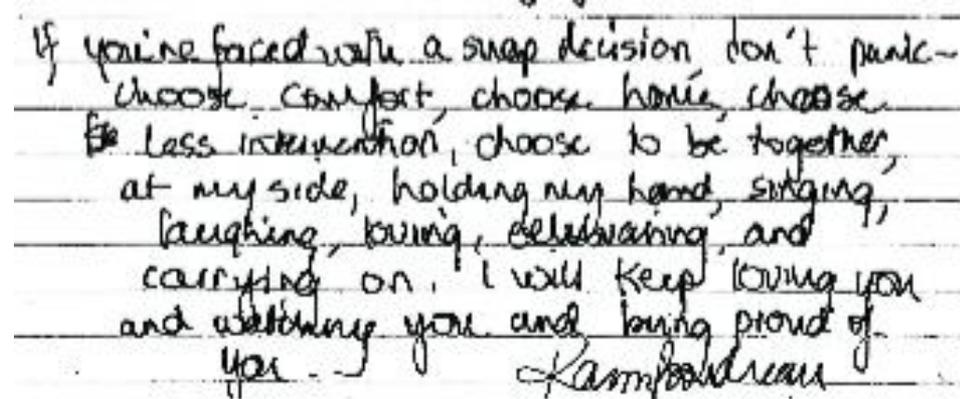
Choose home,

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?

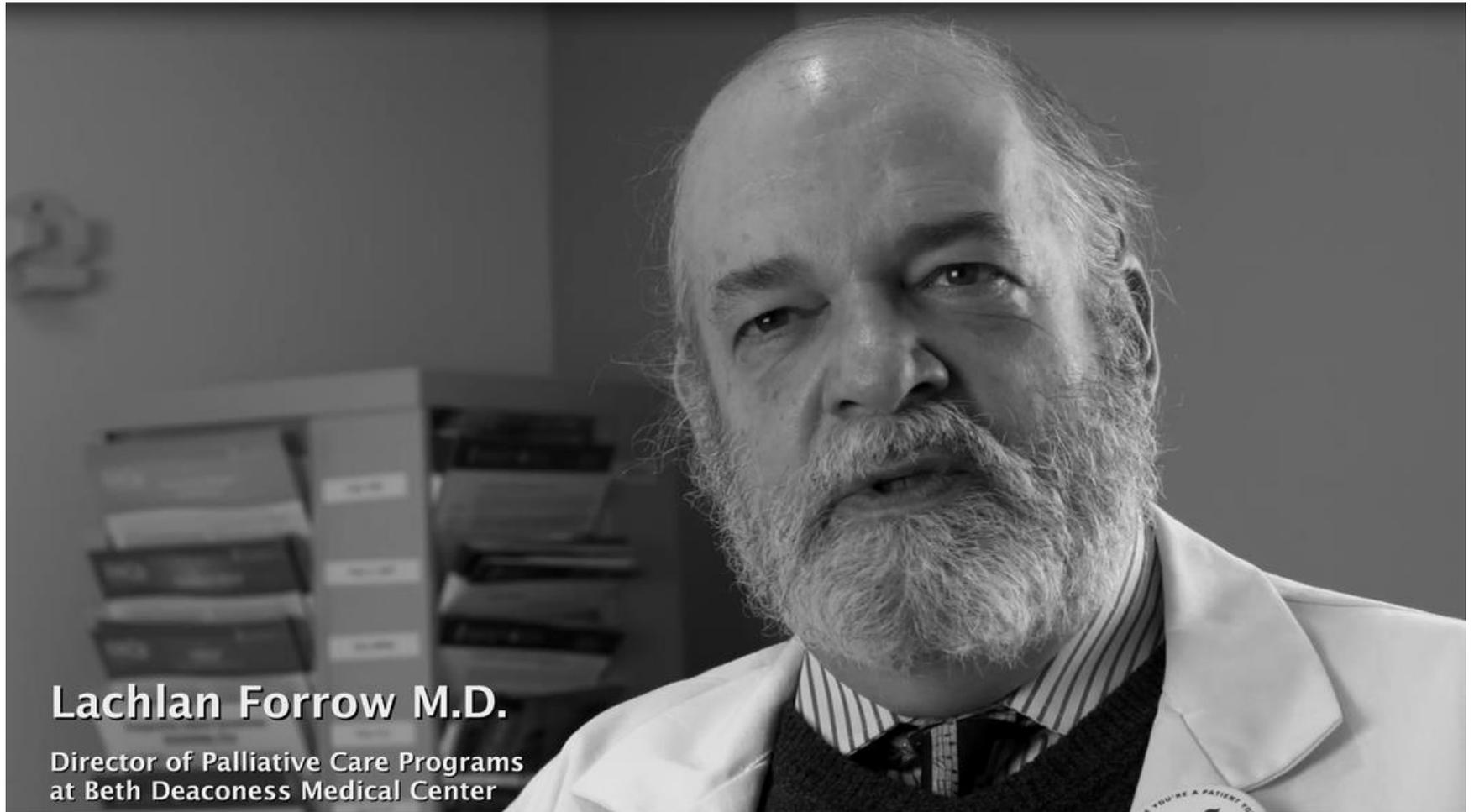
Your name and organization

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



Facilitation Tips

- Give current answers
- Home is not always feasible. Learn more.
- Ask if this person will/can honor your wishes
- Tell more than one person
- Have two conversations
- “It’s ok if you can’t honor this”
- 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

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 people to take?

- What do you want 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)
- 5 week follow up survey
 - Capture email addresses

- Available on our Community Resource Center
 - <http://theconversationproject.org/resources/>
 - “Measurement” Category

The Community Resource Center

- Community Organizing
 - Identifying partners and sample work plans
- Hosting Events
 - Invitations and agendas for events
- Materials and Tools
 - Translations and videos
- Measurement
 - Suggested metrics and evaluation plans
- Publicity
 - Press releases and social media strategies

Upcoming Community Calls

The next Conversation Project Community Call will take place on:

Wednesday, May 16th, 3:00-4:00 pm ET

Date and Time	Topic
Wednesday, May 16 th , 3:00-4:00pm ET	Community Highlight/Hot Topic:
Wednesday, June 20 th , 3:00 – 4:00 pm ET	Community Planning 101
Wednesday, July 18 th , 3:00 – 4:30 pm ET	Virtual Speaker Training

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?

