Bringing Advance Care Conversations to Your Congregation
Staff

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Welcome to today’s session!

Please use Chat to “All Participants” for questions.

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Raise your hand

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Where are you located on the map?
Faculty

Rev. Rosemary Lloyd, BSN, MDiv
Advisor to Faith Communities
The Conversation Project

• Graduate Georgetown University and Harvard Divinity School
• Ordained Unitarian Universality Minister, Served The First Church in Boston
• Graduate of Metta Institute
• Former R.N., CPE intern at DFCI, Hospice Volunteer
What we hope you will take away

- Best practices for bringing conversations about what matters most when it comes to care through the end of life to your faith community
- Feel prepared to have these conversations in your personal and professional life
- Understand the resources available to help individuals and families have *the conversation*
- Develop a plan for bringing best practices to your home institution or community
Agenda

- Call Series Overview: 6 parts
- The Gap between wishes and reality
- Why Congregations?
- TCP’s Free Conversation Starter Kits
- Action and Accountability
- Q & A
Webinar Series Content

1. Introduction to TCP mission and tools
2. Developing Strategies for Success
3. Sermons, Texts, and Timing
4. Advance Care Planning and Pastoral Care
5. Programming That is Practical and Spiritual
6. Bringing it Together
Reflection

• What brought you to this session?
• Pause to reflect on a time when you experienced a “good” or “hard” death - either personally or professionally
• What difference do you want to make in how our communities talk about end-of-life care?
“Our ultimate goal, after all, is not a good death, but a good life to the very end.”

– Atul Gawande
A public engagement campaign dedicated to assure that everyone’s wishes for end-of-life care are expressed and respected.
70% WANT TO DIE AT HOME.
70% ACTUALLY DIE IN THE HOSPITAL
WANT TO TALK WITH THEIR DOCTORS.
17% have had a conversation with their doctors.
7%

HAVE HAD A CONVERSATION WITH THEIR DOCTORS
THINK IT’S IMPORTANT
TO HAVE THESE CONVERSATIONS
HAVE ACTUALLY DONE SO
100%

MORTALITY RATE
It’s too soon.

I don’t want to upset my ________.

I don’t know what to talk about or how to bring it up.
Some Tools That Can Help

- 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
Six Reasons for Congregations

1. Existing communities - shared values
2. Encouraging more compassion and less fear
3. Story-telling communities
4. Planting seeds of cultural change
5. They like to eat together!
6. Positioned to support and people with serious illness, their families and clinicians
The Conversation Starts with You
Setting a Theological Frame

❖ What texts, teachings, rituals, or practices support having courageous, values-based conversations in your faith tradition?
When I think about the end of my life, what matters most to me is:

.............
peaceful
quiet
dignified
comfortable
joyful
quick
with family and friends
natural
musical
surrounded by friends and family
died
no regrets
calm
a good story
painless
easy for my family
happy
laughter
graceful
filled with music
celebrated
at home
respect
celebration
full of love
simple
life
bias
uncomplicated
bias
memories
compassion
undeclared
birth
life
faith
forever
bias
anypersons
love
label
bias
embrace
uncomplicated
label
peace
family
at home
bias
incarcerated
uncomplicated
life
peace
uncomplicated
bias
forever
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.)
The Starter Kit: Get Set

How long do you want to receive medical care?

- 1: Indefinitely, no matter how uncomfortable treatments are
- 2
- 3
- 4
- 5: Quality of life is more important to me than quantity

What are your concerns about treatment?

- 1: I'm worried that I won't get enough care
- 2
- 3
- 4
- 5: I'm worried that I'll get overly aggressive care
The Starter Kit: Get Set

As a patient, I’d like to know...

1. Only the basics about my condition and my treatment
2. All the details about my condition and my treatment

As doctors treat me, I would like...

3. My doctors to do what they think is best
4. To have a say in every decision
5. 
The Starter Kit: Get Set

How Involved do you want your loved ones to be?

1. I want my loved ones to do exactly what I’ve said, even if it makes them a little uncomfortable

2. I want my loved ones to do what brings them peace, even if it goes against what I’ve said

When It comes to your privacy...

1. When the time comes, I want to be alone

2. I want to be surrounded by my loved ones
Complete Starter Kit Reflection

- Notice which questions seem easier, harder to answer
- Do some answers seem very situationally dependent? Is that a cue that more conversation is important?
- Answer in your present tense body and mind.
- Complete this document and talk to someone—by Tuesday.
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: 

the conversation project
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 [blank], and it made me realize...”

“Even though I’m okay right now, I’m worried that [blank], 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.”
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.
Q & A

Any questions?
Action and Accountability

- Download TCP Conversation Starter Kit guide and go through it
- Have a conversation by next Tuesday
- Download the Getting Started in Congregations Guide and browse
- Find videos on [www.theconversationproject.org](http://www.theconversationproject.org):
  - Talking Matters in Congregations
  - ABC World News clip Diane Sawyer Practice Makes Perfect video
Next Call and Survey

The next session will be:
Tuesday, April 24, 2018 @ 8:00-9:00 PM EDT

Before shutting down your computer, please complete the survey that will pop up at the conclusion of this call.

THANK YOU! Have a beautiful week!
“Our ultimate goal, after all, is not a good death, but a good life to the very end.”

– Atul Gawande