

the conversation project



Bringing Advance Care Conversations to Your Congregation

Staff



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The Conversation Project

- Graduate of University of Massachusetts Amherst
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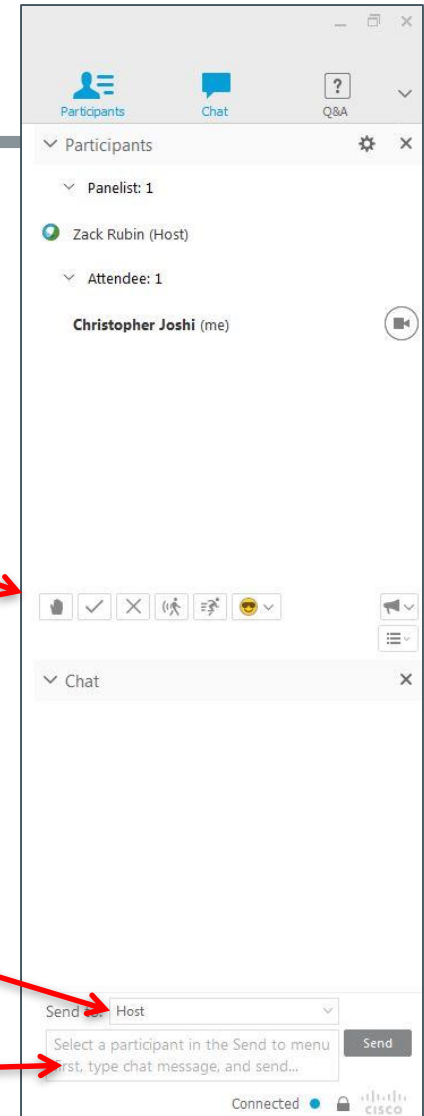
WebEx Quick Reference

- 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)

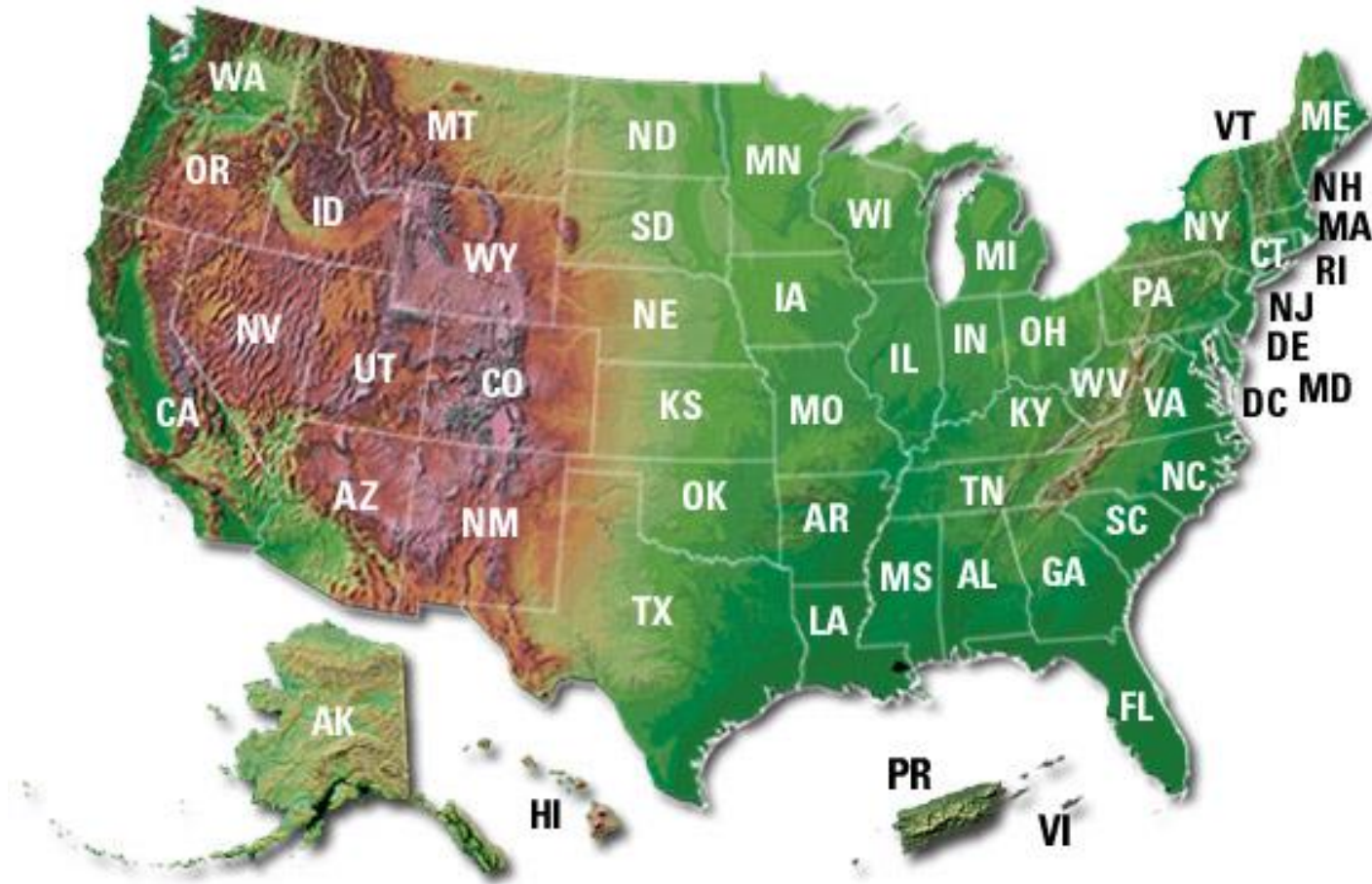
Raise your hand

Select chat recipient

Enter Text



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.

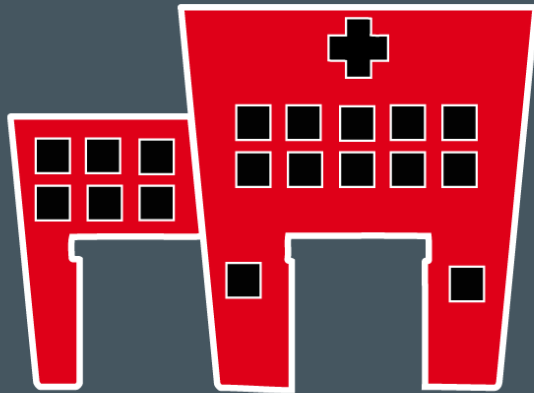
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70%



WANT TO DIE AT HOME.

70%



ACTUALLY DIE IN THE 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

100%



MORTALITY RATE

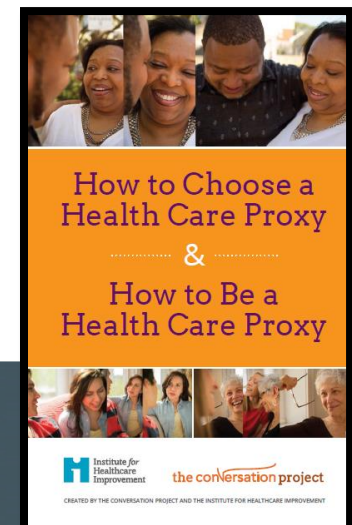
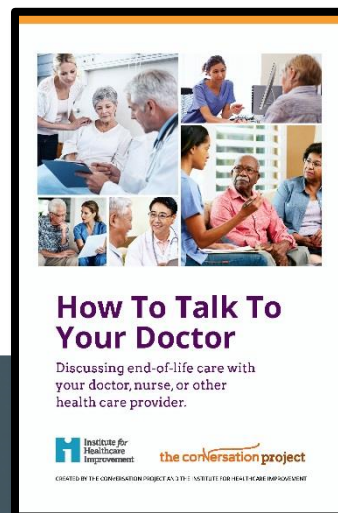
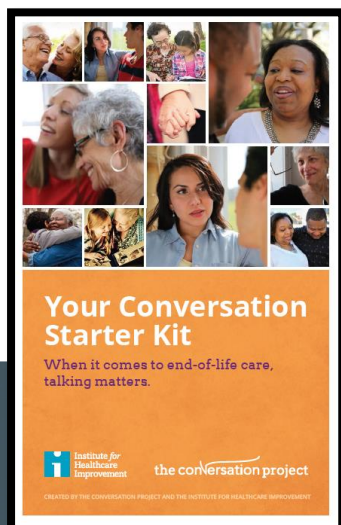
It's too soon.

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 Project

Getting Started Guide for Congregations



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CREATED BY THE CONVERSATION PROJECT AND THE INSTITUTE FOR HEALTHCARE IMPROVEMENT

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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:

.....

quick joyful with God
calm quiet tranquil
natural peaceful
surrounded by friends and family
a good story full of love
comfortable
easy for my family happy
laughter easy graceful filled with music
painless
at home
celebrated loving
dignified
no regrets
musical
memories
with family and friends
celebration
respect
uncomplicated
family
party supported
respected
courageous
hope
peace
pride of my children
and others
hope
blessed
grateful
embraced
celebration
celebrated
loving
dignified
no regrets
musical
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with family and friends
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uncomplicated
family
party supported
respected
courageous
hope
peace
pride of my children
and others
hope
blessed
grateful
embraced
celebration
celebrated
loving
dignified

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.)

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: Get Set

As a patient, I'd like to know...

☐ 1

☐ 2

☐ 3

☐ 4

☐ 5

Only the basics
about my condition
and my treatment

All the details about
my condition and
my treatment

As doctors treat me, I would like...

☐ 1

☐ 2

☐ 3

☐ 4

☐ 5

My doctors to do what
they think is best

To have a say in
every decision

The Starter Kit: Get Set

How Involved do you want your loved ones to be?

☐ 1

☐ 2

☐ 3

☐ 4

☐ 5

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

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

☐ 2

☐ 3

☐ 4

☐ 5

When the time comes, I want to be alone

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?

- | | |
|---|---|
| <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"/> |

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."



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,

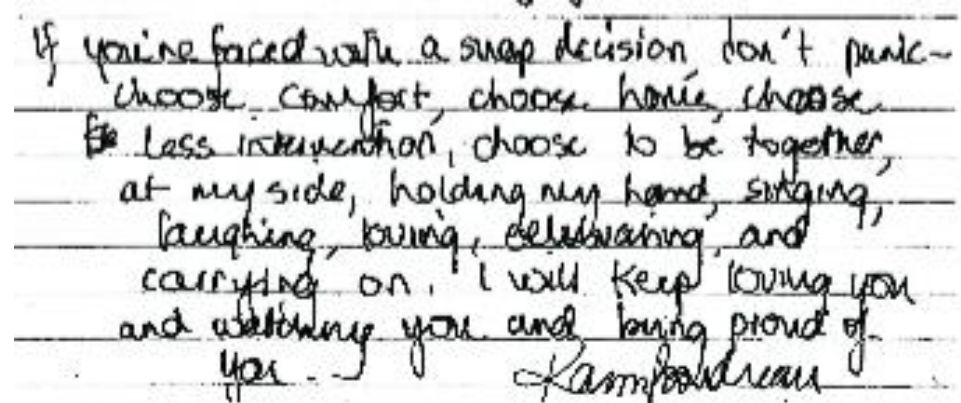
Choose home,

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

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:
 - 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