

Working Together: Organizing and Building Coalitions

The Conversation Project



May 15, 2019

WebEx Quick Reference

Welcome to today's session!

Please use Chat to "All Participants" for questions

For technology issues only, please Chat to "Host"

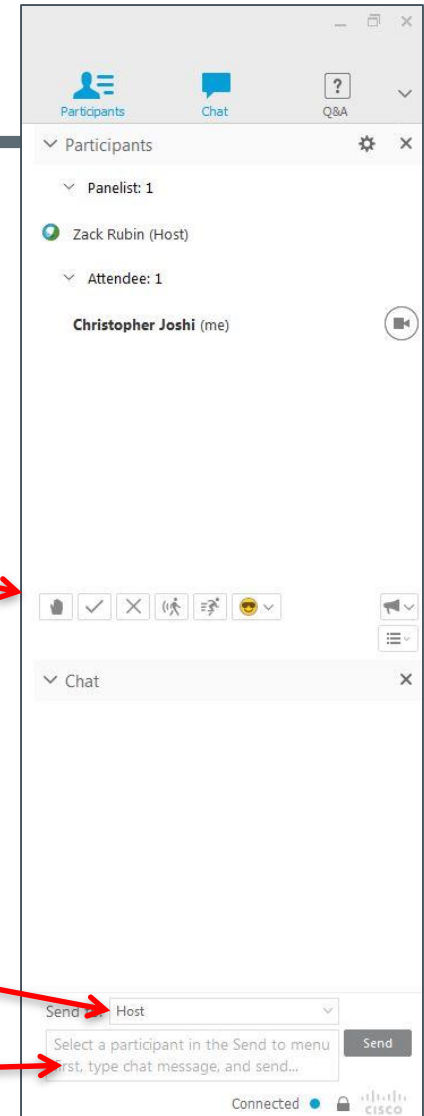
Raise your hand

WebEx Technical Support: 866-569-3239

Dial-in Info: Audio / Audio Conference (in menu)

Select chat recipient

Enter Text



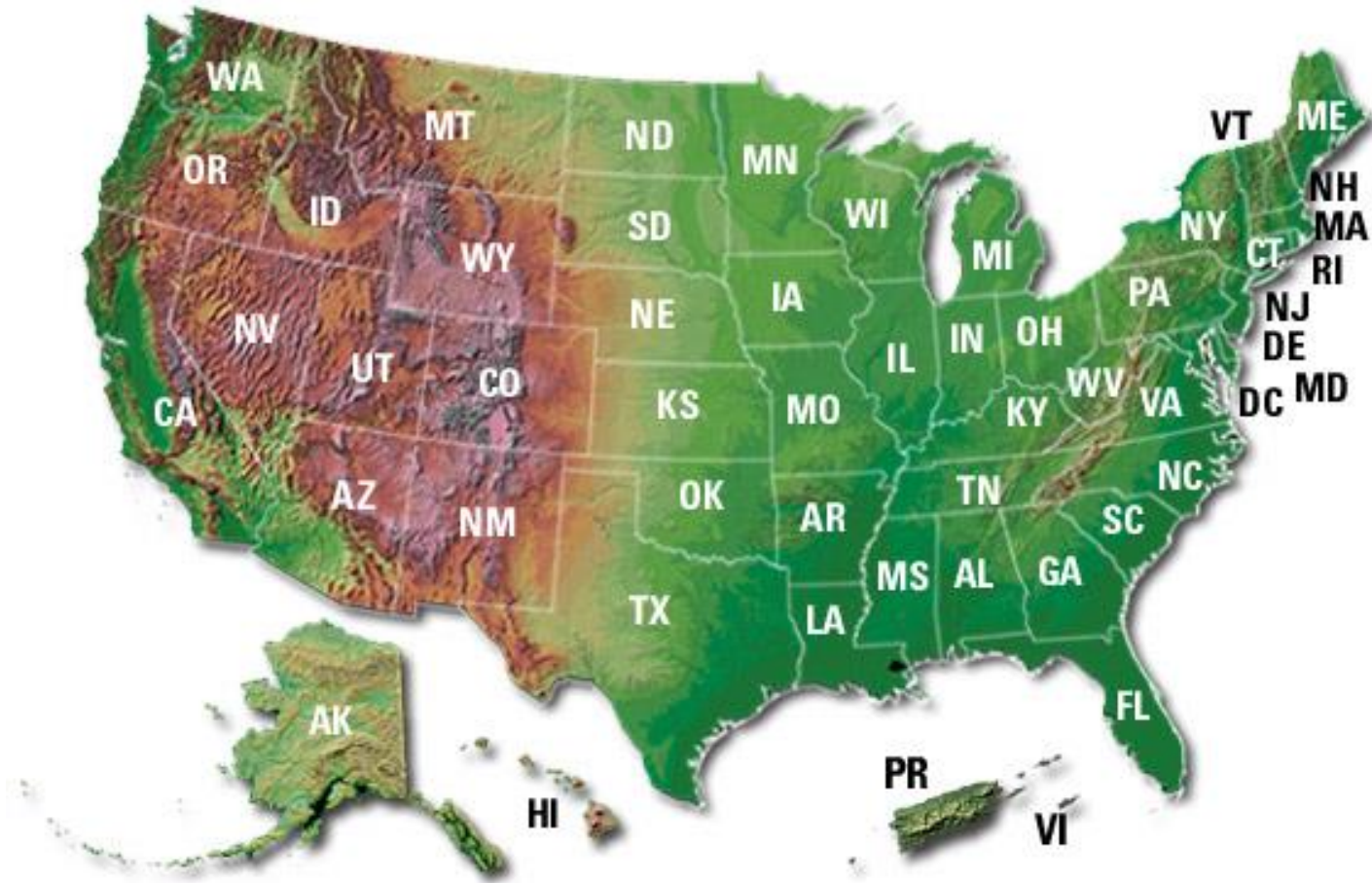
Ice Breaker Question

Type into the chat box your response to the following:

How did you hear about this call?

Make sure you send your message to “All Participants.”

Where are you located on the map?



The Conversation Project Field Team



Patty Webster
Improvement Advisor



Naomi Fedna
Project Coordinator

Call agenda

- Framing
- Community highlights: Three examples of grassroots organizing and coalition building
- Questions and discussion
- TCP additional resources/updates
- Wrap up

Initial reflections - Chat

What brought you to this call?

- General learning? A burning question(s) you want to explore? Challenges you want to discuss? Successes you want to share?

What experience do you have with building coalitions or networking with others?

- Newbie, Seasoned, Somewhere in Between?

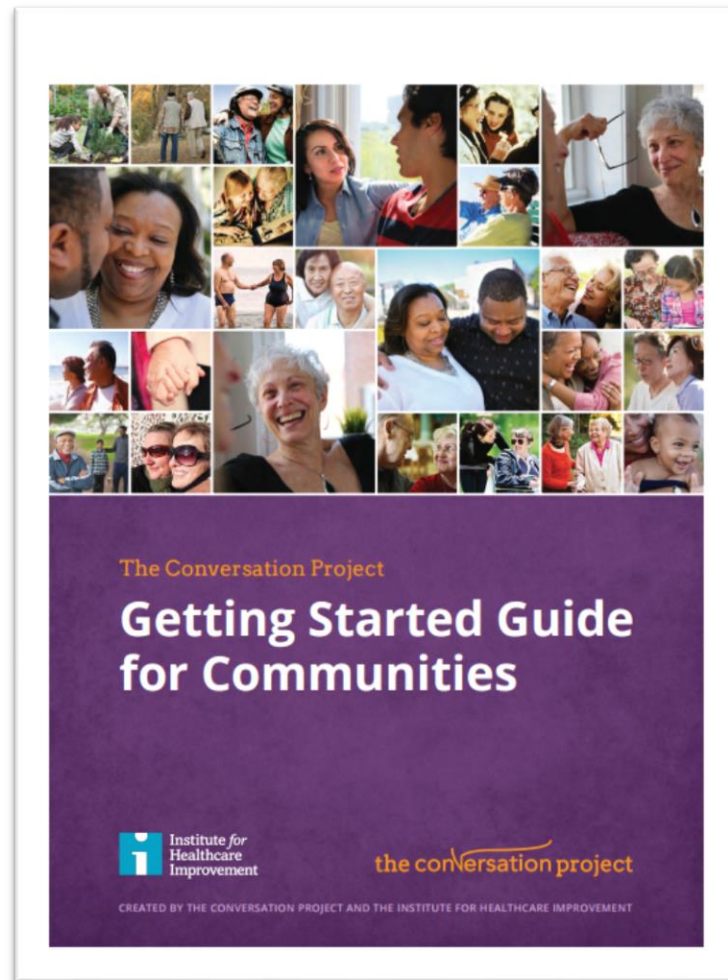
A public engagement campaign dedicated to assure
that everyone's wishes for end-of-life care are
expressed and respected.

the conversation project

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

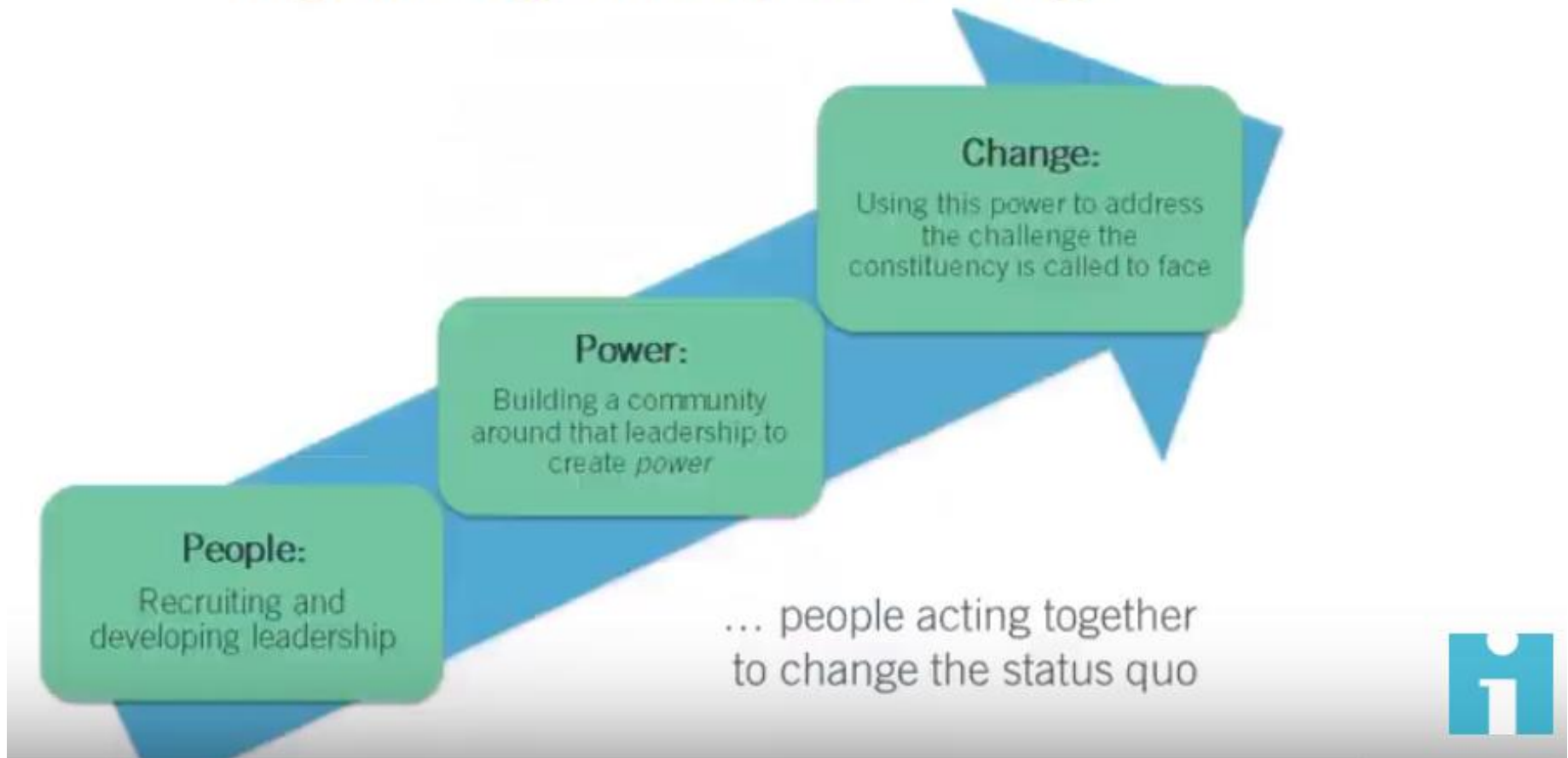
Building Local Community Engagement



Recap: Getting Started Questions

- *Who* do you want to reach? And by when?
- *What* do you want to support them to accomplish? What actions?
- *How* do you want to reach them?
- *What* is the context of this topic for population you're trying to reach?
- **Who else is already doing this work in your community? Who else could you be working with?**
- **Who are respected leaders or organizations that could help you advocate for the importance of this work?**
- *Who* will be responsible for actually doing this work in your community?
- *How* will you measure successes and challenges?
- *How* do you plan to reach diverse groups of people in your community?
- *What* can you do by next Tuesday?

Organizing Theory of Change



Source: Institute for Healthcare Improvement's Virtual Course, [Leadership and Organizing for Change](#)

Organizing as a strategy

- ❑ Organizing starts with connections, relationship building, mutual trust
- ❑ Organizers bring individuals together to create collective capacity that's not present when individuals act alone
- ❑ Organizing can accelerate your success

Possible Community Partners

- Assisted Living Facilities
- City Employee Retirement System
- Dept. of Public Health, Mental Health, Behavioral Health
- Elected Officials
- EMT providers
- Estate/Legal entities (elder law, local bar association...)
- Employers
- Faith-based organizations, clergy, chaplains ministerial associations
- Financial community (banks, CPA firms, financial advisors)
- Health plans/insurers
- Home care/VNA
- Retirement communities and home owners associations
- Homeless shelter/services
- Hospice
- Hospitals/Health systems
- Local resources: libraries, Chamber of Commerce, Lion/Rotary/Elks Club...
- Media channels (local, state, regional)
- Medical/Nursing/Hospital Association
- Nursing homes, rehab facilities, long term care
- Physician office practices/primary care
- Prisons/jails
- School District – employee benefits, Parent Teacher Organizations
- Senior Advocacy Organizations/Elder Services (Area Agency on Aging, senior center, transportation services, meals on wheels)
- Universities – students, faculty, alumni
- Veterans Services

“If you want to go fast, go alone.
If you want to go far, go together.”
—African Proverb



Andrew Ingall
Co-director, Relmagine





re
imagine

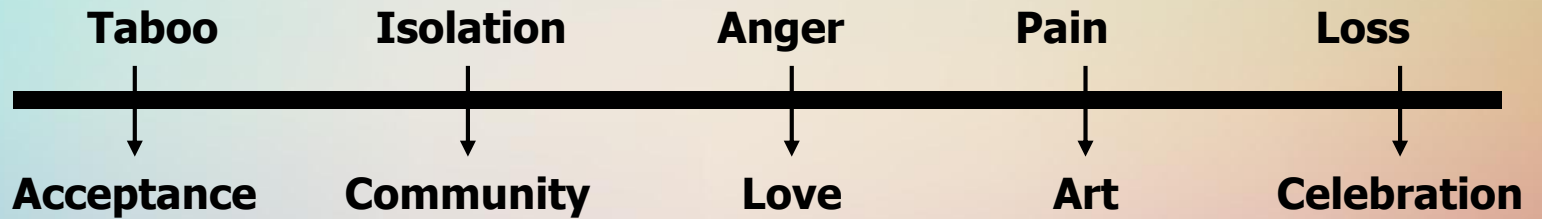
End of Life



Our Purpose

Reimagine End of Life aims to transform our individual and collective experience around death, dying and *living*.

Our Vision



A vertical white line on the left side of the slide, with a small white square icon containing a diagonal line, positioned between two segments of the line.

Our Method

Reimagine hosts community-based programs that bring a week of vital discussion, education, inspiration, and interpersonal connection to cities around the world.

Our 4 Pillars

Arts+Culture

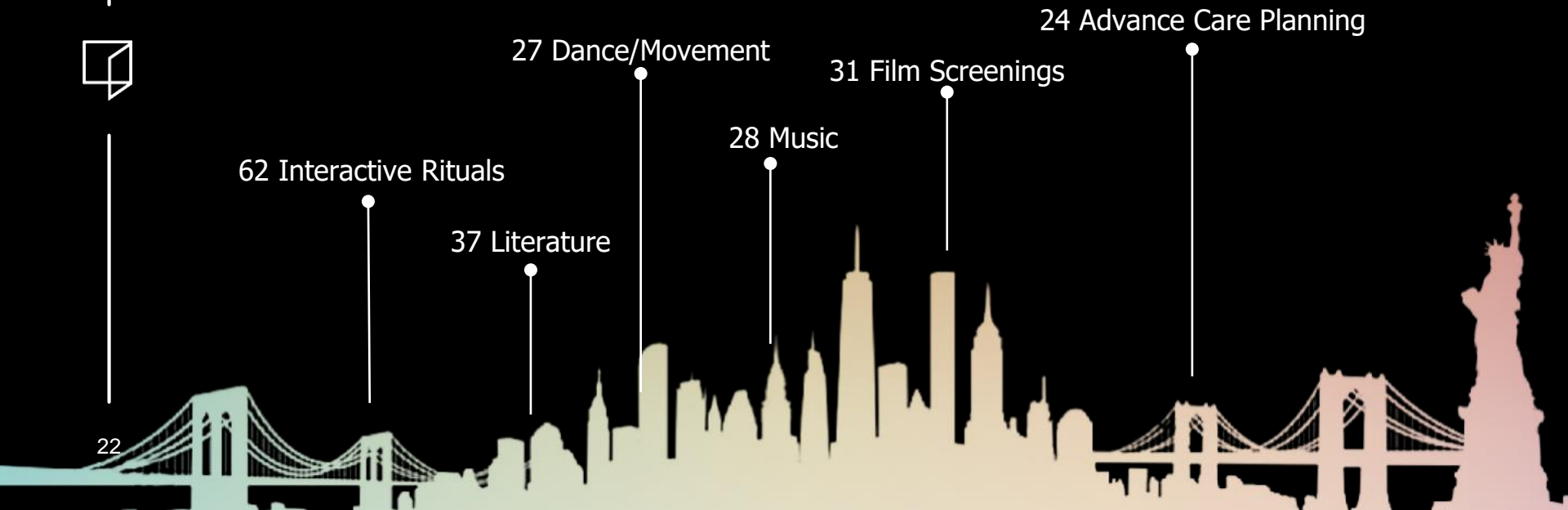


Health+Medicine

Design+Technology

Faith+Spirituality

Reimagine New York City 2018 encompassed more than 350 events over the course of one week, including:



Changing attitudes towards death and life.

91%

of surveyed attendees
said Reimagine

**helped make
talking about
death easier.**

76%

of surveyed attendees
said their experience at
Reimagine led to

**new
conversations on
life and death.**

89%

of surveyed attendees said
that Reimagine made them

**more grateful
for their lives
and those
around them.**





Who goes to Reimagine?



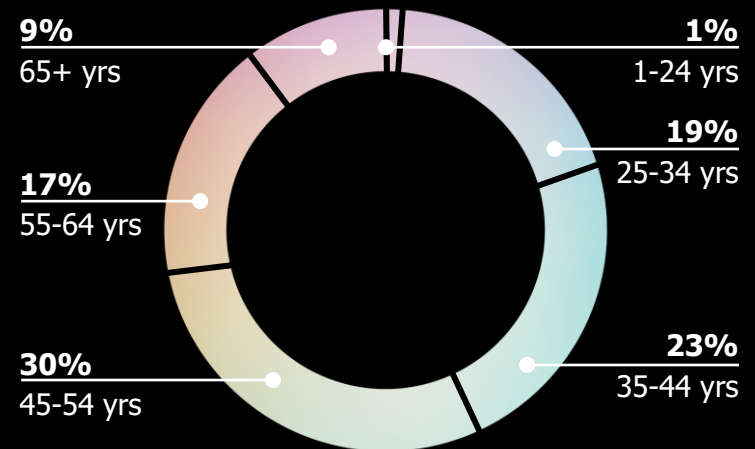
Reimagine is for everyone.



Festival attendees are intergenerational.



Our social media followers also are intergenerational.



And a few words from festival attendees...

"What really struck me was the beauty of the community assembled at each event I attended."

"Over and over I found myself connecting with and expanding upon my own thoughts about life and death, meaning, message."

"We were instantly united in the universality of our own mortality."

"We were able to feel and think deeply together about loss, pain and death. It was very beautiful."

"It reminded me of the generosity and complexity of souls within the strangers in my midst every single day."

"The people I met, the fact that there are people who want to reimagine end of life, love and memories the way I do. I thought I was alone."



A low-angle shot of a person wearing a dark jacket, a grey beanie, and glasses, reaching up with both hands to hold a large, cylindrical, light-brown paper lantern. The lantern is illuminated from within, casting a warm glow. The background is a dark sky filled with numerous small, out-of-focus, warm-toned lights, creating a bokeh effect. The overall mood is warm and appreciative.

THANK YOU



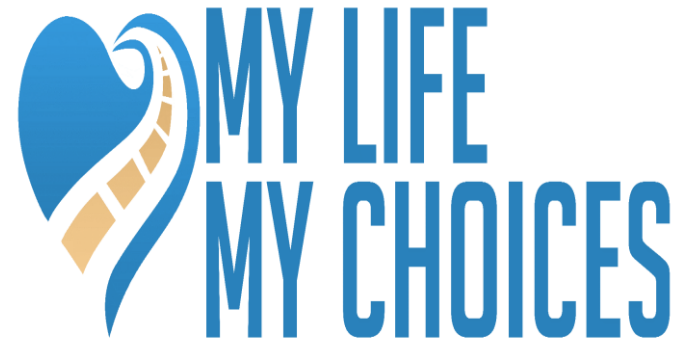
Marisette Hasan, RN, BSN
President & CEO, The Carolinas Center
Co-Chair, CSI Advance Care Planning
Workgroup
mhasan@cchospice.org



John Ropp III, MD, MBA
Chairman, South Carolina Medical Association
Chairman, CSI
jropp97@gmail.com

South Carolina Coalition for the Care of the Seriously Ill (SC CSI)

Transforming Advance Care Planning through Friendly
Processes



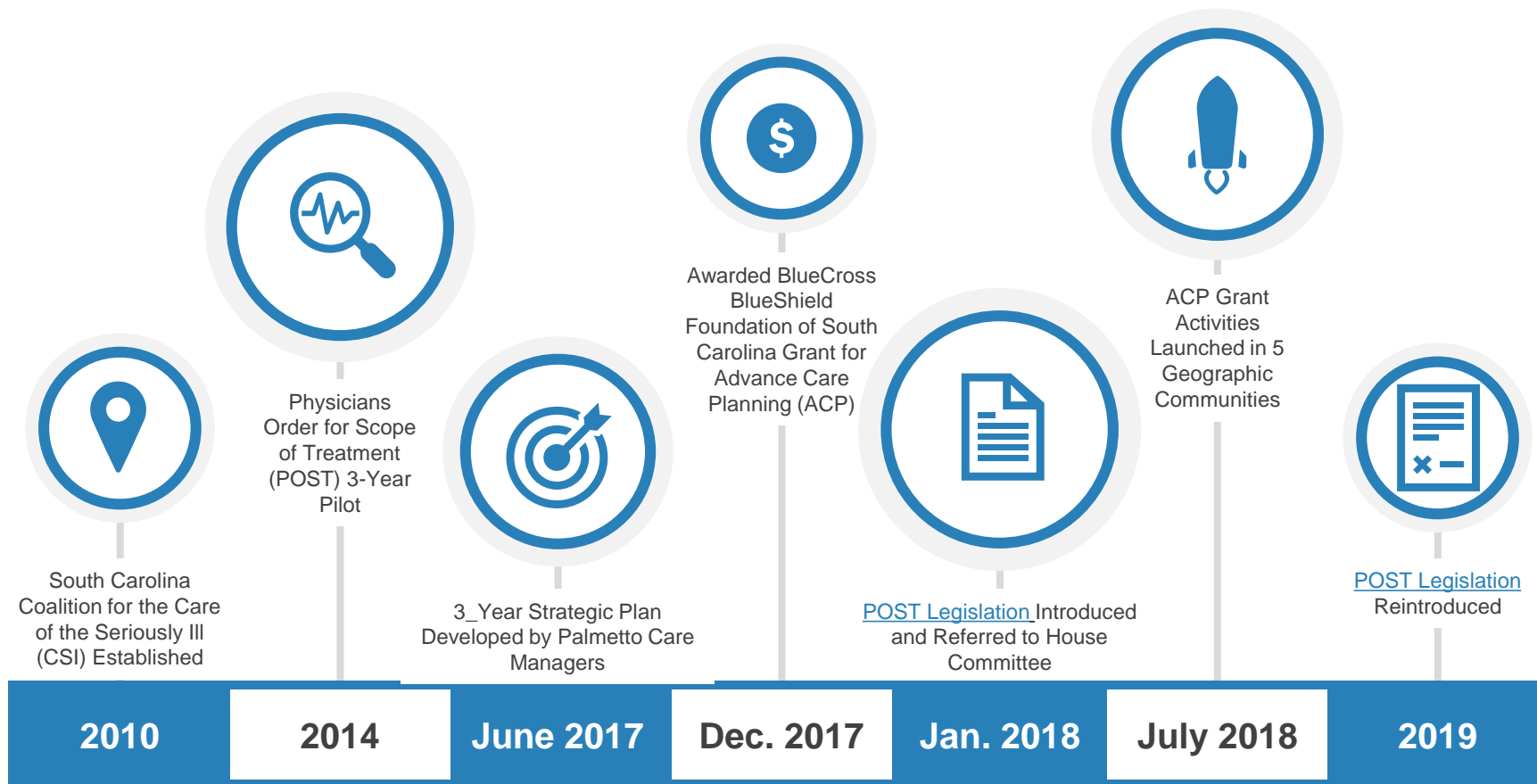
How Did CSI Become an Effective Coalition?

- ✓ Identify and recruit champions who have a passion for the work (clinicians, providers, payers, consumer advocates, etc.)- who is NOT at the table who should be?
- ✓ Organize a structure that promotes engagement and participation of all members- open meetings held regularly at the same central location
- ✓ Collaboration and Consensus- takes time to build trust among members (years!)
- ✓ Commitment from Core members- time, services, “in-kind” offerings
- ✓ Seek funding that will help start and sustain your work- start small and show commitment and early successes (payers, health systems/providers, foundations)
- ✓ Grass roots community engagement of diverse groups- get out town! Go to where the people are in civic groups, churches, annual meetings, etc.
- ✓ Identify and address conflicts of interest as soon as possible



South Carolina Coalition for the Seriously Ill

History and Timeline

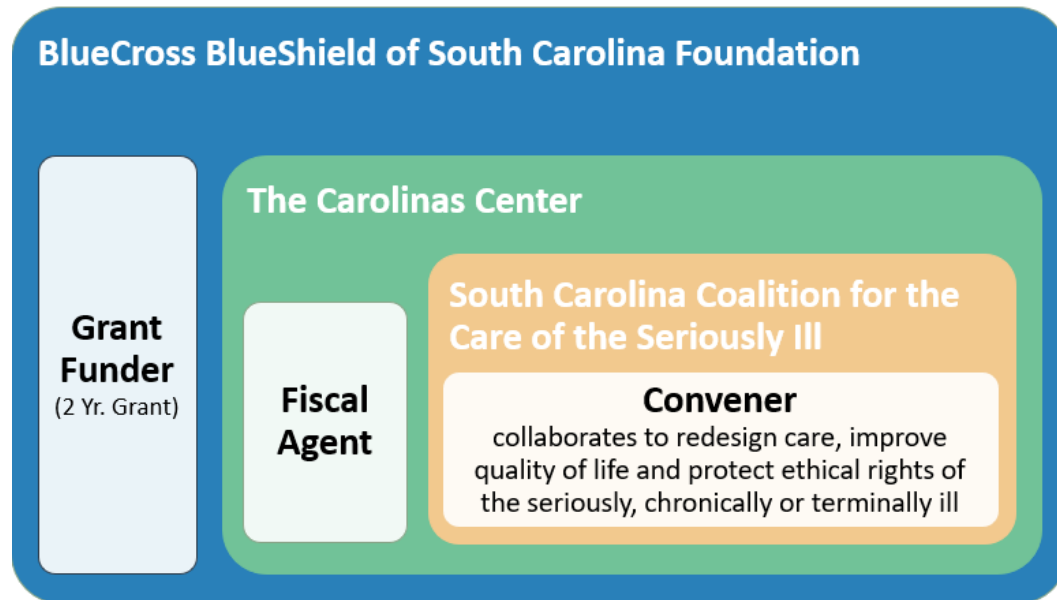




My Life My Choices

Community-based ACP Initiative

- Utilizes **Respecting Choices® Implementation Framework**:
Community Engagement, System Redesign, Education and Training and Quality Improvement
- Leverages strengths and priorities of **key partners**
 - AARP SC, SC Hospital Association, SC Medical Association, USC Core for Applied Research & Evaluation
- Implemented in **five (5) geographic areas**
- Primarily focused on **vulnerable and underserved populations**





Collective Impact

Key Metrics *(July 2018 – March 2019)*

4,194

Community
Members
Educated

442

Providers
Trained

748

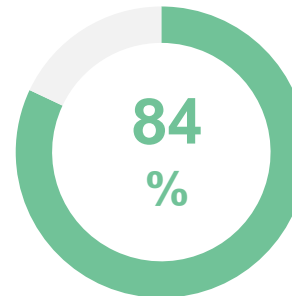
ACP
Conversations
Conducted

257

Advance
Directives
Completed



Percentage of Participating Community
Members Willing to Have the Conversation

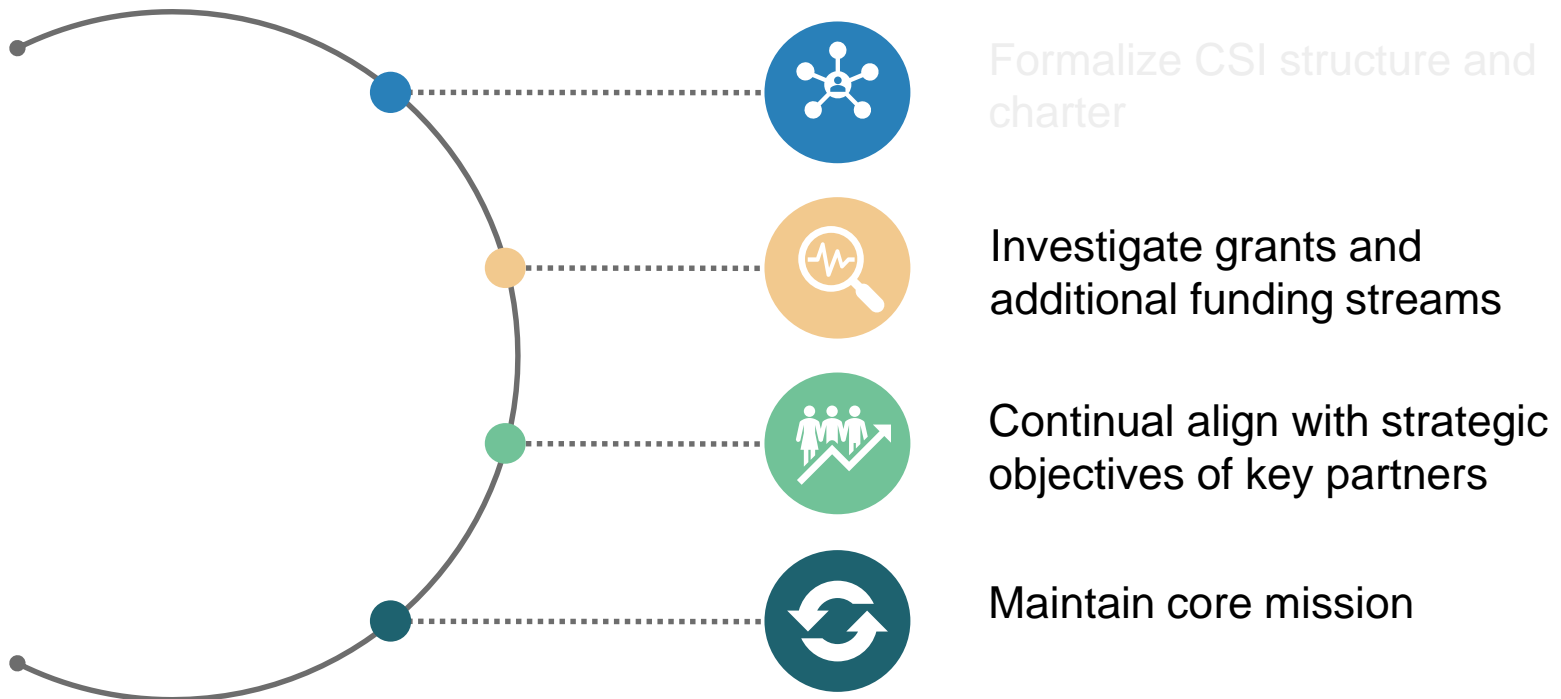


Trained Health Care
Professionals Expressed
Greater Confidence in
Conducting ACP
Conversations



Next Steps

Sustaining Coalition and Grant Work





Thank You

John Ropp III, MD, MBA

Chairman, South Carolina
Medical Association
Chairman, CSI
jropp97@gmail.com

Marisette Hasan, RN, BSN

President & CEO, The Carolinas
Center
Co-Chair, CSI Advance Care
Planning Workgroup
mhasan@cchospice.org



@MLMC
SC



www.mylifemychoices.or
www.sc9post.org



@MLMC_
SC



Micki Jackson
ACP advocate, volunteer
& grassroots organizer

Bellingham, WA

Rebecca Rech Cutler, BSN, RN, CRRN (Certified Registered Rehabilitation Nurse), CHPN (Certified Hospice and Palliative Nurse).

Rebecca has been a RN for 30 years with 15 years of Home Health and 5 years of Hospice experience.

Bill Lombard, MD

Nephrologist and medical director of the DaVita Mt. Baker Kidney Center. Dr. Lombard has been practicing in Whatcom County for over 35 years.

"Helping others understand what care and treatments you would want if you were unable to communicate yourself is the biggest gift you give yourself as well as those you leave behind. Help us make sure your wishes are known and understood and mention to your doctor that you'd like to complete an advance directive."

- Scott Foster, MD, MPH,
Chief Medical Executive,
PeaceHealth Medical Group

"Realities of Advanced Medical Interventions' supports good decision-making before an accident or serious illness occurs. This presentation is a conversation starter to help you prepare to talk to your family, friends and to your doctors so that you can make your healthcare wishes known."

- Micki Jackson, advocate for
Advance Care Planning &
Community Palliative Care

Resource Contacts for Assistance with Advance Care Planning

Hilary Walker

PeaceHealth Program Coordinator for Advance Care Planning | Palliative Care
360-752-5267 | hwalker@peacehealth.org

Advance Care Planning Volunteers & Facilitators

Whatcom Alliance for Health Advancement
360-788-6594 | info@whatcomalliance.org

Information on Realities of Advanced Medical Interventions

Micki Jackson, Coordinator

360-201-7840 | micki98226@aol.com



THE REALITIES OF ADVANCED MEDICAL INTERVENTIONS



Bill Lombard and Rebecca Rech Cutler will present in frank terms the meanings of advanced medical interventions, and what their outcomes could mean for patients in the short and long term. Advance care planning, advance directives, and the importance of palliative care are discussed. These interactive sessions include Q&A.

— 2019 Quarterly Schedule —

St. Luke's Health Education Center,
3333 Squalicum Parkway

March 6, 2019, Wednesday, 6:00PM

Presenter: Rebecca Rech Cutler, BSN, RN, CRRN, CHPN

June 5, 2019, Wednesday, 6:00PM

Presenter: Rebecca Rech Cutler, BSN, RN, CRRN, CHPN

September 4, 2019, Wednesday, 6:00PM

Presenter: Rebecca Rech Cutler, BSN, RN, CRRN, CHPN

December 4, 2019, Wednesday, 10:00AM

Presenter: Bill Lombard, MD



Examples of Collaborations



Whatcom Transport Authority for NHDD

"Now I know, what I didn't know, is what I need to know."
- Mike Diehl, DIEHL FORD (member)

Rotary Club presentations

The Realities of Advance Medical Interventions

Make Your Wishes Known

May 13, 2019 6:30 PM

UNITED CHURCH OF CHRIST

885 4th St (4th & Clark) BLAINE

Contact: Mary Libby
360 - 961 - 2370

waha

Rebecca Roth Cutler, RN, BSN, CRRN, CHPN
Whatcom Hospice & Home Health Experience
REALITIES OF ADVANCED MEDICAL INTERVENTIONS

For free, confidential assistance in completing your Advance Directive, reach out to WADA. Call (800) 788-6086 to make an appointment.

Rebecca Roth Cutler, BSN, RN, CRRN, CHPN, has been a nurse for over 30 years, with 15 years of Home Health and 5 years of Hospice experience. She will present in layperson's terms the meanings of advanced medical interventions, as well as what the outcomes could mean for patients in the short and long term. Advance care planning, advance directives, and the importance of palliative care are discussed. Rebecca will explain what a POLST is - Physician Order for Life Sustaining Treatment. This interactive session includes Q&A.


Health Ministries Network



Local Subaru Dealership for NHDD



Example of How Grassroots Grows



PROVIDENCE
Health & Services
Southwest Washington

"I've Got Mine" Campaign Template
(Beginning efforts in SW WA to customize for individuals and groups ready to share the message and LEAD BY EXAMPLE)



I've Got Mine!
(MY ADVANCE DIRECTIVE)

*Joan Arledge, Senior Manager, Employee Relations
Bridget O'Connell, Chief Executive
Providence Southwest Washington*

I've Got Mine!
(MY ADVANCE DIRECTIVE)

*Providence Southwest Washington Leadership Team members
'Leading by Example'*

I've Got Mine!
(MY ADVANCE DIRECTIVE)

*Joan Arledge, Senior Manager, Employee Relations
Providence Southwest Washington*

I've Got Mine!
(MY ADVANCE DIRECTIVE)

*Joan Arledge, Senior Manager, Employee Relations
Providence Southwest Washington*

Thanks to Marie Eaton and Team for the video

Thanks to Micki Jackson, Whatcom County community advocate, who conceived the "I've Got Mine" campaign for PeaceHealth Medical Group, and to all the ACP volunteers in her community and throughout Washington State

Q&A and Discussion




Additional example

Boston Theological Interreligious Consortium (BTI) Life Long Learning conference

Organizers: Co-sponsored by Boston Theological Institute, with support from The Conversation Project and the Massachusetts Serious Illness Coalition (MASIC), BCBS

- **Aim** to reach clergy in formation, faculty, alumni, and clergy in practice, lay leaders with an interest in how to bring Advance Care Planning to their faith institutions.
- **Motivational pull** - theological grounding for “why do it.”
- **Structured** for maximum inspiration and practical information
- **Stories shared** about how other congregations have done this successfully
- **Tools for action** including the Hello Game, The Conversation Project’s Starter Kit guide

<https://pj.news.chass.ncsu.edu/2019/05/06/getting-their-internal-house-in-order-a-day-of-conversation-prepares-clergy-to-help-congregants-face-end-of-life-issues/>



Dying Well
Multi-Religious End of Life Conversations

Tuesday April 2, 2019
9:30 a.m. – 3:00 p.m.

Hebrew College
160 Herriek Road, Newton Centre, MA

Conversations about what it means to live well until the very end have a powerful impact on how we live -- and how we die.

Conversations can help preserve personal autonomy and respect for our faith-based values and practices. They can save families from making uninformed medical decisions when confronted by a crisis. They are an entryway to a deep spiritual practice, and ultimately, they become a gift and a blessing for all.

While 90% of Americans think having these conversations is important, most of us don't know how to begin them, or wait until it's too late.

The BTI Consortium's Inaugural Lifelong Learning Conference is designed to provide you with direct experiences and resources you can use to facilitate these sacred conversations in your families and institutions so that no one is left in the dark about what would matter most.

Limited seating - Registration required:
\$25 - Members of the Public
\$10 - BTI Consortium Students, Faculty, and Staff
All attendees will receive a free set of Hello: The Conversation Game about Living and Dying and What Matters Most





At the Lifelong Learning Conference you will:
Be inspired by faith leaders who will introduce you to various theological perspectives on care and conversations through the end of life. A panel discussion with Aida Mansour (Islamic Chaplain, Hartford Seminary); Chris Berlin (Buddhist Studies, Harvard Divinity School); Dr. Philip Marmalakis (Pastoral Care, Hellenic College Holy Cross Greek Orthodox Seminary); Rabbi Joel Baron (Habrav Senior Life); Dr. M. Sarah Rosenthal, PhD (University of Kentucky); moderated by Rabbi Or Rose (Habrav College).

Enjoy rich conversational interactions facilitated by the co-designer of the game, Start with HELLO, Jethro Heikco. Learn from the deep experience of having Planning Ahead conversations in her congregation with Rev. Dr. Gloria White-Hammond, MD, MDiv.

Reflect on what matters most to you with the Advisor to Faith Communities at The Conversation Project, Rev. Rosemary Lloyd, BSN, MDiv.

Leave with your own copy of The Hello Game and Conversation Starter Kit.

Info & Registration at:
bostontheological.org

TCP Additional Resources and Updates

Upcoming Community Calls

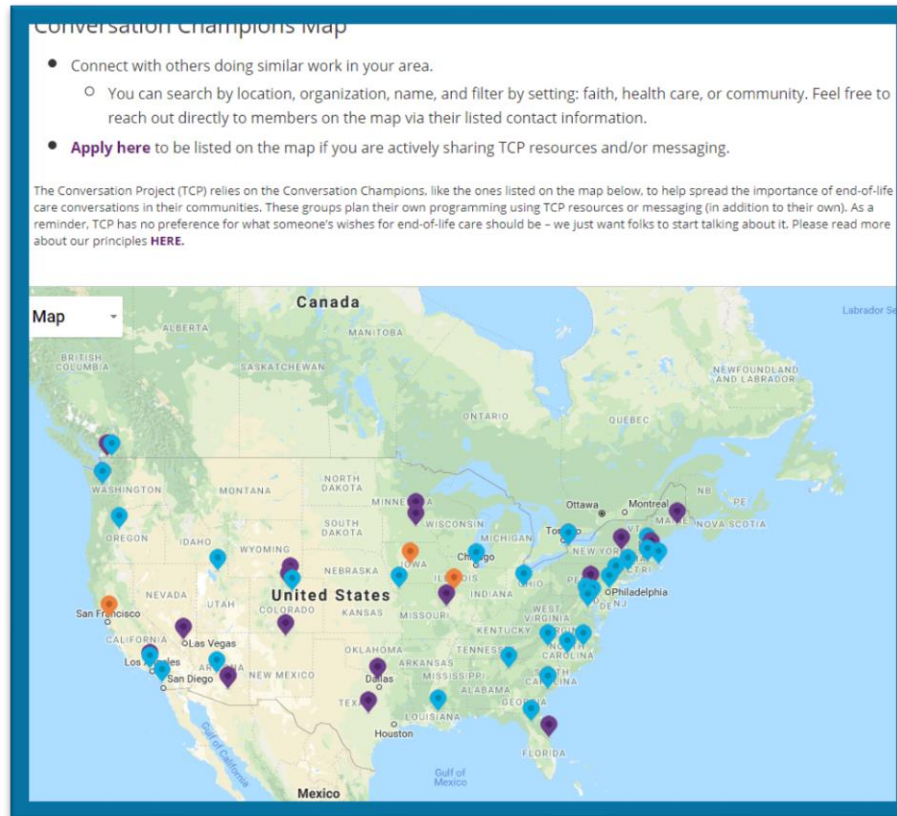
The next Conversation Project Community Call will take place on:

Wednesday, June 19th, 3:00-4:00 PM EDT

Date and Time	Topic
Wednesday, June 19 th , 3:00–4:00 pm EDT	Community Planning 101
Wednesday, July 17 th , 3:00–4:00 pm EDT	Community 201: Lessons on Messaging from the Massachusetts Coalition for Serious Illness Care
Wednesday, Aug 21 st , 3:00-4:00pm EDT	Special Interest: Conversation Sabbath

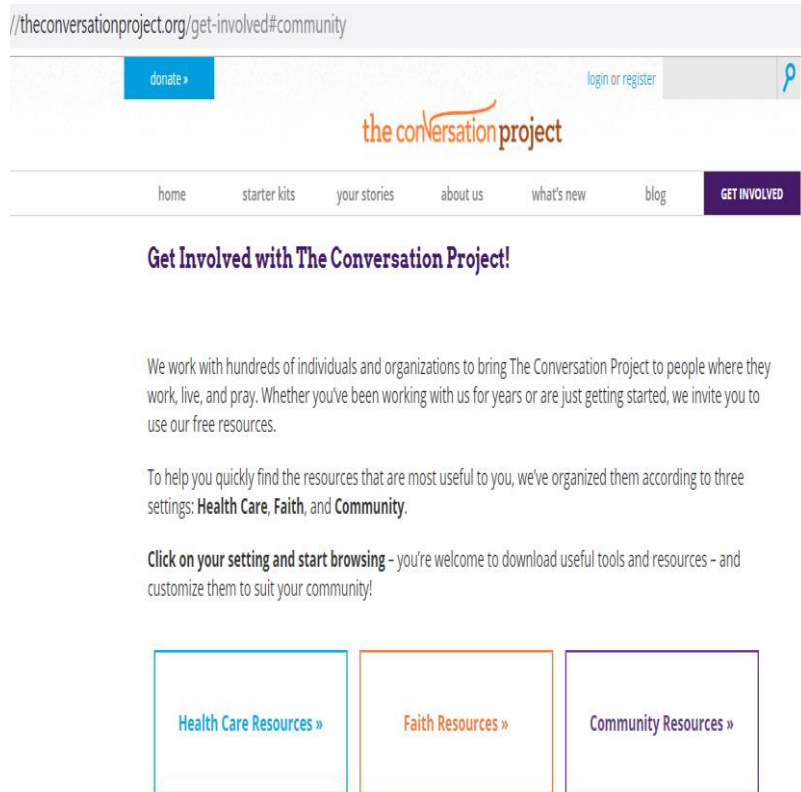
TCP Conversation Champions Map

- Search, connect/network and learn together



<https://theconversationproject.org/get-involved>

TCP Get Involved Page: 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>

New Resources

- How to Talk to Your Patients about End-of-Life Care: A Conversation Ready Toolkit for Clinicians

<http://www.ihl.org/resources/Pages/Tools/Conversation-Ready-Toolkit-for-Clinicians.aspx>

- 6 Go-to Health Care Resources: Respecting End-of-life Care Wishes

<https://theconversationproject.org/tcp-blog/6-go-to-health-care-resources-respecting-end-of-life-care-wishes/>

- Resource Recap and Highlights of the Month: April 2019

<https://theconversationproject.org/tcp-blog/new-content-april-2019/>

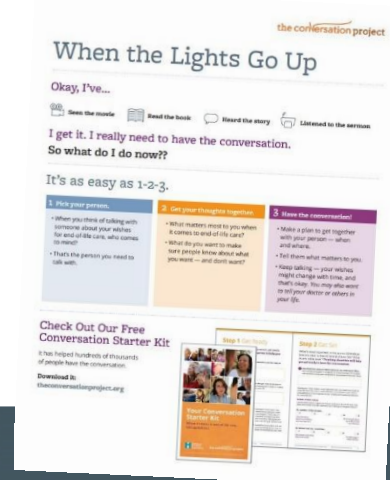


How to Talk to Your Patients about End-of-Life Care

A Conversation Ready Toolkit for Clinicians



conversation ready



Write a Letter to Your Loved One

- Write a letter to your loved one(s) about what matters most to you and email your letter to conversationproject@ihi.org

“And for God’s sake, have mercy and trim my chin and upper lip hairs.”

“No heroics. Listen to your mother.”



We want your feedback!

After this call you will be redirected to a Survey Monkey form.

Please take a few moments to answer questions that will ask you to rate the overall effectiveness of this call.

THANK YOU!

Thanks and appreciation



The John A. Hartford Foundation
Dedicated to Improving the Care of Older Adults