

Respecting Wishes: Lessons from Conversation Ready

The Conversation Project



April 17, 2018

WebEx Quick Reference

Welcome to today's session!

Please use Chat to "All Participants" for questions

For technology issues only, please Chat to "Host"

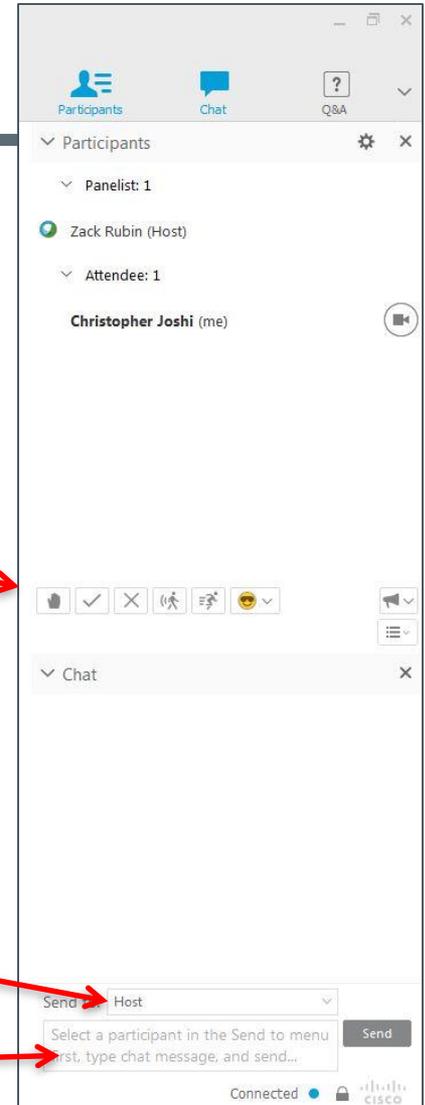
Raise your hand

WebEx Technical Support: 866-569-3239

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

Select chat recipient

Enter Text



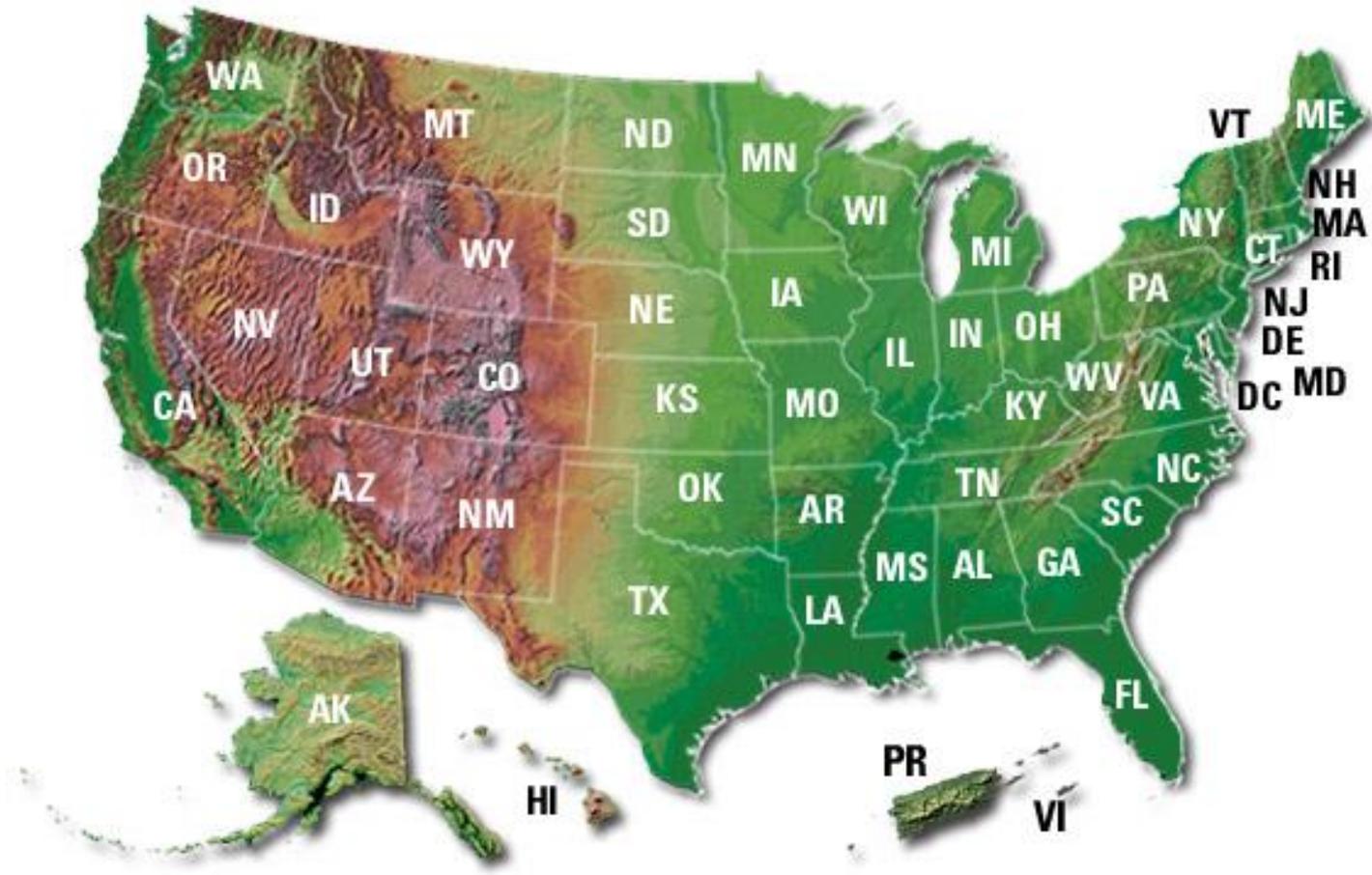
Ice Breaker Question

Type into the chat box your response to the following:

**What type of organization/institution
are you affiliated with?**

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

- TCP Updates/New Resources
- Framing
- Working across Boundaries to be Conversation Ready
- Questions and Discussion
- Wrap up

Upcoming Community Calls

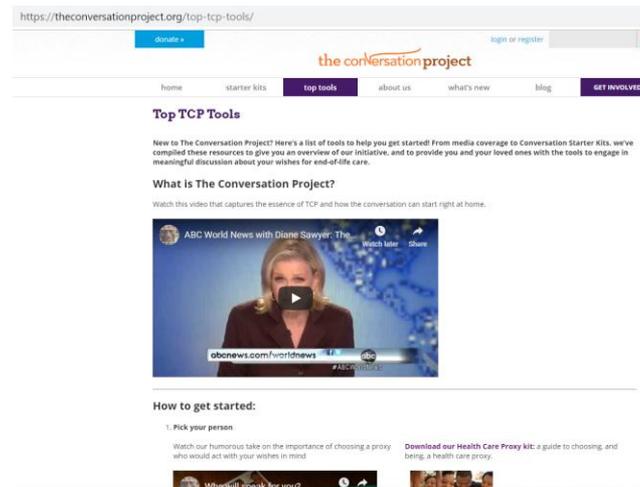
The next Conversation Project Community Call will take place on:

Wednesday, May 15th, 3:00-4:30 PM ET

Date and Time	Topic
Wednesday, May 15 th , 3:00-4:30pm EDT	Special interest: Working together – organizing and building coalitions
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TCP Updates: New Resources

- Ellen Goodman does the math video
<https://theconversationproject.org/ellen-goodman-does-the-math/>
- TCP standard slide deck and end-of-event evaluation - Spanish versions
<https://theconversationproject.org/resources/community>
- Top Tools Page



TCP Conversation Champions Map

- Search, connect/network and learn together

Conversation Champions Map

- Connect with others doing similar work in your area.
 - You can search by location, organization, name, and filter by setting: faith, health care, or community. Feel free to reach out directly to members on the map via their listed contact information.
- **Apply here** to be listed on the map if you are actively sharing TCP resources and/or messaging.

The Conversation Project (TCP) relies on the Conversation Champions, like the ones listed on the map below, to help spread the importance of end-of-life care conversations in their communities. These groups plan their own programming using TCP resources or messaging (in addition to their own). As a reminder, TCP has no preference for what someone's wishes for end-of-life care should be - we just want folks to start talking about it. Please read more about our principles [HERE](#).



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

TCP Community REMINDER

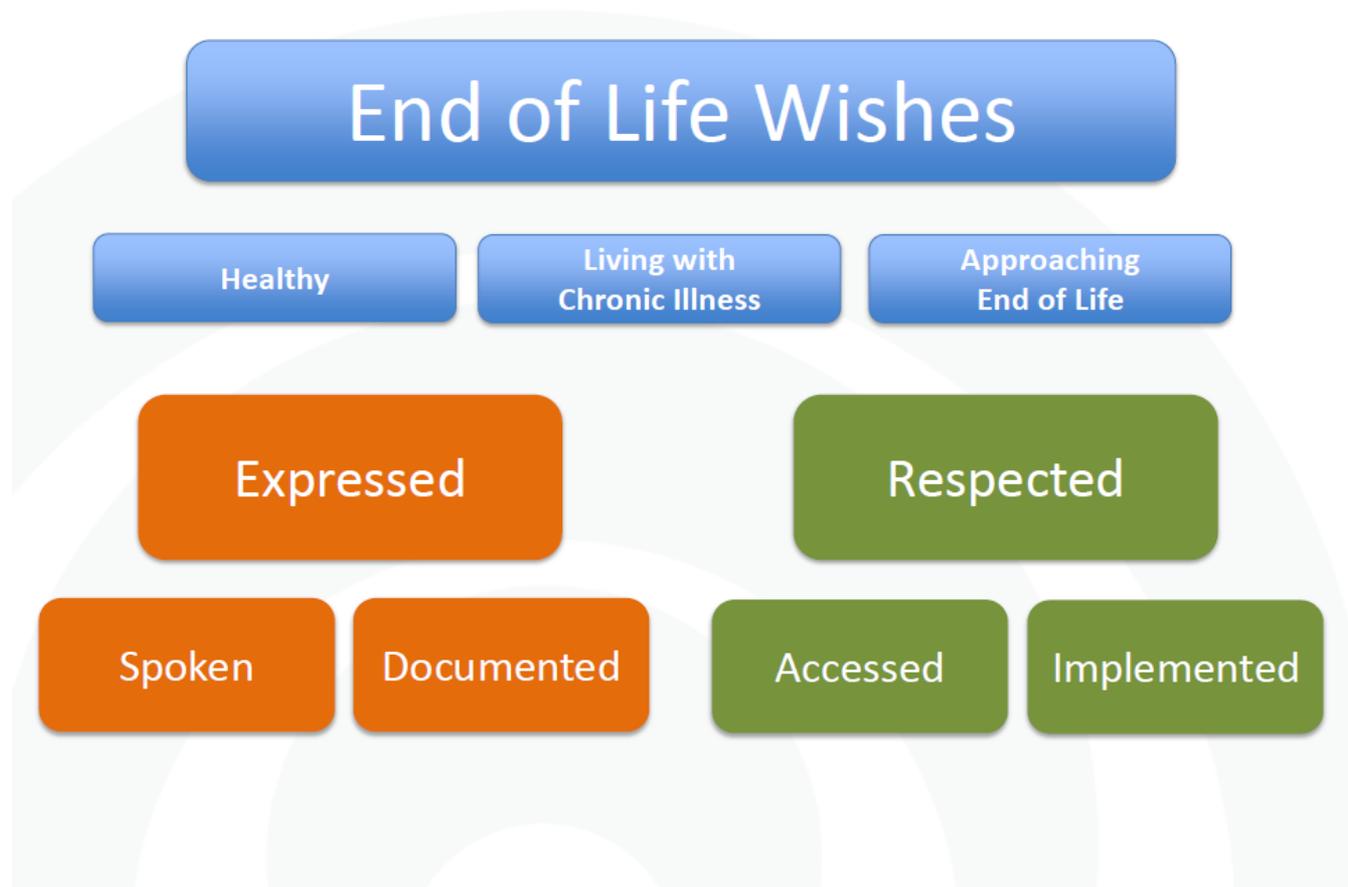
Quarterly [Community Activity Survey](#) is open
until Friday April 26th!

<https://www.surveymonkey.com/r/DP325TF>

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

the conversation project

The Conversation Continuum



What
Matters TO
Me?

As Well As

Health Systems Transformation

What's the
Matter with
Me?

Public Awareness Community
Engagement



Kelly McCutcheon Adams, LICSW



Kelly McCutcheon Adams, MSW, LICSW, is a Senior Director at the Institute for Healthcare Improvement, where she focuses on critical care and end-of-life care. She also teaches the IHI Breakthrough Series College regarding running successful collaboratives. She is an experienced medical social worker with experience in emergency department, ICU, nursing home, sub-acute rehabilitation, and hospice settings. Ms. McCutcheon Adams served on the faculty of the U.S. Department of Health and Human Services Organ Donation and Transplantation Collaboratives as well as on the faculty of the Gift of Life Institute in Philadelphia. She has a BA in political science from Wellesley College and an MSW from Boston College.

Working Across Boundaries to be Conversation Ready

Kelly McCutcheon Adams, LICSW



Getting Started

- "..being a physician involves much more than handing out diagnoses and treatment; it involves playing a role in some of the most intimate decisions of a patient's life. This requires a considerable amount of human delicacy and judgment..." -Oliver Sacks

History of the work: 2012-Present

- The Conversation Project
- Pioneer Sponsors
- First Collaborative
- Seminar, White Paper, Expeditions
- Howard County (MD) and Massachusetts Collaboratives
- Just published: Conversation Ready White Paper
- Coming VERY soon: Conversation Ready Toolkit

There is a gap

More than **9 in 10** Americans think it's important to talk about their loved ones' and their own wishes for end-of-life care



Nationally...

32% have discussed what they want when it comes to their end of life care with their loved ones

In one state...

13% had a conversation with a health care provider about end-of-life care wishes

27% of patients with a ***serious health condition*** had a conversation with a health care provider about their end-of-life care wishes

Conversation Project Survey, 2018
Massachusetts Coalition for Serious Illness
Care Survey, 2018

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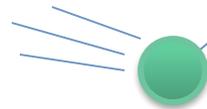
The gap matters to patients & families

Goal **discordant** care can cause harm...

- Exposes patients to the risks of treatments they *don't* want
 - Or deprives them of the benefits of treatments they *do* want
- May cause patients (and their families) to lose opportunities to have spent their time differently
- Fosters distrust of the involved health professionals and organization when patients realize there was a better alternative for them
- May make them less willing to return or to recommend
- At worst → an undignified death



Clinicians decide
No patient input



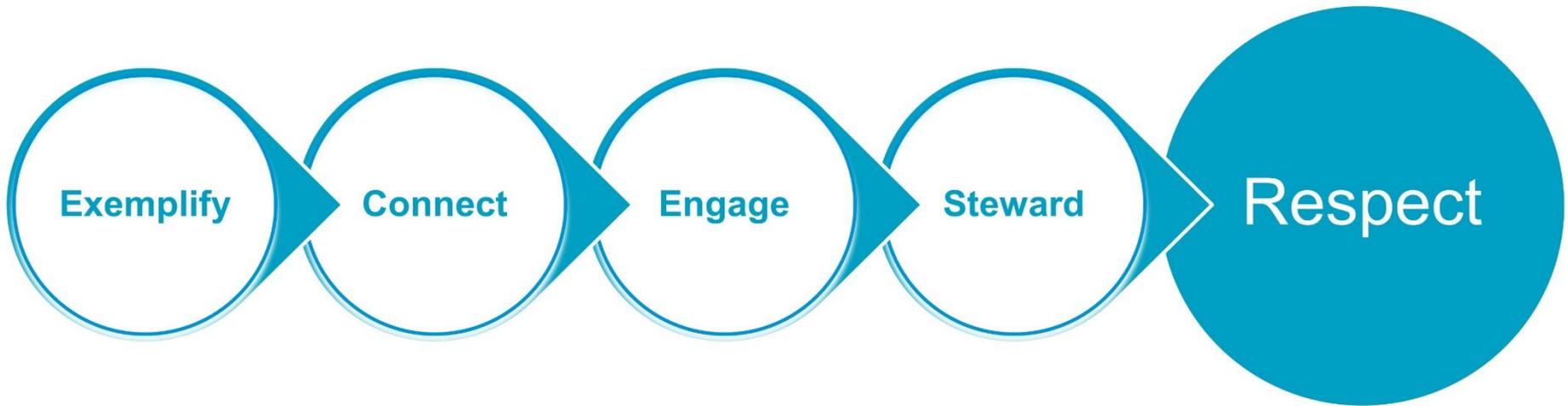
Patient decides
No clinician input

The Pendulum of Decision-Making

Conversation Ready Principles



Conversation Ready Principles



Conversation Ready Principles

1. **Exemplify** this work in our own lives so that we fully understand the benefits and challenges
2. **Connect** with patients and families in a culturally and individually respectful manner
3. **Engage** with our patients and families to understand what matters most to them at the end of life
4. **Steward** this information as reliably as we do allergy information
5. **Respect** people's wishes for care at the end of life by partnering to develop a patient-centered plan of care

Exemplify: Walking the walk



Beth Israel Deaconess: Talk Turkey

BIDMC TODAY

"Talk Turkey" Encourages End-of-Life Discussions

Published: 11/21/2013 9:00:00 AM

As families around the country gather for Thanksgiving, BIDMC's Department of Social Work and Ethics Support Service will hold its annual "Talk Turkey" campaign to educate staff, patients and visitors about the importance of health care proxies on Monday, Nov. 25 and Tuesday, Nov. 26.

Health care proxy forms in multiple languages and other advance directives materials will be distributed at the east and west campus cafeterias, as well as the West Clinical Center and Carl J. Shapiro Clinical Center lobbies



Erie County Medical Center

“...in addition to our community outreach efforts, we have started to engage med students, residents, nurses and nursing students, case managers, and social workers. Fortunately, we have a wonderful [palliative care] doctor on our outreach team, she has... been a huge asset to the team... [connecting] me with ... different departments throughout the hospital to schedule presentations... we’ve received a lot of positive feedback in doing this, and have even been asked to do 2-3 part series for the different groups. It’s very encouraging!”

Connect: Finding cultural humility



Clergy at the Intersection of Life & Death

“Henry Ford Health System has worked for decades with the faith community, ...but before the IHI Conversation Ready program challenged us, we had never brought the two communities together.”

- Over 200 clergy and clinician dialogue partners
- They post resources for faith communities
<http://www.henryford.com/body.cfm?id=59375>
- Tailor advance care planning outreach to underserved or underrepresented populations

Other Connect Examples:

- Contra Costa Interpreter Training
- Boston Senior Home Care – work with Chinese elders in housing communities

An amazing resource from Stanford

- Ethnogeriatrics modules

- [African-American](#)
- [American Indian](#)
- [Asian Indian](#)
- [Chinese](#)
- [Filipino](#)
- [Native Hawaiian and Pacific Islander](#)
- [Hispanic/Latino](#)
- [Japanese](#)
- [Korean](#)
- [Pakistani](#)
- [Vietnamese](#)

Engage: Moving from reactive to proactive

Tar Wars®

ASK AND ACT
A TOBACCO CESSATION PROGRAM

Care New England



Care New England
“Conversation
Nurse”

- New Palliative care program experienced explosive growth
- About 70% were for goals of care
- Needed a way to engage more patients with limited resources
- RN very skilled in having goals of care conversation
 - Re-labelled her “Conversation Nurse”

Lally, et al. 'The Conversation Nurse' An Innovation to Increase Palliative Care Capacity. *Journal of Hospice and Palliative Nursing*. 2016;18(6):8.

How the Conversation Nurse role took off

- Contacted directly by MDs to have goals of care conversations
- Now broad acceptance by providers and patients
- Hospital sees Palliative Care as a team-based program
- Have expanded to three nurses

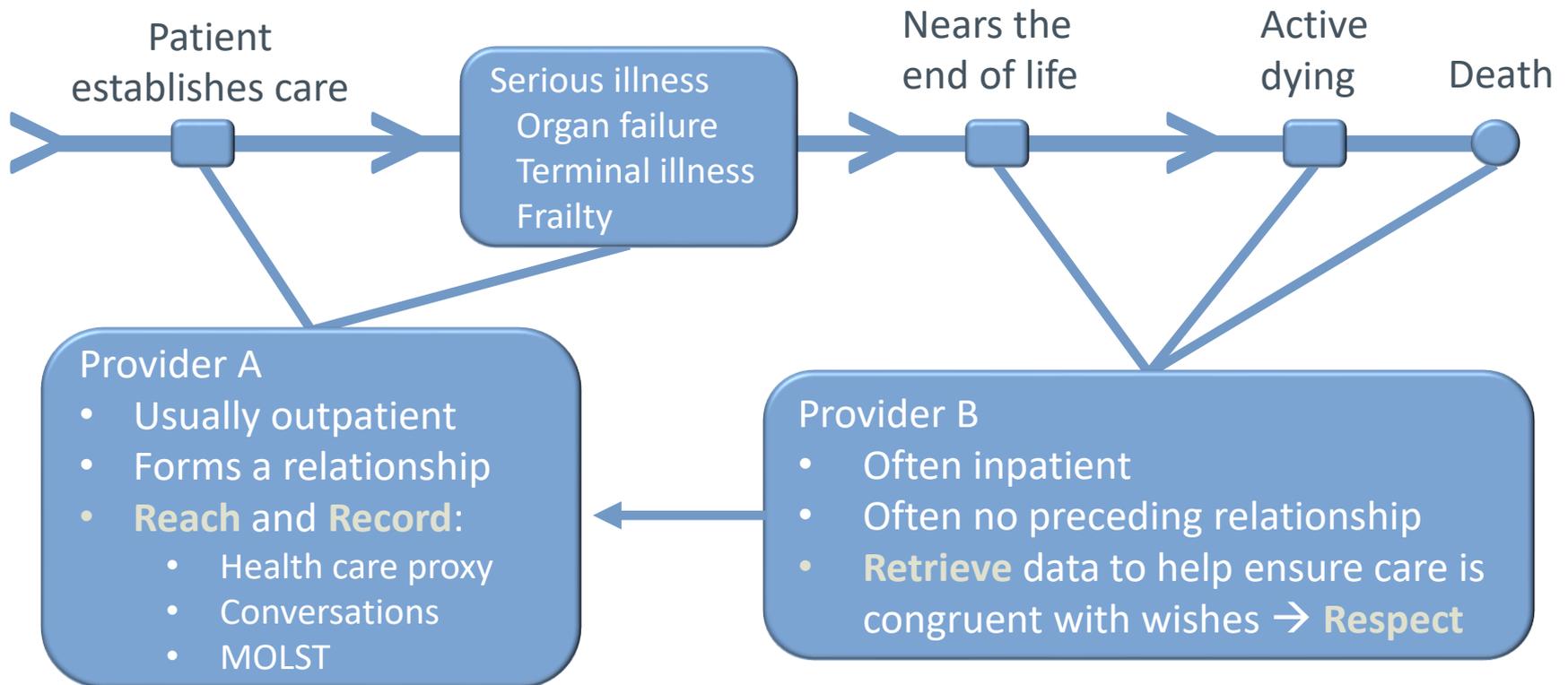
How to Change the Culture

- Document what you hear when you ask
 - **“What Matters Most to You?”**
 - Examples:
 - I want to die at home.
 - I want to see my sister before I go.
 - I want to continue all treatment until it is clear that I cannot communicate with my family.

Steward: The Allergy Analogy



Advance care planning as a process



Allergy analogy

Lunney et al., "Profiles of Older Medicare Decedents," J Am Geriatr Soc, 2002

Virginia Mason Medical Center's Electronic Medical Record

This page is not a complete source of visit information

VMPages Ambulatory Summary Loaded 12/2/2010 11

Visit Info
Admission Date: 12/02/2010
Hospital Days: 0

Advance Directive
No Known Advance Directive
Advance Directive Notes: (may include Care Planning notes prior to 10/20/2010)
07/08/2010 15:56 Auth (Verified)

Allergies
NKA (Active)

Problems
Medical
CAD - coronary artery disease(414.00)
CHRONIC ANGLE-CLOSURE GLAUCOMA(365.23)
Concept - High-Risk Vascular Disease(NONE)
Parkinson's disease(332.0)
PULMONARY EMBOLISM, 2009, after immobility from back pain(415.1)
Skin cancer, probable basal cell, s/p Mose surgery nose(173.9)

Surgical History
CABG 1 vessel(NONE)
cervical laminectomy?(NONE)
lumbar laminectomy(NONE)
Neuroplasty and/or transposition; median nerve at carpal tunnel(NONE)
pituitary tumor(NONE)

Family History
No Family History Found



Monday, January 30, 2012

- Messages
- Administrative Documentation
- Clinical Notes
 - Advance Directive Note
 - 05/03/2012 18:52 Coates MD, D Evan - "Comfort Care Decision Making"
 - 05/03/2012 14:49 Powell MSW, Elizabeth A - "Palliative Care Inpatient Note"
 - 05/02/2012 12:05 Powell MSW, Elizabeth A - "Palliative Care"
 - 05/01/2012 12:46 Coates MD, D Evan - "POLST"
 - 04/25/2012 16:34 Bumpus ARNP, Molly K - "Supportive care outpt clinic visit"
 - 04/25/2012 14:33 Bumpus ARNP, Molly K - "Goals of care"
 - CAR Electrophysiology
 - Care Plan/Pathways
 - Consultation



Respect: The real outcome



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,

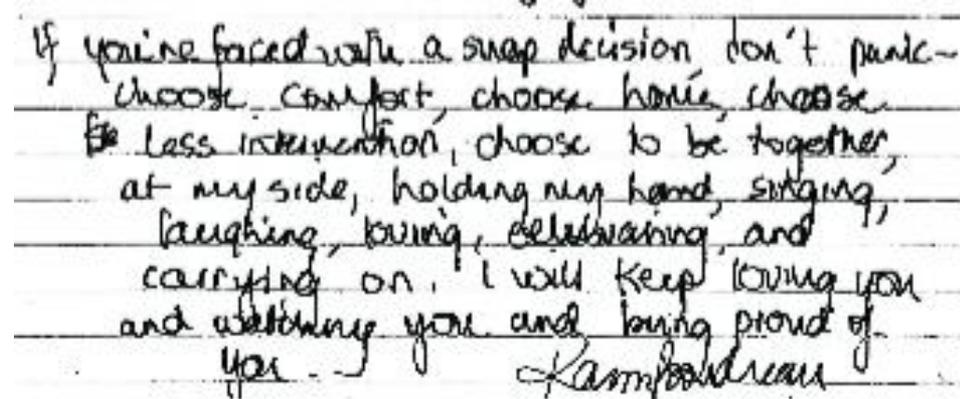
Choose home,

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

A starting place: Death Chart Review process

- One of the simplest ways for organizations to get started learning about their systems and thereby better focus their efforts is to perform a Death Chart Review, which is done by noting the following items for each of the last 10 to 20 patients who died in a relevant setting of care:
- Location of death, the circumstances of the death (traumatic, sudden, prolonged, expected, etc.), and the presence of any serious illnesses (cancer, dementia, heart failure, etc.)
- Documentation of legally authorized surrogate medical decision maker (e.g., durable power of attorney for healthcare, health care proxy, etc.)
- Evidence of other advance directives (e.g., living wills, and not that they were just noted to exist, but that they could be accessed and understood)
- Documentation of “what matters most” to the patient
- Documentation of provider and patient conversation(s) about end-of-life care wishes (or with surrogate decision maker, if patient not able to participate)
- Evidence of POLST-paradigm type form(s)

Thank you



Q&A and Discussion



Monthly Community Calls

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TCP Health Care Resources

the conversation project

home starter kits top tools about us what's new blog GET INVOLVED

Resources for Healthcare Professionals

How to Engage Patients and Families About End-of-Life Care

Online Course: Basic Skills for Conversations about End-of-Life Care: In collaboration with the IHI Open School and Boston University School of Medicine, The Conversation Project offers this free course to help develop skills to have conversations with patients and their families about their preferences for care at the end of life.

New! IHI White Paper: "Conversation Ready": A Framework for Improving End-of-Life Care (second edition): The Institute for Healthcare Improvement developed a detailed framework based on the work of The Conversation Project to help health care organizations begin the process of becoming Conversation Ready. This paper describes the Conversation Ready framework, including suggested changes and measures to guide improvement of end-of-life care. This second edition was published in March 2019 based on additional learning from several years of work with dozens of diverse health care organizations and hundreds of health care professionals.

Medicare Reimbursement for End-of-Life Conversations

Frequently Asked Questions: This short, one-page guide answers FAQs around Medicare reimbursement for end-of-life conversations, and provides brief suggestions and goals for providers to have the conversation with patients at different stages of illness.

2016 Virtual Call Series: End-of-Life Care Conversations — Preparing Your Team for Success and CMS Reimbursement: Whether you are uncertain about the new rules for CMS reimbursements, or about starting those conversations with patients, this call series serves as a helpful reference in understanding the new landscape for end of life conversations. Recordings of this call series are available to purchase for \$99.

Cultural and Ethnic Considerations: resources to having culturally/ethnically sensitive conversations.

Ethno Geriatrics Training: modules from from Stanford School of Medicine for health care providers to raise awareness of specific cultural, racial, and ethnic influences on health and health care of older people from specific ethnic backgrounds.

New! Phyllis R. Coolen: Cultural Relevance in End-of-Life Care: an article addressing three major areas of cultural relevance in end-of-life care: cultural competency in clinical practice; advance directives; and pain management.

New! Avoiding Cultural Assumptions in Palliative Care — An Interview with Two Sojourns Scholars: an episode from Cambia Health Solutions' HealthChangers Podcast.

Resources for Engaging Patients and Families

Starter Kits: a series of guides to help people discuss end-of-life care wishes.

Conversation Starter Kits: a guide to help people have conversations with their family members or other loved ones about their wishes regarding end-of-life care.

Health Care Proxy Kit: a user-friendly guide offers facts and tips necessary to make sound decisions about choosing, and being, a health care proxy.

How to Talk to Your Doctor: a guide to help people engage their health care team about end-of-life care wishes.

Co-branding: Two options to co-brand our kits with your organization's logo and contact information.

Ariadne Lab's Serious Illness Conversation Guide: a step-by-step guide to elicit important information from your patients about their goals and

- White Paper:
 - Conversation Ready: A Framework for Improving End-of-Life Care (2nd edition)
- Free course/call series
- Resources on cultural and ethnic considerations

<https://theconversationproject.org/resources/healthcare/>

Related article/videos

- Conversation Ready's Kate Lally, MD: Having the Conversation I Encourage Others to Have
<https://jamanetwork.com/journals/jama/fullarticle/2730118?resultClick=1>
- David Wood, MD, CMO Beaumont Health, MI shares challenging experience he faced as the surrogate decision maker for his father at the end of life
<https://theconversationproject.org/When-wishes-are-not-respected-at-end-of-life>
- Lachlan Forrow, MD, asks Dolly Baker simply and deeply: “what would make today a good day for you?”
<https://theconversationproject.org/tcp-blog/the-doctor-and-the-jazz-singer/>

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



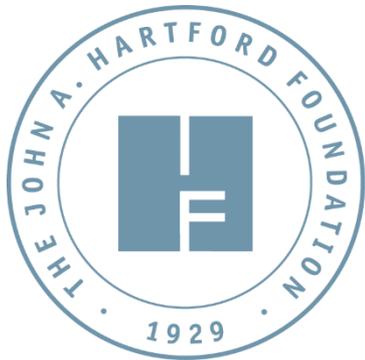
We want your feedback!

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