L2: Respecting Patients' End-of-Life Wishes

Kate DeBartolo, Director
Kelly McCutcheon Adams, Director

These presenters have nothing to disclose.

Session agenda and objectives

- Overview of The Conversation Project and Conversation Ready principles
- Introduce you to resources available to help patients and families have “the conversation”
- Review questions to consider for your region
Introductions

- Name
- Organization
- What brings you here today? What are you hoping to learn?

A public engagement campaign dedicated to assure that everyone’s wishes for end-of-life care are expressed and respected.
WANT TO DIE AT HOME.

70% WANT TO DIE AT HOME.
70% actually die in the hospital.

80% want to talk with their doctors.
Have had a conversation with their doctors

Massachusetts: 17%

California: 7%

The Conversation Project
90% THINK IT'S IMPORTANT TO HAVE THESE CONVERSATIONS

30% HAVE ACTUALLY DONE SO
The Conversation Continuum

End of Life Wishes
- Healthy
- Living with Chronic Illness
- Approaching End of Life

Expressed
- Spoken
- Documented

Respected
- Accessed
- Implemented

Awareness: Media Engagement
Accessible: Our Tools

- Conversation Starter Kit (translations + EMR summary)
- 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
- Starter Kit for identifying and being a good proxy

Community Efforts
“The new hope is that we can change the culture to treat the patients as they wish to be treated rather than treating them because we can.”

-Billie Kester, Reid Hospital, Indiana, Conversation Ready Health Care Community Member
Six years ago on a trip to New York…

History of Conversation Ready

- 2012-2013: Pioneer Sponsors
- 2014: First Collaborative
- 2015: White Paper, seminar, Expedition
- 2016-2017: CMS Stat call series, Howard County Collaborative
- 2017-2018: Massachusetts Collaborative
Conversation Ready Pioneer Sponsors: September 2012-September 2013

- Beth Israel Deaconess Medical Center
- Care New England Health System
- Contra Costa Regional Medical Center
- Henry Ford Health System
- Mercy Health
- North Shore–Long Island Jewish Health System
- St Charles Health System
- UPMC
- Virginia Mason Medical Center

Contributing Sponsor: Gundersen Lutheran

Conversation Ready Principles

Engage - Steward - Respect

Exemplify - Connect
Conversation Ready Principles

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

Engage: proactive
Steward: The Allergy Analogy

Respect: Like Birth Plans
Exemplify: Follow Me

Connect: Culture Matters
Break

Please be back in 15 minutes

A Tale of Two Health Systems

- How was this created?
- Where we have been: Retaining Hope Health Care
- Where we are going: Reliability Health Care
At **Retaining Hope Health Care**, conversations about wishes for end-of-life care are consistently pushed downstream, as no provider wants to be seen as “taking away hope”. Death is seen as the enemy and acceptance of its inevitability is not normalized in the provider and patient relationship. Discussions of end of life care wishes are separated out from discussions of smoking, weight, home safety, and blood pressure and often do not occur until Palliative Care is consulted for a patient in the intensive care unit who is receiving multiple high-level interventions and has been bouncing in and out of the hospital.

At **Reliability Health Care**, providers are proud of their integrated, person-centered approach to understanding what matters most to their patients. They normalize discussions of wishes for end of life care alongside many other important topics like smoking, weight, home safety, and blood pressure. They set the tone for this being an important aspect of life and follow-up on the topic throughout the life course of their patients. Patients cared for in this system see this engagement with their providers as a part of their responsibilities as adults – alongside naming guardians for their minor children and securing life insurance.
Taking a look

- Engage section of Change Package

STEWARD

At Retaining Hope Health Care, fragmented and unreliable processes and systems cause information about advance directives and conversations about wishes for end of life care to be scattered among patient records and inaccessible across time and boundaries. When asked about documentation of wishes, patients say that they gave a copy to their doctor or have them locked up in a safe deposit box. Although providers have high reliability in tracking patient allergies, the same cannot be said of end of life care wishes.
At Reliability Health Care, information about patients’ wishes for end of life care are inquired about, tracked, and confirmed as reliably as allergy information. An integrated information system makes information about both relevant documents and critical conversation with providers easily accessible in a timely way and across boundaries of care. Just as allergy information should not be hidden in safe deposit boxes, patients understand that their wishes are an important driver of their care plans.

Taking a look

- Steward section of Change Package
At Retaining Hope Health Care there is a disconnect between anything that is known about patient wishes and their actual care leading up to their deaths. Still not wanting to take away hope and not wanting to declare that the end is nigh, care planning conversations do not surface the gravity of patient situations and opportunities to direct care differently. Families expressed being surprised afterwards that death was so close when they still thought treatment would be effective.

At Reliability Health Care, early engagement and reliable stewarding means that there is confidence that what has mattered most to patients over time is known and that this information is accessible and ready to be confirmed and adapted to current circumstances as patient gets closer to death. Patients and their loved ones are not caught off guard about the gravity of their illness and have an opportunity to take actions that have meaning to them prior to the end of their lives.
Taking a look

- Respect section of Change Package

EXEMPLIFY

At Retaining Hope Health Care, professionals rarely discuss the implications of their own end of life care wishes in the context of their work/interactions with patients. There is a strong culture of being death denying and the dynamic of not wanting to take away hope persists even in how colleagues talk with one another about their futures.
At Reliability Health Care a strong culture of “walking the walk” exists among providers. There are programs to prompt employees and physicians to undertake the work of examining their own wishes and discussing those with their loved ones. Providers have no sense of hypocrisy when they talk with their patients about having these conversations and can say with confidence, “I have done this myself, there were some bumps, but overall, it is a tremendous gift I have given to myself and to my family.”

Taking a look

- Exemplify section of Change Package
CONNECT

At Retaining Hope Health Care providers are in a “set it and forget it” mode when it comes to examining the effect of culture on decision-making style and the decisions themselves. Values default to Western, upper middle class perspectives on death with a presumption of Judeo-Christian traditions. Families are relied on for language interpretation and there are few connections to non-dominant tradition clergy. Cultural differences are seen as a source of frustration and something that slow providers down.

CONNECT

At Reliability Health Care there are systemic, reliable efforts to understand the influence of a patient’s cultural values on end of life care decision-making. Cultural values are seen as being different but still equal. Professional interpreters are used and bridges are built to smaller faith communities within the area served by the system. Providers have the humility to admit what they do not know and to approach families in a spirit of curiosity rather than superiority.
Taking a look

- Connect section of Change Package

Discussion

- What are you hearing in these two contrasting stories?
- R-E-S-P-E-C-T
- What does that look like?
- How can we go deeper in understanding whether we have respected our patients’ wishes?
- What changes can we test?
Getting involved

“I see three choices: to run, to spectate, to commit.”
Movie: City of Joy, 1992

Building Local Community Engagement

The Conversation Project
Getting Started Guide for Communities
Beyond your walls - 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

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Planning for your community

- **Who** is the audience you’re trying to reach?
- **How** is it best to reach them?
- **What** actions do you want them to take?

- **Who** do you want to work with?
- **How** are you going to do this? How much time will you have?
- **What** actions are you going to take to move this forward?
Design questions

- What do you want to accomplish?
  - What would make you proud?
  - What would success look like to you and your community?
- What do you need to do to get there?
  - What activities/key ingredients will you need to accomplish what you are working towards?
- How will you know if you’ve reached what you set out to accomplish?
  - What can you keep track of that will tell you you’ve reached your ultimate goal?

Getting Started Questions

- Who do you want to reach? And by when?
  - Your employees?
  - Everyone over age 75 in your community?
  - Staff working in the local retirement communities?
  - A study group within your faith community?
Getting Started Questions

- Who do you want to reach? And by when?
- How do you want to reach them?

How do you want to reach them?

- What are ways you can reach your target audience where they:
  - Work
  - Live
  - Pray

- What activities might help you engage your target population? For example:
  - Writing op-eds in the local newspaper
  - Speaking at conferences or educational events
  - Creating PSA Campaign to raise awareness
Regional Examples

- Hospice of the East Bay, CA
- Boulder, CO

SC Healthcare Decisions Day (SCHDD)

- SC Bar submitted proclamation for SCHDD
- Op ed templates, articles, presentations
- “Isn’t it time we talk?” brochure by The Carolinas Center for Hospice and End of Life Care, SC Medical Association, SC Bar, SC Hospital Association
- Advance Directives and FAQ on websites
- Attorney-physician pairs on local news stations, call in programs
Getting Started Questions

- Who do you want to reach? And by when?
- How do you want to reach them?
- What action do you want these folks to take?

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?
Getting Started Questions

- Who do you want to reach? And by when?
- How do you want to reach them?
- What action do you want these folks to take?
- 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?

Letter Text:

"Requesting hard copy of Conversation Starter Kit. Please mail to..."
Stakeholder Analysis

<table>
<thead>
<tr>
<th>Group Name</th>
<th>Stop?</th>
<th>Let?</th>
<th>Help?</th>
<th>What Matters to Them</th>
</tr>
</thead>
<tbody>
<tr>
<td>Academia (early adopters)</td>
<td></td>
<td></td>
<td>X</td>
<td>Educating the next generation of health care professionals to provide outstanding patient care in a changing environment</td>
</tr>
<tr>
<td>Academia (late adopters)</td>
<td>X</td>
<td></td>
<td></td>
<td>Educating the next generation of health care professionals with a deep understanding of science and sharing what they have learned during their tenure</td>
</tr>
<tr>
<td>Medical Student Associations</td>
<td></td>
<td></td>
<td>X</td>
<td>Networking with like-minded students and providing value to members; being on the cutting edge</td>
</tr>
<tr>
<td>Nursing Student Associations</td>
<td></td>
<td></td>
<td>X</td>
<td>Networking with like-minded students and providing value to members</td>
</tr>
<tr>
<td>Pharmacy Student Associations</td>
<td></td>
<td></td>
<td>X</td>
<td>Networking with like-minded students and providing value to members</td>
</tr>
<tr>
<td>Boards</td>
<td></td>
<td></td>
<td>X</td>
<td>Ensuring boarded members will be good practitioners</td>
</tr>
</tbody>
</table>

Getting Started Questions

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- What action do you want these folks to take?
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- 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?
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

Getting Started Questions

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- Who will be responsible for actually doing this work in your community?
Getting Started Questions

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- Who will be responsible for actually doing this work in your community?
- How will you measure successes and challenges?

Outcome Measures

High-level targets you are trying to improve

- # people who complete the Conversation Starter Kit
- # people who discuss wishes for end-of-life care with health care provider
- # people who complete an advance directive
Process Measures

- Specific steps in a process that lead to an outcome measure

Examples:
- # individuals who receive Conversation Starter Kit
- # individuals who attend a Conversation Project workshop
- # media placements about The Conversation Project in local newspapers or magazines
- # presentations to community partners about The Conversation Project

Getting Started Questions

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- 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?
How will you reach diverse groups of people in your community?

- Consider the diversity of your community
  - language
  - age
  - race
  - religion
  - sexual orientation
  - gender identity
  - socioeconomic status

- What partners can you engage to help introduce this to a more representative audience?

Community Engagement Resources

Community Resource Center

Welcome to the Community Resource Center! Over the past couple years, we’ve been working with hundreds of individuals and organizations to bring The Conversation Project to people where they work, live and play. Here we’ve collected tools developed in our TCP communities—all available to you for free. You can download, use and share them to suit your community. There is no “one size fits all” approach to this work—you’ll have to test what will work in your own community.

Tips from our Community Getting Started Guide for an overview of how to begin this work:

- We’re looking forward to supporting and learning with you!

  *If you would like to stay connected, join our free monthly community call. Email conversationproject@bxu.org to sign up.

Download the Community Meeting Handbook.

You will need to edit a few figures and charts, and replace all references to our TCP conversations and how to get engaged other communities in your area. Please consider the Community Banking Guide.

- Community Getting Started Guide
- Community Organizing Resources
- Hosting Events
- Materials and Tools (translations, ACP resources and videos)
- Publicity and PR Materials
## Monthly Community Calls

<table>
<thead>
<tr>
<th>Date and Time</th>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wednesday, April 19th, 3:00 - 4:30 pm ET</td>
<td>Virtual Speaker Training Session</td>
</tr>
<tr>
<td>Wednesday, May 17th, 3:00 - 4:00 pm ET</td>
<td>Community Highlight</td>
</tr>
<tr>
<td>Wednesday, June 21st, 3:00 - 4:00 pm ET</td>
<td>Community Planning 101</td>
</tr>
<tr>
<td>Wednesday, July 19th, 3:00 - 4:30 pm ET</td>
<td>Virtual Speaker Training Session</td>
</tr>
</tbody>
</table>

### Planning Time
Developing Your Action Plan

Change takes place when people decide to take action. *What action do you want to take?*

- Who do you need to talk to when you get back?

- What information will you still need?
Developing Your Action Plan

Change takes place when people decide to take action. *What action do you want to take?*

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- In one year, if you were to have wild success, what will have been the factors of this success?
- In one year, if this project was a flop, what will have been the factors of this failure?
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- What would you like to see in place in 30 days? In 90?

Developing Your Action Plan

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- In one year, if you were to have wild success, what will have been the factors of this success?
- In one year, if this project was a flop, what will have been the factors of this failure?
- What would you like to see in place in 30 days? In 90?
- What will you try by next Tuesday?
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.