L6: Having the Conversation About End-of-Life Care: Personal and Professional Experiences

Harriet Warshaw, MSW, Executive Director,
The Conversation Project
Jessica McCannon, MD, Physician,
Pulmonary and Critical Care Division, MGH

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Objectives

- Understanding the importance of Having The Conversation from the Personal, Professional and System Perspectives

- Describe The Conversation Project and the role of both health care providers and individuals in discussing personal wishes for end-of-life care

- Identify the barriers to having end-of-life care conversations and the strategies and tools available to promote action

- Develop a conversation action-plan that includes both a personal and professional conversation
Today’s Speakers

Jessica McCannon, MD
Faculty, The Conversation Ready Health Care Community and Medical Director, The Conversation Project

Harriet Warshaw, MSW
Executive Director, The Conversation Project

Agenda

- 9:30-9:45am Welcome, Review of Agenda, Introductions
- 9:45–10:15am The Conversation Project Overview
- 10:15-10:45am Going Deeper: Having The Conversation In Your Own Life
- 10:45-11:00am BREAK
- 11:00-11:30am Overcoming Professional Barriers
- 11:30am-noon Conversation Ready Overview
- Noon -12:15 Leaving in action
- 12:15-12:30pm Questions, Final Reflections, Evaluations
The Conversation Project

The Life and Death of Marcy Glanz
The Conversation Project

- Public Engagement Campaign
- Expressed and Respected
- Co-Founded by Ellen Goodman
- Rooted in Personal Stories
- Double Helix of Change
- Change in Cultural Norm: from Not Talking to Talking
TCP’s Strategy for Creating Cultural Change

- Awareness: National media campaign
- Accessible: Tools to help people get started
- Available: Bringing TCP to people where they work, where they live, and where they pray

Media Coverage to Date
Our Tools

- Conversation Starter Kit
- How to talk to your Doctor guide
- Conversation Group Coaches guide

Field Strategy:

- Working with the States, Counties and Cities
- Monthly newsletter and call for Conversation Project Communities
- Identify and share best practices among regions
- Design new business opportunities with regions (currently: Atlanta, Hawaii, Portland…)
- Boston Faith-Based Initiative
- A Catalyst for Change
Learning to Date

- Universality of issue
- Starter kit is very accessible
- Having the conversation makes a major difference in peoples’ lives
- Not every conversation is perfect, need to start.....
- Not everyone wants to have the conversation
- Major impact on health care providers
- It always too early until it is too late!
The Gap

90% of people think it is important to talk about their loved ones’ and their own wishes for end-of-life care.

27% of people have discussed what they or their family wants when it comes to end-of-life care.

Source: The Conversation Project National Survey (2013)

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.

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Going Deeper: Having the Conversation in your Own Life
I want mine to be…

• “I want to say goodbye to everyone I love, have one last look at the ocean, listen to some 90’s music, and go.”
• “A tingling sensation of sadness combined with gratitude and overflowing love for what I leave behind.”
• “Paced (and with enough space and comfort so that I can make it a ‘quality chapter’ in my life.) I want time and help to finish things.”
• “Without suffering and without reproach.”
• “Peaceful, pain-free, with nothing left unsaid.”
• “In the hospital, with excellent nursing care.”

The Starter Kit: Get Set

Now, think about what you want for end-of-life care.

What matters to me is _____.

Start by thinking about what’s most important to you. What do you value most?

What can you not imagine living without?

Now finish this sentence:

What matters to me at the end of life is __________________________.

Sharing your “What matters to me” statement with your loved ones could be a big help down the road. It could help them communicate to your doctor what abilities are most important to you—what’s worth pursuing treatment for, and what isn’t.
The Starter Kit: Go

Mark all that apply:

Who do you want to talk to? Who do you trust to speak for you?

☐ Mom  ☐ Partner/Spouse  ☐ Doctor
☐ Dad  ☐ Minister/Priest/Rabbi  ☐ Caregiver
☐ Child/Children  ☐ Friend  ☐ Other: _______________________

When would be a good time to talk?

☐ The next big holiday  ☐ Before my next big trip  ☐ Other: _______________________
☐ At Sunday dinner  ☐ Before I get sick again
☐ Before my kid goes to college  ☐ Before the baby arrives

Where would you feel comfortable talking?

☐ At the kitchen table  ☐ On a walk or hike  ☐ Other: _______________________
☐ At a cozy café or restaurant  ☐ Sitting in a garden or park
☐ On a long drive  ☐ At my place of worship

Debrief
The Starter Kit: Keep Going

Congratulations!

Now that you have had the conversation, here are some legal and medical documents you should know about. Use them to record your wishes so they can be honored when the time comes.

- **Health Care Planning (ACP):** the process of thinking about your wishes—exactly what you have been working on here.

- **Advance Directive (AD):** a document that describes your wishes.

- **Health Care Proxy (HCP):** identifies your health care agent (often called a “proxy”), the person you trust to act on your behalf if you are unable to make health care decisions or communicate your wishes. In some states, this is called the Durable Power of Attorney for Health Care. This is probably the most important document. Make sure you have many conversations with your proxy.

- **Living Will:** specifies which medical treatments you want or don’t want at the end of your life, or if you are no longer able to make decisions on your own (e.g. in a coma).

You can find more information about these documents from the link in the “Keep Going” section of the website Starter Kit at www.TheConversationProject.org.

Remember, this was the first of many conversations.

Overcoming Professional Barriers
A memorable conversation

How did you learn how to do this?
How does this compare?

Pie in the sky
Conversation Ready and the Conversation Ready Health Care Community

One chance to do it right…

“When you talk about dealing with people who are nearing the end of their life and their family members, the work that we do stays with them forever. It’s the same way that people tell stories about the birth of their children, they also tell stories about the death of a loved one. And I just feel like you have one chance to do it right, and if we can work harder and harder to get it right on each patient and family, then that’s what we have to do. People in the hospital recognize that, even people who may not like working with patients at the end of their life, they understand that when that’s their task they have one chance and they need to get it right that time.”

Julie Knopp, NP, Palliative Care, Beth Israel Deaconess Medical Center
Conversation Ready

- The Conversation Project aims for individuals’ wishes for end-of-life care to be expressed and respected.
- In order to achieve this aim, health care systems must be prepared to receive an activated public and respect end-of-life wishes.
- IHI is working with leading health care organizations in the US and internationally to ensure the health care delivery system is prepared to **receive, record, and respect** patients’ wishes.
- Over the past year, a group of Pioneer organizations collaborated with IHI to design and test the Conversation Ready principles for use in their own systems and for possible adoption elsewhere.

Conversation Ready Pioneer Sponsors

- Beth Israel Deaconess Medical Center (Massachusetts)
- Care New England Health System (Rhode Island)
- Contra Costa Regional Medical Center (California)
- Henry Ford Health System (Michigan)
- Mercy Health (Ohio)
- North Shore–Long Island Jewish Health System (New York)
- St Charles Health System (Oregon)
- UPMC (Pennsylvania)
- Virginia Mason Medical Center (Washington)

**Contributing Sponsor:** Gundersen Lutheran
Going Forward

Last month, the Conversation Ready Health Care Community launched. It is a nine-month collaborative focused on continuing to refine and expand the Conversation Ready principles and the associated changes.

Twenty-three organizations have joined us for this phase of work.

We look forward to sharing our learning in the future.

Current 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 shared goals of care
4. **Exemplify** this work in our own lives so that we understand the benefits and challenges
5. **Connect** in a manner that is culturally and individually respectful of each patient
1. Engage with our patients and families to understand what matters most to them at the end of life:
   • St Charles – Heart Failure University
   • Mercy and Contra Costa – Primary Care appointments

2. Steward this information as reliably as we do allergy information
   • Virginia Mason – Advance Directive Note Type
   • BIDMC – IT revision
   • NSLIJ – MOLST work with skilled nursing facilities
Examples From the Field

3. Partner with our patients to develop appropriate goals of care
   • Care NE – Conversation Nurse
   • UPMC – Partners Program

Examples From the Field

4. Exemplify this work in our own lives so that we understand the benefits and challenges
   • UPMC – Day of Conversation
   • Mercy – Employee Focus Groups
   • BIDMC – Talk Turkey and Story database
Examples From the Field

5. Connect in a manner that is culturally and individually respectful of each patient
   • Henry Ford – faith community summit
   • Contra Costa – medical interpreters

Next Steps:
Leaving in Action
Next Steps…

- What can you do by next Tuesday?
- **Have the Conversation**: Personally & Professionally
- Share Starter Kit & other tools with family and loved ones.
- Share your stories on our website.

Discussion
Reflections
Questions?