The Conversation Project

Harriet Warshaw
Executive Director

Stern family circa 1962
Introductions

- Name
- Organization
- What brought you to this session?
  - Share a time when you experienced a “good” or “hard” death - either personally or professionally

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

70% ACTUALLY DIE IN THE HOSPITAL WANT TO DIE AT HOME.
WANT TO TALK WITH THEIR DOCTORS. HAVE HAD A CONVERSATION WITH THEIR DOCTORS
THINK IT’S IMPORTANT TO HAVE THESE CONVERSATIONS.

HAVE ACTUALLY DONE SO THINK IT’S IMPORTANT TO HAVE THESE CONVERSATIONS.
1. The Institute of Medicine releases its report, "Dying in America".
2. Atul Gawande's book on aging and end of life rises to best seller list and stays there.
3. The Conversation Project logs its 250,000 website visitor.
4. "The Fault in Our Stars" earns a stunning $48.2 million the first weekend.
5. Massachusetts rules that doctors must have a conversation about advance planning with terminally ill patients.
6. Roz Chast’s cartoon book is named one of the Top Ten Books of the year by the New York Times.
7. Brittany Maynard’s illness and death provokes a national debate.
8. The Writers Guilds East and West invite The Conversation Project to discuss End of Life Care.
9. The American Medical Association recommends reimbursement to doctors for holding conversations.
10. CMS Issues Payment Guidelines for End-of-Life Care Conversations.

**10 Signs of Cultural Change**

- What Matters to Me
- AS WELL AS
- What’s the Matter with Me

Public Awareness/Community Engagement

Health Systems Transformation

*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

Awareness: Media Engagement
Getting the Conversation Started

- Conversation Starter Kit (translations + EMR summary)
- How to Talk to Your Doctor Starter Kit
- Starter Kit for Parents of Seriously Ill Children
- Dementia/Alzheimer’s Disease Starter Kit

Available: Where People Live, Work, and Pray

- Conversation Ready Communities: 300 organizations in 40+ states
- Conversation Ready Companies: Tufts Health Plan, Goodyear Tire and Rubber Company, Fidelity, and Dow Chemical bringing TCP to their employees
- Conversation Ready Health Systems: 40 systems
- Conversation Sabbath: an interfaith initiative in Boston engaging many faiths in November
Role of Public Policy

- Awareness
- Education

The Conversation Starts with You
Setting the Table

- How it works
  - Give current answers!
- Ground rules

**Example Ground Rules**
- Privacy. Please do not share others’ personal stories.
- Listen quietly. This is not a time to offer advice or solve problems.
- Turn off cell phones.
- Everyone is here as a person, not a “role” or “title.”
- What else is important to people in the group?

---

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.)
What Matters to Me…

“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

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: Go

**MARK ALL THAT APPLY:**

1. **WHO do you want to talk to?**
   - Mom
   - Dad
   - Child/Children
   - Partner/Spouse
   - Sister/Brother
   - Faith leader (Minister, Priest, Rabbi, Imam, etc.)
   - Friend
   - Doctor
   - Caregiver
   - Other: [ ]

2. **WHEN would be a good time to talk?**
   - The next holiday
   - Before my child goes to college
   - Before my next trip
   - Before I get sick again
   - Before the baby arrives
   - The next time I visit my parents/adult children
   - At the next family gathering
   - Other: [ ]
What Did You Learn?

- What plans did you make?
- Questions
- Concerns
- Surprises
- Trends

The Conversation Continuum

End of Life Wishes

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

- Expressed
- Respected

- Spoken
- Documented
- Accessed
- Implemented
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

Resources

- IHI Open School Course – free CEUs
- TCP YouTube channel
- TCP website (stories, translations, materials)
- Monthly community calls
  - Third Wednesday of each month, 3-4pm ET
  - Next call is Wednesday, 10/21
- Quarterly speaker trainings
  - Next call is Wednesday, 10/7
A Soul Doctor and a Jazz Singer