

The Conversation Project: Stories that Change the Culture

March 15, 2013
Ellen Goodman



Our Goal

The goal of The Conversation Project is to ensure that everyone's end-of-life wishes are **expressed and respected**.

www.theconversationproject.org

The Gap

60% of people say that making sure their family is not burdened by tough decisions is “extremely important”

56% have not communicated their end-of-life wishes

Source: Survey of Californians by the California HealthCare Foundation (2012)

70% of people say they prefer to die at home

70% die in a hospital, nursing home, or long-term-care facility

Source: Centers for Disease Control (2005)

80% of people say that if seriously ill, they would want to talk to their doctor about end-of-life care

7% report having had an end-of-life conversation with their doctor

Source: Survey of Californians by the California HealthCare Foundation (2012)

82% of people say it's important to put their wishes in writing

23% have actually done it

Source: Survey of Californians by the California HealthCare Foundation (2012)

What is The Conversation Project?

- National media campaign aimed at having all people's end of life wishes expressed and respected
- Uses social and traditional media
- Website and tools to help people get started
- Working with employers, hospitals, faith-based groups
- Change culture around end-of-life conversations in America (and beyond)

HAVE YOU HAD THE CONVERSATION?

Help get it out in the open.

I want mine to be ...

Share how you want to live the end of your life.

1,230,176 people have spoken. Join them. 80 [SPEAK](#)

I want mine to be with whatever treatments keep me with my family the longest.

WHAT it's all about



Hear from co-founder Ellen Goodman about what The Conversation Project is, what we're asking people to do, and why she got involved.

WHY it's important

60% of people say that making sure their family is not burdened by tough decisions is "extremely important"

56% have not communicated their end-of-life wishes

One conversation can make all the difference.

Source: Survey of Californians by the California Health Foundation (2012)

HOW to get started

Explore our Starter Kit for tools and tips to help you have the conversation.

[EXPLORE STARTER KIT](#)

Everyone has a story



Len Fishman
Co-founder

"At that point I decided not only to honor my mother's wishes, but also to give her the best possible death."

[Read more](#)

Have you had the conversation with a loved one? We want to hear how it went.

[SHARE YOUR STORY](#)

CONNECT WITH US:



SHOW YOUR SUPPORT

The Conversation Project depends on foundation grants, corporate sponsorships and individual contributions to support its work. Please consider a gift to honor a loved one's memory.

[DONATE NOW](#)

Our Tools

- Conversation Starter Kit
- How to talk to your Doctor guide
- Conversation Groups



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About Us > Ellen Goodman

Lachlan
Forrow, MD
Advisor to The
Conversation
Project



"We talked about everything except one thing: how she wanted to live at the end of her life."

~Ellen Goodman

Otilie McManus
Director

Ellen Goodman
Co-Founder and Director

My mom was one of those people who could talk about your problems until you were bored with them. We talked about everything except one thing: how she wanted to live at the end of her life.

Once or twice when we heard about a relative or friend who was comatose or on a feeding tube, she would say, "If I'm like that, pull the plug." But, of course, when the time came there was no plug.

In my mom's last years of life, she was no longer able to decide what she wanted for dinner, let alone what she wanted for medical treatment. So the decisions fell to me. Another bone marrow biopsy? A spinal tap? Pain treatment?

Antibiotics? I was faced with cascading decisions for which I was wholly unprepared. After all the years I had written about these issues, I was still blindsided by the inevitable.

The last thing my mom would have wanted was to force me into such bewildering, painful uncertainty about her life and death. I realized only after her death how much easier it would have all been if I heard her voice in my ear as these decisions had to be made. If only we had talked about it. And so I never want to leave the people I love that uneasy and bewildered about my own wishes. It's time for us to talk.

"I realized only after her death how much easier it would have all been if I heard her voice in my ear as these decisions had to be made."

The Starter Kit: Get Set

How long do you want to receive medical care?

| | | | | |
|---|----------|----------|----------|---|
| 1 I want to live as long as possible, no matter what | 2 | 3 | 4 | 5 Quality of life is more important to me than quantity |
| 1 I'm worried that I won't get enough care | 2 | 3 | 4 | 5 I'm worried that I'll get overly aggressive care |
| 1 I wouldn't mind being cared for in a nursing facility | 2 | 3 | 4 | 5 Living independently is a huge priority for me |

Look at your answers.

What do you notice about the kind of care you want to receive?

The Starter Kit: Go

Mark all that apply:

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

- | | | |
|---|--|---------------------------------------|
| <input type="checkbox"/> Mom | <input type="checkbox"/> Partner/Spouse | <input type="checkbox"/> Doctor |
| <input type="checkbox"/> Dad | <input type="checkbox"/> Minister/Priest/Rabbi | <input type="checkbox"/> Caregiver |
| <input type="checkbox"/> Child/Children | <input type="checkbox"/> Friend | <input type="checkbox"/> Other: _____ |
-

When would be a good time to talk?

- | | | |
|--|--|---------------------------------------|
| <input type="checkbox"/> The next big holiday | <input type="checkbox"/> Before my next big trip | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> At Sunday dinner | <input type="checkbox"/> Before I get sick again | |
| <input type="checkbox"/> Before my kid goes to college | <input type="checkbox"/> Before the baby arrives | |
-

Where would you feel comfortable talking?

- | | | |
|---|--|---------------------------------------|
| <input type="checkbox"/> At the kitchen table | <input type="checkbox"/> On a walk or hike | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> At a cozy café or restaurant | <input type="checkbox"/> Sitting in a garden or park | |
| <input type="checkbox"/> On a long drive | <input type="checkbox"/> At my place of worship | |



Conversation Ready Health Systems

- IHI is working with leading health care organizations in the US and internationally to ensure the health care delivery system is prepared to **receive and respect** patients' wishes.
- Pioneers are collaborating with IHI to design and execute the “Conversation Ready” program for use in their own systems and for possible adoption across the US and internationally.
- Pioneer health care organizations pledge to be “Conversation Ready” by September 2013.

Health Systems Committed to Becoming Conversation Ready

- Beth Israel Deaconess Medical Center (Massachusetts)
- Care New England Health System (Rhode Island)
- Contra Costa Regional Medical Center (California)
- Gundersen Lutheran Health System (Wisconsin)
- Mercy Health (Ohio)
- Qulturum in the Jönköping County Council (Sweden)
- North Shore–Long Island Jewish Health System (New York)
- UPMC (Pennsylvania)
- Virginia Mason Medical Center (Washington)
- Henry Ford Hospital (Michigan)



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Have YOU had the
conversation???

