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.

1,239,175 people have spoken. Join them.

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 (2011)

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

"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:

Facebook  Twitter  YouTube

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
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 had 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.
### The Starter Kit: Get Set

**How long do you want to receive medical care?**

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

**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?

- [ ] 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 the baby arrives
- [ ] Before my kid goes to college

**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
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)
Have YOU had the conversation???