



Starting the Conversation

A Conversation with Ellen Goodman

Tell us about The Conversation Project.

The Conversation Project is a public engagement campaign to ensure that everyone's wishes for end of life care is expressed and respected. It grew out of our understanding that many people are dying in a way they would not choose and that many survivors are left bereft, guilty and uncertain about whether they have done the right thing. Many of us have a story about losing a loved one and those stories are either about a good death or a hard death. The difference seems to be whether they had a conversation with the people they love.

How does The Conversation Project help you start a conversation?

A lot of people approach end of life conversations thinking they are going to be grim, scary, and full of difficult medical questions. What we did was to write the Conversation Starter Kit that is user friendly and can help you get your thoughts together about starting a conversation. It's about your values and not about your anatomy. It asks 'what matters to you' and not 'what's the matter with you'. The starter kit allows you to open up a conversation and talk about where to have the conversation, what you might ask, and how you might think about these issues.

As you talk to people and they share their stories and experiences, what seems to be the hardest part of starting a conversation with a loved one?

Death is a universal experience. Everyone knows that 100% of us are going to die yet there has been a conspiracy of silence around mentioning the word, about acknowledging what we already know. It makes it very hard to open up this conversation, to look at someone they love and acknowledge to themselves and that person that they know we are all going to die. I think that is a big barrier for some people to get over. In some cultures it's a taboo to acknowledge, and in many of our hearts it feels very hard.



What happens when people take that first step and have a conversation?

We have found that people who have had the conversation almost universally say these have been some of the richest and warmest conversations in their life with the people they love. It's not that these are easy or unemotional, but they are deeply personal and enriching conversations.

How do we keep the conversation going over a lifetime?

We say you should have these conversations with the people you love at the kitchen table, way before there is a medical crisis and not in the hospital ICU. Probably there will be second, third, and fourth conversation as medical issues change and decisions are renewed overtime. Once you have started these conversations, it can be easier to continue to talk and make decisions when that time comes.

What about talking with our doctors and care providers?

We have a tool kit called [How to Talk to Your Doctor](#) to help start the conversation with your doctors and health care providers. Sometimes it's hard to begin this conversation. A simple opening line might be "I have had this conversation with my family and I want to share it with you so you will know how I feel when that time comes." You might even hand the doctor a copy of your tool kit saying I filled this out and I'd like to share this with you.

Why should we do this now?

There's a saying- "It's always too soon until it's too late." Having the conversation early on makes a huge difference for the people we love. There may come a time when you can't make decisions for yourself and that burden passes to someone very close to us. We care about the people in our lives and we want to leave them well off. We have an obligation to help them out.

What has this experience been like for you sharing stories and experiences?

It's been a wonderful experience, partially because we are at a tipping point in our culture and people really do understand the benefits of having these conversations. You could say it has made 'the adult checklist' of responsibilities to make sure we all start a conversation with the people we love.

Biography

Ellen Goodman is Co-Founder and Director of The Conversation Project. You can read more about The Conversation Project's national public engagement campaign, and download "The Conversation Starter Kit" and the "How to Talk to Your Doctor Kit" at www.theconversationproject.org